

**Conceptualising psycho-emotional aspects  
of disablist discrimination and impairment:  
Towards a psychoanalytically informed disability studies**

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## Declaration

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## ABSTRACT

Since the 1970s, the international disability movement has galvanised around the "social model" of disability, as an adversarial response to traditional, individualising "medical" accounts of disablement. The model foregrounds "disablist ideology", identifying systematic exclusion and discrimination as central mediators of disabled life. Latterly, feminist authors within disability studies have problematised the "arid" materialist orientation of the social model, for its eschewing of personal and psychological aspects of disability, and poor theorising of embodiment. Social model orthodoxy construes the psychological as epiphenomenal, diversionary, and potentially misappropriated in the buttressing of pathologising accounts of disablement. A legacy of "traditional" psychoanalytic theorising on disability implies causal links between bodily difference and psychopathology, eliding a critical interrogation of oppression in mediating the severely marginal social and economic destiny of the disabled minority. The new "critical" psychoanalytic approach to disability interprets broad social responses to disablement as the enactment of defences engaged in reaction to the universal unconscious existential conflicts evoked by disability images. The present work seeks to elaborate the integration of psychoanalysis into disability studies, towards development of a *politically situated psychology of disability oppression*, which creates theoretical links connecting ideology with the nature of individual subjectivity. Conceptual ideas to begin describing the *psycho-emotional aspects of disablist oppression and impairment* were developed via an integration of clinical data with a renewed, psychoanalytically informed critical synthesis of disability-related research from a range of disciplines. Clinical data was gathered via psychoanalytically oriented group psychotherapy with severely physically impaired university students. Full transcriptions and in-depth field-notes were utilised as a record of data, which was then analysed via interpretive, psychoanalytic and "interpretive auto-ethnographic" methods. Follow-up interviews were held to assess the resonance and utility of new concepts. A range of theoretical contributions was combined in illuminating the modernist cultural and political underpinnings of oppressive responses to the impaired body, and integrated with accounts of the psychological and relational predicaments of disablism gleaned from the clinical record. Topics drawn from literature, critically evaluated, developed and re-synthesised included narcissistic culture, the family, "medicalisation", social mirroring, internalised oppression, liminality, and representations of disability in charity, art and modern bioethics. The nature of countertransference dynamics in therapeutic work with disabled people was considered. Key concepts from the clinical data were developed and progressively reformulated; these included the distortion of boundaries, the discourse of loss, control, independence, identity, complicity, trauma, and the imperative to silencing the subjective experience of disabled life.

## OPSOMMING

Die internasionale gestremdhedsbeweging mobiliseer sedert die 1970's rondom die "sosiale model" van gestremdheid - in afwysende reaksie op tradisionele individualiserende, "mediese" diskoerse. Dié model plaas die kollig op "gestremdhedsideologie", en identifiseer sistematiese uitsluiting en diskriminasie as die sentrale bemiddelaars van die gestremde lewe. In die laaste tyd word die "droë" materialistiese benadering van die sosiale model egter deur feministiese outeurs binne gestremdhedsstudies geïnterproblematiseer, spesifiek as synde ontwykend van die persoonlike en sielkundige aspekte van gestremdheid, en vanweë die model se swak teoretisering van beliggaming. Die ortodokse sosiale model beskou die sielkundige as 'n epifenomeen, 'n afleiding, en potensieel kaapbaar in diens van patologiserende narratiewe oor gestremdheid. 'n Nalatenskap van "tradisionele" psigo-analitiese teoretisering oor gestremdheid impliseer kousale verbande tussen liggaamlike alteriteit en psigopatologie, wat lei tot die weglating van 'n kritiese ondervraging van verdrukking in die bemiddeling van die uiters marginale sosiale en ekonomiese lotsbestemming van die gestremde minderheidsgroep. Die nuwe "kritiese" psigo-analitiese benadering tot gestremdheid interpreteer breë sosiale response op gestremdheid as die aktivering van verdedigingsmeganismes in reaksie op universele onbewuste eksistensiële konflikte wat deur beelde van gestremdheid na vore geroep word. In hierdie verhandeling word daar gepoog om die integrasie van psigo-analise binne gestremdheidstudies uit te dy, en 'n aanset te lewer tot die ontwikkeling van 'n *politieks-geïntegreerde sielkunde van gestremdhedsverdrukking*, waardeur teoretiese verbande tussen ideologie en die aard van individuele subjektiwiteit gelê word. 'n Aanvanklike begripsapperatuur ten einde die beskrywing van die *psigo-afektiewe aspekte van gestremdhedsverdrukking en -benadeling* aan die gang te sit, is deur middel van 'n integrasie van kliniese data met 'n hernude, psigo-analitiese skatpligtige kritiese sintese van gestremdhedsgeoriënteerde navorsing in 'n verskeidenheid van vakdissiplines ontwikkel. Kliniese data is met behulp van psigo-analitiese-gerigte groepspsigoterapiesessies met fisiek swaar gestremde universiteitstudente versamel. Volledige transkripsies en uitgebreide veld-aantekeninge is gebruik as data-rekord, wat dan vervolgens deur middel van interpretatiewe, psigo-analitiese en "interpretatiewe auto-etnografiese" metodes geanaliseer is. Opvolg-onderhoude is gehou ten einde die mate van weerklank en bruikbaarheid van die nuwe konsepte te evalueer. 'n Verskeidenheid teoretiese bydrae is gekombineer ten einde die modernistiese kulturele en politieke stutte van verdrukkende response tot die belemmerde liggaam te belig, en is voorts geïntegreer met beskrywings van die sielkundige en verhoudingsmatige verknorsings van gestremdheid wat uit die kliniese rekord vergader is. Onderwerpe wat uit die literatuur ontleen, krities geëvalueer, ontwikkel en hersintetiseer is, sluit in die kultuur van narcisme, die gesin, "medikalisering", sosiale spieëling, geïnternaliseerde verdrukking, liminaliteit, sowel as uitbeeldings van gestremdheid in barmhartigheidsdiens, kuns en bio-etiek. Die aard van teenoordrag-dinamiek in terapeutiese werk met gestremdes is ook in oorweging geneem. Sleutelbegrippe ontleen aan die kliniese data is ontwikkel en voortdurend herformuleer; hierdie sluit in die verwerking van grenslyne, die diskoerse van verlies, van beheer, onafhanklikheid, identiteit, medepligtigheid, trauma, en die imperatief tot stilswye oor die subjektiewe ervaring van die gestremde lewe.

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# CHAPTER ONE

## Introduction and opening reflections

If we had a keen vision and feeling of all ordinary human life, it would be like hearing the grass grow and the squirrel's heart beat, and we should die of that roar which lies on the other side of silence.

*(Middlemarch – George Eliot)*

### Introduction

The history of the social phenomenon of disability is probably as old as humankind itself, incorporating a myriad of cultural representations and societal responses to the "marked body". The propensity of images of bodily difference to evoke psychic responses of an especially visceral, even primitive order has, over at least the course of modern history, translated into the manifesting of social forces which have driven disabled people to the margins of society, denying such individuals an equitable stake in the production of a shared culture (Marks, 1999a; Watermeyer, 2006). Modernity has witnessed an unprecedented and subduing mass socio-political offensive upon the disabled minority, rendering a host of systematic exclusions from social process, operationalised via biomedical measurement, bureaucratic categorization and cultural "othering" (Davis, 2002; Stiker, 1982). Around the globe, the hallmarks of the social predicaments of disabled persons are poverty, mass unemployment, discrimination and the indignity of denigrating social prejudices (Barnes, Oliver & Barton, 2002a; Coleridge, 1993). The silencing and disregard of disabled people is woven deeply into the structural and functional nature of societies which have been designed and developed with the needs of only a proportion of the population – the "nondisabled" majority – in mind.

Over the course of the twentieth century, the rise of the biomedical model of health care within Western nations saw theoretical understandings and institutional responses to disablement becoming ever more dominated by medicine (Abberley, 1996; Barnes, 1990;

Marks, 1999a; Oliver, 1990). Critics of the medical "establishment" pointed to its systemic inattention to social factors in mediating the experience of illness or disability, which was, instead, viewed purely as a phenomenon of "diseased bodies". For the disabled population the power and influence of biomedicine was to hold particular and oppressive implications, via the reductive ascribing of social and economic marginality to individual, rather than socio-political factors (Oliver, 1996). What came to be pejoratively described as the "medical model of disability" effectively placed responsibility for the poverty and exclusion of disabled persons at their own door, viewing this social predicament as an unavoidable outcome of functional flaws of the body or mind. This critique led to the early galvanising of the disabled minority as a political movement, which sought redress based upon the view that it is discrimination and systematic exclusion, not bodily frailty, which is at the heart of the appalling social suffering of disabled persons (Barnes et al., 2002a). As an adversarial response to the maligned medical view, a group of disabled scholars and activists in Britain proposed a radical new approach, which came to be known as the "social model" (Barnes, 1990; Oliver, 1990; 1996; Swain et al., 1993). This political device reformulated the marginality of disabled persons as a product of social oppression, which selectively inflicted the "disabled identity" upon certain citizens, as a means whereby the state may absolve itself from responsibility for the fulfilling of citizenship rights. The architects of the social model were located in disciplines such as sociology and social policy, and of a largely materialist or Marxist orientation (Thomas, 1999a). True to this paradigm, it was the materiality of access to economic participation which was foregrounded as a fundamental priority in the emancipation of their constituency. The diagnostic and "rehabilitative" aims of medicine in the lives of disabled people were vehemently eschewed, as instruments of silencing and social regulation, rather than upliftment (Barnes, 1990). But the social model was to bring its own silences, based upon its deliberate materialist elision of the uniqueness of individual experience and psychology.

To the political vanguard of the social model, psychology (including psychoanalysis) had been at the forefront of medicalising and pathologising control in the lives of disabled people, which had contributed to the construction of disability as chance "personal tragedy", rather than heinous social injustice (Finkelstein & French, 1993; Goodley & Lawthom, 2006a). Exploration of psychological aspects of disability, to these critics, would only divert attention from the real, material issues of deprivation, whilst perpetuating the cycle of "victim-blaming" (Finkelstein, 1996). Over more recent times, however, mainly feminist voices from within the discipline of disability studies have come to object to the materialist orthodoxy of

the social model, asserting that its exclusive focus on the "public" world of economic participation has sidelined the equally politically salient world of the personal, the bodily, and the psychological (Morris, 1992; Thomas, 1999a; Wendell, 1996). The social model's disabled subject was a disembodied, homogeneous phantasm, devoid of feeling or unique agency, and bearing a psychological identity mysteriously unaffected by lifelong oppression (Hughes & Paterson, 1997; Shakespeare, 2006). The political expediency of such a figure was clear, yet this meant that the social model framework left much of the real-life experience of the disabled population unseen, un-mirrored, and uninterrogated. Whilst it is true that much psychological theory pertaining to disability is profoundly uncritical, and lacking in any rigorous analysis of the typically definitive influence of oppression in disabled lives (Asch & Rousso, 1985; Goodley & Lawthom, 2006a; Thomas, 1999a), this does not mean that a critical, contextual psychology of disability is, by nature, unfeasible. Such a psychology would take care not to become ensnared in the oppressive delineation of the "psychopathology of disability", but rather would aim to use psychological concepts to illuminate the intra-psychic and intersubjective mechanisms of prejudice, as well as tracing the psychological positioning of disabled persons within a disablist social milieu (Watermeyer & Swartz, 2008).

A legacy of psychoanalytic research and theory regarding disability has tended to imply causative links between bodily impairment and pathological mental states, via the necessarily distorted nature of the "body ego" (Asch & Rousso, 1985; Thomson, 1997a; Watermeyer, 2006). Such theorising neglects the often immense impact of bodily difference in perverting the social mirroring and socialisation to which disabled persons are subject, and thus circumvents a critical analysis of the role of ideology in shaping both the manifest and internalised oppression of disabled people (Watermeyer, 2002). Latterly though, a new "critical psychoanalytic" approach to disability oppression has emerged, which seeks to use analytic concepts for the interrogation of prejudice and exclusion, which are viewed as manifestations of defensive intra-psychic responses to the unconscious existential threats which the impaired body has come to symbolise (Marks, 1999a). This is a psychoanalysis which is as preoccupied with social critique as it is with the intra-psychic states of the individual. In particular, the appropriation of disabled persons as projective containers for the disavowed psychic material of a control-oriented, narcissistic modern world (Lasch, 1978; 1984) is foregrounded, posing questions regarding the need for the consistent re-creation of the disabled minority as helpless, dependent, damaged and incapable (ibid.).

Meanwhile, within the ranks of materialist-orientated disability studies, calls for the integration of personal, psychological and bodily aspects of disability experience had led to the fashioning of an "extended" social model, in an attempt to make provision for aspects of disability not reducible to the material nature of "disabling barriers" (Thomas, 1999a). The social model, however, is based upon a "fatal" conceptual paradox (Hughes & Paterson, 1997; Shakespeare, 2006). Due to the pressing political imperative to identify "discrimination" as paramount in disabled lives, the social model elides impairment altogether, effectively surrendering disabled embodiment to the depersonalising taxonomies of medicine (ibid.). As is often the case with revolutionary movements, the social model orthodoxy relied upon irreducible binaries, including the splits between "medicine" and "politics", "nature" and "culture", and, most especially, "disability" and "impairment" (Shakespeare, 2006). Attempts at forging a psychological framework with which to make sense of disability oppression from within this paradigm seem destined to prove fruitless, due to the persistent disdain and suspicion with which research concerned with the subjectivity of disability is viewed from social model quarters. In addition, the materialist basis of the disability studies academy renders a paucity of psychological knowledge with which to undertake new theorising. A key point of departure of the current work holds that achieving a satisfactory theoretical understanding of oppression of any sort must make adequate conceptual provision for the intra-psychic. As corollary to this position, "oppression" is not viewed as a simple, unidirectional "force" which emanates from the dominant group; instead, it is viewed as a dynamic social process, which notably involves the internalisation amongst members of the subordinated group of denigratory meanings (Frosh, 2006). By consequence, social change is regarded as only being possible when all participants in oppressive relating are brought to a point of insight regarding specific roles in the cycle of domination. A conceptual frame for understanding the internal, psychological environment of the subordinated is, consequently, indispensable.

A key question thus emerges regarding whether it is feasible to create a socially situated, ideologically critical psychological framework to describe disability oppression. Psychoanalytic social theory has often been criticised for a propensity to reduce the real-world drama of political conflict to the intra-psychic realm of the personal and symbolic, thus tending to depoliticise the individual, rather than subvert the societal status quo (Gordon, 1995). The key difficulty surrounds the forging of meaningful connective threads between the world of ideology and the realm of the subjective, in a manner which tracks back the marginal positioning of oppressed minorities to the internalisation of perverse and oppressive

socialisation (Davids, 1996; Marks, 1999a; 1999b). The current work aims to begin a process of developing psychoanalytically informed concepts which make sense of disablism discrimination in relational terms, whilst also remaining rigorously cognisant of the broader contextual (that is, material) nature of disability oppression. Typically, analyses which are preoccupied with intra-psychic phenomena tend to "mislay" the political, instead attributing subjective distress to individual, neurotic origins. What is required is a psychological account of the trauma of socially situated disability, which manages to avoid such snares through the careful and deliberate connection of subjective struggle to the distortion of social formations which surround the disabled body.

The present study is based upon a psychoanalytically oriented group psychotherapy process involving severely physically impaired university students. Using a non-directive group analytic approach, clinical material regarding the subjective nature of social life with severe, visible impairment was collected, with a view to the development of conceptual ideas regarding the psychological underpinnings and effects of prejudicial treatment. Particular attention was paid to countertransference phenomena within this process, with a view to illuminating the often distorted interpersonal dynamics which emanate from the extraordinary evocativeness of visible bodily difference. An interpretivist qualitative methodology was applied to the data, with ongoing field-notes being used to incrementally develop theoretical ideas regarding the lived psychological and relational nature of disablism. After completion of the therapeutic process, the resultant conceptual ideas were re-presented to group members in individual interviews, in order to establish the degree of resonance which these carried.

The intended contribution of this dissertation lies not only in the clinical data, but more broadly in a renewed, critical and interpretive synthesis of the literature. As noted above, a history of psychological theorising on disability has been (largely justifiably) rejected by the social model disability movement, due to its uncritical, individualising – and hence effectively victim-blaming – stance. The current work aims to re-introduce psychological – in particular, psychoanalytically informed – concepts into disability studies, within a renewed vision of socially situated and critical analysis of individual psychic experience. This is a new amalgamation, born of useful ideas salvaged from the debris of discarded psychological and psychoanalytic work, in combination with an original, psychoanalytically oriented critical synthesis of existing disability studies theory. Thus, existing literature, as well as clinical material, is regarded as "data" within the study. The approach is unconventional. Since the

primary aim of the work is the development of new conceptual ideas, the dissertation is largely theoretical, with clinical material used more to exemplify and enliven than "create" the suggested concepts. The implementation of the psychoanalytic method in research is, by its nature, *interpretive*, as it involves the positing of descriptions of unconscious phenomena not fully falsifiable by empirical means (Hollway & Jefferson, 2000). The utility (or otherwise) of the conceptual ideas regarding the psychological nature and effects of disablism presented here will be determined by the extent to which these are experienced by disabled individuals as resonant, and illuminating of the often obscure (and internalised) modes of oppression inflicted upon this group. The dissertation proceeds as follows:

In the balance of this chapter, I present a consideration of the cultural phenomenon of bodily symbolism; that is, the resilient logic that the nature of the soul, or the self, is "written on the body". Thereafter, a brief orientation to the worldwide development challenges facing the disabled community is presented, with a view to familiarising the reader with the appalling gravity and pervasiveness of disablism oppression (*Disability: The international development context*).

Chapter Two (*The body, ideology & society*), the first of three purely theoretical chapters, opens with an account of the ideological contrasts between the so-called "medical" and "social" models of disability, followed by a consideration of burgeoning criticisms directed at the latter. Central aspects of this critique pertain to the model's stubborn rejection of the assertion that personal and psychological aspects of disability carry political significance (*Prohibiting the personal*), as well as the neglect of the subjective reality of disabled embodiment (*The vanishing – and re-appearing – body*).

We turn in Chapter Three (*Psychoanalysis, social constructionism and the contextual phenomenology of disability*) to psychoanalysis; in particular, the potential of the paradigm as a framework for subversive social critique. This assessment is made in preparation for the following section, which recounts the largely oppressive, individualising history of psychoanalytic work regarding disability (*Psychoanalysis and disability: A brief history*). The new, critical psychoanalytic approach to the disability phenomenon is then outlined, leading into a consideration of the role of particular defence mechanisms in (destructively)

mediating the social treatment of disabled persons. Three related concepts, *stigma*, *liminality* and *monstrosity* are thereafter examined, in order to assess their potential utility in illuminating the symbolic as enacted within cultural formations surrounding impairment. In the following section, entitled *Disability and bioethics*, we explore how the unconscious meanings and evocations surrounding disability may be socially (that is, medically) enacted through debates within modern bioethics to do with how "worth living" life with impairment may be. The dark history of eugenic extermination and forced sterilisation inflicted upon the disabled population (in *Eugenics*) are viewed as lending credence to the so-called "expressivist critique" of bioethics policies which seek to eliminate impaired bodies from the human population. Finally, we explore the specific salience of elements of the critique of biomedicine in the lives of disabled persons (*Disability and the medical encounter*).

In Chapter Four (*Impairment, culture and identity*) an attempt is made to broadly sketch the cultural backdrop to disablist othering, and the distortions of socialisation suffered by impaired persons. The influence of the acquisitive and autonomous imperatives of narcissistic modernity on out-group denigration has special, pernicious salience to the disabled minority (in *Narcissism, normalcy, modernity and the market*). In addition, artistic, literary and charity representations of disability "damage" (explored next) serve to reproduce the disabled imago of dependency, damage and abjection. In narrowing the focus of cultural influences upon the disabled self, we consider issues within the family regarding impairment-difference (*Attachment and infancy*), the striving for normalcy (*The body, ideology and surgery*), and the unconscious psychic concomitants of "bodily defects" (*Guilt*). In *Identity politics and the movement* the complexities of political mobilisation surrounding a maligned, deeply devalued social identity are explored, locating the disabled individual – unlike members of other political minorities – as typically isolated in the face of oppression. The four subsections of the following segment (entitled *Psycho-emotional aspects of disability*) are concerned with an examination of psychological concepts relevant to the shaping of the disabled self, including the Winnicottian notion of *mirroring*, the contested and under-developed concept of *internalised oppression*, and the question of what disabled persons "need" in psychological terms in order to overturn (internal) relations of subordination (in *Disability: What is development?* and *Disability and psychotherapy*).

Chapter Five (*Research methods and issues*) begins by outlining the origination and nature of the empirical study which buttresses the balance of the dissertation. An account is provided

of how the psychotherapy group for physically impaired students came into being, what the intentions of the intervention were, and the nature and recruitment of participants. Power relations, and a history of severe exploitation, are key concerns within research methodology in disability studies. A section is therefore devoted to these very significant ethical issues (*Disability studies: Research and emancipation*), which takes the narrative temporarily away from the research story of the present work. In the section headed *Qualitative and interpretivist*, the essential philosophical position from which the research study was undertaken is described, leading thereafter to a declaration by myself (the author) of my own subjective position in relation to the issues at hand (*Researcher's orientation to data*). As a disabled person (partially sighted), a disability studies researcher and a clinical psychologist, my multiple identities and personal standpoint surrounding the field of study are of direct relevance, particularly as I assume an openly interpretive (interpretivist and psychoanalytic) position with regard to the data. In part, I locate myself as shaping the data analysis via an "interpretive auto-ethnography", in which I draw upon my own history as a disabled person, and disability studies researcher, in making (interpretive, unconscious) sense of the accounts of the research subjects.

After conclusion of the research methodology narrative, the following chapter presents aspects of the clinical material, synthesised with relevant disability-related research from a range of fields. In this segment (Chapter Six – *Group psychotherapy with severely physically impaired adults: Conceptualising aspects of clinical material*) incorporates the major conceptual contribution gleaned from the clinical intervention. Here, concept clusters regarding the relational-psychological nature of the social positioning of disabled persons are presented, exemplified with direct quotations from data, and (critically) integrated with theoretical contributions from the research literature. The first section introduces the relationship, in common cultural discourse, between images of disability and anxiety within the observer. This relates closely to the topic of the following section, which deals with the ubiquitous social forces of silence enacted upon disabled subjectivity by an anxious and defended world (*Imperative to silence*). In *Trauma and its re-enlivening* we focus attention upon the vexed question of how to relate the social experience of oppression with the uniqueness of individual psychology and history, in a manner which holds the significance of both; that is, without blaming the victim, or negating the individual. The pivotal concept of the distortion of personal and psychic boundaries in the lives of persons with impairments is thereafter considered in a segment comprised of nine subsections. The aspects of this key issue which are discussed begin with the social forces militating against "real" and authentic

relating, with the related implication of disabled persons (in this study) often feeling unseen and unknown in relationships (*Being real and Being seen*). The nature of some forms of (unconsciously motivated) relational response to the disabled figure is then described; these include what I term "manic" defensive responses, and the drive toward establishing "solutions" to the perceived dilemmas of impairment. The final three subsections present ideas regarding the collusion of disabled persons with relational silencing, the role of manifest deprivation in distorting relationships (*The reality of limited choices*), and the salience of the notion of transitional space. Next, the section entitled *The discourse of independence* presents a critical interrogation of this highly salient notion in the lives of disabled persons, via colloquial stereotyped ideas, as well as imperatives operationalised through medical and rehabilitative institutions. The subjective, psychological experience of disablism and impairment are foregrounded via the following three topic segments, which are concerned with the relinquishing and denial of control, the experience of depression and suicidality, and the nature of punitive, internalised imperatives which emanate from lives of continual denigration (*Control, Depression and suicidality*, and *Disabled superego*). The final major section arising from the interpretation of clinical material provides a critical analysis of the fraught notion of loss in the lives of disabled persons. Traditional medical and psychological views of disability apply grief and bereavement concepts to the onset of impairment, in a manner which tends to reduce social oppression to a personal, neurotic battle with "losses" in bodily functionality. Against the backdrop of a vigorous critique of this "loss discourse", we consider the question of how such stereotyping diminishes social space for the accessing and communication of authentic, unique and personal experiences of loss which life in a disablism society will so often bring (*Acceptance and denial, On being "un-disabled" and Disability, entitlement and loss*).

The Appendix (*Group psychotherapy with severely physically impaired adults: Aspects of process*) provides additional enrichment to the reading of clinical material presented in Chapter Six, through a close examination of technical issues and relational dynamics within the therapeutic setting which arise from the practicalities and evocations of impairment. The segment opens with four sections discussing aspects of the psychotherapeutic work, some of which highlight the manner in which severe physical impairment presents challenges to the clarity and boundedness of the traditional psychoanalytic frame. These issues include, firstly, the reality of inconsistent attendance due to the ongoing, exhausting nature of life negotiating the combination of complex illness and impairment factors, and the unremitting experience of exclusion and prejudice. A second issue pertains to the unavoidable contravention of physical

boundaries which attended the clinical process, with a consideration of concomitant unconscious meanings. The role of interpretation in therapeutic work with members of oppressed minority groups is then considered; this is a delicate and complex issue, relating to the psychoanalytic dilemma of the relevance of "internal" interpretations in the face of real, material, *external* forces of oppression. The remainder of the appended chapter is devoted to five sections concerned with aspects of countertransference gleaned from the clinical record. These issues are described with a view to beginning to conceptualise how culturally condensed and archaic anxieties surrounding disablement may translate into countertransference dynamics in clinical work with disabled individuals. Key issues here include my own experience of a severe performance anxiety (*Pressure-anxiety*), and tightly held political investment in "emancipatory" outcomes (*Political investments and therapeutic boundaries*), as well as the powerful, even irresistible nature of projection and other primitive defences in relational spaces surrounding the visibly impaired (*Our most damaged selves, and the struggle of "not knowing"*).

The dissertation draws to a close with Chapter Seven, entitled *Conclusions*. Here, key themes and implications of the study are concisely drawn together, and combined with reflections on the rich capacity of the disability phenomenon to contribute to our insights regarding social oppression, the silencing of subjectivity, the shortcomings of hegemonic notions of identity, and the commonalities of the human condition. We begin, thus, with a discussion of the cultural mystique surrounding the subjective experience of bodily impairment; that is, the persistent belief that the nature of the self is somehow *written on the body*.

## **Written on the body<sup>1</sup>**

Across world culture, there exists a long history of attributions for behaviour, indeed, for selfhood, to the nature of bodies. Somatic characteristics are by their nature compelling and material, and draw an instinctual attention which may, at least in those crucial first moments of contact, circumvent a consideration of more subtle aspects of personhood. The body

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<sup>1</sup> After having decided upon this descriptive phrase, I became aware that it is also the title of a novel by Jeanette Winterson (1992).

mesmerises and captivates us, indelibly marking out to the observer constraints upon what or whom the soul it carries may be. It is the body which provides a material, "corporeal anchor" which, to the observer, both reflects and constitutes the psychological realm (Thomson, 1995, p. 603). Perhaps the most pervasively influential bodily signifier is that of skin colour, which has in every context come to hold a myriad of personal meanings, typically showing as binary oppositions between members of racialised groups. Frantz Fanon placed fantasies about blackness at "the heart of European civilisation" (Frosh, 1989, p. 23; Fanon, 1952). Further, as Morris notes, the notion that physical attributes signal undesirable aspects of the psychological self is, to say the least, "a familiar one" to the feminist movement, which has sought to locate such assumptions within a critical socio-political context (Morris, 1993a, p. 86). Rosemarie Garland Thomson (Thomson, 1995, p. 599) tells of her dismay at a bedtime fairytale she is reading to her young daughter, in which the "good" girl's sexual and personal worth emanate from "an outer beauty that parallels her inner virtue". Conversely, the "bad" girl's poverty of morals and character is mirrored and confirmed by her indelicate and unfeminine features (ibid.). For the "bad" girl, the fact of being a woman is made more condemning by her failure, in her already devalued female state, to redeem herself with beauty. Attractiveness, thus, is firmly linked to virtue (Asch & Fine, 1988, p. 16.<sup>2</sup>).

In such a world of fervent somatic symbolising, hungry as it is for the ascription of meaning, disability must inevitably fill some version of centre stage. Bodily differences or "defects" have commonly drawn the observer into questions regarding whether such discernible flaws are analogous to deeper moral or civil shortcomings (Mitchell & Snyder, 1997, p. 13). In Shakespeare's *Richard III*, there is no question that the protagonist's sinister and "bestly" ways are constituted mutually with his bodily deformity. In fact, he brazenly conspires with the audience to the effect that, since he is not worthy of this world's purer pleasures, villainy and avarice can be his only ambitions. In the horrific unfolding of the play, every twist can be "traced back to Richard's consciousness of himself as a 'deformed, unfinished' man" (Kriegel, 1987, p. 31). Richard is described as having teeth from the moment of his misshapen birth, allowing him to "gnaw a crust of bread when only two hours old". Clearly identifiable here are ideas regarding base oral obsession, deprivation and greed, which are located within

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<sup>2</sup> In a slight divergence from APA (American Psychological Association) referencing format, I choose at many points to provide page numbers without the presence of a direct quotation. I believe this to be helpful in the context of a review of literature of the size and breadth of the current work.

Richard from his very birth. As such, his evil is not so much a result of his deformity, but rather a co-constituent with it of his overall self.

The emergence of modernity, with its promise of solutions and technologies to master the natural world, has brought with it possibilities – which quickly transmutate into moral imperatives – to perfect the body. Bodies successfully made to appear youthful and powerful have "increasingly become a sign of social worth", and pivotal to the "notion of the self as a project" (Giddens, 1991 cited in Turner, 2001, p. 253). The fantasy of a body entirely amenable to the perfecting, subduing action of technology positions those who fail in this task as inferior, negligent or immoral. Davis (1997b, p. 15) traces the development, through the late modern era, of scientific assignation and measurement of the essential bodily identity, ranging from scores on intelligence tests to fingerprinting, with all such characteristics purportedly expressing one's coded genetic essence. The marking of bodies with an indelible corporeal identity, interspersed with measurements of prowess such as intelligence, causes an individual to be laced into an "identical relationship" with his or her body (ibid.); ultimately, the body "embodies" the identity. Consequently, one's resultant identity becomes "as indelible as one's place on the normal curve" (Davis, 1997b, p. 15). Achieving normalcy on that same curve – via a body that is "natural and healthy" – thus becomes a prerequisite for "a good life", "one worth living" (Michalko, 2002, p. 37). As we shall see, in the case of persons with divergent bodies, the converse attribution of lives that are *not worth living* is readily to be found in modern society.

So prized and praiseworthy are physical characteristics of vitality, health, vigour and energy in common-sense accounts that, at first glance, questioning the association of these characteristics with virtue may seem incongruous. Habitually, observations regarding how closely a body approximates the fantasy media ideal are accepted as compliments, which cleanse and illuminate the body's "inhabitant", not simply the body per se. We revel in praise for our stamina, our ability to work long hours, our resilience and energy. But hearing a discourse wherein health is constructed not as a chance occurrence, but as an admirable achievement, from within a disabled body, positions one as not only physically, but *personally*, lacking (Wendell, 1997, p. 269).

In the cases of race and gender mentioned above, critical interrogation of societal forces and the action of civil rights campaigns have worked to erode away bodily attributions, as

evidence of oppression has grown and overtaken the irresistible urge to ascribe poverty, backwardness, immorality or any other form of inadequacy to bodily difference. Disability, though, presents to the observer opportunities for such attribution and symbolisation which are that much more legion, more provocative and fantastic, rendering the field of fantasies regarding the nature of the disabled self correspondingly florid. If the shape of the disabled body is infinitely diverse, infinitely contorted, so must be the shape of the disabled soul. Here, fantasies of potentially limitless bodily (dys)morphology feed, and feed upon, ideas regarding the horrific and endlessly diverse states and shapes of the human character. Thomson describes, via a consideration of the history of the American freak show, how a distorted body may be so saturated with symbolism as to become "pure text"; humanity, then, is obliterated by the all-enveloping body (Thomson, 1997b, p. 59). Such "enfreakment" (ibid.) is, of course, at one extreme of a continuum upon which admixtures of body and self are able to be heard. However, what her image demonstrates is the element of a degree of squeezing away of the self by bodies that are all-too-readily appropriated as text. The hegemonic status of the body as a textual marker of identity is evident in our universal drive to repair, correct and enhance our bodies. When we improve our bodies, *we improve ourselves*. Paradoxically, this position both frees and entraps; we are seduced by the modernist possibility of change, whilst endorsing a meaning system which affixes our selfhood to an ultimately fragile and failing body. We have the illusion of control, at the cost of subjection.

The textual message emblazoned on the bodies of disabled persons is, first and foremost, one of suffering and abjection. Disability and suffering, writes Henri-Jacques Stiker, remain, throughout history, "inseparable companions" (Stiker, 1999 cited in Michalko, 2002, p. 1). If life and identity are organised within liberal societies around axioms such as free agency, mastery, progress and individual will (Thomson, 1997b, p. 47), the image of the disabled person flouts and destabilises the very foundations of convention, rendering a radical counterpoint to the "good life". Within popular media in the United States, Hevey asserts that the image of the impaired body is the "site and symbol of all alienation ... The contorted body is the final process and statement of a painful mind" (Hevey, 1992, p. 73). The disabled body, in such a context, is not only inscribed, but *created*, with social relations (Thomson, 1997b, p. 22). So dominant are cultural associations to bodily frailty and illness, according to Susan Sontag, that it is not possible to "take up one's residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped" (Sontag, 1991 cited in Barnes and Mercer, 2001, p. 518).

Linguistic traces of the association of bodily impairment with suffering and wretchedness may be found in a range of popular discourses, such as that regarding what it means to be "fortunate". Allocation of individuals to the categories of "fortunate" and "unfortunate" occurs here around a fulcrum of the body. In the midst of life crises or losses, the mantra that one is, *in fact*, "fortunate" to have "my health", is axiomatic. Bodily impairment, consequently, precludes temporality or change in how one's sense of self is viewed; one simply *is* "an unfortunate", with the unspoken nature of disabled experience occupying the pinnacle of a shadowy, yet consensual, hierarchy of suffering. If the self is written on the body, the wretched self is written on the impaired body.

In preparing the way for an extensive consideration of theoretical knowledge regarding the social and psychological formations which surround disability, I now turn to a brief sketching of the global context of disability development needs.

### **Disability: The international development context**

Throughout the world, overwhelming evidence bears witness to the lived oppression which disabled people, largely en masse, continue to experience. Charlton (1998) calls this social reality "a human rights tragedy of epic proportions", which embodies "a fundamental critique of the existing world system" (Charlton, 1998, p. ix). Poverty, indignity, exclusion, manifold deprivation, and the routine contravention of basic human rights are the cornerstones of the social predicaments of the world's disabled population. Disablist oppression is woven deeply into the fabric of societies designed and developed within frames of reference which take no account of the needs, experiences and lifestyles of persons with bodily or psychic impairments. As such, it is manifest in visible and invisible, deliberate and inadvertent, active and passive aspects of everyday cultural, economic and political life. Rather than simply the work of a bigoted minority, disablism, through the mechanics of ideology, draws all into its net, by virtue of the inheritance of societies founded upon deeply embedded, interdependent cultural phenomena which provide only for the participation of a proportion of the populace.

Developing functional definitions of disability is a notoriously complex task. Consequently, the widely divergent global range of definitions provides statistical prevalence data sets which are "inherently problematic" (Coleridge, 1993, p. 104). It was inevitable that attempts at combining this bewildering store of data involved compromise, leading initially to an international prevalence estimated at 10% of the world population, which quickly became prominent within the discourse of disabled lobby groups worldwide. The figure, though, has been severely criticised as a coarse oversimplification (ibid.). This one-size-fits-all estimate has fostered the assumption that one tenth of any population is disabled; a suggestion "rarely borne out in practice" (ibid.), and one brimming with the possibilities of blunders in policy. Instead, careful comparison of survey data points to a wide variation in disability prevalence, within as well as between countries. A complex of factors shape disabled populations as potentially substantially above or below the oft-quoted 10% mark (Coleridge, 1993, p. 104). The World Health Organisation (WHO), which was previously responsible for the 10% estimate, now embraces a figure of approximately 4% for developing countries and 7% for developed nations (ibid.). This figure, however, is set to escalate continually for many decades to come, as a product of population ageing, deterioration in the natural environment, and incidence of social violence (Albrecht & Verbrugge, 2000 cited in Braddock & Parish, 2001, p. 52).

As noted above – and perhaps contrary to popular intuition – prevalence of reported disability in the developed world is considerably higher than that of the developing world, although the majority of the world's disabled population reside in developing contexts (Barnes & Mercer, 2005a, p. 2). Greater prevalence of disability in wealthier countries is attributed to three major causes. Firstly, in such contexts the far longer life expectancy, and consequently larger population of aged persons, provide for higher incidence of age-related impairment. The second causal factor pertains to the typically extensive nature of health and other support services in developed states, which produce higher rates of survival of persons with congenital as well as adventitious impairments; parallel with this consideration, individuals are also more likely to self-identify as disabled if this leads to the procurement of services. Lastly, a range of less conspicuous or visible impairments may be grossly under-identified in developing contexts. Conditions such as dyslexia may go unnoticed, or not be considered to carry the substantial functional limitation which justifies recording as an impairment (Barnes & Mercer, 2005a, p. 2; Coleridge, 1993). Whilst maintaining the proviso that all demographic and prevalence patterns should be approached with a keen sense of caution, it appears that an urban bias is often present. This bias is accounted for by such factors as the

greater urban occurrence of road and industrial accidents, the attraction of more sophisticated social services, better medical care, a better chance of obtaining sedentary employment, and opportunities for begging (Coleridge, 1993, p. 106). Radically different scenarios are typically created by localised incidence of medical conditions, such as river blindness, which has a prevalence of 30% in some rural areas of the Democratic Republic of Congo (ibid.).

In both wealthy and under-developed nations, however, disabled persons reliably remain amongst the poorest of the poor (Barnes, Oliver & Barton, 2002a; Coleridge, 1993; Schriener, 2001). Schriener (2001) assures us that it does not "overstate the case" to declare that disabled people are "almost universally on the bottom rung of the socio-economic ladder" (Schriener, 2001, p. 645). Through the course of the 1990s, international rates of unemployment amongst the disabled population changed little, notwithstanding the fact that (disability-related) anti-discrimination legislation was introduced in several countries during the decade (Oliver, 2001, p. 153). Within even the world's most developed nations, rates of unemployment amongst disabled persons are frequently of the order of 80% and beyond, with average personal income falling in the lowest decile (Braddock & Parish, 2001, p. 53). Taking the United States as an example, by 2002 72% of the disabled population remained out of work, with the poverty rate amongst working-age disabled adults topping three times that of their nondisabled compatriots (Davis, 2002, p. 148). One third of all disabled children in the United States live in poverty (ibid.). One might safely assume that the marginal economic circumstances of disabled communities in less affluent parts of the globe are, for the most part, that much more dire.

Economic disadvantage is often deeply interwoven with the denial of access to resources basic to participation in social life. For example, gaining – or retaining – employment is simply impossible for a mobility impaired person in the absence of appropriate, accessible transportation. Mutua (2001, p. 105) relates how, in Kenya, many physically disabled individuals survive in a "uniquely paradoxical state of being ... present, yet completely invisible", as a result of being entirely excluded from societal participation due to the profound isolation engendered by the lack of usable transportation. The World Health Organisation estimated in 2001 that only 1% of disabled persons in the developing world have any access whatsoever to rehabilitation or other institutional disability-related services (Barnes & Mercer, 2005a, p. 4). Disabled children, especially girls, are "routinely denied formal schooling" in many developing nation contexts (UNESCO, 1995; UN ESCAP, 2003;

both cited in Barnes & Mercer, 2005a, p. 7). Flood (2005, p. 189) estimates that 2% of disabled children in the developing world receive a meaningful education

The absence or under-resourced nature of disability-related social services in the developing world contrasts dramatically with the far greater financial and human resources which are channelled into palliative, preventive and rehabilitative medical services in wealthier countries (Barnes & Mercer, 2005, p. 4). Nevertheless, it should be noted that such services are typically rooted within health systems which remain insulated from, and bear little influence upon, the broader social exclusions suffered by most disabled persons Hagrass, 2005, p. 148). In rich and poor countries alike, disabled citizens face "formidable barriers to housing, transportation and freedom of movement, as well as exclusion or segregation in education and public accommodations" (Hahn, 2002, p. 165). In reviewing the development of accessible transport services within the European Union, Lawson and Matthews (2005, p. 80, 84) conclude that, over the last decade, only a degree of progress has been made toward full acknowledgment of the problem, with actual reparative interventions described as "tentative" and grossly insufficient. Where attempts at providing key resources such as housing, education, transport and public accommodations are made by developed world administrations, disabled people have typically been positioned in life-worlds characterised by "a more pervasive form of segregation...than the most rigid policies of apartheid enacted by racist governments" (Hahn, 1997, p. 174; see also Drake, 2001).

The voracious capital imperatives of an increasingly globalised economy, characterised as it is by the deregulating of employment stipulations, international trade, and the global labour market, seem destined to further compound the economic exclusions of disabled workers heralded by earlier eras of industrialisation (Holden & Beresford, 2002, p. 194, Kelly, 2001). Priestley (2005) provides an analysis which poses important questions regarding the complex, often conflictual, interchange between European Union disability policy and the particular national interests of member states. The predominance of unfettered market forces has historically provided for a strong link between disability and poverty, which, according to many disability studies critics, seems set to deepen internationally. It seems clear that the increasingly hegemonic and accelerating market imperatives of a global economy are unlikely to position the investigation and dismantling of disabling social and physical structures as any sort of pressing priority (Holden & Beresford, 2002, p. 194).

The challenge to disability scholars, thus, is to re-orient analyses in a manner which takes account of the integrated nature of the global economy, incorporating critique of the influence of multi-national corporations and financial institutions (such as the International Monetary Fund and the World Bank) on forces shaping access to, and management of, labour (Sheldon, 2005, p. 118). It is for the fate of developing contexts that the fact of globalised capital appears most ominous, yet, a lack of concerted research, as well as poor infrastructure and service provision, mean that little systematic knowledge exists regarding the life-situations of the majority of developing-world disabled persons (Charlton, 1998, p. 3<sup>3</sup>; Barnes & Mercer, 2005a). Against the backdrop of this void of knowledge, myths and stereotypes regarding the "backward" or "traditional" treatment of disabled people in poorer countries have flourished. One such myth is the notion that people in non-Western countries "hide, abuse, and even kill" their disabled family members (Ingstad, 2001, p. 774). Whilst it is not denied that cases of abuse and hate crime exist, it seems that a systematic bias prevails in the manner to which such incidents are regarded as broadly representative. As Ingstad puts it: "We do not take single cases of child abuse to be typical examples of child care in industrialised countries" (Ingstad, 2001, p. 775). Beyond the sheer lack of evidence to support the myth, it also carries the dangerous potential to provide an excuse for governments who wish to obscure the reality of premature deaths of disabled persons resulting from poverty and a lack of health care (ibid.).

Notwithstanding the fact that the prevalence of disability in poorer countries is estimated to be significantly lower than that of developed nations, by the reckoning of some disability studies researchers, as much as one half of all such impairment could be prevented through the promulgation of effective policies to fight poverty and malnutrition, and improve sanitation, the quality of drinking water, and conditions of labour (Barnes & Mercer, 2005a, p. 4; Charlton, 1998). The banishment of disabled people from the world of work in many poorer countries, argue Harber and Davies (1997), is policed by the institutional gatekeeping of access to education. Exclusion from the educational system in early life, which, as noted

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<sup>3</sup> Although accepted APA (American Psychological Association) referencing format dictates that listed references in parenthesis should be alphabetized, at many points I place a single source first in order to indicate its significance; thereafter, the remainder of the list is alphabetized.

above, is overwhelmingly typical for the disabled children of the "periphery", serves to legitimate lifelong inequalities, via attribution of chronically low occupational status to failure in prior educational achievement (Harber & Davies, 1997 cited in Barton & Armstrong, 2001, p. 693).

Within international policy frameworks, growing interest in disability as an axis of inequality began emerging in the 1970s, beginning with the United Nations' Declaration of the Rights of Mentally Retarded Persons (1971) and Declaration of the Rights of Disabled Persons (1975; Barnes & Mercer, 2005a, p. 8). This was followed by the year 1981 being proclaimed the International Year of Disabled Persons (IYDP), and the ten year period from 1983 to 1992 the Decade for Disabled Persons. However, the impact of these seemingly radical developments was hamstrung by the broad and ongoing hegemony of individualistic medical and rehabilitationist understandings of disability (*ibid.*). The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (formally adopted in 1993; Barnes et al., 2002a, p. 3), whilst carrying no legally enforceable imperative, were proposed in order to provide an international benchmarking of standards for disability-related legislation, policy, and programme implementation (Braddock & Parish, 2001, p. 50).

Meanwhile, the World Health Organisation has attempted to develop a theoretical and conceptual framework for research and policy development in disability, initially launched in 1980 as the International Classification of Impairment, Disability and Handicap (ICIDH), and revised in 2000 as the ICIDH-2 (later re-named the International Classification of Functioning, Disability and Health, or ICF). Whilst successive versions of the model represented a substantial attempt to move away from a traditional biomedical view of disability, the framework nevertheless sustained heavy critique from disability studies quarters (Thomas, 2002a, pp. 41-2; Pfeiffer, 2000). In essence, the WHO's approach has been regarded by a substantial quorum of disability scholars as prioritising the prevention of impairment, rather than foregrounding contextual issues such as discrimination and systematic exclusion (Marks, 1999a, p. 54). In addition it is argued that the schema carries an inherent logic which tends ultimately to ascribe disadvantage to intra-individual, impairment-based factors (Thomas, 2002a, p. 42; Fougeyrollas & Beauregard, 2001; Lunt & Thornton, 1994), although this is disputed by some (e.g. Bury, 2000; Shakespeare, 2006). Pfeiffer (2000, p. 1080) goes so far as to brand the ICIDH-2 a "threat to the disability movement worldwide", due to its lack of a critical, constructionist approach to such issues as normalcy

(*ibid.*). In a somewhat more mischievous vein, Miles pokes fun at institutional attempts at developing an all-encompassing disability vocabulary, with the view that such "heroic linguistic labours" as those undertaken surrounding the ICIDH and ICIDH-2 – in order to establish internationally relevant terminology – are inevitably futile (Miles, 2001; see also Altman, 2001; Fujiura & Rutkowski-Kmitta, 2001).

One strategy to counter the economic exclusion of disabled persons is that of so-called "anti-discrimination legislation". Leading the international trend towards this approach was the United States, where the Americans with Disabilities Act (ADA) was promulgated in 1990. It was hoped – believed – that the implementation of this legislation would embody a "watershed moment" for global disability rights (Braddock & Parish, 2001, p. 50). As a point of departure, this promising new law affirmed that it was socio-political phenomena such as discrimination, and the history of segregation and isolation, which engendered the unequal positions of disabled persons in modern society, rather than intra-personal factors such as impairment (*ibid.*). Thus, the Act stipulated that discrimination against disabled individuals in the domains of employment, public services, public accommodations and telecommunications was recognised as unlawful (*ibid.*). This mandated that reasonable adjustments to physical environments and practices should be undertaken by employers in order to facilitate equitable inclusion of disabled persons. During the course of the 1990s, several other nations quickly followed suit, by adopting similar policy legislation, or amending constitutions in order to prohibit disability-based discrimination; these included Great Britain, Australia, Germany, Austria, Brazil, South Africa, Malawi, Uganda, and the Philippines (*ibid.*, p. 51).

Focusing on the lead taken by the United States, however, the disability movement was to be sadly disillusioned by what was to follow. In what Lennard J. Davis has described as "a judicial backlash", well over 90% of cases of discrimination brought by disabled citizens in terms of the ADA have been denied relief in US courts (Davis, 2002, p. 148; Colker, 2005). Judges in such cases have adopted a narrow and conservative reading of constitutional stipulations, in reaching judgments overwhelmingly unfavourable to disabled plaintiffs (Hahn, 2001, p. 62). This unfolding pattern, Hahn argues, is founded upon nondisabled lawyers and judges approaching disabled civil rights issues from within a "functional limitations" rather than a "minority group" paradigm, and hence abrogating "their historic role of defending disadvantaged minorities and seeking to fulfil the promise of equality" (Hahn,

2001, p. 62). Harlan Hahn, along with a substantial proportion of scholars within the disability studies discipline, now has ruefully forsaken much of the hope that significant progress towards disability equity can be achieved through the splintered – and so far fruitless – tactic of litigation (ibid., p. 64). With Bickenbach and colleagues (Bickenbach, Chatterji, Badley & Ustun, 1999, p. 1180), he now concludes that disabled people "cannot expect emancipation by appealing to one of the many social institutions that oppress them".

An episode which was to become a watershed moment in the early galvanising of the global disability rights movement took shape at a world conference of Rehabilitation International (RI) in Winnipeg, Canada, in 1980. A dispute regarding the full participation of disabled people in policy decisions being debated at the conference led to the 250 disabled delegates deciding to boycott proceedings (Flood, 2005; Barnes & Mercer, 2005a). These delegates facilitated collaboration between sectors of the disabled population from many countries to create a new organisation, Disabled People's International (DPI), composed of and steered by disabled persons (Barnes & Mercer, 2005a, p. 8). The first international congress of DPI was held in Singapore in 1981, and incorporated a vehement message to the world that it was henceforth unacceptable for discussions to be held regarding the issues of disabled persons without their thorough and equitable participation (Flood, 2005, p. 184). A sober analysis of the status of the disabled population across the world reveals, however, that this principle remains one which is commonly flouted (Hurst, 2005, p. 77; Hahn, 2002).

In terms of sheer numbers, the disabled community's lobby for the creation of societies which are barrier-free, and which outlaw prejudice, is clearly destined to swell considerably over the coming decades. The world's population is ageing, due to shifts in patterns of reproduction, and advances in medical technology and access to safer resources which increase longevity. A striking incongruity within the construction of disability in contemporary society as "other" is the fact of age-related impairment somehow "escaping" the devalued disabled identity. According to Pope and Tarlov (1991), the average individual who achieves the age of 75 will experience some form of limitation due to impairment for 13 of those years (Pope & Tarlov, 1991 cited in Marks, 1999a, p. 136). And yet somehow, it seems, the fact of ageing being our universal human fate has led to the cultural fashioning of an artificial gulf between the "real" disabled, and the (honorary) "normals" who are merely "old". The issue of culturally condensed meanings buttressing the disabled identity will be examined in more detail later (see *Culture and prejudice*, p.147). For our present purposes, though, the WHO predicts that

by 2020 the planet will house more than 690 million people over the age of 65, in comparison with the estimated 380 million of 2002 (Davis, 2002, p. 4). Of course, this massive inflation in the elderly population will radically change epidemiological patterns and health care needs (ibid.). Of key interest is the extent to which the reality of world ageing impacts upon governments as well as citizens, in mobilising change toward societies which are more accessible to persons with impairments. The ageing of the planet's population may, if used strategically, be instrumental in repositioning disability experience as a universal variable, rather than an alienated, binary "other".

In this opening chapter, I have sought to sketch the centrality of the body in cultural ascription, as well as to outline some prominent elements of the development challenges which the world faces regarding its disabled population. We turn in Chapter Two to a consideration of ways of thinking about disability, along with the respective consequences and implications which each approach ushers in.

## CHAPTER TWO

### **Disability theory I: The body, ideology and society**

For centuries, people with disabilities have been ... isolated, incarcerated, observed, written about, operated on, instructed, implanted, regulated, treated, institutionalised and controlled to a degree probably unequal to that experienced by any other minority group.

(Davis, 1997a, p. 1)

#### **Introduction**

The stark reality reflected in the quotation above – of the omnipresent nature of the oppression and repression of disabled people – is surprising when juxtaposed with the observation that, to much or most of the world's populace, the mere association of the notion of disability with oppression would seem surprising, even incongruous. Whilst we are well accustomed to the idea that race – and more latterly gender – are axes of discrimination and unjust disadvantage, the association of the words "disabled" and "oppressed" remains, in common sense accounts, a yet un-established one (Watermeyer & Swartz, 2006, p. 1). Instead, disability remains understood as personal misfortune, with social consequences which, while regretted by all, are considered "natural" and largely immutable. The slippery, invisible nature of social oppression based on disablement in contemporary culture is highlighted by Olkin (1999). For the sake of argument, she asks us to call to mind the restaurants we have visited which are not accessible to wheelchair users. Of course, if one frequents restaurants, these are plentiful. We freely patronise these establishments, which bar access to mobility impaired people; yet, how would we feel about patronising restaurants which did not serve Jewish or black people? Of course, to most thoughtful people, this would feel deeply "unpalatable". Yet, we inhabit and calmly support the perpetuation of societies which are drenched with discrimination, in terms of practices, assumptions, built environments, prejudices and innumerable careless, yet unqualified, exclusions.

Until relatively recently, the seeming unawareness and muteness within society surrounding this reality was largely mirrored within academic discourse. Indeed, Abberley (1998, p. 80) remarks that "the most common response of modern social theory to the disabled person's inquiry 'what about me?' is *silence*" (my emphasis). We shall, over the course of this chapter, meander through many of the important theoretical contributions that have expressly aimed to tackle the disability phenomenon, but it should be noted that these accounts exist against a backdrop of social disciplines within which disablist oppression has been largely ignored. For example, the feminist movement, whilst formulating an ever more incisive critique of the cultural origins of unequal gender relations, has largely failed to relate such critique to the predicaments of disabled women (Thomson, 1997b, p. 19; 1997a; McLaughlin, 2003; Thomas, 1999a). This is made that much more remarkable by the fact that, for feminists, it is the body which has been regarded as the major arena for political contestation (Wendell, 1997, p. 260; Meekosha, 1998). Nondisabled feminist scholars at the epicentre of critical theorising have perpetuated a neglect of the oppression of disabled women, constructing them as "childlike, helpless and victimised" while symbolically – and at times manifestly – ostracising them from feminist ranks, in order to promote "more powerful, competent and appealing female icons" (Thomas, 1999a, p. 66).

The explanations we carry for the underprivileged situations of social groups (such as racial or ethnic), I suggest, are informative as to our internalised prejudices regarding members of those groups. The lack of critical engagement with the social marginality of disabled persons has meant that culturally condensed assumptions regarding the origins of that marginality have, like racial stereotypes, largely remained manifest in an invisible hegemony. In other words, our socialised understandings of what disability is and does remain, for the most part, uninterrogated, inadvertent, and hence largely invisible. "Socialisation" here denotes meanings and prejudices regarding disabled persons which, in their unquestioned state, masquerade quite convincingly as common sense – that is, as essential, self-evident and unremarkable truths. Typically, these common-sense accounts reflect an "individual model", which portrays the social marginality of disabled people as "unfortunate", but *ideologically neutral*.

Priestley (1998, p. 75) provides a matrix of ways of thinking about disability which incorporates two key dichotomies, viz. individual versus social accounts, and materialist versus idealist positions. Examples of theories of disability (both formal and colloquial)

which apply an individual unit of analysis are approaches which are concerned with biological and medical aspects, or with identity and the management of social roles at an individual level (ibid.). Individual accounts may be materialist or idealist in their emphasis – in other words, prioritising either the physical or psychological concomitants of bodily impairment. Examination of more socially oriented models shows analogously that some are preoccupied with material and structural aspects of society, while others foreground cultural representations of disability (Priestley, 1998, p. 75). The paradigmatic roots of these orientations reflect an enduring debate within sociology, between materialist (often Marxist) analyses, emphasising the influence of the economy upon culture, and idealistic standpoints, rooted in the work of Max Weber, which argue the converse (ibid., p. 76). What is noteworthy for our purposes is that Priestley's (1998) taxonomy allows, at best, an awkward space for accounts of disability which attempt to relate social phenomena with *psychological* aspects. That is, it seems that analyses which focus on the psychological realm are, in his view, necessarily "individualistic".

What the foregoing means is that no theoretical "bridge" has thus far been created which attempts to connect ideology – the societal realm of beliefs and practices – with the subjectivity of the individual. Hitherto, accounts of the psychological aspects of disability have tended to lack a critical ideological "situatedness". It is possible, in fact, that Priestley and others believe that an account of disability which focuses on individual psychological phenomena could not, by its nature, satisfy the requirements necessary for qualification as a critical, contextual – and hence politically useful – theory. The current work calls this assumption into question, through aiming to develop bi-directional conceptual links between culture and individual subjectivity, via the mechanisms of lifelong socialisation. Put simply, the question posed here pertains to whether it is possible to think about the psychological experience of disability, whilst retaining a rigorous analysis of the political context of disability discrimination. Typically, and as demonstrated by Priestley's taxonomy, these strains of theorising have, in the past, tended to be mutually exclusive.

Before beginning to build the parameters of a position which attempts such a synthesis, we turn in the following sections to an examination of the two broad and opposing views of what disability is about; that is, the so-called "medical" and "social" models of disability.

## The "medical model"

The development of modern Western medicine has, over the course of the past one hundred or so years, heralded the predominance of a philosophy of health and illness which is centrally preoccupied with the "scientific" investigation and treatment of the body. Within this dominant *biomedical model* of health care practice, the prevailing epistemological hierarchy dictates that biology is prized above all else as an explanatory paradigm (Feinstein cited in Good & Delvecchio-Good, 1980, p. 165; Kleinman, 1987, p. 450). What this means is that the predominant, indeed overwhelming, focus of modern medicine over the course of the last century has been the identification and (attempted) "correcting" of structural or functional difference or defect within the body. In the words of critics such as Engel (1977, p. 130), though, this orientation "leaves no room within its framework for the social, psychological and behavioural dimensions of illness". A growing current of this form of criticism has emerged, notably from writers in the discipline of medical anthropology, who, like Engel, view the stance as ideologically problematic and impoverished due to its failure to take account of the socio-political environments within which illnesses are experienced (Kleinman, 1986; 1987; Swartz, 1999).

Within academic writings more specifically concerned with disability, what has come to be termed the "medical model of disability" – rooted broadly in biomedicine – has endured a barrage of critique for its failure to interrogate the context of societal responses to impaired bodies which serve to systematically exclude and disadvantage individuals socially positioned as "disabled" (e.g. Abberley, 1996; Barnes, 1990; Barnes & Mercer, 2005b; Barnes, Oliver & Barton, 2002a; 2002b; Lunt, 1994; Marks, 1999a; Oliver, 1986; 1990; Thomas, 1999a). Whilst these authors would argue that biomedicine at large responds inadequately to the unique, socially situated aspects of all illness, it is the disabled population who are placed in particularly nebulous predicaments by virtue of its principles.

Disability, as was seen in the previous section, connects bodily difference with pervasive and often severe social marginality. Paul Abberley encapsulates the point elegantly: the so-called "medical model", he writes, "functions to link together the experiences of an individual in a logic which attributes disadvantage to nature" (Abberley, 1996, p. 62). In other words, the deeply institutionally entrenched prioritisation of "biological realities" within biomedicine serve to focus attention on body difference as a mode of attribution for social marginality,

whilst circumventing a consideration of oppressive socio-political factors. In this way, the social disadvantage experienced by disabled persons becomes viewed, perhaps by a sort of default, as the inevitable outcome of intra-individual, impairment related factors (Thomas, 2002a, p. 40). A potential consequence is the papering over of the layers of unnecessary and systematic disadvantage inflicted upon disabled persons by societies unready and unwilling to implement appropriate accommodations. Of course, it is unsurprising that professionals trained in the biological functioning of the body, rather than in social critique, are drawn to prioritising somatic factors in making sense of disability. Medical practitioners tend toward a preoccupation with the body, with "dialectically exploring the relationship between symptom and somatic disorder" (Good & Delvecchio-Good, 1980, p. 165), rather than with the interrogation of societal formations. Brisenden (1986) comments that, as long as disability experience remains examined within institutionally embedded concerns surrounding its medical implications, it will tend to remain largely viewed as an issue of physical or intellectual dysfunction, with all other aspects receding in salience (Brisenden, 1986 cited in Johnson, 1993, p. 620).

Through portraying the (marginal) lives of disabled persons as a function of bodily difference, a form of subtle depoliticisation of struggle becomes propagated. Construing disadvantage as the consequence of defective bodies obviates a critique of social institutions and cultural formations which underpin the contravention of the citizenship rights of disabled people. Instead, deprivation rooted in the maldistribution of resources becomes viewed, even by the disadvantaged, as the result of individual deficiency (Abberley, 1987, p. 17; French & Swain, 2001, p. 736). Tacitly, and often by omission, the denial of access to full participation by disabled persons in the business of cultural production is affirmed and justified, absolving the social order from accountability for its careless brutality. The "damaged" body is excised from its context of power relations and capital exchange, thus exculpating the political order from responsibility for "social suffering" (Kleinman, Das & Lock, 1997). Similarly, "curative" medical intervention which "problematizes" bodies tends to deflect attention away from those aspects of societal life which cause illness and impairment, thus precluding the indictment of modes of production and exchange which may be harmful or damaging to individuals (Abberley, 1987, p. 10; Csordas, 1988, p. 416; Oliver, 1986, p. 16). Further, Marks (1999a) points to what she terms the "curative zeal" of much Western medical practice. Here, medicine's bodily preoccupation with "repair" leads to the proliferation of a culture of "normalisation", in which the imperative to correct places those with "irredeemable" bodily differences in a questionable moral light (Marks, 1999a, p. 75, Hughes, 2002a). The

disciplinary regulation of bodies exercised upon all by modern health care (Foucault, 1976), therefore, is brought to bear more acutely in the lives of disabled persons (Marks, 1999a, p. 75; Brisendon, 1998).

Telling evidence of the moral imperative to "healthy normalcy" is to be found in public health campaign messaging, which regularly depicts disabled persons as the negative consequence of "unhealthy" actions or lifestyles (Lollar, 2001, p. 754). Importantly, the clinical encounter between health practitioners and disabled patients has historically been one of asymmetric relations of power, where the professional voice of medical authority has often been deferred to. French (1994a) characterises this "traditional" encounter as one in which health workers have "defined, planned and delivered" health services, while disabled persons remain "passive recipients with little if any opportunity to exercise control" (French, 1994a, p. 103).

The attribution of this highly criticised "medicalising" mode of practice to health care professionals has, understandably, come to be experienced as a stereotyping affront, which tends to paint all health care workers as equally blameworthy. Clearly, it is reasonable to assert that the disabled community has historically had good cause for vigorously problematising modern medicine's inattention to factors such as discrimination and systematic exclusion in shaping their lives in society. Yet, this reality has at times led to a destructive, simplistic and over-zealous vilification of medical professionals en masse. The term "medical model" seems, logically, to be one intended to apply to "medicine" in its entirety, and for this reason it has come to be experienced as a slur (Shakespeare, 2006, p. 18). Furthermore, since the term was coined largely to describe a critique, it is – unsurprisingly – not possible to find anyone who chooses publicly to espouse the "medical model" view (ibid.). Oliver (1996) concurs, preferring the broader category of "individual" models of disability, of which medicalisation forms one significant element (Oliver, 1996 cited in Priestley, 1998, p. 75).

My own view is that the term is most usefully thought of in the medical encounter as denoting a particular clinical stance which, *to a greater or lesser extent*, may permeate health care practice. Thus, it is not "medicine" per se, but rather a mode of "performing" medicine. The essence of this mode of practice embodies operating within an uninterrogated myriad of signs, overt communications and embedded assumptions – an entire "curriculum" of meanings –

which surround the idea of bodily impairment as central signifier and causal variable in shaping social destiny. That is, a symbolic and manifest foregrounding of bodily difference occurs, typically flanked by meanings such as loss, damage, defectiveness, dependency, and the mandatory, moral striving for normalcy – for "cure". However, the idea of the primacy of the body as prescriber of role and status within society is not exclusively that of health professionals.

The assumption that it is bodies that shape the social lives of disabled persons is one typically deeply internalised by practitioner and patient alike, by virtue of shared cultural socialisation. In this sense, the idea of a "medical model of disability" has relevance as a colloquial, common-sense view of what disablement means, in addition to its usage as an idea pertaining particularly to medicine. All who have grown up in a racialised society have inevitably internalised differential conditioned responses to individuals of different racial groups, depending on the subtle or overt meanings and associations surrounding experiences of racial difference – perhaps particularly during the early years of life. Analogously, what the critique of the "medical model" usefully points towards is that store of meanings and attributions which we have, similarly, accumulated regarding bodily difference and disability, via cultural representations of loss and damage, the internalised meanings of segregation, and the like. These assumptions may seem invisible, as they remain well cloaked as "common sense". Yet, honest self-exploration may reveal powerful, culturally condensed assumptions regarding what impairment "does"; and why it is that disabled people deserve our empathy for their "suffering". Primarily, this socialised view surrounds the idea that disabled people suffer shame, incapacitation, deprivation and helplessness emanating from the fallibility and brokenness of the body; not from discrimination, social oppression and systematic exclusion. Disabled people, hence, need "cure" – and care – not political representation or social reform toward equitable access. The "problem" of disability is one of damaged bodies, not damaging societies. In this sense, we may broaden the view of the "medical model", to incorporate our shared legacy of embedded, inadvertently prejudiced and misleading assumptions about what disability means. The model, in this view, is not "medical" because of its association with health care, but rather due to its broad, culturally based "medicalising" logic. It is this logic which one would be most likely to apprehend amongst average citizens on an urban street corner – a logic which associates "disability" with medical "problems", to the exception and detriment of any consideration of oppressive social "ills".

Thus, the picture which emerges is one of a raft of culturally condensed assumptions regarding what is definitive within the lives of disabled persons. Pervasive associations of loss, compassion, shame and misfortune ensure that it is intractable "medical" issues which remain perceived as central to disabled lives. Medical practitioners are typically located within long-established health care systems and installations which, by their nature and design, tend to direct attention toward the biological, and provide minimal or awkward spaces for consideration of socio-political aspects of disabled lives. These issues will be expanded upon in a later section (see *Medicalisation as a defence*, p.107). We turn, now, to an examination of the disability movement's attempt at presenting a viable, emancipatory alternative to the medicalising view of disability.

## **The "social model"**

Proponents of the so-called "social model of disability" emerged in Great Britain during the 1970s, as disabled persons bearing an overtly adversarial and challenging response to the dominance of biomedical accounts of disability. Their vehemently held, revolutionary position was founded upon the conviction that it is the *selective inattention* of social systems to the participation-needs of individuals which is at the root of the marginality and deprivation experienced by disabled people (Abberley, 1987; 1996; Barnes, 1990; Oliver, 1986; 1990; Swain et al., 1993). The exclusion of disabled persons from full participation in all aspects of social life, according to this radical position, is an entirely avoidable artifact of oppressive ideology, rather than part of the inevitable "sequelae" of bodily difference or dysfunction (as held by the traditional medical view).

In embarking upon a searing critique of prevailing modes of thinking about disability, which directed attention instead toward a critical interrogation of society, these authors began by drawing a key conceptual distinction between the notions of "disability" and "impairment". Within the new schema, "impairment" was defined as a narrow, medical account of difference or dysfunction of the body or its systems. Separating off this "diagnostic", somatic layer paved the way for a new, inherently subversive account of what composes disability, which was designed to bring the ideological mediation of disabled lives firmly into relief. Whilst social model definitions of the "narrow" and theoretically specific concept of disability have varied, this variation has been slight, and merely the result of ideas and wording being fine-tuned over time. This example of such a definition is typical, and instructive:

Disability: The loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers.

(Finkelstein & French, 1993, p. 27)

In separating out these concepts, the architects of the social model inverted the prevailing logic on disability. Instead of the bodies of disabled persons being placed under the microscope, the new subject of interrogation became society itself – the complex, layered world of "barriers", be they cultural, physical, legal, institutional, or whatever, which obstruct impaired individuals from full and equitable participation. So, in the minds of the social modelists, would begin a long and intricate process of unpacking society's multifarious, distorted, and disadvantageous responses to persons with impairments. From the stubbornness of prejudiced myths, to the sweeping narrative of socially engineered segregation; from rehabilitation, normalisation and control, to the demeaning exploitation of the freak show; from educational and occupational exclusion, to the alienation engendered by a physical environment racked with unnecessary barriers; such aspects as these are the subject matter of the model's cross-examination. The social model, in contrast to the scientific "crispness" of medical attributions for the marginality of disabled persons, directs complex, testing questions at the social order, seeking out multifaceted and layered answers embedded within the very fabric of society's organisation. A notion of disability with the concept of social oppression at its epicentre had begun to move into view (Abberley, 1987, p. 5). To "be disabled", within this theoretical position, was to be identified as subject to a "complex system of social restrictions" inflicted upon persons with impairments by "a highly discriminatory society" (Abberley, 1996, p. 61).

Advocates of the new social approach vociferously demanded that attention be drawn toward how so-called "normal" human modes of living are structured and constrained by an inherently discriminatory societal context; one which is designed and constructed with exclusive consideration of the needs of non-impaired persons (Abberley, 1996, p. 61). Correspondingly, the ostracisation and systematic deprivations experienced by disabled persons within contemporary society remain justified and entrenched by medically and culturally sanctioned – yet illusory – notions of normalcy and aberrance (Braddock & Parish,

2001, p. 13). In launching a fierce attack on the role of biomedicine in the perpetuation of "individualising" accounts of disability, social model theorists branded the medical approach a "personal tragedy theory" (Oliver, 1986, p. 16). What was meant here was that modern medicine's somatic preoccupation created a meaning system surrounding disability which reduced what were, in fact, complex and atrocious societal ills, to chance personal experiences of misfortune. Furthermore, medicine's subtly depoliticising sleight of hand created the illusion of immutability around disability struggle, in a manner which obviated societal accountability for human rights violations which were – in the social model schema – entirely avoidable (Barnes et al., 2002a, p. 5). Oliver (1986, p. 16) locates this "personal tragedy theory" of disability as one "victim-blaming" model amongst many others, all serving the purpose of obscuring the political and economic structures which underpin social oppression. Examples of such "deceptive" accounts of social phenomena include the use of deficit theory to explain poor scholastic performance, character weakness as a cause for poverty, or sickness as an explanation for criminal behaviour – in each case, individuals are condemned as deficient, to the detriment of social critique (Ryan, 1971 cited in Oliver, 1986, p. 16). The onus for dealing with "deficit" is, via such understandings, placed on the individual. Thus it is that, notwithstanding what Imrie (1998, p. 129) describes as the "design apartheid" of Western cities, mobility impaired persons are required to "confront" and "deal with" built environments riddled with impossible obstructions (Imrie, 1996).

As will be explored later, the social model was not without its conceptual shortcomings. Nevertheless, its radical re-focusing of attention upon modes of exclusion served, and continues to serve, an extremely valuable purpose in facilitating personal recognition amongst disabled people of the everyday contravention of citizenship rights (Thomas, 1999a, p. 26). It is the hegemonic nature of such aspects of one's life-world that may cause even quite palpably oppressive contradictions to remain, until consciously questioned, cloaked in a disguise of familiarity. The social model provided a device capable of transforming a domesticating and unjust self-blame into rightful outrage at one's unnecessary exclusion; the social model message was a clarion call to political action.

The advent of the social model repositioned disability as a temporally and contextually specific phenomenon; not a "natural" or "essential" aspect of being (Marks, 1999a, p. 76). Thus ran the logic: if disability is a social accomplishment – an artifact of the arbitrary neglect of the needs of impaired persons – then an optimally accessible society is feasible, within

which impairment may be present *without* disability. It is at this theoretical juncture that the original, roundly materialist version of the social model approach – described by Priestley (1998, p. 80) as a "social creationist" view – begins to intersect with a more social constructionist interpretation of the model. Within the social constructionist philosophical position (Berger & Luckmann, 1966; Gergen, 1985), reality is viewed as intersubjectively socially constructed (Lunt & Thornton, 1994, p. 226), situating "disability" as an illusory cultural artifact. The distinction between these deeply interwoven orientations is one of emphasis, with the Marxian historical materialist genealogy of the original social model position being primarily concerned with economic relations of production and exchange, rather than cultural representations.

A more constructionist orientation may, *inter alia*, focus on the buttressing of social identity via processes of "othering", which compose identity as pairs of binary oppositions, offering the opportunity for the affirming of one's favourable status in opposition to a denigrated "other" (e.g. Tajfel & Turner, 1979). Oliver (1990) notes that "there can be no such thing as madness without the idea of 'unmadness'", or "reason without unreason" – it is in the moment of positioning oneself as the favourable, unblemished "opposite" that pathology and deviance become exclusively located within a devalued "other" (Oliver, 1990, p. 47; Foucault, 1995). Thus it is, continues Oliver (1990), that the notion of disability as an individual pathology only becomes feasible upon formulation – and reification – of an idea of "individual able-bodiedness" (Oliver, 1990, p. 47). Here we find that, despite the staunchly materialist leanings of the early social model theorists, the psychological realm must begin to be brought into view, as we consider individual, psychic needs for the disavowal of unwanted or feared aspects of the self. Cixous and Clement (1975; 1986) regard the need for the reaffirmation of one's positive identity distinctiveness via the denigration of its (constructed) social counterpoint as so intrinsic to psychic functioning that "if there were no other, *one would invent it*" (Cixous & Clement, 1975; 1986 cited in Kitzinger & Wilkinson, 1996, p. 8 – my emphasis). It is a central aim of the current investigation to begin the work of creating a synthesis between social and intra-psychic levels of analysis of the disability phenomenon. The lack of conceptual space for an integration of psychological aspects within the social model approach has, in my view, foreshortened the model's relevance and impact, through affording only a partial capacity for the reflection, and hence validation, of disabled life.

Finkelstein (1980) argues that the bureaucratic delineation of citizens into the binary categories of disabled and nondisabled, with profound consequences for participation in all aspects of social life, was catalysed by the labour demands of early industrialisation in Europe. New and ever more highly differentiated patterns of division of labour arising during the industrial revolution led to imperatives to measure, categorise and separate out those with different or compromised capacities to participate in production. Over time, these roots of division solidified into increasingly structural segregation, the rise of institutionalisation, and the entrenchment of a myriad of constitutional elements which situated disablement as an axis of discrimination (Barnes, 1990, p. 10; Finkelstein, 1980). The nature of the social predicaments of disabled persons during mediaeval, pre-industrial times is an issue of some dispute. Historiographical accounts of the premodern disabled world range from an idealised view of an integrated, diverse society, uncontaminated by the distortions of capitalist markets and production (e.g. Finkelstein, 1980), to reconstructions which portray disabled lives as characterised by unmitigated hardship, ostracisation, deprivation, and death (Winzer, 1997; see also Borsay, 2002).

Henri-Jacques Stiker (1982), within the Foucaultian discourse analytic tradition, adds a further contextualising layer by associating the horrors of "the war to end all wars" with the rise of modern biomedical rehabilitation, and the drive to "normalise" disabled bodies (White, 1995, p. 267; Stiker, 1982). The catastrophic devastation during World War I of the material and cultural stuff of which society was composed was mirrored, macabrely, by the multitudes of distorted and damaged bodies to be re-incorporated into an ailing social world. A fervent need, in Stiker's terms, for belief in quasi-magical repair found form in prostheses, and quickly generalised to a dominant notion of people – and society at large – as "machines" amenable to reconstruction and restitution (ibid.). Such projects of reconstruction, however, inevitably became directed toward an illusory, idealised fantasy of what came before the apocalypse – a perfect, harmonious society, populated by pristinely shaped and functional bodies. Biomedical normalisation, and the submission of the "docile body" (Foucault, 1979) to the "rehabilitating" gaze of medicine, was born. Stiker carefully distinguishes between the notion of "cure", which he defines narrowly in relation to health, and the profoundly ideological actions of normalisation and re-integration, which exert forces of uniformity and control at the social level (Stiker, 1982, p. 141). Correspondingly, proponents of the social

I model, whilst virulently critical of medicine's "normalising" imperatives, reiterate that their view does not preclude the appropriate implementation of health care interventions where needed (Oliver, 2004 cited in Momin, 2005, p. 65). On the contrary, states Oliver and others, the denial of such services should be viewed as a contravention of citizenship rights (ibid.).

Varying historical factors within the United States of America and the United Kingdom led, during the course of the second half of the twentieth century, to contrasting disability rights movements. In the USA, the diversity of the population, and the rise of the civil rights movement during the 1960s, contributed to a disability lobby whose strategic emphasis lay in litigation, and the promise of anti-discrimination legislation (Hahn, 2001, p. 59). The Americans with Disabilities Act of 1990 was the culmination – albeit a deeply disappointing one to most – of this approach. Many view this tactical manoeuvre, known as the "minority model" view (Hahn, 2001, p. 62; Olkin, 1999), as one which fragmented the disability issue into the legal ramifications of the cases of individual litigants, diffusing the potential impact of a mass challenge to the status quo. Conversely, the roots of the British movement, based as these are within a tradition of Marxian class politics, fostered a brand of disability struggle which foregrounded the economic hardships of disabled persons, in a manner which situated such struggle within differential access to the means of production (Hahn, 2001, p. 59). The original social model aimed, thus, to forge an attack on social disadvantage based in group solidarity, and a rigorous – at times orthodox – adherence to theoretical "policies" on the "real" nature and origins of disability. Both viewpoints, though, have faced massive obstacles to liberation and progress (Hahn, 2001, p. 59). Not least of the social forces retarding the propagation of a fresh, emancipatory view, is the fact of disability in the developed world as a multi-billion dollar industry, incorporating an elaborate web of professional, organisational and cultural concerns (Albrecht & Bury, 2001, p. 586).

One strand of the orthodoxy attributed to social model theorists pertains to the (at times) acrimonious controversies concerning terminology. One significant quarrel amongst many others is that between advocates of so-called "people first" language (preferred within the US "minority model" tradition), and UK-based social model theorists who volubly denounce this usage (Albrecht, Seelman & Bury, 2001, p. 3; Stone, 1999). "People first" language is of the form of "persons with disabilities" rather than "disabled people"; it is intended to recreate the idea of disability as one human characteristic amongst others, not something inherent and all-encompassing. In addition, the usage interfaces with an American capitalist emphasis on the

importance of the individual within society, and concurrently with the US disability movement's opting for a litigation-based counter-oppression strategy (ibid.). Social model authors favour the term "disabled people", here connoting the anti-medicalising idea of "people who have *been disabled* by society". These writers testily assert that "people first" language naively accommodates the prevailing cultural impression of disability as a defective aspect of the individual, rather than an exogenous social force.

The project of re-authoring the disability concept as a shared, group-based characteristic of oppression, in opposition to the splintering, diversifying medical view, involved the adoption of a certain "strategic essentialism" (Thomson, 1997a, p. 283); the (initially) self-conscious illusion of homogeneity amongst members of the disability movement. Hence, the need to underscore a common predicament led to the papering over of a mosaic of diverse experience, of both societal and bodily origin. The reluctance of social model adherents to engage with the confounding multiplicity of impairment within their ranks was later to form the thrust of a key critique of their standpoint. Interestingly, this criticism of social modelist zeal – of which there will be more detailed discussion later – brings the wisdom of an early disability studies pioneer, Irving Zola, into clearer relief. Zola, ever cautious regarding the distorting influence of political expediency, proposed a model of disability as a continuum, rather than a categorical absolute (Altman, 2001, p. 100; Williams, 1998; 2001; Zola, 1988).

Within all social movements bent on uncovering and delineating suffering, as well as directing accountability at those elements within society held to be responsible for such troubles, disputes over "politically correct" terminology seem ever-present. Sinason (1992) argues that the constant flux and change in what nomenclature is "permissible" relates to the intolerable nature of those unconscious evocations (within the observer) with which such provocative ideas as disability are associated (Sinason, 1992, p. 42). For her, the clamour of shifting positions regarding the acceptability of terms for sexual orientation, mental illness, race, disability, and the like, reflects an obsessive, insatiable hunger for euphemisms able to momentarily thwart the reality of human difference (ibid.). The wish to deny such difference, always only temporarily gratified, recreates the need for new ideals, and new villains – the world of learning disability (or, mental handicap / intellectual impairment / mental retardation) is an instructive case in point. The lack of flexibility and nuance which characterises the social model will, along with a range of related criticisms, be considered in the following three sections.

## Criticising the social model

It was perhaps inevitable that the social model's historical materialist philosophical foundations would, in the effort to galvanise political action, fall short in the task of accurately mirroring a complete portrait of the experience of disabled personhood. The motivation behind the social model was, first and foremost, one of catalysing resistance and revolution; clearly an approach which does not lend itself to nuanced, finely toned representations of social reality. It is, of course, in the nature of revolutionary movements that the outrage of oppressed peoples be harnessed via the over-simplified – even crude – drawing of binary distinctions between villains and victims, in a manner which tends to reify and homogenise both groups. At a psychic level, the defensive distortions of "splitting" (in the Kleinian object relations tradition of psychoanalysis), seem elemental here, drawing all, to a greater or lesser extent, into the reverberating snares of simplified divisions between self and other (Klein, 1946).

Critics of the early social model pointed to a host of questionable assumptions made by its authors. In order to argue for a consistent, oppressed predicament afflicting all disabled persons, it was essential that the rubric "disabled people" be defined in such a manner as to foreground commonality – a commonality rooted in the shared experience of oppression (Oliver, 1990). However, this forced alignment of experience was to evoke a steady stream of objection, notably from feminist disability scholars (e.g. Morris, 1989; Thomas, 1999a; Wendell, 1996). At issue was the differential (though inconsistent) impact of a range of superimposed social identities upon the nature and degree of marginalisation experienced by disabled people (Marks, 1999a, p. 87).

In a manner analogous to the narrowly white, middle class and Western assumptions which (problematically) shaped early feminism, social model theorists were accused of reducing the experiences of a richly diverse disabled population to the common denominators of their own lives; that is, the experience of middle class, male, white, Western wheelchair users (ibid.). A model of disablist oppression forged exclusively within this sub-community, would not be well placed to illuminate the struggles of disabled members of ethnic or sexual minorities (Begum, Hill & Stevens, 1994; Shakespeare, Gillespie-Sells & Davies, 1996), or, indeed, of

disabled persons with vastly different impairments (notably of a sensory, psychiatric or intellectual nature; Crow, 1992; French, 1993a; Morris, 1991). Instead of some amalgam of oppression and impairment, the social model's exclusive focus was vigorously directed at material "barriers" to inclusion, and, at that, the "barriers" experienced by a specific subset of impaired persons. The need for an adversarial counterpoint to medicine's individualising account of disability had wrought a theoretical picture with a limited ability to tolerate the uniqueness of individual experience. Such evidence of diversity would come to be regarded as a contaminant to the forceful purity, the clarity, of a credible and unified movement. Exploring the unique aspects of disabled experience might, in the minds of the social modelists, leave the movement vulnerable to a regressive confirmation of the "individual" nature – and origins – of the marginality of disabled persons. If entertained, such depictions of disability would quickly be misappropriated in buttressing precisely those medicalising views which the social model aimed to dismantle. As we shall explore, the "personal" was to be prohibited.

Recognition of the partial, strategic image of disability which the social model prism allows, has led some authors to allege (or concede) that the model should never have been regarded as a "theory" in the first place, but more as a political device. Carol Thomas (1999a) considers the model an essential conceptual point of departure, but one which "poses rather than answers important theoretical questions about disability" (Thomas, 1999a, p. 26). At the very heart of the social model is the "disability" versus "impairment" binary – relying upon the proposition that culture has no corporeal substrate, and that a pristine, presocial body exists before and beyond social construction. It must be reiterated at this point that, notwithstanding its imprecision, this schema has contributed immensely to the liberation of minds, through its interrogation and exposing of disadvantage. The social model defied the hegemony of acquired wisdom, and ripped into a store of suffering and atrocity which was hitherto directed at the self, or branded as deviance. Without the model, this sea change would not have occurred. Now, though, it seems that the resultant psychosocial debris which has been exposed is too complex, too tangled between society and soma, to be adequately dealt with in rude dichotomies. Shakespeare (2006), in a blistering assault on the British social model "establishment", describes the model's key insight as "important and unarguable", but latterly having evolved into a rigidly held, ossified, and crudely misleading ideological orthodoxy (Shakespeare, 2006, p. 01). The essence of this "dogma" lies in the declaration that disability is *everything* to do with social barriers, and *nothing* to do with individual impairment" (ibid. – my emphasis). In contrast, however, a number of disabled authors relate how unclear the

origins of their struggle appear – decidedly not entirely impairment-based, but also not entirely socially produced (e.g. French, 1993a). Despite this, it must be recognised that many of these writers would profess that their personal journey toward an understanding of disability as an axis of oppression has been – transformatively – driven by the social model.

Sally French, a partially sighted woman, describes vividly how her life has been shaped by discrimination and unnecessary exclusion based upon her impairment; yet she also points out how a layer of her life's difficulties lies "in between" her body and society. This layer of experienced struggle is not reducible to her impairment, but is also not amenable to social intervention. For example, her inability to recognise people, though spoken of assertively in relationships, nevertheless constructs dynamics of misunderstanding or misattunement which disrupt or confuse easy relating (French, 1993a, p. 17). She points to the danger of a rigidly held assumption that, if disability is reducible to social barriers, scrupulous removal of those barriers will render a Utopian society of complete equity and equality. One arena in which this dangerous illusion may arise is that of assistive technology. French (1993a) relates how, as a student, she required assistance in identifying and finding literature from librarians at her university, as library data-bases and cataloguing systems were inaccessible to sight impaired persons. Later, and, it seems, with not a little fanfare, the university installed a computer data-base system within the library which incorporated voice synthesis technology, for use by visually impaired students or staff members such as herself. Enthusiastically, though tacitly, endorsing the social model "fantasy" of disability being an entirely eradicable social artifact, university authorities proclaimed that "henceforth" visually impaired students had full and equal access to the means of performing library research. This was, in the experience of French and others, quite untrue.

In what is by now a familiar paradox, the installation of assistive technology never fully fills the diverse and complex needs of a highly varied impaired population; but what does occur is that the entitlement of such individuals to personal assistance is abruptly diminished (ibid.). Of course, none of the foregoing is intended, in any way, to question the need and imperative for the provision of all forms of assistive technology which promote equitable access; indeed, the neglect of implementation of such universal access embodies a contravention of human rights. And yet, the argument that provision of a "barrier-free" social environment will provide fully for the needs of an infinitely diverse impaired population, is a dangerous myth. It is the *modus operandi* of the social model strategy to foist every fragment of struggle

experienced by disabled persons onto societal neglect and exclusion. And, of course, the pervasiveness and extent of the atrocious, dehumanising circumstances under which a vast population of disabled people live worldwide, lend a good deal of sense and credence to this approach. This drive toward a dogged resolution that all disadvantage is due to social barriers is an irate reaction to a world where the prevailing logic is unable – or unwilling – to resist gravitating toward the "failings" of the body. Routinely, the assertion that inherent lack will always prevent "complete" overcoming of inequity becomes an underhanded, convenient justification for the everyday atrocity of avoidable societal barriers remaining unaddressed. The logic here is one which says that "we can't change society to suit everybody ... everybody's needs are just too different", or "it will cost too much". The fact, thus, that a residual layer of "impairment effects" (Thomas, 1999a) will always remain, is thus used as a rationalisation for doing nothing at all.

In sum, Shakespeare (2006, p. 5) argues that, since the disability-impairment distinction is at the root of the social model, and its logic is unsustainable, for him the model should be abandoned. The "ivory tower" created by British social model authors has, he believes, led to the impoverishment of disability studies as a discipline, as such writers have been very reluctant to recognise or integrate disability research from other parts of the world, due to its not subscribing to a "rigorous" social model philosophy. Important and potentially useful work has, on the basis of "politically incorrect" terminology such as the "people first" principle, or adherence to the maligned ICIDH2 (Bury, 2000), been rejected or demeaned. Researchers who have suffered the ire of the staunch British social model school – in this case in the person of Colin Barnes – include figures as important as the American theorists Harlan Hahn, Susan Wendell and Lennard Davis; they, too, have found themselves relegated to the research junk-heap labelled "medical model" (Shakespeare, 2006, p. 24). The labour politics roots of the British social model movement, for Shakespeare (2006, p. 13), show up in the "hard, combative and ideological" methods which its champions employ. The resolute belief at work here is that "progressive approaches are impossible in the absence of the social model", and that only individuals who overtly endorse the social model are capable of "respecting [the] rights and individuality", and "promoting inclusion" of disabled persons (Shakespeare, 2006, p. 27). In its orthodoxy, the social model is "alone amongst political movements", in allowing no revision or acceptance of critique; instead, it remains "like a fundamentalist religion" (*ibid.*, p. 34). Lee (2002) notes how the often simplistic applications of the social model promote an "underdeveloped" politics which "inhibits the development of realistic strategies" (Lee, 2002, p. 148). The model's disdain for all things personal precludes

what Lee (2002) terms "a politics of individual actions and interventions" (ibid.), which does not simply tolerate medical or rehabilitative involvement, but makes nuanced theoretical provision for it, in interaction with conceptual spaces that allow for the unique and individual layers of disability. Clearly, Shakespeare (2006) is correct in identifying the social model's founding principles as "unarguable"; yet it does not always follow that these are always useful (see Dewsbury, Clarke, Randall, Rouncefield & Sommerville, 2004). Lee (2002) draws an analogy with leftist intellectual accounts of poverty; here it is, of course, true to ascribe this social ill to systemic, rather than individual, failings. However, whilst accepting that poverty is structurally generated by capitalist society, the "logical" response to this – that we eradicate poverty (only) through a wholesale conquering of capitalism – represents a "phenomenally simplistic politics" (Lee, 2002, p. 149-150; see also Borsay, 2002, p. 105). The construct of oppression represented within this view of society is one of a unidirectional force, exercised upon faceless individuals wholly subjectified by crushing ideological machinery; a system of villains, victims, and malevolent forces to be overthrown. Lee (2002) is quite correct in asserting that it would be "naive" to assume that individual behaviour in no way contributes to the compounding of poverty. This recognition, as we see it mirrored within the disability arena, finds us on the threshold of what is, to the social modelists, the unspeakable terrain of complicity. It is precisely this juncture, this beckoning conceptual space, which has led to the spurning, by social model writers, of virtually all things psychological. And, as we shall see through our examination of prior psychological accounts of disability rooted within the medicalising view, their misgivings regarding how a "psychological" approach to disablement may collude with the most dehumanising, obliterating ideological forces, have not historically been at all unfounded.

A critical consequence of political movements choosing to rely on the sustaining of simple binaries for their cause is that the identities concerned become increasingly reified. In this case we consider a situation in which progressive, critical thinkers, notably operating from a social constructionist viewpoint, would seek to undermine disablist oppression via the disruption and debunking of the category of "disabled person" itself. However, the political course embarked upon by the "narrow" social model movement relies on quite the opposite; that is, on an endorsement of the disabled-nondisabled binary, through strategies such as the development of "positive" disability identity (e.g. Swain & French, 2000). Shakespeare (2006, p. 80) argues that such separatism is not a necessary ingredient for a progressive politics of disability; a strongly contextual position may also incorporate space for theoretical nuance and individual variation. Paterson and Hughes (1999, p. 600) comment that radical

politics concerned with a variety of social issues has, over recent times, arrived at something of a watershed; a position rendering "turmoil and reorientation". In their influential words: "The Marxist certainties of the past have given way to post-Marxism and post-modernity, to a context in which politics spills into culture, if not amorphousness..." (Paterson & Hughes, 1999, p. 600).

The tendency for the separatism we see, incorporating the inevitable splits and oversimplifications of political rhetoric, is, I argue, fuelled by disability's exceptional capacity for the evocation of experiences and fantasies of psychic trauma. The construct of disability is so imbued with evocative cultural meanings, notably surrounding damage, as to position disabled people and "disability issues" within a realm of thought profoundly channelized by the psychic need for management of anxiety-provoking, often unconscious parts of self (e.g. Bion, 1970) – typically via crude defences such as splitting. This observation in no way detracts from the reality of suffering experienced by disabled persons worldwide at the hands of a brutally negligent, or frankly malevolent, society. However, it is essential in the case of the disability phenomenon that space be made for a mutually constitutive interaction of both of these powerful sets of variables – the social and the psychic. The current work aims to highlight, and attempts to begin to address, the social model's shortcomings with regard to the latter. The social model movement, not unlike many political formations aiming to mobilise some sort of revolution, requires, but simultaneously cannot tolerate, the personal – that is, the psychological.

## Prohibiting the personal

Our anger is not about having a chip on the shoulder, our grief is not a failure to come to terms with our disability. Our dissatisfaction with our lives is not a personality defect but a sane response to the oppression which we experience.

(Morris, 1992, p. 163)

Jenny Morris (1992) reflects upon the crucial moment in the development of feminist discourse, in which the subjective experience of women – of struggle, rage, grief and confusion – ceased to be viewed as an endogenous artefact of biology. This watershed moment began opening the way for an investigation of women's experience as a

phenomenology of gender domination, rather than an individual outpouring of temperament or personality. The "moment" in the unfolding of the disability movement which was ushered in by an awareness of the conceptual lacunae of the social model – pertaining to the personal and the psychological – seems precisely analogous. Disabled people had begun to recognise, as early feminists did, that their experience was worthy of contemplation; that the roots and consequences of oppression were to be found in the inner, as well as the social, world (Thomas, 2001, p. 49; Hughes, 2002a). Within this new, emancipatory frame, experiences of emotional turmoil came to be seen not as evidence of madness, *but as sanity* (Griffin, 1982 cited in Morris, 1992, p. 163). In a form mirroring that of the psycho-political predicament of subordinated women, the lives of disabled persons are (I argue) littered with cultural mechanisms which serve to facilitate the turning inward of anger or distress, in a manner which (to some extent) reduces social oppression to personal shortcoming. The backdrop of profound material deprivation and exclusion, in domains such as education and employment amongst a myriad of others, provides for a virtually limitless supply of subject matter for self-pathologisation. Further, the continued subscription to a modernist Cartesian separation of body from society (Paterson & Hughes, 1999, p. 597) restricts personal experiences – such as those of impairment – to a shadowy inner world, where the layered residues of oppressive socialisation are left to re-inflict their denigrations unhindered.

The "domesticating" influence of a binary split between the public and private worlds allows, within the gender realm, for the pernicious assertion that such issues as women's familial roles, sexual relationships and domestic violence are not, in fact, "political" concerns (Thomas, 1999a, p. 74). The social model's material and "public" focus, arguably allows for corresponding distortions – what Soder terms "contextual essentialism" (Soder cited in Shakespeare, 2006, p. 56). It would be unfair and incorrect to assert that proponents of the social model approach take no account at all of the psychological experience of impaired persons occupying disablist society, yet it is incontrovertible that the model itself allows only for the most awkward and narrow of spaces for the exploration of this layer of disabled life. Faced with the critique of Morris and others, "strong" social model authors have responded by arguing that disabled persons' experience of emotional struggle should, in fact, be regarded as a most direct and painful manifestation of oppression (e.g. Finkelstein & French, 1993, p. 31). Given this, though, writers at the centre of the social model movement have thereafter been at pains to discourage the active exploration of the emotional level of disabled experience (e.g. Finkelstein, 1996), holding firm to the position that "exclusion from the world of work is the

most important factor in what happens to disabled people" (Oliver, 2001, p. 149; 1990). In averring the shift to a more embodied and psychological construct of social personhood, social modelists position their framework as awkwardly out of step with contemporary social theory.

Frosh (1991) frames the scene by noting how "something unexpected" has taken place across social science disciplines, where the political has truly become personal – in fact, "some might say it has become so personal as to *no longer be political*" (Frosh, 1991, p. 1 – my emphasis). The inquisitive gaze of these disciplines has, thus, become increasingly concerned with the intrapsychic coalescing of ideology; with subjectivity as a product – and agent – of social power. Hoggett (1992) reflects candidly on the trajectory of his own political development, seeing in retrospect the poverty of social paradigms which unabashedly ignored the individual: he comments: "The mysteries of life and death, of feeling and passion, of dreaming and imagination, of love and terror – it was as if these things didn't exist" (Hoggett, 1992, p. 3). Within this socialist milieu, one could only succeed in being recognised as "politically committed" if one pledged allegiance to an ("incontrovertibly") "shallow view of life" (ibid.). For him, the contradiction inherent in a framework which claims a materialist orientation, yet refuses to acknowledge the materiality (the flux, the advance and decay), of the body, had come into a relief too stark to overlook (ibid., p. 6). Further, theoretical provision for a psyche which has "its own laws of structuration and process" (ibid.; see Pinker, 2003) was set to confound the Marxist view of humans as "some kind of putty on which social forces work" (Hoggett, 1992, p. 6). Axel Honneth (1995) delivers a harsh critique of frameworks of social theory which exhibit a "fixation on the dimension of interest" (Honneth, 1995, p. 166). In his view, such exclusively materialist readings of society embody an active obscuring of the crucial – the quintessentially human – significance of moral feelings on the shaping of the social order. In light of this circumstance, he calls upon theoreticians to execute a "correction", which offsets the centrality of material interest as a mediator of social processes. Crucially, Honneth asserts that the fact that a collective interest corresponds with a certain social conflict, does not mean that the social conflict is reducible to that collective interest. Rather than being something "ultimate or original", the collective interest associated with a conflict may, instead, "have been constituted within a horizon of moral experience that admits of normative claims to recognition and respect" (Honneth, 1995, p. 166). Thus, besides the question of material interest, the theorising of social conflict must make provision for, in Honneth's terms, "the moral grammar of social struggles" (ibid.). With particular reference to disability, the implication here is that the social status (the esteem, the

identity) embodied by disabled persons must be thoroughly considered as part of a mutually constitutive dialectic, which, along with material concerns, shapes and justifies the social destiny of disabled persons. Borsay (2002) further destabilises the social model understanding of the origins of the marginal position of disabled persons, through calling its account of the economic history of Western disability into question. The social modelist view, seemingly, seeks to reduce the development of power relations within Western society to the rise of industrialisation, which centralised economic and political power around mechanised manufacture and professionalised states (Borsay, 2002, p. 103; Barnes, 1990). For Borsay, this account is not only historically flawed, but also conceptually inadequate, since no provision is made for a cultural dimension (ibid.). A credible and thorough historical picture, instead, must succeed in holding "materialism and culturalism – or structure and agency – in tension" (ibid., p. 104).

Whilst Frosh (1991) and others appear to revel in the "re-psychologisation" of the social subject, "strong" social model theorists fall squarely into his category of those who fear that politics will so collapse into the personal as to no longer be political at all. The "disdain and suspicion" with which these authors view the exploration of personal aspects of disabled life is based upon the assertion that such research is "diversionary", and highly likely to be misappropriated in the bolstering of pathologising and individualising accounts of disability (Thomas, 2001, p. 49). What Finkelstein, Oliver, Barnes and others appear to be saying is that disabled persons cannot afford to make their internal struggles known, as social prejudice dictates that attribution for this misery will automatically be made to an inherent wretchedness that accompanies impairment, powerfully offsetting the political drive for recognition of systematic exclusion and deprivation inflicted upon disabled persons. Stereotypes which associate disability with vulnerability, dependency and damage stand to be confirmed by accounts of struggle, in a manner which perpetuates the exculpation of a cruel social order. Finkelstein (1996, p. 34) describes a concern with personal experience as a "discredited and sterile approach to understanding and changing the world", stating that the disability movement has been (partially) hijacked by academics bent on replacing the active vision of resistance with "passive theoretical abstractions" (cited in Paterson & Hughes, 1999, p. 600). There is little question that the argument made for the "dangers" of personal experience research are well founded. However, the social modelist claim – perhaps inadvertent – that it is feasible to theorise social disability without provision for the intra-psychic, seems at best impoverishing; at worst, dangerous.

The antagonism felt by social model theorists towards phenomenological research in disability finds very clear expression in the fractious relationship between disability studies and the discipline of medical sociology (Williams, 2001, p. 124). Medical sociology or, "the sociology of health and illness" is a discipline which explores the experience of chronic illness and disability, often within a framework of symbolic illness meanings, and the personal construction of narrative (ibid.). These "frosty" relations are based on the assertion, by social model theorists, that medical sociology typically epitomises oppressive and individualising disability research, by failing to interrogate contextual factors, and hence buttressing disabled stereotypes (Thomas, 1999a, p. 151). The theoretical perspectives often used in such investigation combine symbolic interactionism (in the tradition of Erving Goffman – e.g. Goffman, 1963), and phenomenology (pioneered by Maurice Merleau-Ponty – e.g. Merleau-Ponty, 1962). Critics of this research tradition describe how a searching curiosity regarding the subjective aspects of disability experience renders an ever-deepening, solipsistic, and even quasi-religious account, which increasingly "loses sight altogether of the structures which make the experience take the shape it does" (Thomas, 1999a, p. 151). For Vic Finkelstein, such work captures the loathsome essence of what he terms "inside-out" research (Finkelstein, 1996) – which begins with the individual, and becomes so entangled within the interstices of the internal world, that the social is never reached. These narratives often deal with how sufferers "cope" with chronic illness or disablement, incorporating "damage" to identities and the re-configuration of self-worth; the social origins of these subjective states are typically not explored (Thomas, 2002a, p. 44).

Barnes responds to the entire "personal versus political" dispute by pointing out that the social model itself grew out of experiential accounts of disablist discrimination (Barnes, 1998, p. 77); a store of early research which has been "overlooked". This, however, does not seem to soften his assailing of disability researchers who seek to integrate the experience of impairment, fatigue, pain and depression into the social model view (ibid.). This, he believes, besides being inherently unhelpful, also embodies an inane replication of the existing, massive and ever-expanding medical sociological literature concerned with these very matters. The key criticism he levels at such work is that it "effectively blurs the crucial distinction between the experience of impairment and the experience of disability" (ibid.), instead foregrounding a tone of "sentimental autobiography". This position, clearly, assumes that, somewhere within the tangle of biology, socialisation, perception and subjectivity, a "clear" distinction between these "entities" serenely awaits our discovery. Interestingly, Barnes (1998) then goes on to inform his reader that the experience of depression, fatigue or

pain is "not unique" to disabled persons; and, conversely, that "large numbers" of disabled persons will never encounter these experiences (ibid.). Of course, what Barnes suggests is unquestionably true; what is of interest, I believe, is his need to reiterate it in the manner in which he does. Understandably, Barnes (1998) seeks to debunk – to sever – the cultural connection between bodily impairment and emotional anguish; yet, in doing so, he risks dissociating the lives of disabled persons from emotional struggle, shearing off psychology and subjectivity with one, expedient, Cartesian stroke. One may readily acknowledge the fact that medical sociological research, due to its paradigmatic emphasis, portrays disability in a partial, problematic manner which invites misappropriation. But to respond to this difficulty, simply, with an adversarial and *equally partial* account, seems intellectually irresponsible, if not petulant. Thomas (2002a, p. 43; 1999a) valiantly aims to resolve the impasse by suggesting that the social model does not "deny" the potential of impairment to impose restrictions on activity, but that such limitations do not constitute disability. Instead, she coins the term "impairment effects" to signify restrictions on activity, thus "rehabilitating" the beleaguered disability-impairment distinction. Whilst the ideological motivation for this conceptual hopscotch is very clear – even admirable – it may be that a fundamental, and insurmountable, fault-line within the social model paradigm is coming, inexorably, into light.

Where we find ourselves, then, in our quest to fashion a conceptual framework which allows for a multi-layered construct of disability, is somewhere between the scylla and charybdis. That is, lost in ever-deepening existential solipsism, or condemned to an arid and dehumanising materialism. Some authors argue that it is possible to remain politically vigorous in conjunction with exploring the "darker phenomenological waters" of individual narrative (Williams, 2001, p. 144; Turner, 2001). The difficulties with this, though, should not be underestimated. These personal accounts of disabled experience emanate from subjectivities which, themselves, have taken shape within a historically specific cultural soup of disability meanings, resonances and evocations; is it possible to study subjectivity alone, in order, thereby, to understand and critique the origins of subjectivity? Celebrated and scholarly auto-ethnographic authors within the medical sociology tradition, notwithstanding their highly compelling and enriching accounts, demonstrate – I believe – the profound lack of theoretical strands with which to connect internal turmoil, bodily difference, and the mechanisms of ideology (e.g. Frank, 1995; 1998; Murphy, 1987; Toombs, 1994). The social and political contexts within which these narratives are situated tend, within the reader, to become overshadowed by feelings of sympathy or pity (Mitchell & Snyder, 1997, p. 11), arising from the profound capacity of disability to provoke conscious and unconscious

processes of identification. The emotional hyper-arousal which accompanies culturally condensed meanings of disability, as we shall see, is an essential factor in the obscuring of the material realities of deprivation suffered by disabled persons. It is "personal tragedy" – not "discrimination" – that evokes instantaneous identification, with its heady paradoxes of enmeshed sentimentality and violent othering. But to evict the personal – the "tragic" – is simultaneously to (at least partially) eclipse the experience of disability, and hence to bury those aspects of disablism which manifest in this realm (Thomas, 2001, p. 55). According to Thomas (1999a, p. 74), this route embodies a denial of the social origins of forms of oppression operating in the personal domain – these include self-identity, interpersonal relations, sexuality and family. The materialist elision of these aspects of disabled life, she continues, renders critical disability theory vulnerable to "psychologists and others", who would "not hesitate" to apply an individualising model in filling these theoretical breaches. Whilst her point is well made, the depiction here of "psychologists" serves to demonstrate the prevailing difficulty with "imagining" a critical, ideologically situated psychology of disability.

In addressing the question of racism, Frosh (1989) leaves his reader in no doubt whatsoever that this scourge is present, and perpetuated, not only at the level of social organisation and collective interest, but also within the recesses of the individual psyche (Frosh, 1989, p. 229). Development of a psychological model of racism is not intended as a substitute for a socio-political analysis, but is an essential, complementary element of any thorough explication of how racism is maintained (ibid.). Individual psyches forged within a system of ideological meanings and competing social interests imbibe societal significations which become inextricably tangled with subjective life, conflating and hybridising agency with ideology, volition with power. This psychic precipitate of social processes, of course, situates all players within its meaning system, shaping the unconscious lives of oppressor and oppressed alike as proponents of values regarding self and other. Similarly, Frantz Fanon (1952, p. 29) came to view the workings of racism as "a story that takes place in darkness" – an internal darkness – thus requiring that "the sun that is carried within me must shine into the smallest crannies" (ibid.; Davids, 1996, p. 215). In other words, in order to understand – to overcome – oppression, it is essential that *all* actors within the social system powerfully look inward.

Returning to disability, Clegg (2006, p. 128) reports findings emanating from an exploration of the psychically embedded meanings which learning disabled persons attach to "rational" social service policies. These are policies which, as per their social model origins, are concerned only with environments and behaviour, to the exclusion of personal experience. Here, introspection reveals a rich store of deeply personal meanings attached to material conditions. For example, it was found that learning disabled boys using respite care often imagine that they have done something wrong, as their siblings are not required to stay away from home. Similarly, persons who have undergone physical restraint often saw this as an arbitrary decision, presumably with implications for the subjective safety – and experience of being valued or wanted – prevailing within the residential setting in question (ibid.). As we shall see, Valerie Sinason's pioneering work in the area of the social suffering of learning disabled persons (Sinason, 1992), movingly and profoundly demonstrates the import of such subjective meanings. Sinason (1992) underscored the immense impact of trauma – the trauma of not being wanted, and of (consciously or unconsciously) recognising one's social role as an exile – upon the psychological *and cognitive* functioning of her learning disabled subjects. Meanwhile, a study by Morris (1989) further confounded social modelist predictions regarding the core concerns of disabled persons. In her interviews with women with spinal cord injury, Morris (1989, p. 24) found that their most common difficulty with health care professionals was a lack of recognition or consideration of emotional aspects of disability. The tendency of the social model approach to "lose" the "phenomena" of human subjectivity – the "real world, real life experiences of disabled people as they go about their everyday lives" – has led Dewsbury et al (2004) to derisively ask whether, in fact, it should be termed the *anti-social* model" (Dewsbury et al., 2004, p. 153 – my emphasis).

Coleridge (1993, p. 38), from a development studies viewpoint, strongly rejects the increasingly global view that "human nature" – in respect, particularly, to the treatment of disabled persons – can be changed and shaped through legislation. He refers, of course, to legal mechanisms such as the USA's Anti-Discrimination Act (ADA), Great Britain's Disability Discrimination Act (DDA), and many others. To assert that such a materialist view is correct, Coleridge contends, is to yield to the idea that the enterprises of development and education are, in fact, redundant (ibid.). The veiled accusation levelled at the social model here is not inconsiderable; viz. the suggestion that a strongly materialist view actually militates against the appropriate prioritisation of resources which foster the development of

human capital. Whilst the basic needs of life – food, shelter, health care – must clearly be provided for, for Coleridge there is a fundamental problem with viewing "development" as primarily a process of fulfilling this function (Coleridge, 1993, p. 213). He writes:

The problem lies in the fact that such needs are passive: if these needs are met, so this approach asserts, then 'development' has happened. But there are other needs which are just as basic: the need to be creative, to make choices, to exercise judgment, to love others, to have friendships, to contribute something of oneself to the world, to have social function and purpose. These are active needs; if they are not met, the result is the impoverishment of the human spirit, because without them life itself has no meaning.

(Coleridge, 1993, p. 213)

Disabled lives, Coleridge urges us to acknowledge, carry every aspect and nuance of human complexity; of relationship, self-regard, loss and hope. A theoretical model which purports to reflect and validate disabled lives must offer conceptual spaces which provide for all such aspects of experience; all aspects of *human* experience. One layer of disabled life which has often been de-legitimated through the collusion of the social model with Cartesian dualism, is the experience of the body – that is, inter alia, the experience of impairment (Crow, 1992). As the figure of the materialist subject will not tolerate the psychological, so, too, is the embodiment of the self anathema.

### **The vanishing – and reappearing – body**

Proponents of the social model, intent upon foregrounding oppression as the defining (indeed, exclusive) feature of disability, unwittingly were directing their movement towards a "somatic impasse". Although the social model had been conceived in diametric opposition to the "traditional" medical model, the disability-impairment binary at its centre – and so dear and elementary to its authors – inadvertently buttressed the exclusive mandate of medicine to "management" of impairment. By asserting – impetuously, to some – that "disability" is purely social, the social model's logic relinquished "impairment" to the realm of the *purely biological* (Hughes, 2002a, p. 67; Thomas, 1999a; 2002b). In so doing, the social model aligned itself with Cartesian medicine's view of the body as "a domain of corporeality untouched by culture" (Hughes, 2002a, p. 67). Impairment, therefore, was to become viewed within this philosophical position as a "reality" which has an existence independent of the cultural milieu in which it arises (Marks, 1999a, p. 17), recapitulating biomedicine's model of

the body as (nothing but) a "faulty machine" (Hughes & Paterson, 1997, p. 329). The irony evident in the profound convergence of the social model with a biomedical view of corporeality, in reproducing the problem of mind-body dualism, is, indeed, remarkable. The model tacitly concurs with traditional medicine, in constructing the body as a "pre-social, inert, physical object, as discrete, palpable and separate from the self ..." (Hughes & Paterson, 1997, p. 329). The construct, the conceptual space, of disability offered by the social model, thus was – and is – a disembodied one.

A further irony surrounds the extent to which the sociology of disability – in the form of the social model – has, over recent decades, been elaborating itself in an epistemological direction which markedly opposes the broader currents of sociological theory (Hughes, 2002a, p. 59). During an era in which paradigms such as post-structuralism and phenomenology have sought to assail traditional enlightenment dualisms, the social model has instead propounded a framework of irreducible polarities – the body and society, medicine and politics, therapy and emancipation, pain and oppression, and, of course, impairment and disability (Hughes & Paterson, 1997, p. 330). The need for such "clean" conceptual splits emanated from the social modelists' drive to stridently dissociate their orientation from the "murky" and "disablist" vagueries of medical sociology. But in doing so, these writers created a seemingly insurmountable obstacle to their own potential development of any sort of sociology of impairment (Hughes, 2002a, p. 59). A most dramatic contrast to this conception is provided by Susan Bordo (1993); for her, the body is everything but a stable or acultural constant. Instead, culture is always, a priori, inscribed upon and penetrated through the "living" of our bodies; there is no "natural" body – instead, "natural" is "the script of culture writ large on the body" (Bordo, 1993 cited in Michalko, 2002, p. 58). Far from the abandonment of the corporeal evidenced by the vanguard of disability studies, in other arenas of social and political conflict and turmoil, the body has become ever more the site of engagement (Hughes & Paterson, 1997, p. 327). Hancock et al (2000) paint the scene thus:

Meanwhile the body was making itself ever-present in social and political life, be it in the shape of a battered woman, a terminated foetus, a victim of torture or televised war, a proud celebration of womanhood, disability, colour or homosexuality, an organ in transit for transplantation, a human-machine stepping on the moon, a sample of DNA under the microscope, a man who was a woman or vice versa, a body transformed by diet, exercise or the surgeon's knife, a homeless person camped on the streets of the world's richest nation, a mass grave, another world record smashed.

(Hancock et al., 2000 cited in Hughes, 2002a, p. 66)

But astonishingly, for disabled persons within the ambit of the social model's analysis, the living, breathing body had vanished; in its place, a "timeless, ontological foundation" (Hughes & Paterson, 1997, p. 327). The impaired body, notwithstanding its purported immersion in forces of oppression, remained itself a "dysfunctional, anatomical, corporeal mass obdurate in its resistance to signification and phenomenologically dead, without intentionality or agency" (ibid.). As Hughes (2002a, p. 66) timeously comments, the preoccupations of disability studies were with the "realities" of furthering the cause of disabled people via political means, rather than with the intricate conceptual trifles of aligning body, mind and society in some form of satisfactory theoretical synergy. However, the implications of these priorities have left the lived experience of impairment adrift in an isolating limbo, between the control and invalidation of biologism, and the unwelcoming disdain of repressive populism.

Social model thinkers may defend their orientation by pointing to the fact that certain ideological analyses of impairment have, in fact, been developed within their framework. Here, primarily within the work of Paul Abberley (1987; 1996) and Mike Oliver (1996), the social origins of impairment are interrogated. Abberley (1996, p. 63) argues – quite correctly – that impairment of various forms always occurs within a certain historical and political context, which may contribute to its emergence, its exacerbation, or its amelioration. Thus, unsafe working conditions, the efficiency of health systems, access to appropriate vaccination, levels of public safety – these and a host of other contextual factors shape the incidence and consequences of impairment (Abberley, 1987; 1996). Whilst the context of factors implicated in bodily impairment is highly salient and deserving of critique, this analysis, however, falls massively short of creating a platform for the examination of impairment as a complex, embodied process comprising both societal and personal aspects. Instead, Abberley (1987) introduces the issue of the social underpinnings of impairment via a structuralist analysis, but then abruptly sets aside the resultant phenomenon of impairment as a reified, unproblematic and consensual "reality" (Paterson & Hughes, 1999, p. 599). The theoretical gateway to an exploration of the social and psychological nature and constitution of impairment experience, thus, remains firmly closed. Loyal to the social modelist penchant for separation, no possibility is proffered here for exploring disability and impairment as interpenetrating, mutually incorporated experiences (ibid., p. 598). For Paterson and Hughes (1999, p. 598), the "Cartesianised" subject fashioned by the social model's binaries eliminates the possibility of disabled people building an "emancipatory politics of identity" – one born of and based upon the delineation and mutual validation of the interwoven threads of cultural and corporeal existence.

One strategic exit route from the conceptual confusion of circumscribing what – and *where* – disability *is*, is provided by post-structuralist and social constructionist approaches, following the writings of Michel Foucault, and the traditions of postmodernism and epistemological relativism (Turner, 2001, p. 255). Within the post-structuralist universe, no direct perception of a unified "reality" of any sort is provided for; all that is available to our grasp are "versions" of our world (Marks, 1999a, p. 18). Consequently, this view holds that it is not just the slippery notion of disability, but *also impairment*, which is entirely an artifact of social construction (ibid.). The secure, stable ground of essential characteristics and intrinsic identities is left far behind, in favour of a subject composed of fluid, shifting and continually negotiated repertoires. From a social constructionist standpoint, the concepts and categories with which the world is delineated and dissected are viewed as entirely culturally and historically specific, arbitrary, and containing no inherent or transcendent robustness (e.g. Gergen, 1985). Disability researchers operating within this paradigm would seek to wrest control of "disability meanings" from positivist accounts, which incorporate a "western conception of objective, individualistic, ahistoric knowledge" (Gergen, 1985, p. 272). Such a re-alignment, which repositions disability as a social accomplishment rather than an inherent characteristic, embodies a valuable counterpoint to biological essentialism. Yet, within the critical constructionist view, it must be noted that all such accounts are equally illusory.

Whilst the view of disability as a product of society's organisation is shared by social constructionist approaches and the social model, the units of societal analysis prioritised by these orientations differ. The social model, identified by Priestley (1998, p. 80) as a *social creationist* position, focuses primary concern on the structural "realities" of society's disabling barriers. By contrast, a *social constructionist* agenda foregrounds the cultural representations of disability which predominate within a society, holding that it is the production and perpetuation of these meanings which provides the repertoire, the subject matter, for oppressed disability experience (ibid., p. 81). Of course, the principles of these and other approaches are not entirely mutually exclusive, but for the purposes of explication, it is helpful to contrast the essential leanings of each. Within a rigorously constructionist account of disability, the body is momentarily "rehabilitated" as a salient frame of discursive struggle – along with endless others – but then immediately engulfed by the imperatives of deconstruction, which evacuate it of any shred of non-contingent meaning (Turner, 2001, p. 254; Price & Shildrick, 1998; Thomas, 2002a). As noted earlier, a form of biological essentialism is, by default, acceded to via the social model's abstention with regard to the body. This essentialism, true to its positivist character, allows no scope for the unique

"living" of the disabled body. But the social constructionist perspective fails to balance the equation, instead replacing an arid biological essentialism with an equally depersonalising "discursive essentialism" (Hughes & Paterson, 1997, p. 333; see also Hacking, 1999). Instead of breathing life into the body, deconstruction dissolves the body into nothing more than the constituent cultural signifiers that imbue it (transitorily) with meaning (ibid.). Rosemarie Garland Thomson (1997a) takes a pragmatic, strategic view, which seeks to make the most of the interrogative and emancipatory potentials of both orientations. First, she argues, it is imperative to employ a "strategic constructionist" argument in order to launch a "denaturalising" assault on reductionist accounts which portray disability as bodily incapacity, substituting this with a critical and contextualised analysis of disability as the product of an interaction of bodily difference with a misattuned cultural environment (ibid., p. 282-3). Here, group delineation of the identity of "disabled" is unclear; an illusory product of ascribed, rather than inherent, identity characteristics. Second, Thomson advocates that this constructionist view be amalgamated with a "strategic essentialism", in order to affirm, to preserve, the historical reality of the disabled body. Embodied differences, such as the use of a wheelchair or living without sight, may thus be claimed and elaborated – both personally and collectively – by those who live them, rather than be left to the denigrations of a prejudiced society (ibid.). She explains the compromise:

Thus, a strategic constructionism destigmatises the disabled body, locates difference relationally, denaturalises normalcy, and challenges appearance hierarchies. A strategic essentialism, by contrast, validates experience and consciousness, imagines community, authorises history, and facilitates self naming.

(Thomson, 1997a, p. 283)

Seminal work concerning the human experience of disease and disability within the social constructionist paradigm is that of the Foucaultian discourse analytic tradition (Foucault, 1976; 1995; Stiker, 1982). As alluded to above, notwithstanding the piercing social critique embodied in these investigations – notably surrounding the notion of normalisation – the discourse analytic view allows little conceptual space for exploring the nature of subjectivity, or providing for the possibility of individual agency (Whyte, 1995 cited in Turner, 2001, p. 255). In fact, on the nature of the everyday lived experience of the subjective world, discourse analysis is altogether silent – ruling out, in the words of Shakespeare and Watson (1995), the development of an "ethnography of physicality" (cited in Turner, 2001, p. 257).

In addition, whilst the "strategic essentialism" recommended by Thomson above does admit the body as palpable, the positivist biomedical realm which is its natural home is not well suited to an elaboration of the intricate threads of subjective embodiment. Thomson (1997a, p. 282) develops her position by positing a "universalising disability discourse", which, drawing on the feminist altercation with gender hegemony, asserts the body as a "cultural text which is interpreted, inscribed with meaning, [and] indeed, *made* within social relations of power" (my emphasis). The critique wrought by this assertion is crucial in the destigmatisation of "damaged" social identities, but it also tends toward obscuring the "real" material (lived) effects of those differences, simultaneously destabilising the very social identity categories with which we render oppressed experience collectively meaningful (ibid.). We are oppressed by the ascriptions of these categories (gender, race, disability), yet require their reificatory effects for the legitimation of our – otherwise groundless – experience, not to mention for the purposes of critical social analysis. In Thomson's (1997a, p. 282) words, "the post-structuralist logic that destabilises identity potentially frees marginalised people from the narrative of essential inadequacy, but at the same time it risks denying the particularity of their embodied experience". The complex implications of this predicament for the development of a cohesive disability movement – one able to attract clear identification from its constituency – will be considered in some detail later (see *Identity politics and the movement*, p.191)

The (presumed) nature of "different" bodies is, doubtless, at the heart of the medicalising domestication of disabled persons; yet, the specific character of this embodiment seems an essential – an elemental – aspect of the lived reality of oppression, and, perhaps consequentially, of identity (Turner, 2001, p. 254). Deconstructing contested social categories will, to some extent, neutralise or obscure the political aspects of the material differences which they signify (Thomson, 1997a, p. 282). In reducing the body to a "phantasm" of collected representations, much of the self, the subjective life, of disabled individuals risks similar corrosive deconstruction. At the current point in history, the disability movement at large simply cannot afford to discard the category of disability as per the post-structuralist critique of identity (ibid.). Interestingly, a sector of the global deaf community has adopted this tactic, choosing, via the principles of deconstruction, to promote the community as a cultural and linguistic minority, whilst stridently disidentifying with the disability movement (e.g. Corker, 1994). From this standpoint, it is not only "disability" which is attacked as an arbitrary socio-linguistic product, but "impairment" as well. In sum, though, the scepticism expressed by a range of authors regarding the ultimately self-defeating

relativism, and lack of explanatory capacity, of a radically constructionist approach seems well founded (Thomas, 1999a, p. 117; 2002). Perhaps more significant, however, is the groundswell of (predominantly) feminist-oriented writings within disability studies which call for a simple, visceral – common-sense – return to the lived reality of bodies. As reflected upon in the previous section, "impairment", for these writers, is an essential aspect of disabled life, and must, therefore, be conceptually provided for.

Crow (1996) is vociferous in her critique of how the social model has marginalised the experience of impairment in her own life. She writes that the disability movement, under the auspices of the social model approach, has sought to portray impairment as "irrelevant, neutral, and, sometimes positive, but never, ever as the quandary it really is" (Crow, 1996, p. 208). For Crow (1996), this "glossing over" of that layer of subjective life which concerns impairment disguises the contradictions and complexity, the confusion and ambivalence, which are inevitably incorporated within the physicality of social life in an impaired body (ibid.). If pain, for example, is subjectively meaningful – and in psychological terms this seems incontrovertible – it must, therefore, also be culturally meaningful (Paterson & Hughes, 1999, p. 602). Within this socially mediated view of pain, its experience is not viewed as "physical sensation with additions of meaning, but as permeated with meaning, *permeated with culture*" (Jackson, 1994 cited in Paterson & Hughes, 1999, p. 602 – my emphasis). Hughes and Paterson (1997, p. 333) point to the sinister implications of social modelist "dumbing down" of the lived nature of impairment, correctly observing that the bodies and impairments concerned are generated within a biomedical frame, hence offering "sovereign" control of the nature of impaired life to medical authority. Michalko (2002, p. 56) concurs, arguing that the social model's "naturalisation" of impairment embodies an impediment to the political conscientisation of disabled people. The social model, thus, offers no harbour to Crow's (1996) experience of "quandary"; instead, she finds her experience negated, and herself subjectively marooned. But Hughes and Paterson's (1997) alarms run still deeper; surely, in their analysis, a biomedical discourse which has had "free reign" over the realm of impairment would render bodies, and to some extent, subjective states, continuous with its categories – that is, "a particular genus of body with its appropriate signs, symptoms, behaviour and normative expectations" (ibid., p. 333). The challenge, then, for disabled persons such as Crow, is not simply to express her experience of impairment, but, first and

foremost, to *find* that experience amongst the control and debris of a socialisation steeped in a medicalising, depersonalising silence. Turner (1994) seems to hold hope for this endeavour, remarking that, in the postmodern era, the body is singular in its capacity to defy regulation – an arena in which desire will always, in some form, survive the subordinating onslaught of reason (Turner, 1994 cited in Hughes & Paterson, 1997, p. 327).

Thomas (1999a, p. 38) grounds the discussion by simply asserting that a layer of the everyday, palpable realities of impairment must remain irreducible to both medical and deconstructionist abstractions. "Surely", she writes, "it is obvious that *some* restrictions of activity are caused by limited physical, sensory or intellectual functioning?" (ibid.). This observation does not necessitate a corresponding value judgment placed upon the richness or worth of impaired life; instead, the path is opened to exploration of the multiplicity of ways in which life, with its ubiquitous hopes and dreads, may be lived and imagined (Wasserman, 2001, p. 222). Wendell (1997), with a candour disarming to constructionists and materialists alike, asserts that many, and perhaps most, forms of impairment draw upon the energy and stamina of the impaired individual, in a manner which may have a limiting effect beyond the confines of restriction in a particular (impairment-salient) area of activity (Wendell, 1997, p. 271). In a similar, if somewhat more conservative vein, French (1993a) has noted how parts of the lived implications of her sight impairment, whilst clearly having a social aspect, are not amenable to environmental modification – instead, these facets of impaired life occupy a "middle ground" between the social and the somatic (French, 1993a, p. 17). Shakespeare (2006, p. 56), in further elaborating his orientation as social model dissident, states, simply, that "people are disabled by society and by their bodies" – and, that it is "inescapable that some forms of impairments are more limiting than others". Arrival at such a seemingly self-evident conclusion might, to the less careful observer, belie the very real and complex political concerns which have caused the path thence to have meandered so. The location reached via this bewildering journey – a place where impairment may be re-admitted – is altogether different from the biomedical view which begins, and remains, within the reactionary territory in which physicality informs social status (Hughes & Paterson, 1997, p. 326). The social model, thus, is required to engage in a critique of its own philosophical – that is, *dualistic* – foundations, in order to provide for the now evident necessity of a body which is "part of the domain of history, culture and meaning" (Hughes & Paterson, 1997; 326). Whether the model is sufficiently robust to survive this interrogation remains a question upon which opinion is divided.

Thomas (1999a; 2002a) presents her own solution to the crisis by circumscribing the bounds of a "materialist ontology of impairment and impairment effects" – an ontology which is "neither biologically reductionist nor culturally determinist" (Thomas, 1999a, p. 125). She believes it to be feasible that these constructs be applied alongside the retained essence of the social model, within an "extended" social-relational approach. As noted earlier, her concept of "impairment effects" is defined as "restrictions of activity which are associated with being impaired but which are not disabilities in the social relational sense" (Thomas, 1999a, p. 43). These "effects" are "profoundly bio-social, that is, shaped by the interaction of biological and social factors", and "are bound up with processes of socio-cultural naming" (ibid.). Impairment, thus, becomes re-located at the juncture where biology and culture meet (Hughes & Paterson, 1997, p. 329). Disability and impairment, here, are not experienced as discrete entities, in "separate Cartesian compartments", but as part of "a complex interpenetration of oppression and affliction" (Hughes & Paterson, 1997, pp. 335-5). This view of the body as the very "stuff of human affliction and affectivity" as well as the subject and object of oppression, point us towards the value of a phenomenological sociology of the body (ibid.). Here, the living and lived body incorporates selfhood which is no longer extrinsic to its functioning, but embodied within its viscera, its sensation. Rather than the body being an object for the subjective view of the self, the lived body incarnates the individual's point of view on the world (Toombs, 1994, p. 338). The body, in short, is not possessed, but *lived*. The contribution of a phenomenological sociology of the body to the conceiving of a sociology of impairment lies in its capacity to bring "sentience and sensibility" to the notions of disablist oppression and exclusion (Hughes & Paterson, 1997, p. 334).

The current of theoretical development, thus, is toward a dialectical approach to the body, which is able to contain a symbiosis lived between the somatic and the social (Lupton, 1995 cited in Marks, 1999a, p. 93). In this new world the body re-appears, "filling up" the metallic spaces of positivism with desire, sensation, flux and caprice. Shakespeare (2006, p. 54), seeking conceptual apparatus with which to accommodate this body, recommends to us the model of critical realism – this view attends to the realness of bodies; "bodies which sometimes hurt, regardless of what we may think or say about [them]". Williams (1999, p. 798) concurs, noting how the critical realist view, whilst able to allow the biological body back in, does so "without stripping agency of agency or structure of structure".

This re-embodiment of the disabled subject is directly analogous to developments within feminism, where the prior, politically expedient sex-gender split reflects the social model's dualist strategy. Within this conceptual frame, sex was viewed as the pre-social substrate "upon" which gender became inscribed via the workings of ideology. Latterly, influential feminist authors (e.g. Butler, 1993), have discarded this binary, ushering in an era in which "the materiality of the [female] body will not be thinkable apart from the materialisation of that regulatory norm" (Butler, 1993, p. 2; Williams, 1999). Put another way, the experiences of feminine and impaired embodiment are both profoundly cultural ones. Williams (1999, p. 798) refers to the centrality, within the critical realist model, of provision for "mind-independent generative mechanisms", where the body and (cultural) experience of the body are indissoluble. With reference to an earlier section, the body is not "written upon", but rather, simply, "written"; the body has an ontological depth which is untouched by constructionist epistemological claims (Williams, 1999, p. 806). As such, and in stark opposition to the materialist appeal, "humanity ... is never a gift from society" (Archer, 1995 cited in Williams, 1999, p. 806). An extremely important aspect of the critical realist perspective, for our purposes, is the proposition that layers of experience, of embodied selfhood, lie beyond the reaches of consciousness. This proposition, uncomfortable though it doubtless is to both materialists and post-structuralists, provides for the "critical" and "emancipatory" potential of the model (Williams, 1999, p. 810) – for the possibility of the "discovery" of oppressive, internalised layers of embodiment. For Williams (1999, p. 810), the potential for "emancipation" here is a promise of something "far more concrete and tangible than the shift to alternative discursive registers". Rather, the development of a conscious awareness of structural internalisations is provided for, in a manner which beckons the subject to an emancipatory interrogation of self.

The critical realist approach, in addition, combines synergistically with the theory of phenomenology (Merleau-Ponty, 1962), which provides a conceptual frame for the exploration of the lived nature of the body, and thus, of impairment. To Merleau-Ponty (1962), the body is "like a work of art", because, in each case, it is impossible – in fact, meaningless – to attempt to distinguish the expression from what is expressed (Langer, 1989, p. 53). Like proponents of a critical realist view, Merleau-Ponty eschews fantasies such as the "purely bodily" or "purely psychic", replacing these with the notion of an integrated, simultaneous subjectivity, in which all levels of experience "interfuse" (ibid.). There remains, by consequence, a constant dialectical tension between "having" and "being" a body (Lyon & Barbalet, 1994 cited in Paterson & Hughes, 1999, p. 601). The body, within Merleau-Ponty's

(1962) vision, is the primary and fundamental route through which humans gain access to experiences of the world; it is the body which holds the *phenomenology of perception* (Lyon & Barbalet, 1994 cited in Paterson & Hughes, 1999, p. 601; Merleau-Ponty, 1962). Whilst the "phenomenological body" is clearly a social product, this process of making, becoming and being a body incorporates the project of making, and living, a self (Turner, 2001, p. 260). At this juncture, again, there appears a particular salience to the theorising of social disability – embodiment and enselfment are construed as entirely interwoven and interdependent projects (ibid.). Disability, then, is neither the exclusive outcome of oppressive societies or impaired bodies, but an emergent property, which flows from the interplay of structural constraints, physiology, and cultural elaboration – a "materialist phenomenology" of disability. Williams (1999) summarises his view of disability through this new, combined conceptual lens: "A dynamic, dialectically unfolding process between body and society, located within a temporal frame of reference (both historical and biographical)" (Williams, 1999, p. 813).

Where we find ourselves, then, is within a new conceptual landscape, in which we allow the body to live, but remain wary and critical regarding the encroachment of the dehumanising effects of biologism. Simultaneously, a phenomenological approach shows up the continuous life of bodily perception, set against the (critical) "reality" of bodily difference and societal structures; here, the impaired body is a lived cultural phenomenon, rather than an ahistoric biological fact. Disability studies, with the aid of these new instruments, is afforded the opportunity to elaborate theories of the culturally situated nature of disabled selfhood, "with the body at the centre of its analysis" (Paterson & Hughes, 1999, p. 601). Within this domain, a space for development of the socially situated and embodied nature of the psychological experience of disability is created; this space beckons us to psychoanalysis.

## CHAPTER THREE

### **Disability theory II: Psychoanalysis, social construction and the contextual phenomenology of disability**

#### **Preamble**

To some, the psychoanalytic model may appear as an unlikely lens through which to interrogate the disability experience. Our common-sense associations with the idea of psychoanalysis render images of a small, plush room in an urban, western setting, with an analyst's couch, and professional and patient engaging in a lengthy and very expensive process of individual psychotherapy – a far cry from the often stark development needs of the world's disabled people. We tend, to our detriment, to be less aware of the remarkable critical power of the psychoanalytic model to make sense of behaviour at the *broadest social level*, as well as at the level of the individual. What the model provides us with is a means to begin to interrogate the phenomena of the intra-psychic world, toward developing an understanding of how these processes in turn profoundly influence and shape collective action within society. In the case of disability, psychoanalysis directs our attention at the unconscious meanings with which bodily difference is imbued, and beyond, toward an analysis of how universal anxieties regarding these evocations manifest in oppressive social formations (Marks, 1999a; Watermeyer, 2006). As alluded to, the "identity" of psychoanalysis as a critical, even emancipatory theoretical frame is, to say the least, controversial. To some – not least, those of a materialist orientation aligned to the social model – psychoanalysis may be anathema; a symbol of class separation, and the solipsistic indulgences of the bourgeois. Before examining its specific application within the disability arena, therefore, we turn first to a consideration of psychoanalysis' "credentials" as a frame for interrogating oppression. In order to do this, we shall assess a range of opposing opinions regarding the model's utility – or otherwise – in the field of social critique.

#### **Psychoanalysis and social critique: Depoliticisation or subversion?**

As noted above, the idea of psychoanalysis calls to mind images of the couch and consulting room, typically involving the rarefied exploration of internal, individual concerns. Partly

because of the immense expense attached to this enterprise, which renders it available only to a tiny, moneyed fraction of Western society, the commonly held view of psychoanalysis is one far removed from ideas of social critique, let alone political subversion. Instead, the work of psychoanalysis is viewed as of only solipsistic relevance, seeking, as it does, to explore, describe and "integrate" the complex, layered intricacies of the internal psychological world. As we begin to consider this discipline, and its potential relevance for our purposes, it is important to establish that the concerns and foci of psychoanalytic discourse extend well beyond the realm of clinical therapeutic work. It is clinical material that offers a route to unconscious processes – the key unit of analysis of the discipline – yet, the implications of psychoanalytic knowledge, as we shall find, are argued to extend way beyond the individual, to the shaping and dynamic interchange of group processes, and the broad nature of the social order. Further, the psychoanalytic frame has been applied directly to societal phenomena, in a manner which seeks to interrogate the unconscious underpinnings of everyday social life, as these are shaped via ongoing dialectical interchange between intra-individual and social psychological processes. The efficacy of the psychoanalytic model for social critique, is, however, one perennially contested between its earnest proponents, and equally earnest critics. The latter often hail from a materialist tradition – recalling the social model of disability – within which individual characteristics such as emotional functioning are regarded as epiphenomenal, and a tiresome distraction from the "real" material issues of socio-political life (Figlio & Richards, 2002, p. 183). By contrast, authors working within the psychoanalytic tradition have, over recent decades, displayed burgeoning interest in the links between intra-psychic and social processes (Hinshelwood & Chiesa, 2002a, p. 1). As we begin to ponder over this complex relationship, Temperley (1984, p. 25) presents us with a key distinction in approaches to its theorising. First, a "Utopian" view, which attributes the countless ills of society to the nature of the social order itself, hence reasoning that, if social structures were rectified, a naturally benign human nature would freely express itself in beautiful harmony. The second, darker view of the human condition, holds that the human psyche is constitutionally imbued with not only kindly, but also hostile forces, which are reflected and enacted within social evils. Here, the injunction to each individual, if society is to be improved, involves taking cognisance of, and responsibility for, one's own direct and inadvertent role in creating and perpetuating social troubles (ibid.). The battle between forces which allay, and those which perpetuate, the suffering and brutality which afflicts society, is regarded within this perspective as a reflection of the insoluble, intrinsic conflict elemental to human psychological functioning. Upon both earthly and psychic terrains, writes Samuels

(1993), there is a "fight between consciousness, liberation and alterity on the one hand, and suppression, repression and omnipotent beliefs in final truths on the other" (Samuels, 1993, p. 4). With this brief orientation, let us consider, first, key criticisms of the psychoanalytic model, particularly with reference to its application to social process.

The interplay between societal and intra-psychic levels of functioning has, according to some critics, led psychoanalysis into a form of "psychic reductionism", in which social actions, such as political radicalism, become interpreted "as nothing more than the manifestation of individual needs to manage internal existential conflicts (Figlio & Richards, 2002, p. 194). The "repressive" implication of such a state of affairs lies in the tacit location of struggle within the internal, in a manner which tends to obviate an interrogation of social structures which may be implicated in human suffering; here, psychoanalysis risks "dumbing down" social suffering, in a manner which erodes the subjective legitimacy of political resistance. The psychic wounds arising from social oppression, thus, may be read as the sequelae of personal neurotic fallibility. However, the fact that political commitment may not be reducible to intra-psychic phenomena, does not mean that an analysis of the internal needs which this fulfils is not necessary or fruitful (ibid., p. 196). The difficulty, perhaps, lies in the compelling nature of psychological attributions, which turn accountability inward in a manner seductive to the human predisposition for self-blame. Such analyses – in a manner analogous to the biomedical view of disability – begin with, and consequently become cemented within, the individual. Grossberg (1998, p. 65) laments how the field of cultural studies has become thus ensnared, leading to a retreat from the world of substantive social policy, to an impotent and circular reflection on the components of social texts. Similarly, Gordon (1995, p. 277) paints a dim picture of the psychoanalytic academy, as a "rather self-referential" group, communicating in a remote and rarefied language starkly dissonant with the engaged discourse of viable political praxis. In my view, a theory of intra-psychic functioning which does not interface clearly with history and economics – with the substantive, collective realities of human life – will ultimately flounder in its quest for relevance. Such a model presents society as an individual psyche writ large, with no provision for the dynamic generative capacity of psychological exchange (Hinshelwood & Chiesa, 2002a; 5).

A further, formidable critique of the psychoanalytic tradition pertains to the role of its institutions in, perhaps unwittingly, perpetuating a raft of bourgeois liberal socio-political conventions. The fact that the psychological "discoveries" of psychoanalysis are embedded within a particular historical and cultural matrix, confirms its normalising role, as a discipline

which is not only descriptive, but also inevitably – helplessly – *prescriptive* (Samuels, 1993, p. 275). Exploration and delineation of, for example, how psychological development *may* take place, quickly becomes indistinguishable from models of how development *should* take place, notwithstanding the unavoidable slants implied by the cultural embeddedness of all such investigations. Further, the influential object relations model within psychoanalysis overwhelmingly favours intra-psychic and interpersonal explanations for personality development – including dysfunction – and remains, in this regard, almost exclusively preoccupied with the very early years of life (Samuels, 1993, p. 275). This emphasis on the inner familial "sanctum" as definitively influential in shaping the self tends, by its nature, to disregard other, more collective aspects of psychological experience (ibid.). The normalising imperatives of this discourse are, unfortunately, set against the backdrop of a psychoanalytic "establishment" which is, for ostensibly theoretical reasons, unyieldingly hierarchical (Frosh, 2006, p. 275). This fact, one imagines, may only compound the ready, omnipotent fantasy of ultimate and "sacred" knowledge engendered by rites of occupational closure.

An aspect of the "authoritarian" training and admission culture of psychoanalytic institutions (Frosh, 2006, p. 275) which Samuels (1993) finds especially regrettable is the split between the "public, apolitical, hyper-clinical face of the profession", and the private personhood of clinicians well aware of their political context and history (Samuels, 1993, p. 265). The image created by Samuels (1993) is one of a disingenuous professional persona, which is tireless in its search for intra-psychic attributions for the subjective struggle of its patients, whilst, in fact, battling to find personal balance between attendance to the internal and external exigencies of "real life". It should be noted, though, that in his international survey study, it was British psychoanalysts who most thoroughly fulfilled the depoliticising stance which this scenario implies. The professional reticence of psychoanalytic thinkers is identified by Gordon (1995, p. 277), who remarks that while he is able to name a "horde" of psychoanalysts expert in a range of chosen fields, none of these could be described as "a public intellectual" – that is, a thinker writing in socially relevant areas in a manner which is broadly accessible. The oft quoted reason for this reticence is the nature of psychoanalytic clinical work, within which public visibility presents potential contamination of the transference relationship with psychotherapy patients. Gordon (1995, p. 287) summarily dismisses this explanation as "precious", and "an excuse for doing nothing". Exclusive "devotion" to the therapeutic endeavour, to Gordon (1995, p. 285) represents offering a palliative – a "band-aid" – to society, in lieu of substantive advocacy or activism towards materially transforming societal structures. Instead of societal transformation, individual

change is facilitated, such that the ideological machinery which shapes human subjectivity may continue undisrupted. It should be noted, though, that within depth oriented psychotherapy it is extremely difficult to maintain a focus on the "primary task" of the work – rigorous self-examination – whilst simultaneously offering recognition of the "reality" of, for example, an oppressive relationship. "Understanding" of such relationships is often simply too imbued with a recognition of the patient's own complicity for this to be feasible – the "crisp realities" of political action lie far from this complex, nuanced terrain.

Upon the momentum of developments within feminism during the 1970s and 1980s, a turn within the social sciences toward psychoanalysis came into view, born of the beckoning possibility of closing the conceptual gap between our understandings of emotional states and socio-political processes (Figlio & Richards, 2002, p. 187). What was hoped for by this cohort of thinkers was the elaboration of a "politics of everyday life" (ibid.), in which the dynamic interplay of factors such as social coercion, psychic agency, socialisation and identity may be woven together, fashioning a model of politically situated, *yet psychological*, personhood. Regrettably, the fruits of psychoanalysis' role in this venture have been scant; "at best banal, and at worst deeply normative and conformist" (Gordon, 1995, p. 279). Psychoanalysis, it seems, has been retarded in its development of a "political" psychology through its exclusionary, dogged attachment to theoretical tenets which, notwithstanding their defensibility, remain un-tethered to socio-political phenomena. For example, limiting one's analysis of the requirements for the "flowering" of the developing infant to concepts such as "good enough" mothering in the early years, and aspects of the normative matrix of the nuclear family, whilst providing for important layers of influence upon personality, arguably restricts the reach of explanation to a largely pre-political domain.

Such limited conceptual frameworks, to Samuels (1993, p. 271) are "hopelessly passive in the face of problematic social and political structures". Of course, it is not my intention to imply that concepts such as those describing early attachment and the milieu of infancy are not crucially important – I believe them to be so. But where psychoanalysis has failed in its attempt to forge a politically situated theory of mind is in the connecting of conceptual threads, which bind and expand the familial model of personality development outward into the world of group political struggle. Some influential developmentalists have attempted to create just such a concentric conceptual system (e.g. Bronfenbrenner, 1977), but this initiative has generally not been followed by theorists operating within the psychoanalytic frame (for an

exception, see Kraemer & Roberts, 1996a). A situated psychoanalytic theory must locate the developmental exigencies of, for example, maternal containment and early experience, within psyches which negotiate lifelong social struggles in a profoundly unequal, discriminatory, often brutal and generally atomised social world. But, crucially, this must be achieved without reducing social suffering to internal, individual frailty; instead, formulating models which make provision for organismic, interactive psycho-social outcomes. Models which focus almost exclusively on the material, or the intra-psychic, are equally subject to a "defensive" denial of the reality and import of – respectively – psychological and political factors. The splitting inherent in such accounts, furthermore, is all too readily utilised and reflected in similarly defensive understandings of the underpinnings of subjective experience within the individual – in other words, the idea that "it's all about my own weakness", or, "it's all about oppression". These positions, in turn, may represent a psychic struggle with – again respectively – acknowledging the horrific realities of social oppression, or the dark truth of psychological conflict. Of profound relevance to the concerns of this work, is the simple fact that the experience of oppression, of discrimination and prejudice at the hands of a cruel society, causes psychological damage to its target population. The risks, thus, regarding the previous two sections' debate surrounding the "personal" aspects of disability experience, are heightened by the recognition that, if we examine the psychological functioning of disabled persons who have suffered lives of exclusion, trauma and denigration, we are very likely to find damage. "Diagnosis" of this damage may then, all-too-easily, foreclose our analysis of its social origins in a manner which – true to the pitfalls of psychoanalysis – locates social suffering in personal shortcomings.

Psychoanalysis' focus on the development of concepts to describe the ephemeral world of the internal has, further, shaped a research tradition severely lacking in scientific rigour (Frosh, 2006, p. 275). The model may, to sober, scientific thinkers, appear more as a religious framework than an empirical enterprise, showing a lack of capacity for systematic evidence-gathering (ibid.), and – within opposing camps – the acceptance of conceptual knowledge on subjective, "doctrinal" grounds more than rational ones. Generally, the discipline has failed in the quest to persuade thinkers outside of the "school" of the model's (I believe) incisive interrogative power. Sadly, the discipline's repeated "retreat from collective engagement" since the social science turn to psychoanalysis some decades ago, has created a culture of

commentary, rather than direct, creative social initiative, thus missing the opportunity for a valuable debunking of the intra-psychic politics of everyday social life (Gordon, 1995, p. 277). What, then, does psychoanalysis have to offer us in the realm of a social psychological critique?

To begin with, what psychoanalysis brings to the interrogation of society is a fruitful, provocative suspiciousness regarding the multi-determined nature of social actions. In the words of Paul Hoggett (1992), the objective of psychoanalysis is to assist us in attempting to "lie to ourselves a little less than we do" (Hoggett, 1992, p. 3). Human motivations are reliably complex and layered, imbued with latent valencies not reducible to an equation measuring the number of removes from the means of production. Psychoanalysis introduces the ambivalence inherent in a kaleidoscope of human subjectivity, opening the door to the irrational, and upsetting the hoped-for predictability and stability of a unidimensional material world. Despite the dreary reports on psychoanalysis' more recent attempts at developing a politically engaged agenda (e.g. Gordon, 1995; Frosh, 2006), a radical political strand in analytic theorising has a long history, beginning with Freud's *Civilisation and its Discontents* (Freud, 1930), through the work of the Frankfurt school, and the contributions of several influential feminist writers (Marks, 1999a, p. 5). During the first half of the last century, it was Wilhelm Reich (Reich, 1945; 1946) who most actively advanced the possibilities of psychoanalysis as a revolutionary catalyst, constructing a synthesis of Marxist and psychodynamic ideas in an attempt to explain "irrational" social phenomena – not least, the rise to power of fascism (Hinshelwood & Chiesa, 2002a, p. 10). For Reich (1946), the role of psychoanalysis in politics was clear:

...the area in historical materialism where psychoanalysis has to fulfil a scientific function, which social economy is not in a position to accomplish: the comprehension of the structure and dynamics of ideology, not of its historical basis.

(Reich, 1946, p. 28)

What Reich's (1946) words point to is a theory of ideology as it works "in the head" of its interpellated subjects; that is, how the "facts" of political economy interact in a mutually constitutive dynamic with the nature of subjectivity. The "emotional truth" which lies – or

"writhe" – in this psychological realm, it must be said, is a profoundly shifting and unstable one – the task of conceptualisation is hard. Yet this fact does not in any way reduce the necessity, the imperative, to explore these complexities; indeed, what psychoanalysis can bring, to the exclusion of positivist frameworks, is a ready capacity to acknowledge "limits, gaps, vulnerability, and a lack of knowledge" in its analysis (Cooper & Treacher, 1995, p. 3). Within a historical materialist analysis of society, the identity of the villains – the enemy – is generally all too clear, in a manner which circumvents the "painful" reality that social relations are dynamic and collusive; that victims and perpetrators alike shape the ongoing social tangle which is oppression. The role of unconscious forces in mediating such relationships is, thus, very substantial; dissonance is managed, in order that life may continue. While psychoanalysis may not offer directives regarding the "solutions" to these problems, the uncovering of the myriad of social "inadvertencies" engendered by unconscious motives nevertheless illuminates our understanding of where societal power lies (Gould, 1991, p. 37). Political and social structures are mirrored – and lived – in unconscious phantasy; it is essential that any thorough analysis of societal power relations is able to describe the battle lines of the internal, as well as the material, drama of engagement (Frosh, 2006, p. 174).

In the findings of his international empirical survey of psychoanalytic practitioners in many countries, Samuels (1993) was to encounter many surprises. Chief amongst these was the dramatic contradiction of his assumption that only a small minority of psychoanalysts would "confess" to having openly discussed political issues with their patients. Samuels (1993) expected a picture to emerge of "a massive denial of the 'reality' of socio-political thematic material" brought into the clinical setting, with practitioners tending to "interpret away" such contextual factors as political instability or oppression (Samuels, 1993, p. 216). This would have been unsurprising, considering the psychoanalytic proclivity for viewing such material as symbolic commentary on the transference relationship, or other aspects of intra-psycho conflict. With the notable exception of the United Kingdom, his expectations were strongly disproved. Samuels (1993, p. 235) experienced these findings as "truly amazing", and comments that this evidence calls into question the well-established view that psychoanalytic practitioners "pay no attention to political realities". Samuels (1993, p. 51) elaborates upon his new-found optimism by arguing that, again contrary to expectations, psychoanalytic psychotherapy often does not dissipate individual rage at the horrors of social injustice, but rather focuses generalized feeling in a way which facilitates a directing of accountability at the social milieu. In other words, intra-psycho exploration may be subversive in its undermining of defences of self-blame, via the interrogation of internalised authoritarian

figures. Frosh (2006, p. 168) is noticeably decisive in declaring that prejudice and discrimination, be it on the basis of colour, gender, sexual orientation, disability or whatever, are never satisfactorily accounted for by explanatory models located solely in the social sphere. These social ills, besides being played out on the terrain of manifest politics, are also deeply embedded in the internal realities of individual psychology, rendering, in the words of Michael Rustin, the "tenacity" of a phenomenon such as racism (Frosh, 2006, p. 168; Rustin, 1991). Surely, no theory of social life could aspire to completeness without engaging with subjectivity, emotion, and the non-linear nature of individual agency (Frosh, 2006, p. 275). What excites about psychoanalysis, if critically, courageously, and hence subversively, applied, is its potential to unlock in buried seams of consciousness realities which overturn stereotype and confound simplistic, reified views of the division of social power. Unlike materialist accounts, psychoanalysis carries the capacity to interrogate, and hence to free from within.

A key and ongoing debate surrounding the application of psychoanalysis to the socio-political realm can be traced back to the mid-twentieth century altercation between the so-called "Frankfurt school" (notably the theorists Marcuse and Adorno), and the "Revisionist psychoanalysts" (in particular, Fromm, Horney and Sullivan - Frosh, 2006, p. 174). The crux of this debate centres on the "Revisionist" view that it is possible to separate out human "needs" from the nature of the prevailing social order, and the "critical" psychoanalysts of the Frankfurt school's rejection of this proposition (Frosh, 2006, p. 174). In the minds of the Revisionists, the idea that "human psychological needs" are readily identifiable, and largely universal, created the potential for the forging of a psychoanalytically informed humanism, which would be in a position to prescribe which societal conditions are favourable, or harmful, to human psychological development (ibid.). Within this view, optimal social circumstances may be created for human life, in which the full potentials of each individual may be reached. Whilst these proposals for a mode of socially engaged psychoanalytic theorising seem sensible – and temptingly beneficial – at first glance, it is essential to be cognisant of the attendant ideological implications. Within this position, if psychoanalysis is to be engaged with social change, it must endorse the existence of a "non-social subject"; in other words, a pre-social human self which, although developing within the social world, is not fundamentally conceived by it (ibid.). Psychoanalysis may then issue "directives" on what this inherent "self" needs in order to flower. There are at least two potentially pernicious ideological consequences of this state of affairs. First, a pristine "self" is constructed as the only "real", and hence, "healthy" self – the sort of self that will respond positively to optimal

treatment. Secondly, this posits a human psychic structure which is positioned as unassailable to the enquiries of deconstruction; that is, any interrogation of the role of ideological forces in the shaping of this "primary" psychological substrate is obviated (ibid., p. 175). Wolfenstein (1990, p. 150), along with Marcuse and the balance of the Frankfurt school, regard the existence of such a self as dangerous fantasy. If psychoanalysis is given authority to define the parameters of this "essential" self, the discipline locates itself consequently as the gatekeeper of normalcy; as an authority on what people "need", based upon a fixed, ahistoric notion of what people "are".

For the Frankfurt school, every layer of psychic structure that we encounter in analytic work is always, already, a profoundly social phenomenon. Failing to recognise this reality would lead to development of a "situation specific" psychoanalytic humanism, which would inevitably privilege psychological functioning which fulfils its normative expectations. In my view, this theoretical direction embodies a calamitous missing of the essence of what psychoanalysis offers, which is a framework for interrogation which, in its ideal form, brings no normative expectations, and privileges no sacred cows. Within the disability world, a "humanistic psychoanalysis" would, I believe, tend toward what might be termed a "rehabilitationist psychology", which identifies, a priori, whom the disabled subject "is", and consequently what she needs in order to "function" or "integrate" adequately within the prevailing, culturally specific, social order. This route would, I fear, not only obstruct enquiry into the nature and ideological roots of disabled subjectivity, but consequently would miss the opportunity which this store of oppressed human struggle has for contributing to the broader understanding of socialisation, social life and the human condition. The history of psychological theorising about disabled persons, based upon the assumption of inherent difference (see *Psychoanalysis and disability: A brief history*, p.73), creates a sinister backdrop to this view, foregrounding the all-too-familiar social propensity for the prescriptive control of disabled lives. Any remotely universalising theory of the pre-social disabled psyche will tend to obstruct one's view of the highly complex, intricate and already carefully ideologically obscured roots of disablist culture, and hence socialisation. In the disability phenomenon, we are confronted by prejudices which have exceptionally deep psychic roots, manifesting in social practices which, notwithstanding their brutality, remain bathed in normalcy, and hence invisible. Penetrating the obscure frontiers of these unconscious cultural meanings will require dogged critique of the most rigorous and determined nature. The question of where, theoretically, to place the experience of the ("critical realist") body within this framework, remains an awkward one; it involves holding the incisive instruments of

constructionism, whilst affirming the embodied nature of manifest impairment. To Wolfenstein (1990, p. 150), the positing of the social as "objective" in opposition to a "subjective" individual embodies an illusory split, highlighting the awkwardness of psychoanalysis' encounter with Marxism. He relates how Freud (1921), predicating the Revisionist position, missed the opportunity to create a truly social psychoanalysis by inserting a universalising structure – the notion of the primal horde – into his framework "in the place where human history should be" (ibid.). In so doing, Freud, for the time being, confounded any possibility of theoretically integrating political reality into his psychology. Without this "mystification of history", arising out of Freud's "psychological individualism", the recognition might have emerged far earlier that psychoanalysis is "eo ipso, a social psychology" (Wolfenstein, 1990, p. 178). The post-Freudian work of Klein and Bion present a more dialectical picture of personality development, which would seem to allow more for the interrogation of socialisation; this will be explored with particular reference to disability in later sections.

The advent of Kleinian object relations theory (Klein, 1946; 1948; 1952; 1957) incorporated the conceptualisation of a new range of primitive mental functions with which to relate the intra-psyche with the socio-political realms (Hinshelwood & Chiesa, 2002a, p. 7). Prior to these developments, the Freudian picture of political commitment relied largely on the notion of identification; this was the "glue" that connected the intra-psyche with social action. However, Kleinian concepts such as projection, introjection and projective identification for the first time provided for a bi-directional relationship with an external, and then internalised, object (ibid., p. 7). The importance of these concepts to the business of understanding social action was, for Klein, a relatively insignificant issue, since she herself showed no interest in using analytic principles to unpack social process (ibid.). It is Kleinian concepts which now largely embody the lingua franca of psychoanalytic critiques of society (Richards, 1989, p. 3), utilising a model in which the social group becomes viewed as a collectivity comprising, in fantasy, parts of the personalities of individuals (Hinshelwood & Chiesa, 2002a, p. 6). Intra- and inter-group dynamics may then be understood as, at least in part, enactments of the internal dramas of ongoing object relations (ibid.).

Within psychoanalytic theorising on social process utilising Kleinian concepts, it is the nature of defences erected against the intrusion of infantile, psychotic anxieties which most decisively shape social actions (Young, 1994, p. 74). The psychic need to maintain

equilibrium in the face of threat, however, routinely perverts and distorts cognitions of social reality (Bion, 1961; 1967; 1970), in a manner which may obscure political contradictions, whilst rigidifying adherence to the status quo. In other words, we may, for intra-psychic reasons, "need" to continue to construe social processes in a particular manner (Young, 1994, p. 74). The actions of such defences (including splitting, projection and projective identification) constrict mental space, tending to reduce the world to a system of polarities, in which free, nuanced and creative apprehensions are banished from view. Put simply, it is hard, when such defences are evoked, to think; to make a clear-minded, un-invested and equitable assessment of the manifest (ibid.). It is within this reactionary psychic environment that primitive psychological processes facilitate the unconscious scapegoating of social minorities, such as disabled persons, for unconscious psychic ends. To Young (1994, p. 82), these anxieties are a ubiquitous, inevitable aspect of psychological functioning, with the attendant defences therefore profoundly shaping culture and the nature of social institutions. Social change, consequently, is likely to require "analysis of the common anxieties and unconscious collusions underlying the social defences determining phantasy social relationships" (Jaques, 1955 cited in Young, 1994, p. 88).

The psychotic defences which shape social institutions are, within Klein's model of psychic functioning, associated with the paranoid-schizoid position (Klein, 1946). For Klein, the manifestation of psychotic forms of thought was not remote, not qualitatively removed from "everyday life". Rather, her position makes provision for a "psychotic layer" within all – healthy and afflicted – minds, such that experiences which resonate with unconscious anxieties regularly raise, in all of us, psychotic modes of seeing the world. Within the paranoid-schizoid position, which such psychically provocative experiences may re-evolve in us, parts of the ego become split off, and are experienced instead as aspects of the external world (as in projection and projective identification, to be examined later). Here, an imminent threat to psychic equilibrium has provoked a drastic, contorted re-configuration of psychic elements, in a bid to evacuate unmanageable feelings such as shame or hostility (Greenberg & Mitchell, 1983, p. 130). The world of fantasy conjured by this mobilisation of defences is populated with idealised good objects, set up in opposition to persecuting malevolent ones; a simple, denuded world of good and evil (Young, 1994, p. 78). The prominent presence of paranoia – arising from the projection of malevolent aspects of the ego – make for a vicious, concrete, and desperately self-seeking mode of functioning; that is, one hostile in paranoid anticipation of violent, excoriating attack from the wicked forces which lurk at the edges of consciousness. It is dark fears such as these which effectively hold the social order to ransom,

precluding change via the need to maintain the psychic splits so characteristic of intergroup behaviour. Entry into a particular social group may involve entering into the key splits and projective identifications with which the group achieves (positive) differentiation from other groups (Young, 1994, p. 136). A "complex and subtle interaction", continues Young, is woven between intra-psychic defences of the individual, and those of the social institution (Young, 1994, p. 136-7). The defence system of the individual is repeatedly projected into the institutional defence system, while the social institution's defensive constructions are repeatedly introjected into the intra-psychic realm (ibid., p. 137). Thus do group allegiances and individual strategies for the maintaining of psychic security become interwoven, mutually constitutive, and symbiotically self-perpetuating, rendering a groupwise profile of splitting, scapegoating and stereotyping which simultaneously fills unique, individual defensive needs (ibid.).

As this chapter continues, the utility of these and other psychoanalytic concepts to the project of accounting for the ostracisation, denigration and cruelty perpetrated against disabled persons around the world, will be considered. In opening this discussion, we turn now to a review of the history of psychoanalytic theorising on the issue of disability.

### **Psychoanalysis and disability: A brief history**

In documenting an unusual occurrence in the world of professional psychoanalysis – a psychoanalytic conference segment concerned with treating disabled patients – De La Torre (2002, p. 675) describes the issue of disability as "a topic that has been largely foreign to psychoanalysis". Indeed, with regard to theorising on disability and psychic functioning, the silence from psychoanalytic quarters has, for much of the last century, been deafening (Castelnuovo-Tedesco, 1981, p. 145). This fact is bewildering; surely, one imagines, the experience of bodily impairment, with its concomitants of culturally embedded denigration and discrimination, should be of interest to a discipline concerned with mapping the depth and diversity of human subjectivity. In reading this silence, one may consider a number of possible explanations: first, that psychoanalytic writers felt that there was no reason to believe that disability is associated with mental health concerns which necessitate its being afforded "special attention" within psychological theory. The second, more ominous possibility is that psychoanalysis – perhaps inadvertently – constructs disabled persons as "too damaged" to benefit from the work of analytic psychotherapy. Or, is there something about the mystique,

the evocativeness of impairment, which has rendered a subtle avoidance of the exploration of disabled subjectivity? On a more material level, it may be that the typically disadvantaged socio-economic position of disabled persons has placed their lives beyond the ken of the bourgeois world of couch and consulting room. Evidence from the limited literature seems to indicate that psychoanalytic accounts, like the majority of psychological theorising on disability, assume that the onset of bodily difference necessarily brings with it pathological psychic reverberations (Lenny, 1993, p. 233; Asch & Rousso, 1985; Gill, 2001). The stridently negative, at times damning, prognostications associated with these assessments lend credence to the idea of psychoanalysis' neglect of disability relating to an amalgam of anxious avoidance and therapeutic pessimism. The key issue which forms the backdrop to these reflections pertains to the origins of the psychological difficulties experienced by disabled persons. Of course, not all disabled persons encounter psychological problems, but, as in any population, a proportion will. Writing from a social model perspective, Oliver (1993a, p. 61) argues that nondisabled mental health professionals have, largely, viewed such difficulties as emanating from the functional limitations which arise from impairment. The disability movement, conversely, has averred that it is not bodily difference, but the failure of social and physical environments to provide equitably for the needs of the impaired that is at the root of the emotional distress evidenced by some of their number (Oliver, 1993a, p. 61). An influential piece of "rehabilitationist" research which is held in infamy by disability studies is that of Miller and Gwynne (1972), who portrayed the disabled persons in the institutional settings which they studied as having psychological difficulties which were an inevitable outpouring of their physical "limitations" (Miller & Gwynne, 1972; Morris, 1993a, p. 86). This penchant for forging causal links between the nature of bodies and the health of psychic functioning is echoed through most psychoanalytic contributions on the subject of disability.

Adrienne Asch and Harilyn Rousso (1985), in their cutting critique of psychoanalytic theorising on disability, describe how, in general, this work has done much to compound and reinforce prejudicial stereotypes regarding the emotional functioning and potential for productivity and intimacy of disabled persons (Asch & Rousso, 1985, p. 1). Much psychoanalytic literature, tacitly or overtly, constructs disabled persons as (relatively) unanalysable, due to the (believed) ubiquitous presence in this population of poor levels of ego integration, compounded by primitive psychic defence structures (*ibid.*, p. 4). The logic of these investigations is one which seeks a direct impact of bodily impairment upon personality development; that is, purporting to "read" what of the self is "written" on the body. Having predicated their work upon this assumption, the attention of such investigations

then moves to questions regarding the extent to which the "psychological effects of impairment" are "inevitable, preventable or modifiable" (ibid.). By way of example, Thomas and Siller (1999) recount that typical reactions to disability include "depression, withdrawal, shame, overcompensation and denial", as well as "considerable sensitivity about the disability" and "feelings of inferiority" which are managed via a "generalised hostility" (Thomas & Siller, 1999, p. 182; Siller, 1963; see also Castelnuovo-Tedesco, 1981, p. 145). Whilst each of these "sequelae" are not discounted, and are quite plausible, the key issue at hand is that little or no mention is made in this body of research of the potential pathogenic or harmful effects of the exclusion, prejudice, discrimination and denigration which are the hallmarks of disabled life in most societies. In a retrospective review of analytic work in the area, Castelnuovo-Tedesco (1981) identifies the overwhelming focus on bodily factors within this literature, but in no way problematises this. With a similar disregard for ideological concerns, a range of authors echo Thomas and Siller (1999) in identifying unmastered aggression as a common emotional consequence of bodily defect, with severe maladaptive implications emanating from a lack of ego maturity (Bornstein, 1977; Burlingham, 1961; Castelnuovo-Tedesco, 1981; Niederland, 1965; Ogden, 1974).

Perhaps the psychological effect of impairment most reliably suggested by this legacy of psychoanalytic theorising is that of narcissistic pathology (Harris & Wideman, 1988, p. 117; Davis, 2002). Although, as we shall see, Freud's utterances on the issue of disability are somewhat ambiguous, Niederland (1965, p. 518) buttresses his own position by pointing to the fact that the father of psychoanalysis viewed work with patients with "organic disease" as a key route to understanding narcissism (Freud, 1914, p. 550-51). Note, at this point, that for the purposes of explication of my key difficulties with this early legacy of psychoanalytic theorising on disability, Niederland's (1965) work will be examined in some detail; with some minor variation in positions taken by this clutch of writers, my primary objection to their position is brought clearly to light in his writings. For Niederland (1965, p. 518), bodily "defects" may function as "nodal psychological factor[s]" in the "genesis and perseverance" of narcissistic disturbance". This purported disturbance relates to the assumption that a "damaged" body (from infancy or childhood) will necessarily lead to distortions of the body ego, which, via projection, will render a distorted picture of the world (ibid.; Castelnuovo-Tedesco, 1981). The potential import of this cause-effect assertion for the manner in which subjective distress experienced by disabled persons is interpreted, borders on the horrific; the "damage" which manifests in such distress is forcibly "pushed" into the body, cementing the locus of lack, of defect, of failure, within the individual as an inevitable consequence of a

"spoiled" body. Further, this assertion constructs disabled people as carrying an inherent psychological "difference" which – unavoidably – emanates from within, as a result of "organic factors". Perception of self and other and reality testing, evolving against the backdrop of an "essentially bodily self-image and cathexis" based on an "oral-tactile" early concept of body, are viewed as doomed to severe distortion (Hoffer, 1950 cited in Niederland, 1965, p. 527). The "damage" which inheres in body and body ego, in turn, is responded to within this portrayal by a range of desperate, narcissistic defensive distortions, such as aggrandisement, magical thinking, secretiveness, aggression, and a florid fantasy life, replete with such themes as revenge, immortality, and birth-rebirth (Niederland, 1965, p. 521; Castelnuovo-Tedesco, 1981, p. 146). Niederland (1965) restricts his analysis to subjects who have had bodily impairments since birth or early childhood, thus arguing that basic body ego development has been distorted, via the "oral-tactile" apprehension of the "bodily self". However, the onset of impairment in later life has, elsewhere within the psychoanalytic literature, analogously been viewed as a potent assault on the ego (Lenny, 1993, p. 236; Castelnuovo-Tedesco, 1981, p. 146). Again, an asocial, cause-effect relationship between body and body ego is tacitly postulated, fulfilling cultural scripts of disablement as "personal tragedy", rather than social injustice.

A central question for our consideration is whether it is reasonable to argue that the pre-social experience of an impaired body may, or will, lead to body ego distortion and concomitant narcissistic injury. Freud (1923, p. 636) wrote that the ego is "first and foremost a bodily ego"; the ego is "a projection" of the surface of the body. This would seem to suggest that the nature of bodies directly informs the nature of the body ego, hence carrying formative influence over the ego. Of interest, though, is the question of whether culturally condensed assessments of value pertaining to the normalcy of bodies mediate this "reflection" of the body as it is precipitated into a body ego. Writers such as Niederland (1965) view the imprinting of narcissistic injury upon the ego arising from "*basic* physical experiences" as unproblematic (Niederland, 1965, p. 522 – my emphasis). But elsewhere, Freud (1914, p. 561) seems to intimate a far more "ideologically situated" view of bodily difference or disease. He writes:

In the aetiology of neuroses organic inferiority and imperfect development play an insignificant part. Neuroses make use of such inferiorities as a pretext, just as they do of every other suitable factor.

(Freud, 1914, p. 561)

Here, Freud (1914) locates bodily difference clearly as secondary to psychic functioning – that is, suggesting that somatic "defects" may be utilised as a rationalising "kernel of truth" which allows material sense to be made of what are, in fact, purely psychic, neurotic phenomena. Winnicott (1965) places strong emphasis on the physicality of bodily experience in shaping what he terms "the imaginative self" (Winnicott, 1965, p. 244). Dwelling within, and exploring the "inside" and "outside" of the "live body" provides the subject matter, the shape and sensation, of the coalescing self (ibid.; Erskine & Judd, 1994). But crucially, this does not mean that without the distorted socialisation which is so often the corollary of bodily difference, that the impaired body would nevertheless come to be experienced, in a primary way, as damaged. The body which the congenitally impaired infant possesses is the only body which he or she has ever experienced; its boundaries and shape, its motility and sensation – these are not aspects set against pre-existing ideals, but primary apprehensions of a unitary self. It is difficult to see how evaluative judgments, impacting upon the incremental solidifying of self, can take form without the mediation, the mirroring influence, of the social world.

Asch and Rousso's (1985) core criticism of the legacy of "traditional" psychoanalytic research on disability is expressed by the authors as follows: "Our major criticism ... is that by asking what impact a physical disability has on adult psychopathology, many authors overlook the impact of parental, familial and societal treatment on the psychological development of their disabled patients" (Asch & Rousso, 1985, p. 6). This keen observation is at once compelling and disturbing. What it might suggest is that the gripping evocations associated with disability have led psychoanalytic thinkers to temporarily abandon or disregard basic theoretical tenets of their orientation. To explain: it seems reasonable to assume that researchers operating within most psychoanalytic frameworks would place the influence of the family at centre stage in shaping the development of individual psychic functioning, be it of an adaptive or pathological sort. Yet, astonishingly, this principle seems to have been discarded here. Perhaps the hegemony of individualising modes of attribution pertaining to disability has permeated the views of these authors to the extent that, inter alia, the role of the responses of primary attachment figures in shaping the experiences of self and other of their impaired offspring is hardly considered (e.g. see Castelnuovo-Tedesco, 1981). One of Niederland's (1965, p. 521) research subjects, a woman with a paralysed arm, is portrayed in his analysis as manifesting strong signs of grandiosity which are attributable to her impairment. After recounting this interpretation, he then informs his reader of how she was kept in traction – flat on her back, and presumably in hospital – for most of her first year of

life. Niederland makes no significant mention of the potentially definitive aetiological import of this experience, instead moving quickly to a consideration of her "revenge fantasies", involving bodily dismemberment, mutilation, and the like. Again, there is no reason to question or doubt the presence of, say, revenge fantasies within this woman; the key question is, revenge upon whom, and for what? There is an inherent – even glaring – contradiction within a logic which attributes such phenomena as fantasies of revenge or grandeur to asocial origins. Surely, our investigation should be directed toward the culturally condensed meanings of *lived* bodies, rather than the material, banal "presumed" body. Psychoanalytic research which inadvertently performs the sleight of hand of conflating primary, "natural" bodily experience with cultural, evaluative bodily experience fail to heed the words of Susan Bordo cited earlier. These authors set up "impaired" bodily experience, even in infancy, against the myth of a "natural" body – a body which does not exist; instead, "natural" is "the script of culture writ large on the body" (Bordo, 1993 cited in Michalko, 2002, p. 58). This comment is not intended to diminish or question the embodied reality of impairment; rather, what must be emphasised is the social nature of meanings and significations attached to that impairment. Put simply, Niederland, Bornstein, Burlingham and others fail to investigate how their impaired patients have been responded to throughout their developmental years, by – in all probability – a fretful and frightened social world, deeply unready to engage with the shameful evocations and ambiguity of disablement. Later in the same paper, Niederland (1965, p. 529) does add a few caviats to the rather bald statements recounted above. He writes:

While noting these relations between disturbed ego development and early physical defectiveness, I wish to emphasise that I do not regard the latter as the sole pathogenic influence in their clinical picture. I believe, rather, that the defect, in addition to its significance as a concretising and organising experience of pathogenic import from early childhood, adds a 'kernel of truth' quality and multidimensional aspects to the pathological fantasies which are likely to arise during the developmental phases.

(Niederland, 1965, p. 529)

What the author seems to suggest here is that, to some extent, the impairment becomes – in Freud's (1914) words – a "pretext" into which more basic and universal relational conflicts are projected. Notwithstanding this helpful "afterthought", the overwhelming emphasis, and interpretive logic, of Niederland's account reflects a profound circumvention of social factors in mediating development. Relational considerations are named here in the abstract, but no

space or real endeavour is devoted to imagining the contours of such dynamics. The compelling nature of the damaged body, instead, entrenches itself into a virtual monopoly of attributive meaning.

If bodily impairment is so evocative, so compelling, to psychoanalysts as to bias attribution so, surely its "counter-transferential" effect upon parents of "defective" neonates will – especially during the crucial early years of life – be equally or more significant. The effect of systemic anxieties surrounding sight impaired infants and children, often manifesting in bizarre, even perverse distortions in socialisation and education, has been movingly, and at times disturbingly, documented (e.g. Chapman, 1978; French, 1993b; see also Scott, 1969; Armstrong, 2005). In the psychoanalytic study of congenitally blind children, attempts have typically been made to conceptualise the impact of the "naked" absence of sight upon developing object relations (Blank, 1957; Bornstein, 1977; Burlingham, 1961; Nagera & Colonna, 1965; Omwake & Solnit, 1961; Wright, 1991). These accounts proffer quite unilaterally pessimistic prognoses for what they view as the personality "sequelae" of development without vision. For example, Burlingham (1961, p. 131) argues that blind children are restricted in adaptively managing aggression, through the lack of apprehension of the consequences of their actions via the visual modality. Assumptions, thus, were often made by the children she studied that their actions brought about catastrophic effects, tending to lead to a constriction and anxiety surrounding agency. With a similar tone, Bornstein (1977) observes that blind children are "reduced to helplessness and panic" upon repeatedly failing to verify their mother's existence, through the unsatisfactory, cumulatory modality of audition (Bornstein, 1977, p. 25; Wright, 1991). The blind children studied by Bornstein (1977) showed very poor object constancy at 3 years, as against the typical achievement of this milestone at about 1 year by control children. Correspondingly, Nagera and Colonna (1965, p. 271) reported how, in contrast to sighted children, blind children remained largely rooted in pre-phallic phases of drive development. In making sense of this they argue that blindness interferes so profoundly with identifying environmental means of gratification that such means, when "captured", tend to lead to a fixated preoccupation which prevents their being abandoned, and consequently constrains development. Lastly, Omwake and Solnit (1961) describe a therapeutic intervention with a blind girl: while directing attention to the traumatic experiences of her first three years of life as influential in her (disturbed) development, these authors then frame her impairment as causal in her psychopathology, arguing that her "consequent" under-stimulation rendered it impossible for her to develop psychic imagery necessary for the solidifying of the structural foundations of repression.

Kenneth Wright's (1991) influential contribution to this area has been critiqued in some depth elsewhere (Watermeyer, 2002). What all of these contributions share is a fascination with the "dark world" of blindness, which stunts and distorts the potentially incisive power of an object relations analysis of the dynamic effects of blindness in infancy. The conceptualisations offered by these authors, quite simply, are lacking in a rigorous interrogation of the *relational* implications of impairment; that is, the multifarious, largely unconscious, impact of infantile blindness upon the delicate development of the early dyadic relationship, as this sets a tone for later, systemic constructions of self and other. As shall be argued in the following section, the extraordinary capacity of disability to evoke primitive anxieties in the other, may profoundly disrupt the early developmental milieu, rendering potentially calamitous distortions in key areas such as containment and mirroring. Reference within the work cited above to, for example, inadequate stimulation, is typically made with no attention whatsoever to issues such as parents' struggle in developing a healthy sense of secure belief in their capacity to contain and manage this unexpected, perhaps "tragic" arrival – a blind infant. Again, one would imagine that these issues, viz. the nature and management of parental fantasies and fears surrounding the capacity to parent, to imagine and hold the fantasised internal world of their child – would be of primary, definitive concern to psychoanalytic researchers. Instead – and familiarly – the emphasis of all these analyses begins with, and remains entranced with, the somatic. Where attention should be carefully directed to issues such as the attuned responsiveness of an anxious, ambivalent, and probably un-informed world, Bornstein (1977) instead remains preoccupied with "infantile masturbatory conflicts". The realness of such conflicts, as noted earlier, is not in doubt; but it is the tacit or overt attributions made regarding the origins of these that are of paramount importance. Surely, it is incontrovertible that "symptoms" such as difficulties with channelling aggression, anxiety at not "finding" a parent and consequent poor object constancy, and a lack of appropriate gratification due to paucity of stimulation, are all situations with, at the least, a substantial relational dimension. It is only when one begins by peering in the direction of relational factors that the profound, formative influence of such dynamics begins to crystallize. Dangerously, these dynamics may produce effects which masquerade all-too-readily as the sequelae of impairment; at least in the, at times, extravagant imaginations of minds captured by bodily "defect. By way of one further example, Berger (1967), although developing ideas on chronic illness rather than disability, emphasises the experience of feeling "unknowable" as a virtually ever-present feature of the subjective nature of this personal situation. Again, this layer of experience is attributed, in a largely pre-social manner, to somatic factors (Berger, 1967 cited in Erskine, 1994, p. 49). Now, if, as we are beginning to see, the experience of disability or illness is likely to often be marked with ongoing misattunements and "empathic failures" rendered by a world which is anxious, reluctant, or even manifesting

of a hostility borne of threat, then feeling "unknown", and hence probably "unknowable" is a more than likely consequence. Yet here, we fall readily into the presumption that it is not an experience of *feeling* unknowable – a relational artifact – which is at work; rather, it is the "modernist" reality of *being* unknowable. Whilst these positions reflect variations in emphasis, rather than a categorical contrast, it is my position that a rigorous focus on the relational is typically required in order to overcome our deeply socialised, stereotyping attributions which "favour" the body. To some extent, Freud's most significant contribution to theorising on disability, entitled *The Exceptions* (Freud, 1916), falls into similar snares. It is of sufficient interest to deserve special attention, and will thus be considered in some detail in a later section (see *Disability and the distortion of personal and psychic boundaries: Introduction*, p.260)

The characteristic flaws of emphasis described above may, in psychoanalytic psychotherapy with disabled persons, render oppressive and biasing attributions which may serve to cement, rather than subvert, internalised, individualising defences of self-denigration (Lenny. 1993, p. 236). The flawed logic of such attributions is contradicted by a host of research findings cited by Olkin (1999), which demonstrate that the degree of severity of impairment is not correlated with assessments of psychological adjustment (Olkin, 1999, p. 67). In other words, the mediating influence of relational factors is underscored by the finding that "greater" severity of impairment does not imply more substantial psychological morbidity. A further, ominous fragment of evidence directing attention towards the relationships which surround impairment, rather than some fantasy of its solipsistic course, is the finding that impairment within the child has predictive value in the precipitation of violent child abuse (Milowe & Lourie, 1964 cited in Friedrich & Boriskin, 1976). At particular risk were children whose impairment required some special provision in interaction (such as sight or hearing impairment), with a child's perceived unresponsiveness triggering violent assault by a parent (ibid.).

In closing this brief critique, we come full circle, returning to De La Torre's (2002) account of three presentations on therapeutic work with disabled patients delivered at a psychoanalytic conference in the United Kingdom. Like much of the work cited above, there is no sign in this account of an awareness of disability as an axis of oppression, or as an identity phenomenon likely to profoundly shape socialisation. The impairments of patients in the three contributions are described, but the culture of constructions, of responses, to these

impairments is not touched upon; the word *discrimination* does not appear. What these authors combine in tracing, is the invisible outline of an illusory construct of the "disabled personality"; the "issues" of impaired persons, which require therapeutic attention in order that these may be "overcome". The complex, layered, and – I believe – definitive influence of social factors in giving meaning, life and valency to the impaired bodies of these patients remain uninterrogated, and in all probability take up a reconstructed, malignant residence as subjective "flaws", rather than aspects of oppression. An alternative, critical psychoanalytic view of disability, which aims expressly to cross-examine cultural factors in shaping its situated, lived reality, has been pioneered in the work of Deborah Marks (Marks, 1999a). We consider, and expand upon, her approach during the course of the following section.

### **A critical psychoanalytic view of disability**

In embarking upon an interrogation of social responses to disability, Marks (2002a, p. 2) locates unconscious processes as pivotal. With Obholzer and Roberts (1994), she asserts that both conscious and unconscious processes are "inextricably intertwined" with the shaping and flux of social structures (Marks, 2002a, p. 2). What this means is that the contoured landscape of the social order is constituted and reconstituted mutually, in ongoing reverberation, with its intra-psychic reflection. Social structures, thus, exist for "over-determined" reasons, serving both manifest and logical, as well as latent and irrational – that is, *personal* – purposes. Psychoanalysis, consequently, must take up a privileged position in our work, due to its unique capacity to conceptualise the fantasy structures which resonate with, and shape, political forces (Frosh, 2006, p. 174). The predominantly individual focus of traditional psychoanalysis, besides presenting the risk of ideologically sterile analyses, can be thought of as a strength here, through its spacious ability to shape its description around the myriad of unique, individual aspects of subjective life. The challenge, as noted by a range of authors, is to weave such intra-psychic and personal aspects of functioning into a socio-historical and group-based analysis, which does not reduce social processes to individual neurotic foibles (Gordon, 1995, p. 279). If one accepts the inter-penetration of social and psychic – in particular, the deep, intricate configurations of investments in social outcomes with which the mind is woven together – then one must simultaneously acknowledge that progressive moral changes in society will involve painful psychic struggle (Cooper & Treacher, 1995, p. 7). In other words, such change will require that the deep, unconscious significations which contributed to the perpetuation of certain social ways of being must be abandoned, rendering disequilibrium which will require new strategies for functional psychic

compromise. Defensive profiles, in short, will have to be re-configured. Figlio and Richards (2002, p. 197) neatly capture this point, describing how, if one is to make sense of the impulse towards "civil defence", it is essential that one understands the strategy whereby this becomes the "vehicle" for "psychic defence". Of particular interest to our discussion of contested political models of disability oppression, however, is their further comment that such interpretation of the unconscious underpinnings of social conflict tends to muddy the "automatic rightness" of struggle politics (ibid.). As splits are interrogated and complex ambivalences revealed, crude vilifications are rendered less credible, and less sustainable. It is this "new and important embodied and psychological dimension" which psychoanalysis brings to the critical study of disability (Marks, 1999a, p. 2), which dismays the certainties of depersonalised materialist accounts.

Evidence for the unconscious rootedness of the social order is to be found in the reality that such social ills as racism and disability-based discrimination are not ameliorated by simple educational interventions (Marks, 1999a, p. 13; Žizek, 1990). It is not merely a "lack of awareness" which maintains these evils, but something far more tenacious and obstinate; to some extent, these phenomena embody a ransom for psychic stability in the lives of those who have unwittingly appropriated, and been appropriated by, their societal concomitants. In the arena of racial struggle, it was all too clear to Fanon (1952, p. 224) that equality could not be won by simply compiling a case structured within the logic and rationality of conscious discourse (Davids, 1996, p. 214). Instead, the ascribed, unconscious meanings of skin colour were to be interrogated. Within this set of presumptions, a socially constructed identity formation such as "disabled", comes to be formed, reified and internalised in a manner which shapes and entrenches identity-meanings and relations of both disabled and nondisabled persons. In a sense, all come to inadvertently "rely" on the continued existence of these "socio-psychic instruments". Observable "disability phenomena", such as special schools, rehabilitation units, residential care facilities and so forth, thus can begin to be "interpreted" as outpourings of systems of defence surrounding the particular store of unconscious material which is evoked by, or related to, the idea of disablement. The highly irrational, brutal, perverse and contradictory treatment of disabled persons in all societies surely must point to a relatively centralised, and profoundly influential store of unconscious investment within the general population. The critical question which arises, thus, pertains to what this store of unconscious meanings surrounding disability is composed of.

Although not explicitly working within a psychoanalytic framework, Thomson (1997b, p. 43) provides an eloquent description of the symbolic burden carried by disabled persons in her society:

The disabled body stands for the self gone out of control, individualism run rampant: it mocks the notion of the body as compliant instrument of the limitless will and appears in the cultural imagination as ungovernable, recalcitrant, flaunting its difference as if to refute the fantasy of sameness implicit in the notion of equality. Even more troubling, disability suggests that the cultural other lies dormant within the cultural self, threatening abrupt or gradual transformations from 'man' to 'invalid'.

(Thomson, 1997b, p. 43)

Disabled persons, for Thomson (1997b), have come to be socially – psychically – positioned as the symbolic custodians of damage, brokenness, frailty and defect. Disabled lives, consequently, are reliably constructed within western society as dysfunctional and spoiled (Marks, 1999a, p. 12). Similarly, Shakespeare (1994) sees disabled people as symbolically appropriated by society as “ciphers” (or “dustbins”) for those “feelings, processes or characteristics” with which nondisabled persons cannot deal, rendering the “cementing” of these negatively valued aspects to the disabled community (Shakespeare, 1994, p. 287). A psychoanalytic – in particular, object relations – view of human development posits that emotional “holding” is by its very nature always imperfect (Winnicott, 1947). The young infant, consequently, is subject to progressive “disillusionment” as she or he grows in becoming accustomed to an increasingly separate existence in a subjectively threatening world. Experiences of the terror of abandonment, thus, are universal, and vary only in intensity with the complex interlacing of infantile temperament and parental goodness-of-fit. Later development will, amongst much else, bring further imperatives to separate, the competitiveness of school, anxieties regarding intellectual and sexual adequacy, concerns about acceptability and the capacity to be loved, and fears of dependency in an often cruelly autonomous world. The psychic conflict inherent within the psychodynamic model of mind allows for the selective repression – the *splitting off* – of memories and attendant emotions which surround the long and inevitably bumpy road of maturation. Survival dictates that the conscious acknowledgement and “working through” of this store of trauma be selective, limited and functional, such that psychic stability is maintained, and the ongoing tasks of life can continue to be negotiated. All, thus, carry unconscious seams of suffering, described by Marks (1999a, p. 176) as “universal existential anxieties”. Notions and images of disability

may provide convenient, tangible and sanctioned objects for their elicitation and "vicarious" management. Further, the lack of realistic and even-handed representations of the experience of disability, working in concert with the utilisation of "the Disabled" as containers for unconscious conflicts, ensures that the perceived "emotional experience" of disability remains regarded as not only different to the normative struggles of human life, but as inconceivable and alien to the subjectivity of nondisabled normalcy (Wendell, 1996, p. 43). This, therefore, further entrenches the illusion of sanctity offered by strategies of disavowal such as projection and projective identification. Correspondingly, though, a consideration of psychoanalytic accounts of unconscious fears, feelings and struggles surrounding normality and acceptability reveals that "those [perceived] aspects of disability which generate most anxiety are precisely those areas of human experience which many people struggle with" (Marks, 1999a, p. 170). The disability arena, with its volatile combination of identification, stereotyped sentimentalism, ostracisation and "invalidity", and romanticised redemption, offers a semantic landscape brimming with fantasy potential. This mesmerising, magnetic valency is pictured by Marks (1999a, p. 11) as it plays itself out in a common street interaction involving a visibly disabled person. She writes:

As in a child told not to stare, the desire to look, combined with a fear of something dangerous and unthinkable, yet intriguing, create a heady mix of prurience, insecurity and avoidance of the subject.

(Marks, 1999a, p. 11)

In this vignette, the onlooker is captivated, yet appalled; she desires unconsciously to apprehend a fragment of herself in the other, yet is simultaneously repelled by the impetus of a fracturing split which severs subjective commonality. In the disabled life before her, she sees tragedy, sinister darkness, loss, the unknown; every aspect an affront to her hopes and aspirations (Hunt, 1998, p. 16). In the face of such unstable, catalytic evidence of the dreaded, a moment allows little choice other than deflection and dislocation; the alternative is to acknowledge that of which disability is a harbinger – "that life is tragic and we shall all soon be dead" (ibid.). The repeated, mostly unquestioned attaching of representations of disability to these sinister, shadowy aspects of the human condition, ensures that unconscious emotional transactions involving the positioning of disabled persons as tragic and wretched victims of nature continues unabated, and probably largely unnoticed by all concerned. To question or deny this "natural order" would be to cast into doubt the crucial illusion of

essential difference which is at the heart of othering; it would be to re-position disabled persons as human subjects who suffer oppression, as I might, and suffer the frailty of the body, as I will. This readmission of disabled persons into the human empathic fold would carry with it the imperative to acknowledge that society is "shot through with inequity", to which all are vulnerable; in this sense disabled persons "represent a fearsome possibility" (Murphy, 1987, p. 117).

All relating, throughout life, is deeply shaped by aspects of emotional transference (Klein, 1952, p. 201). Yet, against this backdrop, the presence of disability within the predominant Western cultural milieu provokes the incidence of heightened, channelized and focal evocations which situate disabled persons as the personifications of the disavowed self of the modern subject. Bion (1957) constitutes human subjectivity as necessarily composed of a flux of psychotic and non-psychotic elements, shifting with alterations in the salience of disturbed psychic elements. Here, attacks upon subjectivity from internal objects may be stimulated by symbolic resonances apprehended in the external world, harnessing primitive defences which distort reality for the preservation of psychic integrity (Bion, 1957; Hoggett, 1992). It is the specific distortions characteristic of the psychotic defences – to be examined in the following section – which are of particular relevance as we interrogate prevalent stereotypes regarding disabled persons. It is my contention that the primitive conflicts which are the ready evocations triggered by disability, in turn lead to social responses to disabled persons which are marked by a regression into concrete, paranoid and elementary modes of cognitive functioning – within Klein's (1947) schema, the hallmarks of the paranoid-schizoid position. As described earlier, this mode of being provides no room for a reflective, interpreting subject; instead, both inner and outer worlds are reacted to via immediate, unmediated and paranoid psychic acts of accusation and self-protection. I will attempt to demonstrate that engaging with the fantasies which cluster around disability within most cultures, renders the squeezing away of the thought-space required to soften and re-align cognition in a manner which de-polarises stereotyped splits – in Ogden's (1986) words, the space "in between" self and experience (Ogden, 1986 cited in Hoggett, 1992, p. 83). This, crucially, allows for the availability to consciousness of more than one standpoint vis-a-vis a particular stimulus (ibid.).

Richards (1986, p. 106) explains how social injustices, as well as interventions aimed at managing these, are often especially magnetic to the projection of various personal conflicts

and experiences of psychic fragmentation. This may render the consequence that socio-political actions which purport to resolve contradictions within society may, at an unconscious level, attract very personal hopes for healing or relief (ibid.). As, I believe, in the fraught case of the charity discourse which dominates cultural constructions of disability, these personal investments in the "recognition" of struggle or loss may, in fact, cement demeaning representations, thus confounding social change. We need, perhaps, to identify with the struggle and loss, but we also need the struggle to continue, in order that a chronic desire for discharge may be provided for. Social institutions, thus, whilst aiming to transform the status quo, will often become entangled in complex and paradoxical investments from within and without, rendering a sabotage of precisely the changes which were initially desired (Fenichel, 1946 cited in Menzies-Lyth, 1988, p. 284; Bion, 1962a; Foster, 2001). Within the society's vision of disability – a turgid and shifting world richly laden in subjective poignancy – the definitive effects of constant waves of projection and introjection can hardly be overestimated (Klein, 1959, p. 250). Judgment, consequently, remains unstable.

Gordon (1995, p. 280) questions the extent to which the facilitating of insight into the intrapsychic "functioning" of social processes will reap benefits in terms of substantive social change. To exemplify, Gordon (1995) declares that it was no help whatsoever, during the course of the first Gulf war, to be informed that the global political landscape at that time was dominated by hails of projection. Whilst this instance may be true, in the case of disability, I disagree with the principle. Unlike intercontinental warfare, disablism occurs in some of its most profound forms within relationships of intimate proximity; between professionals and patients, parents and children, "carers" and "cared for". Of course, in the Gulf war case mentioned above, the issue of anti-Islamic prejudice – with or without military activity – is central. Yet, I contend that disablist prejudices lie that much more deeply, interdependently embedded within dominant cultural formations – invisibly hegemonic within cultural groupings, beginning with the family. Within this tightly bound meaning-system, perpetually rich with unquestioned projective and introjective activity, insight which facilitates the recognition and (partial) integration of split off aspects of personality "lived" through disability narrative, can hardly be over-valued. To begin with, in the lives of persons who have grown up with congenital impairments, the degree of insight into these processes amongst parents must be recognised as crucial. Considering the intricate interweaving of "common sense" culture with disablist prejudice, it may be that, in the disability arena more than others, personal insight proves an indispensable asset in shifting stubborn relational dynamics.

Zizek (1990) attempts to further "solidify" the conceptualisation of group allegiance by adding his notion of "enjoyment" to the pattern of symbolic identification described above. This "enjoyment" is described as being "beyond the pleasure principle", situated as an internal seat of deeply culturally embedded narcissistic affirmation of the sanctity and unique worth of the group (Zizek, 1990, p. 51; Frosh, 2006). It is from here that vigorous energy repeatedly seeks to demonstrate the "reality" of certain group attributes. This "enjoyment" is what is held as tying group members together, within an illusory, but ostensibly universally evident and "real" bond of commonality; further, it typically structures relations toward external forces. It is the relationship towards a group's fantasied "enjoyment" which is put at subjective risk by "hazards" to group identity such as assimilation or overwhelming emigration (Zizek, 1990, p. 52; Frosh, 2006). Here, it is the illusion of a consensual material "way of life" which comes under threat from the corrosive forces of out-group culture. The nebulous, wishful nature of the "way of life" which is at stake in Slavoj Zizek's model is highly reminiscent of the group fantasy of "nondisabled culture". Within this formation, an imaginary boundary is prepared, which separates the "ways of normalcy" from the contaminating impingement of perceived difference. The illusory semantic boundary quickly becomes realised in the materiality of social policies and installations, facilitating and legitimating the steady hum of projections which traverse its span. Whilst the nondisabled "way of life" is consciously maintained as inaccessible – indeed, *unliveable* – to disabled persons, it is "nonetheless constantly menaced by 'them'" (Zizek, 1990, p. 52). This irreducible, intricately fabricated "way of life" forms the cement which stabilises internal narcissistic scaffolding, persuading its adherents of the "vivacity and plenitude" which is, by its virtue, theirs alone (ibid.). In this way fantasy marshals very real group political power, where subjective consolation is contingent upon the activity of maintaining separation. In terms of fantasies of the "disabled threat", the historical prominence of demonological beliefs regarding the aetiology of impairment provides clues toward an understanding of the unconscious resonance of this form of otherness (Braddock & Parish, 2001, p. 20).

The threat to nondisabled "enjoyment" may be apprehended in a number of aspects of social life; consider, for example, sexuality. Sinason (1992) describes the darkly portentous, visceral threat imputed to sexual activity amongst learning disabled persons. The "threat" here to the "enjoyment" of nondisabled "majority" culture lies in the catastrophic fantasy that the perceived wretchedness and shame of learning disabled lives will, in some monstrous,

exponential wave, reproduce itself, its swarming numbers overwhelming "civilised" existence. The very long history of deeply oppressive, forceful constraints upon the sexual relating of learning disabled persons is testament to the incipient power of the fantasy. White (2003, p. 136) provides an equally startling, corresponding analysis of the history of "sex education" for blind persons, finding that such "education" would more accurately be described as the fervent, anxious and often dehumanising enforcement of an especially rigid species of heteronormativity. Disability, with its unnerving diversity, and propensity to act as a lightning rod for projections, carries an immense capacity for the destabilisation of much cherished (and needed) "norms" of "legitimate being". It is at times when this "legitimate being" is under threat – by, say, the integration of learning disabled children into early learning centres – that a need to "enumerate disconnected fragments" of "nondisabled culture" may emerge, as nauseous fears of "mixing" bubble to the surface, and social and psychic ranks begin to narrow (Zizek, 1990, p. 52). The "national" (or "nationalist") "enjoyment" of which Zizek (1990) writes is, of course, far more evident (even in its illusory nature) than the invisibly transparent, hegemonic "nondisabled culture". Yet, I believe the concept may throw light on the far more multifarious phenomenon of resistance to social change regarding disability, as well as the complexity – and perhaps futility – of attempts at forging a "disabled identity" (see *Identity politics and the movement*, p.191).

Marks (1999a, p. 22) orients her investigation into unconscious processes implicated in disablist oppression by posing a number of key questions to her reader; questions, she believes, that can only be satisfactorily addressed by a psychoanalytic approach. She asks:

- What is the origin of the excessive emotional energy (be it sadistic, fearful or kind) evoked by images of disability?
- How do we account for patronising, hostile, or avoidant responses of nondisabled people?
- What "emotional payoff" is achieved by nondisabled persons' involvement in "altruistic" disability-related work?
- What typically unacknowledged existential anxieties has disability come to symbolise?
- Why are persons with disabilities repeatedly represented in popular media as dangerous, helpless, disordered or infantile?

(Marks, 1999a, p. 22 [paraphrased])

Marks (1999a) clearly concurs with Rose (1996) as he affirms that fantasy is far from the inconsequential, ephemeral and irrelevant entity which it is held to be by prominent leftist political rhetoric (Rose, 1996 cited in Frosh, 2006, p. 173); by contrast, its influence, and hence its interrogation, must remain central. In Frosh's (2006, p. 173) words, "It is the fantasy that fuelled the politics, as well as the other way around; indeed, it may be that it is the former even more than the latter". Surely, if an analysis is to carry influence which brings some promise of social change – that is, *behavioural* change – it is elemental that one begins by penetrating, and thence operating within, prevalent systems of social signification; viz. the world of fantasy. Thus it is that Murphy (1995, p. 140) rejects unidimensional analyses of both a somatic and historical materialist nature, in asserting that "stigmatisation is less a by-product of disability *than its substance*" (my emphasis). He continues:

The greatest impediment to a person's taking full part in his society is not his [*sic.*] physical flaws, but rather the tissue of myths, fears and misunderstandings that society attaches to them.

(Murphy, 1995, p. 140)

Within normative resistance to the socio-psychic impingement of disability difference, there is nothing less at stake than the modernist project itself; in particular, what Zygmund Bauman (1994) terms "deconstructing mortality" (Bauman, 1994 cited in Frank, 1995, p. 83). Modernism, earnest and desperate, aims to exorcise the fear of human frailty, vividly embodied in the disabled figure, through control, separation, or eradication (Hughes, 2002b, p. 573). It is in this way that not only visible bodily "damage", but, more importantly, the internal "damage" which this symbolises, may, in a magical wish fulfilment, be excised from existence. The post-structuralist axiom that difference will always tend to organise itself into hierarchy is, due to the evocativeness of the "fractured body", powerfully played out here (Thomson, 1995, p. 600). The psychic threat of disability is not novel or foreign; rather, it is of the nature of what Freud (1919) termed "the uncanny" – that which arouses "dread and creeping horror" (Davis, 1997c, p. 68), precisely because of its perverse intimacy with the familiar. To Davis (1997c, p. 62), the feelings of disgust and revulsion evoked by "the uncanny" – *das Unheimlich* – bear marked resemblance to the feelings associated with the visualising of the disabled body by "normals". Freud (1919) himself, makes explicit reference in elaborating the flavour of "the uncanny", to bodily mutilations – "dismembered limbs, a

severed head, a hand cut off at the wrist" (Freud, 1919, p. 49). Sinason (1992, p. 42) observes how it is around particularly evocative markers of difference – race, sexuality, mental illness, disability – that politically correct "euphemisms" tend to cluster, demonstrating the obsessive, splitting nature of attempts at managing the anxious – and probably hostile – fantasies which these evoke. But it is disability which seems to cut the deepest. Davis (2002, p. 3) draws attention to a patently correct, yet shocking reality: it is familiar to see white people embracing the civil rights cause of blacks; likewise, many straight people have taken up the cause of gay, lesbian, bisexual and transgendered people. Yet, it is a small and highly exceptional minority of nondisabled persons who have managed to clearly identify disability as a social oppression issue, and participated within the disability movement's political agenda (Davis, 2002, pp. 3-4). For him, the reasons for this are "telling". As we jointly observe social divisions and inequalities, we are aware that no white persons are at risk of becoming black, and few straight people will during the life course alter their sexual or gendered orientation. Yet every "normal" individual can, and most will, become disabled during the life course (ibid.). The disability phenomenon, thus, possesses most intrinsically Freud's (1919) character of *das Unheimlich*.

The theoretical orientation which I aim to develop is one which combines an object relations-based, critical psychoanalytic position, with the vigour of cultural investigation afforded by social constructionist critique. The pre-Kleinian, more strongly drive-oriented psychoanalytic view is, I believe, one which provides insufficient scope for the interrogation of social representations of the body as these impact, inter alia, upon the unconscious and conscious elements of (especially) early socialisation. In critically reviewing Fanon's work, Davids (1996, p. 223) correctly identifies his model of racialised socialisation as one which locates personality and society within a dialectical, mutually influential relationship. Meaning attributions of, say, skin colour, carry a strong element of social construction, which interacts dynamically with intra-psychic factors in the genesis of racism. However, Fanon positions this model awkwardly within a drive-based metapsychology, drawing on the work of Jung and Adler. To Davids (1996, p. 223), Fanon's project – as ours – would be far better accommodated within a shifting, dialectical, and "partially" constructionist, object relations view. In the current work such an orientation would pose questions regarding the

unconscious, yet culturally influenced meanings of disablement, and how the defensive management of these evocations impacts upon interpersonal dynamics of relevance to the coalescing of selfhood. I turn, in the following sections, to a consideration of specific modes of psychic defence relevant to the evocations of disability, examining in each case the possible oppressive effects of the varying forms of cognitive distortion which these create.

## Defence mechanisms implicated in disablist oppression

A psychoanalytic interrogation of social responses to disability is centrally concerned with exploring the nature and effects of defence mechanisms, which are utilised in response to the unconscious conflicts often evoked by ideas and images of disability. The need, within the observer, to manage unconscious parts of self which are enlivened by exposure to disability may render distortions in social responses to disabled persons, as external "interventions" are applied in the stilling of internal struggles. In this way, every aspect of the world of societal responses to disabled persons – from legislative frameworks to linguistic conventions, service installations to religious rituals, health care protocols to educational policies – may be understood as, to some extent, a manifest expression of profiles of psychic defence. In this manner, the nature of a community's relating to its disabled population may be understood (or *interpreted*) as a reflection of intra-psychic modes of managing the unconscious, anxiety-ridden subjective "meanings" which disability carries. A range of psychic defence mechanisms – to be examined below – act to maintain psychological and material "distance" between disabled and nondisabled persons, such that the former remain available as projective containers for the unwanted, disavowed parts of self of those members of society self-identifying as "normals" (Marks, 1999a, p. 22).

Within the Kleinian view of early development, intense vulnerability and a chronic sense of threat are key aspects of the infant's world, with severe states of anxiety driving the ego to configure forms of psychic defence in order to find equilibrium (Klein, 1946, p. 292). These experiences of a quite undiluted, *psychotic anxiety*, and the (typically primitive) defences which coalesce for their management, form an unconscious psychic template which remains the mode of functioning harnessed during periods when anxiety-provoking stimuli cause regression to rudimentary mental states. The nature and reactivity of this psychotic layer of personality is, to a large extent, dependent upon the degree to which the extreme vulnerability and fear characteristic of the predicament of infancy was tolerated and responded to in an

attuned manner by care-givers. Of course, no parenting is perfectly attuned, and experiences of misattunement are essential if separation is to proceed. But it is the extent, the flavour and intensity, of experiences of infantile abandonment – of unmet primitive dependency needs – which will inform the rigidity of defences employed, and the permeability of psychic splits. Michael Rustin (1991, p. 62) writes how racial prejudices are often suffused with emotion, such that the meanings construed regarding social reality are profoundly mediated by the psychotic defences attendant upon the base conflicts surrounding self and other which race reflects. For Rustin (1991), the simplicities of thoughts wrought within psychotic states of mind fit all too well with the stark "truths" of racial bigotry, thus rendering psychic discharge at the cost of the dehumanisation of others. The intense affect often associated with racial prejudice, of course, has its source elsewhere; a place which could only be revealed to consciousness at the cost of overwhelmingly intense feelings such as shame and terror. Our task, likewise, is to trace the unconscious roots of, in the words of Marks (1999a, p. 22), the excessive levels of kindly, fearful or sadistic emotional energy evoked by disability.

### *Splitting*

This is a primitive defence mechanism whereby an individual avoids the anxiety-provoking ambiguity of a complex world by, instead, endowing individuals or things with "all good" or "all bad", unidimensional qualities (Marks, 1999a, p. 22). This need to divide the world into binary dualities reflects the infant's inability to tolerate his or her aggressive instincts, which must thus be projected into the world – the mother. What is rendered is a maternal figure that is split into good and evil; an idealised "good breast", and a denigrated, hateful "bad breast" (Klein, 1946, p. 293; 1960; Greenberg & Mitchell, 1983). The escape from the fearful, creeping contamination of dangerously ambivalent feelings via the strategy of splitting carries a particular salience for disability. Disablement, by its nature, is evocative of fantasies of inability, brokenness, dependency and loss of control; importantly, the degree of these fantasied states tends to remain uncertain and ambiguous to the observer. For example, when meeting a sight impaired individual, the observer's incipient fantasies regarding life without the environmental command afforded by sight, tend to be exacerbated by an inherent ambiguity regarding the "extent" of impairment. In the face of welling anxieties evoked by our imagining of a life without sight, there emerges a fraught need to gain some form of control via a sense of "knowing" the extent – the "reality" – of the danger. This situation is very closely analogous to that of the anxious infant, who consequently resolves her chaotic world into black and white. For disabled persons, this situation renders the familiar, split

stereotypes of the "useless invalid", and the "superhuman" disabled person, who, in the observer's desperate fantasy, can do "anything". In being forced, through the observer's regression to the use of psychotic defences, into this binary, disabled persons may remain unseen as complex, nuanced individuals, instead carrying wholesale idealisation or denigration. At the edges of consciousness, anxieties evoked by contact with disability may take the form of threatening echoes of dependency, in combination with the fear of becoming impaired, and guilt over experiencing oneself as "able-bodied" (Murphy, 1995, p. 143). Of course, part of the splitting process is that between observer and observed, between nondisabled and disabled, serving to reconstruct an illusory and essentialist notion of disability as a bounded and qualitative characteristic.

Idealisation, as one consequence of splitting, is rendered as a defence against persecutory anxiety, which is based upon unmanageable guilt regarding feelings of hostility (Klein, 1960, p. 274). The picture of the idealised disabled person is a culturally familiar one, typically involving, for example, "heart-warming" accounts of plucky and steadfast resilience in the face of adversity, as well as the attribution of a range of other excessive, unreal, and overly positive characteristics. What this often reflects is an inability within the observer to make mental space available for considering the experience of the individual before him or her, due to the constricting, disquieting threat of imminent, infantile and subjectively malevolent fantasies regarding the intolerable nature of perceived struggle. Klein's (1960, p. 274) reference to echoes of guilt over hostile feelings also seems salient here, framing idealisation of the disabled person as a defensive response to repressed sadism directed at the shameful, disavowed dependency which he or she carries. The history of brutal oppression, forced sterilisation and eugenic extermination suffered by disabled persons provides disturbing evidence of the voracity of this idea. Disabled persons falling on the other side of the split may function as projective containers for a broken, inert and unwanted aspect of the self; helpless and inadequate, and deserving of abandonment. Needless to say, where such a rudimentary, defended repertoire for perceiving disabled persons obtains, empathically accurate relating, and its corollary, an experience of being seen and known, is rendered all but impossible. Foster (2001, p. 81) describes how work with populations perceived as

vulnerable repeatedly draws social service workers back into a mode of relating characterised by splitting, where typically guilt- and hostility-ridden conflicts constrict mental space, and disallow authentic communication. The interesting point here pertains to the truism that it is not the nature of feelings which distorts or corrupts relationships, but rather the extent to which feelings are tolerable to consciousness; this principle is central to many of the propositions of the current work.

To give life to the notion of the idealised disabled person, I have elsewhere employed the following example (see Watermeyer, 2006, p. 37-8): In the film *Scents of a Woman* (Universal Studios, 1992), Al Pacino plays an embittered and isolated blind man, who, despite his "limitations", undertakes a range of breathtaking feats, which include dancing a dramatic tango after simply enquiring about the dimensions of the dance floor, and driving a sports car at breakneck speed under the instructions of a terrified and unwilling navigator. Here, the blind person is represented at both extremes of a split concept of what disablement implies. The first of these positions portrays Pacino's character as the stereotype of an emotionally damaged and isolated disabled person, whose impairment has stunted and distorted his social self. This image, arguably, embodies a reflection of fantasies – held by the screenplay writer, and echoed by societal stereotypes – of "how I would feel if I did not have sight". These fantasies are then employed as the basis for a unidimensional, broken character. The "coping" afforded here by the splitting defence refers to the observer who, in the face of threatening fears about what a blind person's life may (in fantasy) be like, achieves some sense of mastery and control by "deciding" that the blind person's life is, in fact, the way it is fearfully imagined to be.

Conversely though, Al Pacino's ability to perform the antics that he does in *Scents of a Woman* may reflect a need within the observer to overcome the fear that, due to his blindness, he is in fact utterly restricted, desolate, and capable of nothing. Thus, what we see may be a response to a more basic attribution, where the observer has originally disowned and given over feelings of deep inadequacy and incapability evoked in response to the idea of living with blindness, and thereafter has managed these feelings by a form of reversal, which presents the need to portray the blind person as heroic and unusually (implausibly) capable. In some sense, therefore, Pacino's character has been shaped in a manner which allows the observer to feel reassured that his life is not the unmitigated tragedy which we fear, and know, it to be. Distorted constructions such as the foregoing may preclude the perceiving of disabled lives as

carrying the characteristic complexity of "normality"; including strengths and vulnerabilities, hopes and losses, competence and inadequacy. The marked inability of Hollywood to present disabled film characters as normatively complex individuals, muddling through life's challenges with success and failure, hope and disappointment, has been well documented (e.g. Norden, 1994).

### *Projection*

This defence forms perhaps the primary explanation of how unwanted feelings and parts of self may come to be attributed to external objects. For Marks (1999a, p. 23), the concept embodies a "key tool for understanding the psychic mechanisms of prejudice against disabled people". Klein (1960, p. 273) explains how the child feels him or herself to "be bad", and thereafter escapes from the ensuing guilt by coming to regard the "badness" as being a characteristic of others. This, of course, tends to reinforce persecutory anxieties (ibid.), as the boundaries of the psyche rigidify in order to "hold out" the increasing, threatening weight of disavowed psychic matter. Haunting guilt also plays about the psychic shadows, arising from hostile feelings directed at the denigrated other, as well, perhaps, as an awareness of the inauthentic, victimising sleight of hand of the psychic transaction. A scenario called to mind by these thoughts is that of a family system which includes a disabled sibling. Relational dynamics often emerge within such families which serve to reify and concretise splits between the "neediness" or "vulnerability" of the disabled child, and the converse "independence" and "strength" of her nondisabled fellows. Parental anxiety regarding the ability to cope of the disabled child, impacting as it often does upon appropriate separation, may introduce dynamics of splitting which are internalised by each child, rendering the projection of neediness, incapability and emotional frailty into the disabled child, with other siblings inadvertently coming to be seen as comparatively infallible. Guilt, relating to feeling like an undeserving "survivor", may compound such splitting and projection. Within broader society, however, group-based projection, via the mechanisms of insistent mass media representations of disabled persons as broken, damaged unfortunates, continue to reinforce the position of disabled persons as "dustbins for disavowal" (Shakespeare, 1994, p. 287). In this manner, citizens are afforded the opportunity to reaffirm membership of the "normal" class, whilst simultaneously deflecting the internal encroachment of the death instinct (Klein, 1946, p. 298).

Within feminist and post-colonial discourse, the deconstructionist project of investigating how group-identity splits are created and perpetuated, has often embraced a psychoanalytic (in particular, Lacanian) view of the construction of subjectivity (Burman, 1996, p. 138). Within this view, the sentient self coalesces via processes of differentiation from social "others" (ibid.), whose negative characterisation reaffirms the ostensible positive distinctiveness of the subject. As in the case of disabled persons, it is that "Other" who is consequently forced to "carry the burden of difference, the excess, the surplus that will not fit" (ibid.). The model of identity being propounded here is a determinedly post-structuralist one, which leaves no room whatsoever for the "realness" of (projected) aspects of self; indeed, Burman (1996, p. 138) expressly refers to the "fantasy" of a prior time of "unity and completeness", which, in fact, never existed. Whilst not endorsing the notion of an era of psychic or social unity, my position is one which does allow for a residue of materiality within the crossfire of identity fragments. That is, the "reality" – and, the universality – of split off, shame- and anxiety-ridden aspects of self, ever-present by virtue of the drama of infancy. There is, in short, reality to that layer of our shared human condition which we struggle to acknowledge. Frosh's (2006, p. 261) model of the psychic nature of racism fits well with this schema; he writes:

The process of racist ideation is therefore one in which unwanted or feared aspects of the self are experienced as having the power to disturb the personality in so damaging a way that they have to be repudiated and evacuated or projected into the racialised other, chosen for this purpose both because of pre-existing social prejudices and because, as a fantasy category, racial 'otherness' can be employed to mean virtually anything.

(Frosh, 2006, p. 261-2)

Similarly, disabled people in modern society embody a docile and largely voiceless minority, featuring bodily "damage" all too readily utilisable in the business of "rationally" affirming the voracity of ascribed brokenness and inadequacy. The hegemonic value system which constructs health and vigour as moral virtues, further cements the position of disabled persons as deserved exiles of mainstream social life (Wendell, 1997, p. 269).

In a prior section, we saw how the earlier legacy of psychoanalytic theorising on disability was fiercely criticised, primarily for its failure to recognise the significance of social factors in mediating the psychological impact of impairment. However, I believe that the wholesale scuppering of this body of work, as would be advocated by social model writers and others, might embody a grave case of the baby being disposed of with the bathwater. To demonstrate, amongst many authors vilified within disability studies (e.g. Lenny, 1993; Goodley & Lawthom, 2006b) were Thomas & Siller (1999), whose work may here be called upon in support of a critical, socially situated and emancipatory psychoanalytic view. Siller (1970) found that fear of rejection amongst nondisabled persons functioned as a meaningful predictor of unwillingness to associate with disabled persons (Siller, 1970 cited in Thomas & Siller, 1999, p. 183). In other words, what was demonstrated is that the ostracisation of disabled persons bears direct correlation to anxieties regarding acceptability within members of the broader populace. Other researchers cited by Thomas and Siller (Siller et al., 1967; 1995), found that the expectations which nondisabled subjects carried regarding impaired people's emotional response to their disablement, corresponded closely with the profile of internal psychological struggles which each subject manifested. The idea that disablement would, for example, lead to depression or anger, thus embodied a "direct projection of one's own unconscious fears" (ibid., p. 185). Furthermore, these expectations could be related to fears regarding specific forms of impairment. They write:

For example, a woman with intense communication problems expressed greatest fear, if disabled, of being deaf. Paralysis was a particular issue with those showing dependency fears. Cerebral palsy posed a great threat to those for whom control is critical, with physical uncontrol objectifying emotional uncontrol.

(Siller et al., 1967 cited in Thomas & Siller, 1999, p. 185)

Thus it is that the system of meanings within which disability is culturally perceived is *directly related* to defensive needs for projection held by the community at large. Examples of such projections were also identified by Emry and Wiseman (1987); these workers found that disabled persons were "expected" to be socially introverted, psychologically unstable, depressed, hypersensitive, and easily offended (Emry & Wiseman, 1987 cited in Fox & Giles, 1996, p. 266). The essence of the predicament of disabled persons is that which besets all members of oppressed minorities – to have one's abilities, one's character, and oneself, defined from without. Kriegel (1987), in critically analysing representations of "the cripple" in English literature, concludes that, while others cry "I am what I am", disabled people are coerced to submit to the cries of others, saying, instead, "I am what you tell me I am"

(Kriegel, 1987, p. 33 – my emphasis). Only by such submission, according to Kriegel, may disabled people secure a deeply conditional place within the society of "normals" (Kriegel, 1987, p. 33; Barnes & Mercer, 2001, p. 518). Although working from a non-psychoanalytic viewpoint, Hunt (1998, p. 9) describes, in essence, how the nondisabled majority seems invested in maintaining disabled persons as ready, fitting receptacles for projection. He notes how the observer betrays a subtle need for disabled people to show evidence of suffering, in order that the privilege and standing he or she is afforded by nondisabled status be reaffirmed as worthy and valuable (ibid.). If the low-status individual – in this case, a disabled person – shows no sign of misery with his lowliness, this may present an awkward challenge to narcissistic assurances which turn upon a fulcrum of positively distinctive identity. In this manner, all may unconsciously carry a "personal investment" in the convincing perpetuation of the "disability imago".

Taking this analysis one step further: Frosh (1989, p. 237) argues that in the case of racism – like disability – unwanted aspects of the self are projected outward, to then be attacked by the selves that would disavow them. But in association with this projection, the denigrated group is also stereotyped in fantasy as possessing idealised features or privileges. The rejected group is loathed for these "special" qualities, which the "oppressor", with eviscerating scorn, attempts to pulverize (ibid.). What seems closely mirrored here in the disability arena is the familiar, often hateful stereotyping of disabled people as "freeloaders", who have "special privileges" and live lives of passive, gluttonous dependency on the balance of society. Intermingled with these more manifest envies, may be subtle echoes of resentment at the disabled individual's perceived licentious permission for dependency; simultaneously despised, and unconsciously desired. Disabled people, in this "receptive dependent space", may in fantasy be viewed as occupying a mythic, warm and idealised, nurturant and perfectly attuned, intimate environment; the perfect, wished-for maternal dyad. These suggested psychic underpinnings may form an important psychological context for, inter alia, the various forms of abuse and hate crime perpetrated upon the disabled population – aggressive acts which, by their nature, will serve only to enliven and escalate the paranoid ideation which propels them (Zizek, 1994, p. 78). The entire system of images and projections, further, is consistently re-invigorated and confirmed by the demeaning, sympathy-inducing imagery of the disability charity industry (Hevey, 1992, p. 140). Since we are, by definition, disquieted

by the projections – our own – which we apprehend in these images, our ongoing alienation from the subjects we observe is assured. Our incapacity to "see" the complex, nuanced reality of human life in disabled persons is proportional to an inability to consciously experience our own dysphoric selves; others, within this schema, are perpetually reduced to monochrome reflections of a fragmented, dingy inner world (Frosh, 1991, p. 76).

### *Projective identification*

Projective identification is a defensive manoeuvre closely related to projection, in the sense of the attributing of psychic material to others. Yet, the two concepts differ – perhaps along a continuum – in that the (largely consensual) definition of projective identification makes specific provision for the recipient of projections being emotionally affected by the process (Young, 1994, p. 124). Thus, as against "pure" projection, which constitutes nothing but unconscious fantasy in the mind of the "projector", projective identification involves the recipient being unconsciously "drawn in", to a collusory enactment of the attributions made to him or her. In addition, projective identification may serve not only the purpose of evacuating the psyche of noxious contents, but also aim to control the other, to find refuge for a threatened positive part of self, or to secure a non-separate psychic connection (Spilius, 1988 cited in Young, 1994, p. 124). Each of these functions carries the quality of a "psychic appropriation" of the object of projection, incorporating an invasion and exploitation of psychic space. Within the study of racism, the use of projective identification for the realisation of a psychically needed, social "other", has been described as "the internal equivalent of colonial occupation" (Davids, 1996, p. 216). In the last section, reference was made to dynamics of projection involving disabled persons, in which those undertaking the projection evidenced a need for the disabled "other" to visibly fulfill or manifest the personal or psychic characteristics attributed to him or her. Here, the unconscious fantasy of a denigrated "other" moves beyond the psychic, into a relational space, where the "other" comes to be strategically "created" in a manner which reaffirms, solidifies and perpetuates the subjective credibility of the projection. If we examine the myriad of repressive, demeaning material and psychic aspects of the social situatedness of disabled persons, we are led to questions regarding the unconscious utility of these scenarios, in terms of the facilitation of projective identification. Do we in modern society, for example, politically "create" disabled persons who are marginal, ostracised, dependent, uneducated, and emotionally damaged, in order to maintain a material "other" who may "live" these split off parts of ourselves on our behalf? Within institutional settings such as higher education and training, or the world of

work, to name but two, the picture of disabled persons who are "set up to fail" is a familiar one; here, the intrinsic inadequacy which is "written on the body" is repeatedly enacted, as disabled persons are sabotaged by systematic exclusion and disadvantage. Theoretical contributions to the understanding of the unconscious life of organisations may be of great benefit here, in casting light on such destructive dynamics (e.g. Obholzer & Roberts, 1994).

In her definition of projective identification, Segal (1973, p. 124) notes how the projective recipient becomes "possessed by, controlled and identified with the projected parts" (see also Ogden, 1979). Of relevance to our discussion is the fact that, if projective materials are to find a "home" in the other, it is essential that these feelings be experienced as fitting, as familiar, by their recipient. In other words, the recipient must come to experience the feelings as his or her own; originating from within, and fitting with self and circumstance. Now, a key message implicit in dominant cultural beliefs regarding disability is that which is at the centre of colloquial representations of the "medical model"; that is, that disability is a phenomenon of individual defects and shortcomings, which, by their damage, unavoidably preclude disabled persons from participating in, and fruitfully contributing to, social life. Consequently, what we apprehend is a picture in which disabled people suffer chronic and needless deprivation and exclusion at the hands of an oppressive society, yet are "willed" into the adoption of aspects of self which locate the origins of this disadvantage within intrinsic, "natural" factors. It is via this covert colonisation of the self that ideology is lived, as it interpellates all into unconscious collusion.

In psychoanalytic psychotherapy work, a key marker of the presence of projective identification is an uncertainty, within the therapist, of "what is, and is not, mine". What may have occurred here is that emotional materials have been projected into the analyst, but within an unconscious strategy which directs these contents to psychic locations which "fit" with their nature, such that one's own feelings and memories quickly dissolve into indistinguishable continuity with intrusions from elsewhere. Indeed, it is in the very nature of "successful" projective identifications that the recipient remains unaware that projection has occurred, at least until consciously teasing out the tangled strands of what is, typically, a sensitive and charged personal issue. Instead, he or she "holds" the displaced parts of self as his or her "own". In the oppressed and marginal predicaments of many disabled persons in modern society, questions of "responsibility" for struggle are often elemental. In other words, as one battles, against enormous material and cultural odds, to succeed in education,

employment, or the social world, the question of whether "I am to blame", or "society is to blame", is a perennial one. The split over-simplification of this dilemma, I believe, only underscores the anxiety-ridden, concrete and limited thought-environment which a culture of crude projection surrounding disability makes available to all concerned. In the lives of many disabled persons faced with insurmountable obstacles to fulfillment, nagging internal mantras which direct accountability at a self which "didn't try hard enough", or "wasn't organised enough", or was "too needy", or "too difficult", are manifestations of the cultural re-instilling of a self-blame which destabilises identity and entitlement. All, of course, carry the capacity for self-doubt and self-blame, yet it may be that these universal emotional aspects are systematically, continually re-enlivened in the lives of disabled persons, as material and

psychic factors operate in concert to prepare this group as "intrinsically damaged" projective containers. The question of "where" the lack, the defect, the insufficiency, originates and lies, in this most devalued of social identities, is one which goes directly to the heart of the problem of the origins of human subjectivity.

Young (1994, p. 140) emphasises what he describes as the "primitiveness", and the "adhesive, binding power" of projective identifications, which cause these connections, when established, to be very stubborn and resilient. The upshot of this is that projective identification serves as a "profoundly conservative" device, involving constructions of the other – *prejudices* – which are immensely difficult to dislodge (ibid.). Part of the obdurate nature of attitudes towards disabled persons, as mobilised via projective identification, relates to the "adhesive" connection wrought by unconscious investments in the "living" of suffering and struggle. We are compelled, even obsessed, by lives which offer discharge to our own unvoiced psychic fragments, and dogged in our clinging to the opportunity to fulfill controlling roles in such relationships. In their meditative study of philosophical aspects of "helping" work, Ram Dass and Paul Gorman (1985, p. 55) describe the "pull" of such relationships as follows:

It's as if our vicarious involvement with the trials and tribulations of others engages us in the life process in a way that we seem to need, but also want to be able to control. We want to watch it, but be able to turn it off at will.

(Dass & Gorman, 1985, p. 55)

The issue of control is central, as the need within the observer to impose control upon his or her internal world manifests in the material, "worldly" control of those appropriated as ciphers for intolerable parts of self. Hinshelwood (1987, p. 51) uses his concept of "dramatisation" to connect the influence of formative developmental relationships to dynamic, repetitious enactments within the community. "Dramatisation" refers to the playing out of unconscious scripts – the psychic sequelae of imperfect "holding" – in current relationships. The unconscious penchant for repetition leads to the "recruitment" of participants as players in the re-composition of an earlier drama. This, in Hinshelwood's (1987, p. 51) words, is a phenomenon which, in the community setting, corresponds precisely to the notion of transference as it manifests within the therapeutic dyad. Transference, involving, as it does, processes of projection and projective identification which serve to "coax" and invite the analyst into colluding with the archaic dynamics being replicated, demands the "working through" of unconscious material by all concerned, if destructive repetitions are to be overcome (Ogden, 1979, p. 365; Bion, 1967). If we bring these concepts to the political configurations prevalent around disability in societies such as ours, we see, I believe, that the disability phenomenon embodies an immense propensity for the creation of interwoven, chronic repetitions unconsciously sustained by nondisabled and disabled participants alike. Disabled persons, as we shall explore later, are arguably subject to systematic distortions in socialisation; involving, inter alia, the denial of separation by intrusive "caring", control and coercion ("benevolent" as much as malicious), expulsion from the mutuality of a common, human legitimacy of subjectivity, and the like. These formative "object experiences", themselves shaped by the unconscious evocations which hover about the disabled imago, may leave disabled persons vulnerable to projective repetitions which position the other as authoritarian, superior, avoidant, vulnerable, or whatever the case may be. Conversely, and as already outlined, nondisabled persons may bring to the intersubjective field the common multitude of split off fragments of loss, vulnerability, dependency and shame; all too readily "given over" in projective identification to disabled figures.

Whilst this initial dynamic model is necessarily a crude and oversimplified one, it begins to show us the (perilously) rich potential within relationships steeped in the emotive provocativeness of the disability phenomenon, for deeply rooted and ongoing enactments. These, surely, have precisely that "profoundly conservative" quality of which Robert Young (1994) writes. If such "damaged" identities are to be re-shaped, this will require an

extraordinary level of honest, cooperative self-examination, since the relational schemas involved are so deeply imbued with shared, differential archaic meanings. In the everyday world of families, residential care institutions, special schools, places of work, and a host of further environments in which the disability imago makes its presence felt, "dramatisations" involving object relations constantly piqued by disability continue unabated. We must, of course, beware of the danger of pathologising disabled persons as "carriers" of chronically disturbed relating, as this view may easily be misappropriated in buttressing individualising disability models. But it is a more grave error, I believe, to fail to acknowledge the very real, and damaging, impact of the lifelong distortions in relating which may often surround persons with impairments. Projective identification, within this realm, is a concept with enormous explanatory potential in charting the crystallization of disablist ideology into disabled – and nondisabled – subjectivity.

### *Reaction formation*

This is a defence mechanism which protects the ego from intolerable feelings by manifesting their opposite extremes in consciousness (Marks, 1999a, p. 23). Images of disability, provocative as they are, may evoke in us unconscious responses which feel morally heinous, leading to the need for a compensatory, conscious "reparation" or "undoing". Marks (1999a, p. 22) asks that we carefully investigate the "emotional payoff" which some individuals glean from involvement in "altruistic" disability-related work. What she is pointing to, is the idea that a portion of the subjective "satisfaction" felt in such work may relate to the reassuring disavowal of unconscious feelings and impulses towards disabled persons which are of a diametrically opposite nature. If disability does, indeed, mirror to us shameful or intolerable parts of self, it is likely that our instinctive response to disabled persons would be one of wanting to obliterate or conceal such reminders (Watermeyer, 2006, p. 38). The ubiquitous presence of an often irrational pity surrounding disabled persons, when viewed in this light, suggests more hostile, even sadistic, unconscious ruminations. Freud (1933, p. 253) explicitly associates altruism with disavowed sadism, implying that the culturally condensed guilt surrounding a death wish towards, for example, disabled persons, renders intolerable guilt which is managed through "good works". If we are correct in asserting that the atmosphere surrounding disability tends to be thick with conflictual unconscious material, then it is self-evident that individual motivations to undertake caring professions within this field are probably highly complex and worthy of our attention. To begin, it is likely that such individuals are drawn to these professions by motivations which harbour a significant

unconscious component. The ideological influence of such relationships – in residential and nursing care, a range of medical professions, state social service institutions, community rehabilitation organisations, charity and religious groups, and a host of others – can hardly be overestimated. Within such relations, typically between disabled "clients" and nondisabled professionals, such issues as the negotiation of "needs" may be profoundly coloured by unconscious investments in control, or other gratifying discharges, which subdue looming unconscious fears. The vast tract of critique levelled at health care, rehabilitation and other social services by the disability movement, bears testament to the often perverse distortions manifest in these arenas by the deeply personal, often uninterrogated motives of practitioners. The long and ongoing struggle waged by disabled people for the right to a decisive voice in the design of such services is a demonstration of needs within the professional community to retain primary influence on how disability is "managed" (Watermeyer, 2006, p. 39).

In the manner sketched above, it is possible to interpret a "latent" motivation underpinning a vast array of societal responses to disability. Control, institutionalisation, adult re-socialisation (Scott, 1969), segregation, enforced rehabilitation, zealous attempts at medical "normalisation" – these and many other responses to the spectre of disability may be interpreted as reactions not only to disabled people, but as specific modes of managing the internal evocations which exposure to disability stimulates. Workers in disability-related social services may be blamelessly oblivious to the residue of unconscious aggression which plays about the seeming "kindliness" of their work. The deep, personal investments in particular, self-soothing types of "disability policy" within service organisations is readily evident in the charged, even vicious controversies surrounding the "right" way things ought to be done, or the question of what disabled people "really" want or need. At the unconscious level, it may be that the drive toward eugenic extermination and smothering, infantilising institutional "care" occupy, in fantasy, not unrelated psychic spaces. It is not in any way my intention to bluntly or obliquely vilify social service workers; quite the contrary. My point, though, pertains to the very specific need for reflexivity, and adequate occupational containment (via such resources as psychological supervision), in order to disrupt the very real danger of malignant unconscious impingements upon disability-related work.

### *Rationalisation*

In the case of rationalisation, guilt-evoking impulses of unconscious origin are managed through the construction of conscious and coherent justifications for the actions they inform (Marks, 1999a, p. 24). With reference to disability, I illustrate with the following (Watermeyer, 2000):

Some 100 kilometres outside my home city is a small town which has, over the past several decades, developed into a centre for disability social services. These include residential special schools for visually and hearing impaired children and residential sheltered employment facilities for sensorily, physically and multiply impaired adults. Now, the conscious explanation for the location of these services, and hence their consumers, in a small rural town, surrounds issues of safety – for example, persons with sensory impairments are regarded as far safer in an environment not characterised by the busy streets and heavy, fast-moving traffic of the city. However, a critical psychoanalytic interpretation of the policy may render an alternative explanation – that is, that at an unconscious level policy-makers were drawn to service development initiatives which made provision for the location of disabled people out of sight, out of the everyday social world. Perhaps such an evacuation of persons with disabilities from the ken of the broader community served to facilitate the fulfilment of an unconscious wish that “damaged” people, and, more importantly, the emotional “damage” which they embody, do not, in reality, exist. It is, in my experience, a familiar scenario that the manifest, overtly described objectives of disability-related social services fall easily and unproblematically on the uncritical ear, within the context of a tacit culturally entrenched belief environment which, broadly, affirms “helping” and “support” as necessarily and self-evidently good and admirable. Put another way, we tend to feel uncomfortable, even outraged, at the questioning of the motives of individuals and organisations which purport to expend time and effort in “helping” those “less fortunate than us”, in a manner sometimes traceable to strands of religious doctrine. This culture of “helping”, which tends to be regarded at baseline as unproblematically praiseworthy, renders a situation in which the possible, and pervasive, latent and unconsciously motivated mediating factors impinging on the implementation of disability social services remain obscured.

In the foregoing illustration, the social service organisations concerned, steeped as they are in self-conscious religious-altruistic orthodoxy, tend to be experienced by the observer as unassailable to critique, since their motives are reconstructed as overwhelmingly above reproach. On the level of consciousness this may well be the case, but, as I have attempted to demonstrate, the potentially widespread influence of the powerful unconscious responses evoked in individuals by the disability phenomenon requires careful, candid and critical reflection. It is clear to me that the nature of institutional and cultural responses to disability, if left uninterrogated, will tend toward ever more not being shaped by the nature of the needs and predicaments of those whose lives are at the centre of the struggles at hand, but by the projected intra-psycho defensive profile of a community unready to reflect on its unvoiced pain.

### *Medicalisation as a defence*

This, of course, is not a "defence mechanism" which one would find in any psychoanalytic text. I create it here with reference to particular repressive strategies which make use of medical discourse in silencing or constricting the voice (in fantasy or reality) of disabled experience. Technically, the defensive manoeuvres which will be described below may be understood within descriptions of a range of "formal" ego defences; those described above, and others. Yet, I regard it as helpful to gather these in terms of a rubric which highlights the role of medical ideology, as appropriated in professional as well as colloquial terms throughout modern society. To begin with, it is in the nature of a health care establishment founded upon Cartesian dualist principles that, in the very act of engagement with medicine – in *diagnosis* – the social experience of disablement is sheared away. In the place of an analysis of oppression, personal tragedy theory locates disadvantage as a morally neutral, individual misfortune. Virtually everything about biomedical installations and practice deflects, or "looks past", the cruel inequality of disability exclusion. Gill (2001, p. 365) argues that the predicament of disabled persons is one more critical than that of racial minorities or women, as the disabled body carries "real" human difference, which can more successfully (though prejudicially) be linked to negative ascriptions. The fact that impairment-based difficulties – such as pain, fatigue or functional limitations – are experienced by many disabled persons, and are not reducible to political factors, allows for such experiences to be easily misused as blanket foundations for devaluing attitudes (*ibid.*). Typically, such aspects of disabled life are overgeneralised, or cited in isolation from other tracts of individual experience, in a manner which evokes a "distorted wholesale disparagement of the disability

experience" (ibid.). The collective identifying of the "medical" as the pivotal locus of causality in shaping the trajectory of disabled lives could be described as a shared introjective identification (Hinshelwood, 1987, p. 71). What has occurred here is that members of the community have, via the facility of an external, supporting "object" – medical discourse – accrued a defensive benefit which allows for the rational deflecting of a fearsome reality – brutal social injustice. The isolation, deprivation, denigration, shunning and wholesale dehumanising of disabled persons prevalent everywhere may, accordingly, be disposed of as the regrettable, inevitable consequences of nature.

At the opposite end of the scale, Menzies (1960) notes how certain introjective identifications are "forced into" recipients despite their will, buttressing demeaning identity ascriptions, rather than providing respite from psychic dissonance (Menzies, 1960 cited in Hinshelwood, 1987, p. 71). The psychic, cultural coercion of disabled persons into the submissive assuming of the role of personifications of a marginal, devalued stereotype seems to fit this description. Meaning-spaces are created by the interweaving of discursive mechanisms with the requirements of psychic expediency, such that it becomes extremely difficult to "imagine" a society in which disabled persons are whole, legitimate and "fully human" social actors. In his ground-breaking monograph of rehabilitation organisations for sight impaired persons in the United States, the shrewd and perceptive social anthropologist Robert Scott (1969) demonstrated vividly how the so-called "rehabilitation" of blind persons was more accurately conceptualised as a process of "adult socialisation"; that is, an exercise in "training" the newly impaired in the business of "being" the society's disabled minority (Scott, 1969). With disturbing clarity, Scott (1969) showed up how "clients" of rehabilitation service organisations were rewarded, or negatively sanctioned, for behaviour and modes of "being disabled" which did, or did not, fit with official protocols. What disabled persons' predicaments involve, and hence what disabled people "need", was unequivocally articulated by "professional", nondisabled agents. For Stiker (1982), the emergence of rehabilitation as an institutional response to impairment heralded the dominance of a culture of "identification"; that is, a drive to making humans identical. This obliteration of alterity will, in fantasy at least, dissolve from society "all that is lacking", creating the idealised illusion of a homogenous social whole (Stiker, 1982, pp. 128, 131-2; McRuer, 2006).

Where the social sequelae of disability are found, an ever-present corollary to these is guilt. This may be within the disabled individual, or others, and conscious or unconscious; but as disability reliably implies inequality and deprivation, it predictably also brings guilt. Wherever the glaring contradictions of differential provision of essential resources to ostensibly "equal" citizens is to be found, it seems incontrovertible that relationships will be distorted by guilt, amongst other conflicted feelings. What the biomedical view of disability offers is the opportunity for the provided-for observer to substitute "disability guilt" with the (often) far milder discomfort of "impairment guilt". "Disability guilt", I suggest, involves a level of real culpability to the observer, in terms of being implicated, by virtue of passive collusion, in the atrocities perpetrated by an unjust society upon some of its citizens. By contrast, "impairment guilt" reframes the issue as one in the hands of destiny, nature or God, hence absolving the society, and the individual, of accountability or blame. The extremely dominant discourses of pity and charity fit very snugly into this defence, as they compose the human objects of "impairment guilt" – the hapless tragics, the chance unfortunates – leaving the onlooker with nothing but the welcome opportunity to be altruistic, powerful and generous in relation to that which earlier brought fault and shame. These concepts are not intended as crisp, neatly distinguishable orientations, but rather as extremes of a continuum, upon which shifting positions are negotiated, as proximity to the awful reality of disability oppression varies in everyday social life. When evidence of this suffering looms, citizens are hence afforded the opportunity to appear – to *be* – the bringers of succour, rather than the causes of affliction.

Fantasies about the lived experience of disability and, in particular, the psychic management thereof, are central originators of a host of oppressive relational dynamics which surround disabled persons. One mode of defending against the looming, projected abjection of "disabled life" is by constructing the body as something which can, by virtue of care and science, be controlled. In particular, it is the chance, indiscriminate incidence of bodily frailty which must be denied; for this purpose, medical discourse is of supreme utility. The propositions of this rationalising logic are twofold: first, that those who suffer the frailty of the body do so through their own negligence, and second, that those who subject themselves properly to medical authority can be restored to wholeness. Susan Wendell (1997, p. 269) tells of her personal experience, after falling severely ill, of friends candidly questioning her regarding what she believed she might have done "wrong" in order to bring the illness upon herself. She writes: "... our cultural insistence on controlling the body blames the victims of disability for failing and burdens them with self-doubt and self-blame" (ibid.). Marks (1999a,

p. 75) identifies a "moral zeal" with which health care is pursued, undoing any possibility of illness or disablement becoming "integrated within conceptions of community and humanity". Obsessive nutritional fads, exercise regimes, rigidly advocated esoteric practices, and a host of further lifestyle imperatives prepare the way for the illusion of somatic and spiritual control. Attachment to this illusion manifests in the moral judgment, and administering of a just damning to illness, of those who have the audacity or carelessness to flout clear directives of what is "right". Sinason (1992, p. 149) comments that, without fail, blame enters the arena of disease "with a vengeance". Fear of illness, of disability, of madness – all evoke the irresistible instinct to blame the victim (*ibid.*). Susan Sontag (1997, p. 233) delineates the defensive ascriptions made to persons living with HIV and AIDS, who are viewed as guilty of indulgence or delinquency, and as addicted to chemical substances or deviant sexual excesses. In an interesting and provocative passage, Tom Main (1989, p. 205) positions medicine and war in parallel, as arenas both satiated with "issues of life and death, crippledom (*sic.*) and loss, sadnesses and terrors about external dangers", as well as, from inner sources, unconscious fantasies of "primitive sadism" and "punishment". All this, of course, is the destabilising stuff of primitive defences and consequently shifting realities.

Through what Marks (1999a) and others term "epistemic invalidation", the voice of medical authority ignores, minimises, or denies outright those aspects of bodily experience which it cannot "subdue" through explanation (Marks, 1999a, p. 54; Kraemer, 1994; Wendell, 1996; 1997). Interlaced with the "psychic expediency" of the denial of experiences of uncontrol, exists a certain "professional expediency" (Barnes, 1990, p. 6), whereby the authenticity of medicine's explanatory powers remains undisrupted by wayward experiential data. Medicine, in this guise of empirical gatekeeper, allows overtly for the disregarding of "the excess, the surplus that will not fit" (Burman, 1996, p. 138). Whether this "excess" be traumatic social or psychological aspects of disability, or rehabilitative outcomes which do not "fit" with professional goals, it is the disabled individual's perceived failings which settle as explanatory ascriptions. By contrast, in Barnes' (1990, p. 6) words, "the 'expert' is exonerated from responsibility, professional integrity remains intact, traditional wisdom and values are not questioned, and the existent social order goes unchallenged". Health care technology is often, within the dominant discursive frame which Arthur Frank (2006, p. 70) terms "neoliberal medicine", regarded as something we "do things *with*", rather than *an act in itself* (Edwards, 2006, p. 55). Medicine's masquerading as a "value neutral" enterprise (Marks, 1999a, p. 51) allows for the defensive, introjective appropriation of its pronouncements by individuals who, thus, may also mindlessly assume moral neutrality.

In giving life to his conception of how the reparative drive of medical discourse reframes, and hence elides, aspects of social experience, Frank (1995) describes how the medical gaze performs an illusory transformation of "mystery" into "puzzle". The curative zeal of medicine cannot allow suffering; this is a "mystery", which can only be faced up to, or tolerated. Within the gaze, note, to be different is, by definition, to suffer. By contrast, a "puzzle" admits solution; thus are disabled lives turned into "puzzles" or "challenges", experiences into problems with "solutions", and identities into blemishes which imply imperatives for repair. Experience and identity can only be valued as "mysteries", which, unlike "puzzles", cannot be "got right" because "there is no 'right' way to get it" (Frank, 1995, p. 81). It is precisely the absence of solutions which make mysteries "a scandal to modernity" (ibid.).

In closing this section, I note that Gliedman and Roth (1980, p. 239) are blunt in their assertions regarding the split-off, discarded and often denigrated position of the psychological in health care. Psychological expertise, they observe, is typically obtained by medical practitioners exclusively via the decades-long process of trial and error experience with live, often troubled patients. Advocates of a narrow social model view of disability should, I believe, take careful cognisance of their complicity in maintaining and justifying this splintering of experience and personhood. It is the "heroic", physiological, curative, depersonalised nature of biomedicine which impoverishes the philosophy of medical ethics to an exclusive consideration of issues of "life and death"; perpetuating the unfortunate myth that the primary purpose of medicine is to control the unruly body (Wendell, 1997, p. 270). A more inclusive, flexible and humanistic view would admit a host of further concerns central to the social living of bodily difference; notably, how medical discourse and society at large "understand, mediate, assist with and integrate experiences of illness, injury and disability" (ibid.). This defended "oversight" means that knowledge regarding how to live in current society with illness or disability, how to uncover and communicate one's experience, and how to sustain life in the face of uncertainty, pain, or functional limitation remains marginal, as unsystematised and largely disregarded irrelevance (ibid.).

Over the course of the balance of this theoretical synthesis, I will consider a range of concepts and topics relevant to the development of a politically situated psychology of disablement. Whilst these areas of concern vary in theoretical proximity to the psychoanalytic model, I

make use of the analytic lens as a common interrogative thread which, I trust, will illuminate and situate the potential contribution of each. I begin with a brief examination of the utility to our discussion of the medical sociological notion of *stigma*.

## **Stigma**

Erving Goffman's (1963) notion of "stigma", though highly controversial, is an ever-present, provocative element in most reviews of disability social science. In *Stigma: Notes on the management of spoiled identity* (1963), Goffman painted a stark, at times disturbing picture of distortions in social relating which surround "stigmatised" identities, such as disablement. Within his view, developed via monograph data, a major aspect of life as a disabled person involves the imperative to deflect, to ward off, social devaluation provoked by one's damaged identity (Gill, 2001, p. 355). Amongst much else, Goffman (1963) focused attention on the strategic means whereby persons marked by signifiers of damage attempted to minimise or disguise evidence of the unwanted identity, in order to avoid or delay the triggering of denigrating responses from others. A range of strategies such as the use of humour, the proving of competence, or the hiding of evidence of difference were identified, which may temporarily allow the stigmatised to "pass" as normals (Gill, 2001, p. 355). Failure to sufficiently mitigate the current of denigration drawn toward one's "broken" body, leads to a more or less inevitable cementing of one's consignment to the social margins; a destiny which, it is subtly suggested, seems predictable to all. As a complex of aspects of relating, stigma embodies a property of the individual, a process between participants, a form of social categorization, and an accompanying affective set (Coleman, 1997, p. 216). As such, it is a difficult concept to categorize as especially "psychological" or "cultural".

Earlier, we considered at some length the traditionally oppositional stance of disability studies towards the discipline of medical sociology; Goffman's work was amongst that most heavily criticised by writers such as Finkelstein and Oliver (e.g. Finkelstein, 1980; Oliver, 1990; both cited in Thomas, 1999a, p. 146). The critical view propounded by these and other social model authors is, in the first place, the familiar – and pertinent – one relating to Goffman's (1963) neglect of a concerted investigation of the broader socio-political context of systemic disadvantage under which disabled persons suffer (Thomas, 1997, p. 146). Beyond this, though, Goffman's work was regarded as representing disabled persons as passive "victims" of prejudicial treatment, living with the "unfortunate but inevitable social consequences of

being impaired" (ibid.). Unsurprisingly, materialist analyses found nothing of value in a study which focused on cultural, relational and symbolic aspects of disability. Within the materialist universe, oppression does not dwell primarily in these phenomena, but in relations of production; Goffman's concepts were consequently regarded as, at best, diversionary.

However, taking a renewed view of his work, from a perspective which foregrounds the micro-mechanics of intra-psychic and interpersonal aspects of discrimination, renders a valuable and insightful contribution to understanding the relational and emotional stressors to which disabled persons are subject.

The social modelist critique of Goffman (1963) seems typical of an overly hasty, even scornful, materialist rejection of "personal epiphenomena". His description of strategies aimed at countering the devaluing gaze of the social world, in the view of Finkelstein and Oliver, serve only to confirm and reproduce stereotypes of disabled persons as helpless individuals relentlessly subject to victimisation. The repressive danger of such a view lies in the following: there exists a very real risk of a desire to propound "positive" images of resourceful and resilient disabled persons disallowing a rigorous and candid representation of the very real, often abject, suffering endured by persons whose identities are, for much of the balance of the social world, a source of disgust. Finkelstein and others seem to regard an examination of stigmatisation as an incidence of generalised slander, rather than an attempt to circumscribe what are, in fact, most painful, even dehumanising, elements of social oppression. In an ironic twist, materialist authors seem to miss the point that the "stereotypes" propounded by Goffman exist as very real sources of shame and suffering in the lives of marginal persons. This, of course, in no way justifies such imagery; on the contrary, within the process of description is an implicit intent of problematisation. Surely, it is the silencing, not the investigation, of denigrating modes of treatment which demeans. It is fair to say that Goffman's (1963) account is vastly inadequate in socio-political critique, but no more unsatisfactory than a correspondingly bald materialist view. Goffman (1963) is clear that stigma is a phenomenon of social relationships, not physical or psychological attributes; the meaning attributions of identity signifiers vary with history and culture (Coleman, 1997, p. 217). Consequently, he is describing "what is", rather than "what is inevitable". A more reasonable criticism of Goffman (1963) is the argument that he underestimates the agency and resourcefulness of individuals negotiating their stigmatisation, tending to describe desperate attempts at survival, rather than calculated coping (Frank, 1988, p. 96). My own view is that the key issue under investigation is the ongoing exigencies of distorted relating directed at persons with impairments, which continue to emanate from modern culture despite the degree to which these may be successfully "managed" by their target population. What Goffman

(1963) illuminates are the processes of projection and projective identification, under the guise of an alternative conceptual framework. Whether, and to what extent, these imputations may be deflected by individuals, the predicament of lives lived in the face of relentless othering must remain a fundamental focus of our exploration of oppression.

Perhaps the most objectionable of Goffman's (1963) utterances to his materialist critics are his intimations regarding how stigmatised persons, perhaps only momentarily, may be drawn into endorsing denigratory views of self (Frank, 1988, p. 96; Watson, 1998, p. 147). What Goffman is referring to is some formulation of internalised oppression, which is anathema to social model materialists. Even the idea that "for a moment" an individual suffering relentless stigmatisation may weaken or waver in her internal resistance to identity assault is viewed as an unacceptable, unthinkable libel. The indispensable contribution of the psychodynamic model of mind finds clear expression here, providing for the human ambivalence which is so patently absent in materialist discourse. This concrete response to the demeaning, projected imputations of a prejudiced social world is a retaliatory and wholesale *re-projection* of the whisperings of damage. As such, it bluntly elides any consideration of how cultural assailants may have taken up residence within. The absurd myth implicit here is that internal conceptions of self are unambiguous, and that feelings of, for example, self-loathing, do not exist as long as we manage to direct our thoughts elsewhere. Far from "dooming" members of devalued groups to "eternal stigmatisation in their own eyes as well as those of society" (Ablon, 1981 cited in Frank, 1988, p. 96), Goffman (1963) was forging the beginnings of a model of oppression which incorporated the relational, and hence, the psychological. Gill (2001, p. 356) takes issue with the fact that Goffman (1963) gives little attention to the case of "deviants" who decide deliberately to forego the struggle for acceptance by "normal" society. She too, I believe, fails to recognise that the hail of projections, the constant hum of denigrating fantasies and representations, is sustained equally by individuals who may choose to negotiate their lives – their selves – in highly contrasting ways. If Goffman (1963) evidences – as I believe he does – a subtle pessimism regarding the prospects for a "solidarity of deviants" based on the affirmation of marginal identities, it is only mildly facetious to argue that this renders his position more clearly resonant with latter critiques of identity politics. Gill (2001, p. 356) also points out how Goffman argued that "deviant" individuals who choose to reject "mainstream" culture in favour of forming alliances with other similarly stigmatised individuals, risk calling attention to their difference, in a manner which reinforces marginality. Whilst such an observation may not expediently serve the purposes of disability politics, what Goffman has attempted to do is thoroughly describe the quandary, the double-

bind, that is stigma; that, often, is disability. Lastly, his caveat that such attempts at an "affirmation model" (Swain & French, 2000) of marginal identity politics will inevitably become snarled in the very acts of categorisation and closure which they seek to defeat, was some way ahead of its time.

## **Liminality**

The anthropologist Victor Turner (1969) coined this term to describe the position of members of society who have no clear status, typically because a prior position, standing, or identity has been expunged, and re-allocation has not yet taken place (Turner, 1969 cited in Murphy, Scheer, Murphy & Mack, 1988, p. 237). Famously, Turner described such persons as "betwixt and between", occupying a state of suspended animation outside of the taxonomies and protocols which govern social life (ibid.), often during the course of rites of passage. Robert Murphy (Murphy, 1987, 1995; Murphy et al., 1988), in his auto-ethnographic disability monograph *The body silent*, identified the concept as peculiarly apt to the social predicaments of disabled persons. He writes:

The long-term physically impaired are neither sick nor well, neither dead nor fully alive, neither out of society nor wholly in it. They are human beings but their bodies are warped or malfunctioning, leaving their full humanity in doubt. They are not ill, for illness is transitional to either death or recovery. ... They are neither fish nor fowl; they exist in partial isolation from society as undefined, ambiguous people.

(Murphy, 1987, p. 131)

The liminal state, in Turner's cross-cultural research, is likened to a range of ambiguous states of existence, including death, being in the womb, being invisible, and bisexuality (Murphy, 1987, p. 135). Liminality is often associated with processes of transition, which are incomplete, and thus embody an ambivalent social status (Marks, 1999a, p. 127). The concept, though, is imbued not only with ambiguity regarding social standing, but expresses a deeper instability concerning one's fundamental nature, one's humanness (Golden & Scheer, 1995, p. 1445). Murphy et al (1988, p. 238) argue that much disability rehabilitation strongly mirrors ritualised processes of transition used to mark passage from one identity to another in so-called traditional societies. Newly disabled individuals are withdrawn from mainstream

culture in order to undergo training in the modes of living which fit their new social status. Scott's (1969) critique of rehabilitation as a process of "adult socialisation" – noted earlier – provides a strong demonstration of this position. Note the implication, in both cases, that rehabilitation functions not only as a palliative medical intervention, but perhaps more importantly as a mode of restoring the taxonomic clarity of the social order. For Murphy, though, the "transition" of disabled persons is typically perpetual; rather than exiting the liminal state as legitimate citizens, these individuals often remain trapped between liminal isolation and an unfeasible social emergence, not "counting" as legitimate citizens (Gill, 2001, p. 358). Such individuals are considered "sociologically dead", and thus present a chronic threat to the legitimacy and coherence of the social order (ibid.). The society, consequently, "manages" such individuals by a form of sequestering, allowing only for the participation of disabled persons in social process within the bounds of narrow, ritualised realms – that is, the "disabled role". This, in Murphy's words, is relegation to "the twilight zones of social indefiniteness" (Murphy et al., 1988, p. 237).

Murphy conceptualises disabled persons as anomalous, as "out of place", and a threat to the social order. As a theoretical parallel, Mary Douglas (1966) developed an anthropological model of the societal management of "contaminants", of anomalous presences which disrupt the cultural categories imbuing social life with meaning. In *Purity and danger* (1966), Douglas elaborated the symbolic, cultural construct of "dirt", broadly defined as discordant elements which defy society's dominant schema of control and predictability (Thomson, 1995, p. 605). For Douglas (1966, p. 35), "dirt" cannot exist in an isolated, acultural space; rather, its menace always implies the presence of a specific, stipulated set of ordered relations. The "threat" of disability, thus, must direct us toward investigation of the specific modes of being – the invisible hallmarks of normalcy – that are menaced by the disability phenomenon. After Honneth (1995), thus, we must turn our attention to the "moral grammar" of modes of exclusion, rooted in cultural mores which, though invisible, carry the mythic essences of our beloved "enjoyment" (Zizek, 1990). The awkward, specific and complex "needs" of disabled persons within societies designed to interface with "normal" bodies, present the essence of disquieting anomaly; that which is ill-fitting, unworkable, and haunted with a shadowy, anxious threat of "systemic failure". The failure of "the system", though, is at the heart of Douglas' (1966) terrain of unthinkable knowledge, which harnesses restorative ritual and

categorical judgment in squeezing the locus of disjuncture, of unfeasibility, "back" into the individual. The legitimacy of the system, thus, is contingent upon the chronic liminality of the individual, the "misfit". Allowing him or her into full, integrated social personhood would translate not into the presence of neutral difference, but an encroachment of pollution, taboo and contagion (Thomson. 1997b, p. 34).

Douglas (1966) outlined five strategies via which societies "deal" with polluting anomaly, which have ready resonance with social responses to disability. First amongst these is the assigning of ambiguous phenomena to a single absolute category, typically within systems of binary opposition (Thomson, 1997b, p. 34). The disabled-nondisabled binary, along with characteristic anxieties pertaining to the uncertain "degree" of impairment, exemplify here. The second strategy is one of simple elimination of the delinquent social ingredient, calling to mind the eugenic extermination and abortion of disabled bodies. Third, practices which allow for avoidance of the anomaly are created, such as the sweeping ideology of segregation and institutionalisation that is the global history of disabled persons. The fourth stratagem involves the distancing and (psychic) control of problem elements through labelling these as dangerous intrusions, with such assignations carrying some form of institutional ratification. Lastly, ambiguous elements may be managed through their incorporation into ritual, in order "to enrich meaning or to call attention to other levels of existence" (Douglas, 1966, p. 40; Thomson, 1997b, p. 34-7). This last possibility is regarded as the only potentially positive or socially transformative strategy in Douglas' (1966) taxonomy. It may – optimistically – imply attempts at a valuing recognition of the contribution of disabled subjectivity to an understanding of the human condition. But perhaps more likely is the appropriation of a constructed version of disabled experience in literature or art, which exploits disability as a metaphor, with, in fact, conservative implications (see *Artistic and literary representations*, p.151). To Douglas' (1966) theory of the management of social anomaly, Murphy (1987, p. 132) adds Claude Levi-Strauss' assertion that the most fundamental of binary distinctions in the human world is that between nature and culture. Within this "grand dualism", impairment of the body presents as an intrusion of nature, which "undercuts one's status as a bearer of culture" (ibid.). In combining Goffman (1963) and Douglas (1966), one may suggest that human stigmata present in the modern world as "social dirt" (Thomson, 1997b, p. 33); the investigation of the lived experience of inhabiting this social space via the approaches of existential phenomenology holds much promise (Kasnitz & Shuttleworth, 2001, p. 30).

To close this section, the constructed, cultural nature of the "dirt" of disability is demonstrated by the clear inconsistency in stigmatisation applied to aged persons with impairments (Priestley, 2006, p. 86). Whilst impairment in child – or adulthood is constructed squarely as aberrance, in old age it is viewed as simply a "generational norm" (ibid.). This cultural "space" for functional limitation in old age rescues this type of impairment from invidiousness and anomaly, "rehabilitating" the elderly as "not disabled", just "old".

## **Monstrosity**

The Latin word *monstra*, from which the English "monster" is derived, means "sign", and also forms the root of the verb "demonstrate" – that is, *to show* (Thomson, 1997b, p. 56). The etymology of the word shows plainly how bodily difference, in particular, birth malformations, have been regarded as omens or portents – typically boding ill – throughout antiquity. Through the nineteenth and early twentieth centuries, the phenomenon of the "freak show" enjoyed its heyday, providing, as we shall see, a platform for the cultural and psychic othering afforded to "normal" society by the spectacle of extravagant bodily difference (Bogdan, 1988). Within the spine-chilling thrills of P.T. Barnum's travelling shows, citizens of the early United States were offered the opportunity to grapple with dilemmas of classification, with which the skills of constructing self and devaluing "otherness" – the skills of "nation building" – could be honed (Thomson, 1997b, p. 58). To Thomson, such shows provided to the rank and file population what science offered to the educated classes – "an opportunity to formulate the self *in terms of what it is not*" (ibid. – my emphasis).

Fiedler (1978) provides a rich and insightful history of the cultural phenomenon of human "freaks", with a view to investigating the role of stark difference in the coalescing of personal and social identities. He traces how, through the medium of religious doctrine, malformed bodies came to carry the projected weight of divine wrath poured out upon a wickedly errant humanity. Indeed, as in the case of the *monster of Ravenna* (b. 1512), individual aspects of the malformation were interpreted as specific messages from God, designating the evils committed by wayward humanity (ibid., p. 25). Traces of this "divine" logic in the, at times, desperate straits of coming to terms with the birth of an infant with congenital malformations are, yet, all but uncommon. In Fiedler's (1978, p. 24) view, the psychic need for images of "monstrous" bodily difference is such that, were we not to have access to such, we would

*create them for ourselves* in narratives and pictures. The "prototype" of the human monster, he argues, is not to be found in embryology or teratology, but in the depths of a human psyche constitutionally troubled with its own physicality (ibid.). Here, basic human conflicts to do with the limits and structuration of bodies are to be found, common to all due to the universal ego perturbations engendered by physical development. As we grow, from infancy through childhood, the development of secondary sexual characteristics, and adult maturity, a constant stream of changes besets our physical sense of self, with the final destinations of these processes always unknown. Primitive and conflicted fantasies regarding bodies and selves litter this developmental path, confronting us with fears about our size, the boundaries and shapes of our bodies, the adequacy of our maleness or femaleness, the animality of our physiques, and much else. In negotiating this shifting, primal terrain, we need markers with which to position ourselves within a host of dualities, viz.: "[between] male and female, sexed and sexless, animal and human, large and small, self and other, and consequently between reality and illusion, experience and fantasy, fact and myth" (Fiedler, 1978, p. 24). Fascination with freakery is elemental to childhood fantasy, arguably because children "need" the extremes of the freakish body in order to reposition the changing self as possessing not "too much" or "too little" of a given characteristic (ibid., p. 27). Observing the hermaphrodite stills anxieties about gender ambivalence, the "bearded lady" normalises the emergence of bodily hair, conjoined twins provide an arena for confronting conflicts regarding merger and separation, giants and dwarfs offset fears of excessive or stunted size; the list continues (Marks, 1999a, p. 170). In each case, the extremes of the monstrous "other" realign self-assessments as clearly normative, as whole, as right. Fiedler (1978, p. 31) captures the point thus: " 'We are the freaks', the human oddities are supposed to reassure us, from their lofty perches. 'Not you. *Not you!*' ".

The juxtaposition of a range of bodily deformations with the imago of "the monster" tells of the primitive significations of bodily impairment, as markers of the dark, disavowed counterpoint to the phrenetic, earnest development of a viable ego. In Mary Douglas' (1966, p. 39) terms, the birth of a child with a congenital malformation may evoke the discordant character of "matter out of place", transforming an infant with neutral bodily differences into a peculiarity, a sign; in some sense, *an object*. She recounts how, in Nuer society, "monstrous" births are construed as baby hippopotamuses, "accidentally" born to human

mothers; disposal of such infants, thus, becomes culturally possible, and the social order is restored (ibid.). In a not dissimilar fashion, the freak show provided a choreographed frame for the reifying of racial, ethnic and disability difference into cultural, even existential otherness, paving the way for the plethora of inequalities to come (Thomson, 1997b, p. 60).

Robert Bogdan (1988, p. 7) criticises Fiedler's (1978) interpretation of the construct of the "freak" as an inevitable consequence of universal existential anxieties. In Bogdan's (1988) view, Fiedler (1978) reifies "the freak" in a manner which condemns persons with unusual bodies to filling the role of custodians of the projected "monstrosity" of others, thus obviating an interrogation of the multifarious influence of culture. The question which this encounter gives rise to is indeed an interesting and weighty one: to what extent may visceral responses to otherness be ascribed to inevitable, constitutional aspects of the human condition? Hoggett (1992, p. 5) is provocative in his confounding of materialist reductionism; he declares that, if political and social thought is to come fully to grips with the contribution of psychoanalysis, it is not sufficient to affirm that "the personal is political". He writes:

It needs to understand that the human being is not an infinitely malleable material but, conversely, that as corporeal beings we have a nature which is not only irreducible to social circumstance but itself is a nature capable of determination. The personal is, to some extent, political; but the political is also, to some extent, personal.

(Hoggett, 1992, p. 5)

In the area of evolutionary neuroscience, with particular reference to gender, a view which positions the political as, to some extent, a complex of both cultural and neurodevelopmental factors, is increasingly incontrovertible (Pinker, 2003). In the absence of such research which may shed light on the constitutional bases of disability-othering, let us consider what psychoanalytic theorising may suggest.

Within the psychoanalytic framework of Jacques Lacan (Lacan, 1977a; 1977b), the process of the formation of a "whole", "coherent" identity is, essentially, one of self delusion. The intrinsic nature of human existential experience is, in his view, a fragmented and chaotic one,

pieced together only via the cultural concoction of a brittle, illusory mask of wholeness. The most basic experience of the body is of a fragmented body, (*corps morcele*), experienced by the infant as chaotic turbulence, as un-integrated parts; an assemblage of limbs and surfaces (Davis, 1997c, p. 60). This flailing, violent disorder of tissues and impulses is shepherded into an unreal unity during what Lacan, 1977b, p. 4) terms "the mirror phase" of development, where the child first dons the unified self-identity which she apprehends in her reflected image (Davis, 1997c, p. 60). The seductive boundedness and coherence of the unitary, mirrored figure provides a relief to the child from the anxious chaos of fragmented impulses, casting the splinters of affect and intention in the gloss of a new unity (Frosh, 2006, p. 184). The perceived integrity of the ego is, in fact, a social construct appropriated for the purposes of psychic equilibrium, rooted in ideology which stresses autonomy and the sanctity of the unitary, independent self (ibid.). Lacan (1977b) points to the creeping knowledge within each of us that we are not whole, not ordered and unified; not the harmonious beings of the modernist dream (Frosh, 2006, p. 184). It is at the level of the infantile, fragmented self that "the real" is to be found; or, rather, to be elided. It is here, perhaps, where constitutional aspects of the human psyche dwell which carry investments relating to the malformed body. Zizek (1991) frames "the real" as that which plays about the edge of the mirror, constantly threatening the placid illusions of cultural life with the contorted core of self (Zizek, 1991 cited in Frosh, 2006, p. 186). Disability, surely, must fill this description as the shadowy harbinger of "a return"; it is disability, to the exception of other identity markers, which lies dormant and ready in the bodies of all. In this sense, it is a "sign" par excellence, delicately holding both the threat of disintegration, and the lure of enlivenment. In his description of the "imagos of the fragmented body", Lacan (1977c, p. 11) makes specific reference to aggressive impulses toward bodily mutilations, including castration, dismemberment, dislocation, and evisceration – unconscious contents seemingly set to resonate readily with images of disability. The complex evocations of disability, including guilt, hostility, and obsessive-compulsive phenomena, also seem to fit well with this imagery. The disabled body, perhaps, is a resonant, animate version of the repressed, infantile fragmented body (Davis, 1997c, p. 60).

If disability does, indeed, operate as a "messenger" from "the real", which consequently has the potential to imbue life with meaning and energy, one means of framing this role is via the idea of "the carnivalesque" nature of the different (the "grotesque") body (Bakhtin, 1981). To Bakhtin (1981), the carnivalesque figure represents the right, the means, to transgress social norms and categories, showing up the illusory nature of these in a wry or clownish manner

(Bakhtin, 1981, p. 159). Social hierarchies are inverted and the political status quo is disrupted, as the "disorderly body" teasingly goads all towards recognition of "the real" (Thomson, 1997b, p. 37). The profound potential of the disability phenomenon to critique and disrupt dominant tenets of identity politics has already been alluded to, and will be considered in more depth later. But here, we find an example of Douglas' (1966) lone "optimistic" incidence of the cultural management of anomaly; that is, the action of "matter out of place" in mobilising a critical reconstitution of cultural discourse (Thomson, 1997b, p. 37). Disabled persons, in this view, may fulfil the role of entitled bearers of valuable and novel perspectives on human existence, in a manner which has the potential to erode and reconfigure political barriers.

In the following three sections, I turn now to a consideration of current debates within the discipline of applied bioethics, which have specific relevance to disability. As before, my intention here is to apply the psychoanalytic lens, in attempting to bring the influence of emotional – and unconscious – factors upon these dilemmas into relief.

## **Disability and bioethics**

### **Lives not worth living**

The uniting concerns of the philosophical discipline of bioethics surround fundamental dilemmas of health and illness, life and death; in particular, the relationship of medicine to nature (Asch, 2001, p. 298). Here, the advent of curative and palliative medicine has given rise to existential questions regarding the quality, the fulfilment, which lives must carry in order to be "worth living" – in order to be preferable to not being alive (ibid.). As such, the discipline carries specific – to some, sinister – relevance to the disabled population worldwide, as it is routinely disabled lives which come under the scrutiny of ethicists in the context of a range of medico-legal scenarios. Adrienne Asch (2001, p. 299) characterises the role of bioethics as one which substitutes the medical question of "can this life be saved?" with a philosophical question: "*should* this life be saved?" The essence of the dilemmas underlying the medico-legal presentations at issue may be expressed as: 1) what are the conditions under which it becomes morally permissible to kill, or to let die, a disabled person? and 2) how potentially impaired must a foetus be in order to justify the prevention of its birth? (Wendell, 1989 cited in Asch, 2001, p. 297). Bioethics has, as a discipline, taken a position

which advocates that assessments of the quality of life after treatment should be a factor in medical decisions, including those regarding the allocation of resources; at times, ethicists have argued against the use of technology and medical acumen in the sustaining of lives of individuals who will carry impairments (ibid., p. 299). Unsurprisingly, the at times livid criticism of disability studies scholars has directed attention to the "medicalising" logic implicit in such assessments, which tends to view quality of life as an acultural function of the integrity of the body. At a deeper conceptual level, the arguments of bioethics must rest on the assumption of some consensus regarding the definitions of the medical terms being employed; the definition of "health" is an excellent case in point. Kelman (1975) regards the definition of this familiar notion as "the most perplexing and ambiguous" issue in the study of medical social services (Kelman, 1975 cited in Altman, 2001, p. 100), thus setting the tone for the slippery and subjective nature of much of the philosophical debate confronting us in this area.

Over the course of this brief critical discussion, we shall consider 3 situations arising from the encounter of bioethics and disability studies, viz.: 1) the withholding of treatment to impaired children or adults; 2) the prenatal testing of foetuses for the presence of congenital disorders, with a view to abortion; and 3) the question of assisted suicide, or "the right to die", for disabled persons. The related issue of the forced sterilisation of persons with heritable impairments will be considered later, in the section entitled *Eugenics*.

#### *Withholding treatment from children and adults*

A common scenario in neonatal and paediatric medicine is that in which parents are charged with deciding whether or not their infant or minor child should undergo treatment, when the child will be disabled after the intervention, but may die without it (Asch, 2001, p. 302). For example, a neonate with Down syndrome may also have heart disease, or an intestinal blockage – some clinicians may counsel parents to let the infant die, rather than treating the illness, and allowing the child to live with Down syndrome (ibid., p. 303). The situation is complicated further when the appropriate treatment is especially invasive, and has a poor chance of success. During the course of the 1990s, many writers in bioethics have defended the position that it is acceptable, if not morally desirable, for doctors to end the lives of babies that would be permanently disabled after acute treatment, citing the suffering inherent in many interventions, as well as the nature of the impairment (ibid.). One painful outcome is

that of the ill child who suffers a brief and miserable life of fruitless medical interventions, compounding and extending the anguish of parents.

In opposition to these assertions, the disability studies critique here centres on the social construction of congenital conditions such as Down syndrome, spina bifida, and cerebral palsy. The argument of these writers holds that decisions regarding the possibility for "quality of life" of children with such conditions represent cultural judgments, merely masquerading as medical realities. The lack of positive, even-handed cultural representations of the life-narratives of, for example, persons with Down syndrome, is implicated in the generally negative and stereotyped view of such lives, manifesting in medical "condemnations". Basnett (2001) provides a telling example of this contradiction, relating the story of a friend – like him, a wheelchair user – who was admitted to hospital with a "minor" chest infection. A junior doctor in attendance wrote in her case notes that, if required, she should not be resuscitated, due to "poor quality of life" (Basnett, 2001, p. 455). In such situations it is, of course, nothing but stereotype which informs potentially lethal decisions. By way of a further example, in a paper attempting to describe the psychological effects of the birth of a congenitally impaired child on parents, MacKeith (1973) comments: "I do not hold the view that it is always the doctor's duty to do everything that he [*sic.*] can to save life; death is sometimes a blessing" (MacKeith, 1973, p. 136). In the lives of acute paediatric practitioners, where death and tragedy are commonplace, it seems fair to recognise the legitimacy and positive intent of the sentiment being expressed here. Yet, what this example foregrounds is the ambiguous, personal layer of variables at play in decisions often perceived as "scientific" or "objective". The history of cultural imagery of disability, and the ideology of segregation, surely must have relevance in mediating assessments of a "worthwhile" life. Princeton philosophy chair Peter Singer has drawn a particularly fierce battering from the ranks of disability studies, due to his outspoken views on the value – or lack thereof – of life with a range of physical, sensory and cognitive impairments (Asch, 2001, p. 305). To Singer (1993, p. 184), "the killing of a defective infant is not morally equivalent to the killing of a person; very often it is not morally wrong at all". While conceding that individuals may maintain meaningful lives with these impairments, he insists that such lives will necessarily be less satisfying than the lives of persons without impairments (Asch, 2001, p. 305). What we seem to be apprehending here, is the logic of subjectivity "written on the body"; and "written large", at that. Singer (1993) even asserts that it is possible to make absolute and infallible statements regarding the comparative nature of unseen individuals, simply on the basis of physical or cognitive characteristics. Consequently, he argues that it is acceptable that parents

kill newborns with such conditions, in order that the "defective" child be replaced by a "healthy" one, who will necessarily enjoy life, and bring more joy, than the unknown impaired child ever could (Asch, 2001, p. 305). With such dramatically divergent positions at play, and with the incontrovertible and chance influence of the cultural exposure of practitioners, the overt and tacit meanings of impairment presented to parents – typically in crisis – are multifarious and potentially definitive. The "medical encounter", thus, is not an engagement with "value neutral" medical science (Marks, 1999a, p. 51), but, at least partially, with some chance fragment of a kaleidoscope of cultural meanings surrounding disablement, of discursive as well as intra-psychic, unconscious origin.

### *Prenatal testing and abortion*

The fast growing international availability of prenatal testing to detect the presence of a range of congenital disorders presents many prospective parents with the dilemma of whether to bear children who will live with impairments (Asch, 2001, p. 305). Asch (2001) writes:

...the vast majority of [bioethics] theorists and health professionals...argue that prenatal testing, followed by pregnancy termination if an impairment is detected, promotes family well-being and the public health.

(Asch, 2001, p. 305)

Against the backdrop of the predominance of a pro-choice philosophy on abortion, one view is simply to locate the impairment question as one amongst many others confronting adults considering the feasibility of parenthood. However, Sinason (2002, p. 38) points to systematic variations. In the United Kingdom, for example, "ordinary" pregnancy has an upper limit for termination of 24 weeks; for foetuses carrying a strong possibility of a range of congenital conditions, this restriction is waived, and no precise limit is provided (see also Shakespeare, 2006, p. 94-95). In an international survey of geneticists, Wertz (1995, p. 1654) found that 54% endorsed so-called "eugenic" goals; that is, the reduction in the number of carriers of genetic disorders in the general population. This position was justified in terms of the unchanging nature of negative social attitudes towards impaired persons, and the conviction that the birth of an impaired child is typically destructive to healthy family functioning (ibid.). Again, the retort of disability studies critics pertains to the socially

constructed, stereotyped idea that a disabled child necessarily cannot provide the fulfilment parents seek in child-rearing (Asch, 2001, p. 305). These critics do not oppose abortion *per se*, but question the cultural underpinnings of decisions to abort particular foetuses on the basis of physical features (*ibid.*, p. 307). The implication of writers from within the disability movement is that the desire to terminate pregnancies involving impaired foetuses embodies an expression of broader cultural antipathy toward persons with those impairments, not just unborn, but living. This, in some quarters, has been termed "the expressivist critique".

In her psychoanalytic work in the area of learning disability, Valerie Sinason (1992; 2002) has found deep evidence of the psychological impact, amongst learning disabled patients, of the knowledge that only a lack of technology allowed for their birth. That is, persons with a range of congenital impairments live with the knowledge that, had parents or medical professionals known of their "nature" before birth, they would likely not have been born. Sinason writes:

The deepest and most painful psychoanalytic theme that comes from long-term work is that learning disabled people can experience extreme annihilatory fear because it is hard (or impossible) to separate out the idea of amniocentesis or abortion of unborn learning disabled foetuses from a death wish towards learning disabled children and adults.

(Sinason, 2002, p. 39)

The essence of the "expressivist critique" lies in the assertion that legal or medical interventions which preclude the birth of persons with certain impairments "express" the, perhaps unconscious, desire of the broader population that living persons with such conditions did not exist. Learning disabled persons, in particular, are argued to carry the most wretched of projected aspects of the human condition; the lack of an intact intellect has widely relegated such persons across world culture to a status below that of full humanness (Parmenter, 2001, p. 290). But across a broad range of heritable impairments, disabled persons routinely have the experience of "genetic counselling" aimed explicitly at preventing the addition of other such impaired persons to the populace. Rod Michalko (2002, p. 45) tells

of his being haunted in young life by the knowledge that "my type of person" – that is, a blind person – "was not welcome in my homeland". After much agonizing over why this was the case, he was brought to a recognition of the imputations culturally at play surrounding the perceived nature of his life. He writes:

What was it about me and my life that recommended not reproducing it? Why should I be prevented from happening again? The answer is simple: blindness is a condition that deprives people of most, and sometimes all, of their eyesight and, in turn, eliminates most, and sometimes all, of their ability and even pleasure.

(Michalko, 2002, p. 50)

Saxton (1998) regards the disability basis for prenatal testing as "the greatest insult", affirming that "some of us are 'too flawed' in our very DNA to exist" (Saxton, 1998 cited in Asch, 2001, p. 308). A key question for our purposes pertains to what the effects upon psychological functioning and identity are of the knowledge that "there are people who go to great lengths to avoid the birth of someone like you" (Glover, 2006, p. 5). Assuming a typically provocative position, Shakespeare (2006, p. 87), stridently diminishes the import of such "cultural messaging".

To Shakespeare (2006, p. 87), the "expressivist critique" embodies an excessive, even histrionic, "plot discourse", which ascribes a systematic, sinister intentionality to reproductive health policy which is mistaken and misplaced. Shakespeare's position is a hyper-rational one, emphasising, in response to the critique of prenatal testing, that "there is no government plan to eliminate disabled people" (ibid.). He responds, thus, to the issue as an illusory "eugenic threat", rather than a lived form of social denigration with potentially measurable effects upon the disabled community. In downplaying the disability movement's concerns, he points to the fact that it is often parents themselves who are active agents in the choice to terminate (ibid.). Whilst this is undoubtedly true, the observation elides a critical recognition of the symbiotic relationship of medicine and culture, as well as fudging any interrogation of the origins of such parents' instinctive views on what disabled life may be like. The glaring lack of exposure of most members of modern society to naturally nuanced, normative, functional disabled lives ensures that assessments of disabled life rely primarily upon

(typically aversive) fantasy, rather than first-hand experience. Further, the fact that reproductive health policy contains no deliberate conspiracy does not change the deep (potential) meaning of manifest events in the lives of disabled persons who, as anyone might be, are harmed and penetrated by the knowledge that they are an accident, unwanted, and of inferior value. A critique of social policy which focuses on *intentions*, rather than *effects*, will surely not render a full, rigorous picture of its lived implications. Undoubtedly, a host of dreadful health care policies have seen implementation under the best possible intentions, but with a lack of understanding of the meanings these will bring to individual lives.

Shakespeare (2006, p. 89-90) continues his clinically rational argument by pointing out the contradiction which inheres in the assumption that, if amniocentesis had been available, "I would not have been born". There would, he writes, be no "I" to be born, as the "I" concerned would not exist. To him, a "more rational" view is one which states that "this technology might prevent future people *like* myself from being born" (ibid, p. 89 – my emphasis). This, whilst still potentially distressing, has less "personal resonance" than the idea of one's non-existence (ibid.). My own view is that the key aspects of this issue cannot be considered adequately in "rational" terms, as they pertain most meaningfully to the deeper, often unconscious, and irrational layers of human experience. Shakespeare (2006) seems unable to allocate thought-space to the reality of a persistent tissue of denigrations surrounding disability which prevail in society more generally, to potentially be crystallized in issues such as reproductive health policy. The bioethics debate, in this schema, is not "the problem", but simply a terrain of engagement surrounding an issue of far broader, deeper import; the complex, cultural territory of identity, trauma and selfhood. In placing prenatal testing amongst a range of innocuous reasons why one might not have been born – if one's parents had not met, if they had used contraception, and so forth – Shakespeare (2006, p. 90) mistakenly equates free-floating aspects of human life experience with those which are applied with specific identity-meanings. In my view, this statement is tantamount to asserting that the experience of "being poor" is identical whether or not one inhabits a racist state in which one's poverty is a function of demeaning, racialised economic exclusion. In the South African apartheid state, the abject poverty and other social deprivations suffered by black persons were inflicted within an explicit logic which connected one's "undeserving" status to one's colour, one's *identity*. Similarly, the potentially toxic thrust of the knowledge that efforts are afoot to prevent the existence of others "like me", must to some extent imbue "my way of being" with a demeaning evaluative assessment; "the reason why the world is attempting to prevent more people like me, is because of *the way that I am*". Thus, poverty,

within the apartheid ideology, tracks back to undeserving, and undeserving tracks back to blackness; the struggle, the affliction, is ultimately within. Here, as in the lives of disabled persons, the experience of deprivation and marginality are tied to identity, to the nature, the essence, of one's being. The reason for poverty coincides with the reason for amniocentesis; and it is in the internal realm that the dark ramifications of these social realities are seeded, and grow.

The above discussion does not imply that it is wrong to aim to prevent impairment, but simply directs attention at the need to explore the human meanings which attend such activities. If taken to absurd – though "logical" – lengths, the expressivist critique may be used as an objection to such self-evidently humanitarian initiatives as polio vaccination, or the clearing of landmines, as these activities may be viewed as devaluing of impaired life (Shakespeare, 2006, p. 90). But the absurdity of these propositions should not deflect attention from the voracity of cultural and personal meanings attached to prenatal impairment prevention.

Assuming an historical and ideological perspective, a central question is whether termination of, for example, a Down syndrome pregnancy embodies a legitimization – an acceptance, a validation – of the discriminatory ideals of people in the broader population, from whom the parents concerned typically wish to protect their unborn child. The termination reduces the extent to which these ideals will be challenged, or will come into clear relief; the persons who propound these ideals will not be forced to confront the logical implications of their actions. Instead, we acquiesce to this threat, in a manner which leaves the social order undisturbed, and deprives culture of the means to overcome the web of implications which are lived as part of invisible disablist ideology. The result is that some impaired individuals live with constant messaging regarding the consensual view that their lives are "not worth living"; messages which would appeal to the more fragmented, more malignant, parts of any human psyche. Disablism, thus, manifestly and materially impacts upon the lives of impaired persons in traumatic ways, via multiple exclusions and deprivations; whilst simultaneously reproducing messages which affirm the futility and meaninglessness of lives. This schema presents very real questions regarding the locus of human experience; of "the real". Occupying a world in which one's existence is overwhelmingly socially constructed as wretched, may *create*

existence thus. Access to only a limited repertoire of the possible natures of experience – one centring on the abject – surely must create massive obstacles to the development of an experience of being which flouts these expectations; it would require that one found oneself somewhere other than in the mirrors of the social world.

*Assisted suicide and the right to die*

An important initial distinction to draw in this highly emotive area is that between supporting assisted suicide in the final stages of terminal illness, and the voluntary euthanasia of persons who are not terminally ill, but have impairments. The crux of this contrast is between the enabling of dying persons to die, and the legal, cultural encouraging of disabled persons to end their lives (Shakespeare, 2006, p. 131). In the second case, the often overwhelming predominance of desolate cultural assessments of the nature of life with, say, quadriplegia, underpins the gathering of discursive forces which recommend the termination of such lives. A number of landmark legal judgments in the United States have dealt with requests for assisted suicide made by persons with severe physical impairments, thus creating a platform for the exploration of social constructs of such lives, expressed via the authority of courts of justice. The question posed to these courts, in essence, regards whether these lives are, in fact, "worth living".

In the now famous case of Elizabeth Bouvia, a young woman suffering from severe cerebral palsy and arthritis, such a request to be assisted in suicide was made in 1983 (Asch, 2001, p. 311). She asked the court to grant permission for hospital staff to keep her sedated, and withdraw tube feeding in order that she would starve to death (ibid.). Bouvia approached the American Civil Liberties Union for support in her endeavour, leading to this organisation representing her case. The ACLU centred their argument squarely on her experience of impairment – that is, on her "intolerable affliction", which caused her to endure a "pitiful existence" involving the "indignity and humiliation" of personal assistance with bodily functions (ibid.). In 1986 the California Supreme Court ruled to uphold this account, stating that "she herself is imprisoned, and must lie physically helpless, subject to the ignominy, embarrassment, humiliation and dehumanising aspects created by her helplessness" (ibid.). It

is important to note that Bouvia's was not a case of imminent terminal illness; it is possible that she may have lived for many years with the correct assistive technology. What was glaringly missing from the assessment of Bouvia's condition and request, was a social and psychiatric evaluation of her life circumstances and mental state.

A non-impaired Elizabeth Bouvia, had she checked into a hospital and refused feeding would doubtless have been diagnosed with suicidality emanating from psychiatric disorder, probably understood as rooted in social stressors. Yet, three psychiatrists regarded Bouvia's decision as reasonable, and not associated with any degree of impairment resulting from psychological morbidity (Herr & Phil, 1992, p. 5). Because of her impairment, Bouvia's suicidality was not regarded as contingent upon her mental state, and, consequently, the ethical imperative to provide appropriate treatment for suicidal mood disturbance was circumvented. More disturbing, though, is an assessment of the life stressors endured by Bouvia in the few years prior to her request for assisted suicide. Bouvia, during this period, experienced marriage and divorce, the miscarriage of a wanted pregnancy, her mother's illness, the death of her brother, many forced moves due to familial problems, chronically inadequate personal assistance, and a withdrawal from university study after being informed by her dean that her disability would preclude her from succeeding in postgraduate social work training (Asch, 2001, p. 311). What these aspects of Bouvia's case call to attention are the multifarious, and often excruciating, social factors which dominate the lives of many impaired persons within a discriminating and grossly unequal society. This is the terrain of disability; wholly ignored by civil society and the judiciary in the assessment of Bouvia's case. Faced with this onslaught of psychosocial stressors, let alone the more disability-specific ramifications of inhabiting a discriminatory and inaccessible society experienced by someone in Bouvia's position, most humans may contemplate the escape which suicide offers (Herr & Phil, 1992, p. 4). But the beguiling nature of her impairment led mental health professionals and judicial authorities alike to "forget" that, for an extended period of her adult life, Bouvia had engaged in the lifestyle practices commonly considered "meaningful" in the modern western world – she had lived independently, completed her college education and begun a masters degree, married, had a sex life with her husband which resulted in pregnancy, and planned her motherhood. What confronts us, thus, is the sleight of hand of a medicalising logic which ascribes – at least substantially – psychosocial ills to the immutable, lived nature of impairment.

In the case of Kenneth Bergstedt, the US courts displayed a similar "impairment bias". Here, authorities constructed a factitious argument purporting to differentiate between physically impaired persons and suicidal nondisabled persons, on the grounds that the latter "enjoyed the prospect of mental rehabilitation that might restore the will to live", and faced "potentially reversible pessimism" regarding their quality of life (Herr & Phil, 1992, p. 6). The cultural view of the inevitably wretched nature of impaired life is reflected here, positioning the lives of persons living with such impairments as, by the nature of their very bodily essence, futile and meaningless. The final example of the case of Larry McAfee is particularly instructive in demonstrating the neglect of any consideration of societal exclusion and oppression in the shaping of impaired experience (Herr & Phil, 1992, p. 8). McAfee was granted his request of assisted suicide by court authorities, who, in their judgment, made no mention whatsoever of the remarkable and appalling details of his final place of residence. As a severely physically impaired man, McAfee was turned away from all residential care facilities in his county, and consequently forced to take up residence in an intensive care unit for the final eight months of his life, although he was not ill or unstable. Now, a condition known as "ICU psychosis" has been identified, involving severe emotional disturbance which results from the "timeless" intensive care environment; there is no privacy, no darkness, intermittent crisis, and constant noise and activity (ibid.). Astonishingly, the Georgia Superior Court agreed that McAfee's ventilator should be shut off with no mention at all of these recent life circumstances (ibid.). In the words of Herr and Phil (1992, p. 8), "the state that had denied McAfee the right to live a meaningful, independent life did not contest his fight to die". The question of respect for the autonomy of disabled persons – as all citizens – in making life and death choices is, of course, one which deserves very real recognition. But when an individual chooses death as the "only escape" from what are entirely remediable, appalling social circumstances, it is "perverse and unfair" to construe such actions as a healthy and appropriate expression of self-determination (Bickenbach, 1998, p. 128). Conwell and Caine (1991), in a study of the medical records of persons who have committed suicide, found that between 90% and 100% of such individuals end their lives during the course of "a diagnosable psychiatric illness" (Conwell & Caine, 1991 cited in Herr & Phil, 1992, p. 10). There is no reason why this principle should not be viewed as applying to the disabled population. Suicidal depression is a life threatening, but largely treatable condition, and consequently presents an ethical imperative to health care services to provide appropriate pharmaceutical and psychological intervention. The prejudiced "common-sense" of the attribution of emotional distress to the perceived immutable concomitants of impairment must, in light of the foregoing, result in substantial under-diagnosis of mood and other disorders amongst impaired persons. Our attention is irresistably drawn to fantasies about the dreadful lived nature of impairment, rather than the materiality of resources such as housing, assistive care, appropriate medical

services, and personal emotional support (ibid., p. 11). In closing this debate, let us consider the black and sardonic words of Bickenbach (1998), as he satirises the contradictions brought to light by cultural assessments of the "liveable" life:

It is telling that...there is never any suggestion that the right to physician assisted suicide should extend to people who do not have a severe disability. Implicit in the judgments themselves...is precisely the prevailing prejudicial social attitude that having a disability is a sensible reason for committing suicide. Perhaps proponents of physician-assisted suicide would be steadfast in their view even if it meant that qualified doctors could patrol school grounds waiting for despondent but mentally competent seventeen-year-olds who, having failed geography or being unable to find a date for the prom, might want to use their assisted-suicide services.

(Bickenbach, 1998, p. 130)

## Eugenics

In composing a picture of the psychic undercurrents which give life to modernity, Frosh (1989, p. 233) writes of a "balance" between the age's "two faces". At one side of this tension we find "multiplicity, contradiction, flow", and the "celebration of heterogeneity". The flipside of these intents, perhaps enlivened by the more primitive of psychic impulses, reflects "rigidity, domination" and "totalitarianism", manifesting in the overt, evaluative divisions of fascism, and the global scourge of racism (ibid.). Disability has not been exempt from the destructive excesses of the latter. Davis (2002, p. 157) exhorts us to "never forget" that it was the physically impaired and the "feeble-minded" who were the first to be despatched to the death camps by the Nazis. It was only after the murder of between 200 000 and 300 000 impaired persons that the attention of the vanguards of the "final solution" moved onto dealing with "racial undesirables" (Ravaud & Stiker, 2001, p. 502). Of concern to this discussion, as we ponder upon the possible cultural pervasiveness of the purportedly "dark intentions" of modern bioethics, is whether a "fascist undercurrent" may be detected in modern society more broadly, which carries echoes of a totalitarian drive toward the obliteration of difference.

The term *eugenics* first appeared in the work of Francis Galton in 1883, spawning a movement whose principle goal was the translation of scientific research regarding heredity into social policy which would prevent the production of "degenerate" human stock (Trent, 1994, p. 136). Of interest, when one considers the colloquial view of the eugenics movement today, is the fact that, during the first decades of the twentieth century, its proponents reflected a broad cross-section – including progressive liberals – of the scientific community. It was, though, the movement's linkages with reactionary ideology which, even to the present, assured its longevity (ibid.). Advocates of policies of racial "purification" propounded the view that, through the progressive elimination of inferior human stock, such social problems as poverty, crime, unwanted children, insanity and mental retardation could be extinguished (ibid.). In terms of the social circumstances of disabled persons, this burgeoning movement coincided with the twentieth century's ever-growing medicalisation of disability (Hughes, 2002a, p. 61). The unruly disabled body, like the "distorted" bodies of "non-European" racial minorities, carried all too clearly the somatic markings of its corruption, rendering it a palpable target for what Foucault (1979, p. 54) termed "the racisms of the state". The onslaught upon disabled persons, when not in the more base forms of genocide or forced sterilisation, was to take the form of a concerted ideology of measurement, seeking to locate all in relation to statistical expressions of normalcy (Fujiura & Rutkowski-Kmitta, 2001, p. 70). It was Charles Darwin's theory of natural selection which provided the backdrop for a construing of disabled persons as "evolutionary defectives", to be purged through the just and necessary balances of nature (Davis, 1997b, p. 14).

As we trace the trajectory of the increasingly scientific (or *scientistic*) measurement and categorisation of humanity through the twentieth century, what seems to emerge is the steady crystallizing of a corresponding, but hegemonic and invisible, "non-disabled" identity. In guiding our consideration of this matter, McRuer (2006, p. 1) describes – analogously – the coalescing of the heterosexual norm during the course of the last century. He writes:

...it was the 'homosexual menace' that was specified and embodied; the subsequent policing and containment of that menace allowed the new heterosexual normalcy to remain unspecified and disembodied.

(McRuer, 2006, p. 1)

Like heteronormativity, the nondisabled figure came to "masquerade as a non-identity, as the natural order of things" (McRuer, 2003, p. 79). Slowly, it seems, the forces of totalitarian sameness were silently engulfing "disability difference", as any and all deviations became shown up as errors of nature, as "glitches", rather than expressions of "natural" diversity.

Pernick (1997, p. 90) regards reflection on the history of the eugenic movement as essential, in illuminating the cultural value judgments that reframe bodily difference as disease or disability. The hideous "pinnacle" of murderous intent toward disabled persons – the extermination of around a quarter of a million impaired persons in Germany between 1939 and 1945 – was reflective of eugenic ideals which were by no means unique to the Third Reich. Not only was German racial purification founded upon the self-same British and American eugenic arguments cited above, but even at the height of the extermination in 1941, prominent British biologist Julian Huxley was publicly bemoaning the lack of decisive application of eugenic policies in Great Britain (Hubbard, 1997, p. 189; Davis, 1997b). More remarkable is the historical fact that, unlike the mass murder of Jewish people, no prosecutions were ever initiated against those responsible for the extermination of disabled persons in Germany (Gallager, 1990 cited in Marks, 1999b, p. 616). In 1933, Germany had instituted a programme of forced sterilisation of primarily intellectually impaired persons, which resulted in as many as 400 000 sterilisations; the policy was modelled on that already in place in California (Braddock & Parish, 2001, p. 40).

Between 1907 and 1949, more than 47 000 forced sterilisations of intellectually impaired persons were recorded in the United States (Woodside, 1950 cited in Braddock & Parish, 2001, p. 40). As in the case of the Nazi extermination of disabled persons, it was medical practitioners who performed these procedures, in the USA as well as several other western countries, upon persons presumably not fulfilling the modern capitalist ideals of autonomy and rationality (Glover, 1977 cited in Marks, 1999b: 616). Post World War II, and far more recent accounts of legalised and illegal enforced sterilisations, have emerged in countries including Spain (Bosch, 1998), Japan (Asch, 2001), Australia (Cordner & Ettershank, 1997), Denmark (Braddock & Parish, 2001), and Sweden (Hughes, 2002a). In these states, the view that "disability represents a contaminant within and a threat to the physical and moral integrity of the population" remained promulgated in the legislative denying of the right of reproduction (Hughes, 2002a, p. 61).

Bringing the account up to the present day, it is argued by some disability studies critics that the modern availability of "genetic counselling" embodies a sanitised, but nevertheless antagonistic, version of the eugenics movement's attack upon the disabled population. Hubbard (1997, p. 196) describes how modern "scientists", simply carrying a new species of the same malevolent motives as their openly fascist predecessors, leave the task of "decisions" regarding the prospective lives of unborn children to pregnant women. Within a "liberal" rights discourse, the illusion of "free choice", in fact, places women in an impossible double-bind in cases of the prenatal diagnosis of an impaired foetus. Typically, in such cases, there is limited means for assessing the severity of the impairment (ibid.). If the prospective mother chooses to not take prenatal tests, or not to terminate her pregnancy in the face of a positive result, Hubbard (1997, p. 196) argues that she tacitly receives responsibility for whatever the disability may mean to the unborn child, as well as to herself and her family. She has, in the convenient, euphemistic distortions of the dream of autonomy, "chosen" this child, this life. Therefore, she is vulnerable, nay liable, to the reproaches of family, society, and the child him or herself, for the pain that may ensue (ibid.). The responsibility she carries, it must be noted, is not simply for physical pain, but also for the anguish engendered by society's shunning of her child; in practice, the logic places this account before *her*, rather than interrogating and problematising the disablist social order (ibid.). In this muted, "rights-based" form, the logic of the selection and extermination of lives nevertheless pertains, in the form of pressures upon women to "elect" to terminate troubled pregnancies (ibid., p. 199). Of course, many women want to implement such terminations, but, for Hubbard (1997, p. 199), one reason why this is so, is that "society promises much grief to parents of children it deems unfit to inhabit the world".

Shakespeare (2006, p. 86), in characteristically challenging style, frankly rejects arguments such as that recounted above, viewing the equation of genetic research with eugenics as irrational and excessive. Whilst in material terms the death camps of Germany are light years from the cool, sterile rationality of a genetic counsellor's consultation room, a question remains regarding whether it is possible to trace the faint outlines of related intra-psychic phenomena underpinning each. Assessment of the credibility of this idea must also be made in a manner well cognisant of the familiar excesses of wholesale, stereotyping vilification of the medical establishment emanating from some quarters of the disability studies academy. There is little reason to doubt that, whilst eugenic ideas assumed peculiarly heinous, florid and terrible expression in Nazi Germany, the essential motives – and unconscious concomitants – of the drive to disallow difference are common across nations and time-

frames. That is, the essence of the human "nature" for destructive and sadistic impulses towards the custodians of projected damage, obtains across a range of its expressions. On making an assessment of the burgeoning body of disability studies research, it is soon demonstrated clearly that the addition of psychological and psychoanalytic constructs to the critical analysis of such questions is much needed, and distinctly overdue. For example, the lack of a psychological conceptual frame of reference, in my view, prevents Shakespeare (2006) from reaching the root of disability studies' furious critique of modern genetics. He is unable to see, to conceptualize, a deep wound telling of the unremitting experience of being construed as intrinsically damaged. Instead, the debate rages about theory and history, rather than about the manner in which the arena of bioethics provides focal issues for the expression of a host of more manifest, yet less material, cultural denigrations, which continue unabated in the fabric of social life.

## Disability and the medical encounter

A discourse analytic view of the social construction of disability (e.g. Stiker, 1982; Foucault, 1976), based upon interrogation of the ways in which the body is culturally produced and regulated, treats medical interventions such as the rehabilitation process, as *normalization* (Turner, 2001, p. 253). The primary purpose of disability rehabilitation, in this view, is the restoration of the social order via the subduing of difference; that is, the imposition of mechanisms of social control upon politico-cultural dissidents. Within a Foucaultian discourse analysis tradition, Stiker (1982) traces the development of what may be described as a medicalistic rehabilitative fervency back to the First World War. He argues that the vast numbers of impaired persons produced by the conflict laid the foundation for an acute paradigm shift in western societies' responses to impairment, establishing notions of "replacement, substitution and compensation" as the benchmarks of medical rehabilitation. He writes:

As the catastrophe of war required reconstruction, so damaged people were to be rehabilitated, returned to a real or postulated pre-existing norm or reference, and reassimilated in society. The process was not one of curing: 'Curing is an expulsion and concerns health, re-integration is situated on the social level and replaces a deficit.

(Stiker, 1982, p. 141)

Stiker (1982) implies that the bodily, and hence social, "ideal" striven for in the normalisation process is, in fact, an illusory construct – an idealised retrospective fantasy of functionality and uniformity which, in reality, did not exist. The imperative to "re-realise" this ideal state fosters a culture of health care practice which is centrally preoccupied with repair, with cure, and consequently ill-equipped to engage with the disability reality of chronic difference. Instead, rehabilitation's key concern, within this reading, is the reduction of any deviation from the norm, incorporating actions upon the individual which seek to "efface any difference" (Ravaud & Stiker, 2001, p. 507). The object, thus, of the devices, prostheses and technologies of rehabilitation is not to assist in the shaping of subjectively functional and fulfilling – but unique – ways of being, but in causing the individual to act "like others" (ibid.). The corrective force of such services is brought to bear upon bodies that wantonly defy the cherished "normate" ideals of self-contained autonomy; in diametric opposition, the disabled body represents –

...the incomplete, unbounded, compromised and subjected body, susceptible to external forces: property badly managed, a fortress inadequately defended, a self helplessly violated.

(Thomson, 1997b, p. 45)

In more specific and applied terms, Rioux (1994, p. 4) observes that success in the design and delivery of rehabilitative services is typically measured in terms of how closely persons using such services approximate the "normal". Evaluative studies tend to be functionalist in nature, and assume congruence between the ideals of providers and users, thus eliding opposing interests or approaches (ibid.). The question of the definition of "needs" is, of course, a fraught one (Fraser, 1989, p. 161; Finkelstein, 1998; Handley, 2000). Theorists writing in defence of particular social service models may point to the real issue of members of the disabled community demanding assistance in becoming "as normal as possible". A difficult balance is required here, between respect for the sanctity of individual choice, and the opposing reality of a broad social environment in which all, impaired and non-impaired alike, are steeped in an ideological denigration of difference. Finkelstein (1993, p. 13) asks that we situate the declared "needs" of disabled persons within the disability-related belief systems of such individuals. Understanding one's suffering as a simple consequence of impairment, he points out, would tend to inform a subjective "need" for normalisation. Conversely, if discrimination is seen as the central difficulty, support aimed at the securing of equal opportunities may be requested (ibid.). The role of professional medical authority in the propounding of certain discourses of needs is significant, in light of the ongoing involvement

of practitioners in the lives of many members of the disabled community (French & Swain, 2001, p. 734). Traditionally, "needs" and corresponding social services have been outlined, designed and delivered by health professionals, positioning disabled persons as passive recipients with minimal opportunities to enforce control upon these processes (ibid.). Rink and Calkins (1996) found that disabled persons in their study tended to acquiesce to professional decisions, at times fearing the loss of privileges or care in institutional settings (Rink & Calkins, 1996 cited in Asch, 2001, p. 310).

Returning to the work of Robert Scott (1969) affords an eloquent description of how rehabilitation dictates the "correct" ways in which disability is to be lived. The trappings and deportment of "the blind man", to Scott (1969, p. 14), such as the guide dog, the white cane, and a docile and melancholic demeanour, represent facets of a narrow and clearly circumscribed script of culturally sanctioned methods of living which "package" the individual in a guise palatable to broader society. In his analysis, a key indicator of rehabilitative success for social service workers was "the degree to which the client has come to understand himself and his problems from the worker's perspective". From a psychoanalytic vantage point, there is potential for the interrogation of such preferred modes of disabled life as phenomena shaped by the nature of defences which, in turn, are erected in response to anxious fantasies which a particular form of impairment evokes. The guide dog, for example, certainly assists functionally in the mobility of a mass of blind persons worldwide, but, as certainly, functions as a reassuring container of projected "blindness fantasies" carried by scores of anxious observers. This is attested to by Scott's work, via the familiar image of ardent, even angry protestations levelled at disabled persons choosing not to make use of such means. The management of fearful unconscious evocations by the application of manifest social control seems elemental in the psychological understanding of a host of forms of "disability normalisation". What results is that identities are contested, often through nondisabled professionals advocating what is "appropriate and normal" behaviour in the lives of disabled "clients" (French, 1999, p. 21).

As alluded to earlier, health practitioners may have an extended, even lifelong authoritative presence in the lives of disabled persons. Consequently, these professionals carry particular responsibility regarding the modelling of attitudes to do with the possibilities and constraints of life with a certain impairment (Hordon, 1994, p. 203). A number of disability studies authors make the important point that health professionals may retain negative, stereotyped

attitudes due to predominant exposure to disabled persons requiring help and treatment, rather than healthy individuals leading independent lives within the community (e.g. Gerhart et al., 1991 cited in Asch, 2001, p. 301; Hordon, 1994, p. 203). Health workers such as those staffing casualty wards and disability rehabilitation centres, close as they are to incidents of trauma, tend to "dramatically underestimate" the life satisfaction of disabled people; in addition, this finding holds regardless of the amount of experience of professionals in such settings (Bach & Tilton, 1994 cited in Asch, 2001, p. 301). Asch (1998) presents the point bluntly: doctors and bioethicists influentially shape disability-related decisions made by patients and families, but cannot provide genuinely informed information about managing life with an impairment if they themselves remain disbelieving or sceptical that impaired persons may lead fulfilling and satisfying lives (Asch, 1998 cited in Miller, 2006, p. 220). Perhaps disturbingly, evidence to hand suggests that attitudes of health professionals towards disabled persons roughly reflect those of the broader population; that is, predominantly negative and stereotyping (French, 1994b, p. 687; Johnson, 1993; Scullion, 1999; Biley, 1994; James & Thomas, 1996). Some studies point to the significance of the nature of contact between professionals and disabled persons, with equal-status, "non-therapeutic" relating garnering the most positive attitudinal results (Basnett, 2001, p. 452; Eberhardt & Mayberry, 1995; French, 1994b). Basnett (2001) argues that the attitudes of health professionals not only accentuate the individualistic accounts prevalent amongst the general public, but also actively promote a medicalising paradigm that buttresses the legitimacy of their own role, and confounds the emergence of critical consciousness in health care settings (Basnett, 2001, p. 452).

One particularly harrowing form of "medical socialisation" recounted by the disabled community is the phenomenon of so-called "public stripping", involving the demeaning, at times naked use of disabled persons as objects for medical tuition. This appalling treatment is now recognised as institutional abuse, with the emergence of first person accounts indicating its disturbingly widespread occurrence (French & Swain, 2001, p. 738). In a study by Lonsdale (1981), one female respondent gave the following account:

My memory is basically of a whole series of experiences of being very coldly and formally mauled around. It's very alienating. It's as if you're a medical specimen...I was never told that I was nice to look at or nice to touch, there was never any feeling of being nice, just of being odd, peculiar. It's horrible. It's taken me years and years to get over it.

(Lonsdale, 1981 in French, 1994a, p. 103)

To Coleridge (1993) it is a common and serious oversight that we underestimate the potential impact of health-related socialisation upon the self-image of the disabled community. Some such individuals endured more or less constant involvement with health practitioners throughout childhood, when "play, enjoyment, and discovery were replaced by stress, medical examinations and developmental programs (Coleridge, 1993 cited in French & Swain, 2001, p. 738). The repressive constraining of healthy psycho-sexual development is a common systemic side-effect of familial-medical preoccupations with childhood impairment, often serving to developmentally stunt normative sexual maturing (McRuer & Wilkerson, 2003, p. 9). Boazman (1999) describes the experience of being composed as a set of medical failings thus:

Their [health professionals] responses towards me varied greatly, some showed great compassion, while others showed complete indifference. I had no way of communicating the fact that I was a bright, intelligent, whole human being. That is what hurt the most.

(Boazman, 1999, p. 18-9)

The advent of internet-based virtual chat and support groups amongst disabled persons has, over the course of recent times, created an environment for the sharing of experiences and lifestyle choices free from the medical gaze, or any institutional affiliation (Gold, 2001, p. 44; Blasiotti, Westbrook & Kobayashi, 2001). Such engagements may provide a thought-space which is more geared toward the sharing of knowledge regarding societal life with impairment-difference, rather than an emphasis upon "medical conditions" and questions surrounding "cure".

As has been noted, a pervasive critique of biomedicine's responses to disability surrounds a primary focus on prevention and cure, which sidelines the development of "emancipatory" knowledge regarding impaired life in a disablist society (Rioux, 1994, p. 3). The "curative zeal" of biomedicine (Marks, 1999a, p. 75) directs health care resources at research and intervention strategies which carry promise of a realisation of "repair", in a manner which positions the permanently impaired as chronic defectives, whilst remediable social deprivations persist. Sinason (1992) identifies how the imperatives placed upon health professionals – to restore the body to functional and aesthetic wholeness – locate the "defective" body as an intolerable insult, a failure, an insoluble blight. The nature of the intra-

psychic defensive correlates of Cartesian biomedicine, I suggest, is one which reflects the binary splits of that philosophical position; where disability is an intolerable absence of cure, and little thought-space is readily available for a consideration of novel, modified "neo-normal" human life. To Sinason (1992, p. 36), health practitioners may, in an unconscious defensive manoeuvre, "go stupid" at evidence of the "incurable", "not just because it is painful, but because it is unbearable to see damage and not be able to repair it". In a similar vein, Main (1989, p. 206) focuses attention on modes of clinical practice which may appear as "hallowed" medical techniques or philosophical positions, but in fact are inadvertently devised as defensive manoeuvres which lessen anxiety within medical professionals. For Tom Main (1989, p. 207-8), the experience – and management – of "helplessness" within doctors embodies a primary theoretical concern in the analytic study of health and illness, expressed in ways as diverse as "laughter, forgetfulness, aloofness, scotomata, denial", and much else. A combination of the primitive evocations characteristic of the disabled imago, and the ongoing exposure of health practitioners to intractable damage and trauma, may constrict the "thought space" available for engagement with the awkward reality of difference (Marks, 1999a, p. 46; Bion, 1967). Considering the widespread influence of the health care establishment over disabled lives, it is not difficult to see how the potential growth of an articulate disabled voice, moving from individualising self-pathologisation toward a politically conversant expression of valued difference, may be derailed by the hegemony of "cure".

Asch and Fine (1997, p. 251) describe how practitioner "needs" surrounding a normalising ideal may lead to disabled patients' assuming of inauthentic, placating roles. Michelle, a 17 year old respondent in their study, told her interviewer that she wore her prosthetic arms only on visits to her doctor's surgery, as they were clumsy, and more a hindrance than a useful addition. She was "perfectly comfortable" with others seeing her short and "deformed" arms, but could not share this with her doctor (ibid.). To further abstract this theme, modern western culture, drenched as it is in the ideals and dictates of "somatic success", prizes and affirms what Frank (1995, p. 78) terms the "restitution narrative". The narrative is to be found in a vast range of cultural contexts – from television advertisements for cold remedies to moralising parables regarding the "consequences" of an unhealthy lifestyle; in each case, the story reflects how things "get better" when one follows stipulated social protocols, and "tells" one's illness in a socially appropriate, "cure-striving" manner. Social or occupational default, in the schema, is the unacceptable outcome of a body poorly managed. In this fantasy world, all is curable, or at least avoidable; it is human dereliction alone which manifests the

emergence of Mary Douglas' (1966) "matter out of place". The need for the shoring up of shared defences against the looming threat of the "cultural heresy" of intractable loss or brokenness, may cause practitioners to deflect or otherwise silence subjective accounts which flout its prerequisites. Hinshelwood (1987, p. 58), writing on the residential care of learning disabled persons, sketches a relational scenario of such avoidance, which is instructive (I believe) in a range of impairment-related contexts. He points out how, in clinical encounters with learning disabled persons, despair is often not clearly recognised or addressed, whilst anger is over-emphasised (ibid.). What may have occurred here is that the patient has attempted to communicate an experience of despondency, which appears pre-consciously to the clinician as the unruly and untenable spectre of intractable loss, perhaps flanked by echoes of guilt and dysphoria over the social and power inequalities at play. This aversive unconscious response may be experienced by the clinician as coming from the client, who is consequently viewed as actively wishing to cause hurt. The incipient guilt of the clinician seems central here, in informing his or her experience of "blameless persecution". What was initially a communication of despair, thus, comes to be viewed as hostility, and this cognition tends to evoke a counter-aggressive response, perhaps of extreme and disciplinary proportions (ibid.). The client, hence, is left with an enactment of the all-too-familiar experience that "others cannot withstand my despair", leading to such emotional experience being driven underground. The stereotype of the "troublesome", "ungrateful", "uncooperative" or "manipulative" disabled client or resident, is not hard to discern here, reaffirmed in the repetition of such dynamics.

Investigations of the nature and influence of medical training upon disability prejudice have led to some alarming findings. Evidence suggests that professional training tends to increase the prevalence of negative attitudes, and decrease levels of empathy (Brilhart et al., 1990; Diseker & Michielutte, 1981; Rezler, 1974; all cited in French, 1994b, p. 689). Training in a critical, empowerment model of disability, it seems, is at best patchy across tuition programs in a range of medical disciplines (e.g. Biley, 1994, p. 786). Before and beyond the influence of training, though, is the question of the personality profile which is attracted to the (predominantly) "reparative" disciplines of modern medicine. In describing individuals drawn to surgery as a profession, Marsh (2006, p. 121) characterises this cohort as "the fixers"; "interventionists" who "need to be the active agents in resolution of situations to obtain personal satisfaction". The awkward, ambiguous and intractable nature of permanent impairment would, one imagines, impart a dysphoric incongruity, a troublesome lack of fit, to the functioning of minds fulfilling this description. Interacting with this pre-existing

personality profile, are the extraordinary, even brutal, demands of training regimens, involving exhausting working hours spent dealing, sometimes relentlessly, with trauma, pain and death. Very little, if any, psychological resources or training is typically provided to assist health professionals in dealing with this onslaught. On the contrary, at times a more authoritarian, rigid and judgmental chain of command may pertain, borne of the split off and denied vicarious trauma of those who have gone before. These practitioners are, in my view, victims of history and institutional circumstance who deserve our empathy, and are typically doing the very best they can in organisational settings acutely disregarding of the psychological needs and struggles associated with medical practice. The highly regrettable, wholesale vilification of health professionals voiced by some quarters of the disability movement deserves to be recognised as the stereotyping which it is (Shakespeare, 2006, p. 80).

A final issue for our consideration in this section is that of the political significance of adequate representation of the disabled community in the ranks of the various health disciplines (Lawthom & Goodley, 2006). To begin, a range of authors have provided evidence of staunch institutional resistance to the admission of disabled persons to training in mental health professions, such as clinical psychology (Asch & Rousso, 1985; Bliss, 1994; French, 1988; James & Thomas, 1996; Stannett, 2006). The legacy of psychoanalytic literature which suggests the inevitable presence of undesirable psychological traits in impaired persons – already considered – seems to imply a corresponding scepticism regarding the suitability of disabled persons for psychoanalytic psychotherapy training (Asch & Rousso, 1985, p. 4; Bliss, 1994). A view which characterises disabled persons as, *inter alia*, borderline, narcissistic, paranoid, grandiose, impulsive, controlling, dogmatic, lacking in insight, prone to denial, detached, isolated, and withdrawn, as the traditional psychoanalytic view does, is clearly going to inform extreme circumspection in the consideration of disabled candidates (Asch & Rousso, 1985, p. 4). A further concern cited is the potential disruption of the therapeutic dyad emerging from the effects of visible impairments upon the patient (Bliss, 1994, p. 117). In response to this concern, Bliss (1994) points out that it is only disabled clinicians such as herself who are in a position to be fully aware of the therapeutic implications of this scenario. Other accounts find that visible impairment may be an asset in therapeutic work, serving as evocative "grist for the mill" which, if managed thoughtfully, may contribute to the analytic process (French, 1988, p. 170; Asch & Rousso, 1985; Levinson & Parritt, 2006). The defining concern of this matter, though, rests in two related points. Firstly, it is incontrovertible that disabled persons are best placed to achieve accurate,

empathic understanding of the predicaments of others with bodily differences; note, though, this is not at all to imply that disabled persons are "by their nature" capable of such empathy. Simply wearing the ascription of a social category (race, gender, disablement) does not equate with conscious, layered understanding of the complex, often paradoxical nature of the oppressions experienced by the group. Rather, it is personal insight which, in interaction with socio-political experience, renders the unearthing of an emancipatory capacity for empathy. The second issue flows from this; that is, the broader ideological need for development of a shared narrative of group consciousness, which emanates from the interrogation of personal experience. The importance of carefully sifting through, critically examining, and documenting existential data surrounding the lived nature of impairment within disablist society, can hardly be overestimated. This is the business of finding a voice which transcends internalised silences, opening the way for identification, and the growth of conscientisation. It is, in regard to identity categories such as race, a self-evident imperative that professions such as those concerned with mental health – that is, concerned with the endeavours of "finding voice" – should reflect appropriate proportional representation in their demographic make-up. It is difficult to see how the same principle should not apply in the case of disability, in mental health disciplines as well as all others concerned with the "needs" and "care" of disabled persons.

## **CHAPTER FOUR**

### **Disability theory III: Impairment, culture and identity**

#### **Introduction**

Over the course of this chapter we will explore a range of aspects of the cultural substrate within which representations of disability take shape, impacting upon disablist social formations, as well as the socialisation of disabled persons. The intersection of denigrating projections regarding the disabled "other" with the dominant ideals of modernity, and the narcissistic drives of the capital market, will be considered, in an attempt to understand the extraordinary resilience of disablist prejudices. In bringing these manifest political formations "inward" to the psychic terrain of the individual, we then turn to a consideration of issues of identity formation within the disabled population, beginning with the complex difficulties of entrenching a positive "disabled political identity". Reflection on the roots of ambivalence regarding this identity brings us to early development and the family, as we examine concepts such as internalised oppression, and the often distorted nature of social mirroring experienced by disabled persons. Finally, the implications of all of these issues direct us toward the question of what "disability development" must involve, if the disabled community is to emerge from social as well as internal marginality.

#### **Culture and prejudice**

##### **Narcissism, normalcy, modernity, and the market**

If such a thing as a psycho-analysis of today's prototypical culture were possible...such an investigation would needs show the sickness proper to the time to consist precisely in normality.

(Adorno, 1951 cited in Davis, 1997b, p. 9)

The predominating, materialist orthodoxy of the disability studies academy would, no doubt, balk at Theodore Adorno's call for a "psychoanalysis of culture", in elucidating mechanisms of prejudice and oppression. A deterministic (or "determined") Marxian account of the disability phenomenon sees no purpose in searching through cultural artefacts for evidence of the roots of oppression, as these are located exclusively in relations of production (Thomas, 2002a, p. 49). Latterly however, a growing number of authors have vigorously problematised this downplaying of the role of culture and discourse in the generation of disability and disablism (e.g. Corker & French, 1999; Shakespeare, 2006). Although such voices in no way intend to argue that access to the world of work is not a cornerstone of disablist oppression – on the contrary – the view from more postmodernist and social constructionist quarters is that cultural processes must be thoroughly interrogated, in assessing the role these play in the reproduction of meanings, practices and discourses which justify and maintain inequality (Thomas, 1999a, p. 138). If we assume that the self is, at least to a partial degree, a "precipitate" of cultural meanings, mediated through language, it is essential that we attend to symbolic significations which emerge in social relating (Stockall, 2001, p. 121). It follows, from the postmodern critique of the strong materialist view of disability, that communities are no less significant sites for the negotiation of power than are institutions (Borsay, 2002, p. 105). Frantz Fanon's model of the propagation of racism (Fanon, 1952) manages, significantly, to demonstrate how social practices find translation into "ideological givens", which, in turn, reproduce psychological phenomena such as feelings and complexes at an individual level (Frosh, 1989, p. 240). It is these functional threads, linking ideology, cultural practices and subjectivity, which must assume centre stage in our investigation of disablist oppression.

As alluded to earlier, both the cultural and psychic phenomena of disablism remain, at present, virtually invisible to most, woven deeply into the groundwork of everyday practices and assumptions. In the words of Lennard J. Davis, "while we may acknowledge we are racist, we *barely know* we are ableist" (Davis, 2002, p. 148 – my emphasis). Similarly, Coleridge (1993, p. 21) describes a journey of discovery into his own prejudices; he remarks: "Even someone starting out with full sympathy and the intent to champion the cause of disability finds himself falling into the very trap that created the problem in the first place". The argument that culture has little or no defining influence upon the marginality of disabled persons, would correspond logically with the proposition that disability is universally associated with oppression across temporal and geographical locations. In contrast, archaeological and historiographical evidence seems to suggest that disablist oppression is

more situation-specific, and hence presumably (at least in part) the product of local cultural mechanisms (Braddock & Parish, 2001, p. 21; Scheer & Groce, 1988, p. 26). In considering the positions of disabled persons in historical and prehistorical realms, it is important to recognise, as first principle, that in such times physical and cognitive difference was the rule rather than the exception (Mitchell & Snyder, 2001, p. 205; Stiker, 1982). As shall be demonstrated later, the extraordinary levels of control and "sterility" embodied in modern, resolutely autonomous life serve to heighten and reify the illusion of essential difference between the "whole" and the "broken". For example, during and after periods when Europe was tormented by plagues (e.g. the *Black Death*, 1347-1351), Stiker (1997) argues that the massively widespread nature of disease actually de-emphasised impairment-difference more than in any other epoch (Stiker, 1997 cited in Braddock & Parish, 2001, p. 21). Evidence such as this lends credence to the view that no universal definition or interpretation of disability pertains across contexts (ibid.).

In what is to follow, I outline and synthesise theoretical contributions to an understanding of western, late capitalist modernity, with particular emphasis on the fundamental role of narcissistic intra-psychic formations in this identity milieu. To begin, I suggest that the central, indispensable nature of narcissistic meaning-making within market economies locates individuals within differential identity hierarchies, relating to variations in material access to the *means* of successful narcissistic self-construction. In other words, the convincing maintenance of capitalist ideals of autonomy, mastery and status – all likely ingredients in narcissistic self-representations – are, to some degree, dependent on access to the commodities, the trappings, of modern, materialistic life. In short, we require access to the material means to adequately bolster our self-identities toward the narcissistic cultural ideal; the luxury cars, sophisticated lifestyles, and perfect bodies of the idealised phantasm of the modern age. The import of this state of affairs for disabled persons is, I believe, twofold. First, recognition of the manifold material deprivations of disabled persons in most societies – of essential services, employment opportunities promising the accumulation of wealth, and broad cultural participation, amongst much else – means taking cognisance of the reality of this population's systematic *alienation from the cultural means of approximating the narcissistic ideal*. Capital accumulation and, in particular, successful "autonomous" life are deeply interwoven with the narcissistic ideal, and as deeply (materially, unnecessarily) alien to the marginal, compoundly impoverished lives of most disabled persons. The second important implication of what has been termed "the culture of narcissism" (Lasch, 1978; 1984), pertains to the penchant for out-group prejudice, and the denigration of difference,

which is so inherent to the identity-reifications of the narcissistic self. Visibly disabled persons, to be sure, fall squarely into that category of troublesome outliers, of shameful misfits, who are the bane – as well as the needed "other" – of the aggrandising self. The just and appropriate upholding of the human rights of disabled persons, it seems, may exist in an impossible tension with the predominance of narcissistic culture. Bauman (1997) paints a picture of modernity which has "a dream of purity", "a vision of order", and "a world clean and hygienic" at its epicentre (Bauman, 1997 cited in Hughes, 2002, p. 573). The imperative to endlessly "purify" existence with ever-new and superior "beginnings" (ibid.) is clear and unrelenting, positioning disabled persons as a rude and unyielding disfigurement upon the age's noble intents. But at a more intrinsic level, the very act of "making order" is indistinguishable from the "announcement" of ever-new abnormalities, which "draw new lines" and identify and set apart "ever new strangers" (ibid.). The crisp lines and categorical differences of modernism act to quell the impinging, chaotic voice of disability; perhaps, of humanity. The ghettos, institutions, retirement homes and terminal care wards of modern societies, write Dass and Gorman (1985, p. 57), are the product of a culture which pays to keep suffering away. But while the modern subject may feel "safe from the troubles of the world", we also, over time, begin to feel "dry, empty and alone in our insulated havens" (ibid.).

Christopher Lasch's (1978; 1984) provocative characterisation of the modern epoch as predicated upon the narcissistic personality, and narcissistic ways of being, presents an image of atomised, self-adoring humans unwilling and unable to give to, or receive from, one another (Treacher, 1989, p. 143; Lasch, 1978; 1984). Lasch (1984) asserts that the self-absorption, rampant individualism and materialism of contemporary consumer culture points to a deep seated existential void, an emptiness, at the heart of modern life, and the individuals who lead it (Frosh, 1991, p. 64). In this existential world, the visual reality of surfaces is central; reality exists in the evidence of apparent states and commodities, as paranoia shapes the customs of conspicuous consumption (Frosh, 1991, p. 65). But this superficial world fosters alienation, as it disallows or neglects experiences of the recognition of self or other (ibid. 65-6). All that is "real" to the "modern man" is the world of objects; or, more accurately, the world of projected aspects of self existing in fantasy as objects – a single plane upon which everything exists "only to gratify or thwart his desires" (Lasch, 1984, p. 30). It is the immediate procurement of gratification that is striven for, the "momentary illusion, of personal well-being, health and psychic security" (Lasch, 1978, p. 7; Treacher, 1989). The sculpted perfecting and adorning of the body – it, too, an object of fantasy – give an

obsequious materiality to the silent self. Murphy (1987, p. 113) refers to this aspect of the narcissistic treadmill as "part of the immortality project of a secularized middle class that no longer believes in redemption of the soul, and has turned instead to redemption of the body". There is no time, no inclination in this abrupt world toward admitting the painful effects of authentic relating, although it is upon these that "the development and sustenance of selfhood depends" (Richards, 1989 cited in Frosh, 1991, p. 66). In a world of arid impermanences, the fleeting, illusory self must be constantly re-conjured, re-created through the denigration of the unsettling "other", into whom all shame and despair are projected. The subversive import of difference is reformulated as the "damage" of the other, in a manner which shores up, although only temporarily, the illusion of value and power.

It is instructive to recall, at this point, that narcissism and narcissistic culture – as, arguably, all culture – is shaped by *what has been lost*. The narcissistic manoeuvres with which we "create ourselves", with which we augment and adorn the facades overlaying the silence of eschewed deprivations, are composed as modes of managing what we could not have, or cannot be. In Freud's (1923, p. 638) words, "the character of the ego is a precipitate of abandoned object cathexes", and the ego thus "contains the history of those object choices". This assertion, in itself, embodies a stark and sobering corrective to the rampant narcissism of the modern West. The ego, in its self-aggrandising attempt at assuming the desired features of the lost object, is forcing itself upon the id as a substitute, to dampen and avert the raw discharge of frustrated desires (ibid., p. 639). The glossy, "sophisticated" excesses of consumer culture are, thus, inherently testament to the shame-ridden, dingy experiences of human abjection which they so vehemently seek to renounce. It is disappointed object-libido that finds new life as narcissistic libido. But let us consider more specifically the relationship between, at the individual intra-psychic level, the symbolic meanings of disability, and the broad incidence of social prejudice based in narcissistic culture. With regard to disability prejudice, an individual, chronological view of psychological development would pose questions regarding the nature of infantile experiences of attunement and distress, which may later form the substance of narcissistic disability-projections relating to dependency, shame, rejection, or whatever. At the cultural level, ongoing processes of projection, projective identification and introjection may then serve to reify and solidify these fantasied meanings, in a manner which facilitates the embedding of shared institutional and societal defences. The phenomenon of disability segregation is a key marker here, forming, as it does, a dynamic, affirming enactment of the "othering" so fundamental to successful projection.

It is interesting that the legacy of impairment-centred psychoanalytic writing on disability makes repeated reference to the purported incidence of narcissistic psychopathology amongst disabled persons. To the extent to which such assessments are (or were) accurate, we know that it is the authoritarian, denying and misattuned treatment of the world which fosters such defences – not amongst this group alone, but within all populations. Further, if our hypothesised links between narcissism, disability-projections and prejudice are reliable, it is likely that incidence of visible impairment within an infant or child will tend to evoke the rigidifying, splitting influence of narcissistic structures, heightening the risk of the re-infliction of the very deprivations which are at the core of all narcissistic formations. The idea that "narcissism begets narcissism" is a maxim that would come as no surprise to those endorsing a psychoanalytic perspective, but perhaps, in the case of disability, this unfortunate principle may have a particular, amplified relevance. The depressed, self-absorbed or punitive authoritarian parent is vulnerable to the primitive, unconscious provocations afforded by images of disability, rendering impaired infants and children vulnerable to permissive or punitive relational distortions, which threaten the likelihood of the attuned mirroring which is so fundamental to integrated selfhood. The gravity of these circumstances will be examined in more detail later (*Attachment and infancy*, p. 162).

Bollas (1987) traces the outline of a personality structure forged within, and synergising with, the certainties and repressions of the modern age. In the "normotic" personality, we find a particularly ardent need for the defining of clear boundaries between normality and abnormality (Marks, 1999a, p. 170). Such individuals are described by Bollas (1987, p. 136) as "abnormally normal"; as complacently preoccupied only with the "thingness" of objects, and "fundamentally disinterested in subjective life". This individual occupies a stable, secure and comfortable world of precise mastery, in which it is only the material constituents of life which have substance, and require "dealing with". Here, rationality is the key to freedom, whilst empathy, imagination and emotionality are steered well clear of (ibid.). The normotic state is reached through the entrenchment of narcissistically oriented defences such as rationalisation, intellectualisation and sublimation, ridding the self of the subversive threats of subjective emotional life. It is socialisation within a materialistic culture, emphasising resources and wealth as the route to personal power and mastery, which fosters the normotic state. Correspondingly, these emphases encompass a failure of key attachment figures in accurately mirroring and validating a child's inner, emotional reality (Marks, 1999a, p. 171). Instead of acknowledgment and emotional authenticity, it is rationality, accumulation and power which are the means of gaining refuge from a shadowy awareness of the shame,

vulnerability and abjection which inhere in the human condition. Like Lasch's (1978; 1984) illusory self, the self of Bollas' (1987, p. 135) normotic individual is "conceived as a material object among other man-made products in the object world". The dangers of emotional chaos have, within this self, led to the "annihilation" of creativity, and with it the possibility of intersubjective symbolisation, communication, and compassion (Bollas, 1987, p. 136). Emotionality within the self, like disability within the community, is "matter out of place", which must be reformed, neutralised, and assimilated. It is the world of objects, not least of the commodities of the "culture of narcissism", which allow for the defensive de-symbolisation of subjective states of mind, through their transfer onto material things. Surely it is the mastery, the aggrandisement, of sophisticated material commodities which offer this opportunity par excellence, evacuating dysphoria and re-populating the self with new, gleaming "objects". As described above, it may be that it is the unconscious, deliberate denial of access to these "defensive resources" which position disabled persons as the designated custodians of human imponderables. In worlds of sedentary isolation, ostracisation, the denial of access to education or other means of personal emancipation, and so forth, disabled persons may be chronically "exposed" to what, in broad human existential terms, lies "beyond" the veil of avid material distractions.

The oppression and marginalisation of disabled people, it seems, is so intrinsically woven into modernist cultural mores such as autonomy, the "free" market, and the narcissistic gaze, that it is – disquietingly – difficult to see how liberation is possible without fundamental social change. The fragmented and disappointing progress offered by "rights" approaches such as that applied in the USA, has led some authors to conclude that oppression will continue until and unless the "very basis of the rules of the market" are questioned (Russell & Malhotra, 2002 cited in Sheldon, 2005, p. 124). Shakespeare and Watson (2001, p. 560) concur, adding that the already splintered and impotent influence offered by "mainstream" concepts such as democracy and citizenship, is further undercut by the growth of the global market, which limits the likelihood of national-level investment in egalitarian reform. The perverse and distorted nature of the "free market" in employment is demonstrated by evidence such as that provided by McDonough (1997), who found that "there are weak correlations between individual physical or mental attributes and work disability at the empirical level" (McDonough, 1997 cited in Schriener, 2001, p. 643). In other words, there is little doubt that prejudice intervenes in excluding disabled persons from a range of feasible occupations (Abberley, 2002). But if we move beyond this point, we find recognition that some impairments will necessarily reduce output in various occupations, notwithstanding the fact

that the disabled individuals concerned may work as hard *or harder* than their colleagues. French (1993a, p. 20) provides the example of sight impairment, which, despite access to assistive technology and a facilitative environment, and the familiar risk of over-work bordering upon self-harm, will in many cases unavoidably reduce speed of productivity. Within the context of modernity's idealisation of the market, she soberly locates this impasse as follows:

Other more profound societal changes, for example paying disabled employees the same amount as able-bodied employees for less work if their working speeds are slow, would more successfully reduce disability, but enormous attitudinal changes within society, and within disabled people themselves, would need to take place before this could be put into practice without causing even worse problems in terms of resentment, guilt and lowering of self-esteem.

(French, 1993a, p. 20)

It is the individual who is coerced into "fitting" the ideology of capital economics; never the converse. Frank (2006, p. 74) brings this truism to life in a manner bordering on the macabre, in describing what he terms "technoluxe" medicine. An example of this phenomenon is the exclusive podiatrists of New York, who perform cosmetic surgery on women's feet in order to make them "look good" in designer shoes; the foot, literally, is transformed to fit the shoe, not the other way around. In this "market" it is those who possess the most resources to channel into their bodies who can produce bodies which accrue the most capital (ibid., p. 76). The discourse surrounding such "boutique" medicine is described by Frank (2006, p. 74) as a "Prozac-like language of transformation and life-change", which calls forth the body as evermore an object, a commodity, an analogue, which masquerades as a self.

The hegemony of the contemporary western notion of the individual, as an autonomous, self-contained sphere of thought and will, is sufficient as to render it invisible as the culturally specific ideological artifact that it is (Rose, 1989 cited in Hughes, 2001, p. 27). This "autonomous" creature is constructed as the exclusive architect of its acts, and solely responsible for its unfolding biography (ibid.). Culpability for social or economic failure, within this schema, defaults to the individual, with discourses of the measurement and hierarchisation of human qualities re-rendering socio-political inequalities as "just desserts". The crux of success in the "autonomous" world, is control, which is exercised via successful

implementation of the conventions of the capital-interest enterprise (Fine & Asch, 1988, p. 15). Independence and self-seeking competitive ability are what secures "just" success, and situates the "undeserving" as, equally "justly", marginal. Imputed morals transform into the constant self-surveillance of the panopticon, as the oracle of the market waits to pronounce on one's progress, and hence one's destiny (Bartky, 1990, p. 64). The imago of disability as a "loss of control", as an eviscerating attack on agency, positions impairment and impaired persons symbolically as a dreaded counterpoint to the moral imperatives of survival in the market. In a study by Albrecht and Bury (2001), an American college student with a spinal injury characterised the neoliberal milieu as follows:

We've been there before but didn't get anywhere. The real problem is not with me nor with curb cuts, elevators and accessible bathrooms nor even with the medical establishment. The real problems are with managed care, access to education and jobs, raw capitalism in the workplace, emphasis on rugged individualism, social values favouring 'good looking', young, productive, high-energy nondisabled persons and a bunch of politicians who want things to continue just as they are.

(Albrecht & Bury, 2001, p. 585)

The framework of social liberalism buttresses the legitimacy of the market by downplaying the reality of human difference, instead touting the illusion of a "level playing field" (Shakespeare & Watson, 2001, p. 558). But even in that elusive Utopia of "equal opportunity", *differing ability* will persist. The "universal, abstract, disembodied individual" of this ideal world of work is, according to Lister (1997), in actuality one who is "male, white, heterosexual and nondisabled" (Lister, 1997 cited in Shakespeare & Watson, 2001, p. 558). If oppressed groups challenge the glaring contradiction, their views are seen as "the rantings of biased, partial and selfish special interest groups that wish to seek favour for their own particular grouping at the expense of the mainstream" (Young, 1990 cited in Shakespeare & Watson, 2001, p. 558). The recognition of equality within democratic revolutions moves, all too quickly, to a desire for, a belief in, sameness (Ravaud & Stiker, 2001, p. 495).

Thomson (1997b, p. 8) conceptualises the invisible counterpoint to disability "difference" as the "normate" – this is the veiled figure whose outline can only be discerned by identification of the bodily "deviants" who flank, and hence constitute, it on every side (see also Swain &

Cameron, 1999). Through societal structures which implement a host of technologies whereby bodies are measured, classified and regulated, the "normate" forms the centrepiece for Foucault's "principle[s] of coercion" (Foucault, 1979, p. 184; Thomson, 1997b). The normate self, to Thomson (1997b, p. 41), is informed by four interlocking ideological principles: self-government, self-determination, autonomy, and progress. The modernist dream is entrusted to this noble, illusory agent, dismissing misfits and eccentrics as troublesome non-contributors to the human project. Davis (1995) launches a ferocious attack on the broad notion of normalcy, which arose with the development of modern statistics, and the advent of the bell curve. Before the nineteenth century emergence of "the normal", no such concept was evident in western culture; indeed, the English word appeared only as late as 1840 (Davis, 2002, p. 105). Prior to this conceptual shift, the dominant schema of human value centred on the idea of "the ideal"; an unattainable, divine quality and prowess, before which one was gladly humbled. All, consequently, were positioned along a continuum of shared imperfection, without the clear delineations of deviance afforded by the normal curve. Later, the homogenisation of bodies coincided with the rise of nationalism, the standardisation of languages, and the emergence of "national types" (Davis, 2002, pp. 105-6; 1995). The epoch of the unitary identity, the narcissism of commodification, and the modernist veneration of progress had begun. Against this backdrop, the bias towards the nondisabled figure presents not as a habit of certain prejudiced persons, but as part of far-ranging changes in European, and thence global, culture and ideology; it is part of the very fabric of Enlightenment (Davis, 2002, p. 106).

Rod Michalko (2002, p. 89) points out the odd arbitrariness of cultural meanings of human variation. Some differences are happily subsumed "within" the normal, such as height or eye colour, whilst others situate their bearer as a somatic pariah (ibid.). Diseases or mutations, correspondingly, are constructed as phenomena with identifiable "causes", such as genetic defects or bacteria. But peculiarly, "non-impaired" biology simply happens "naturally"; or – better – supernaturally. Modern science, he remarks, cannot meaningfully attribute cause to either natural or supernatural forces, since such causes would themselves need to be caused, leading to an unfathomable sense of infinite regress (ibid.). "Normal human biology", "normal human variation", as well as "nature" itself, are all interpretive, highly abstract and metaphoric entities, sculpted into credible, categorical descriptors by assignments of pathology. Thus, the "difference" that disability makes is not one of varying subjective apprehension of the world, but instead resolves into the "wrongness" of disabled experience, and the "rightness" of the "normal" (ibid.). This positioning of disabled persons resonates

clearly with Simone de Beauvoir's feminist critique, where, in an ostensibly symmetrical brace of sexes, the burden of difference, of negativity, is carried entirely by the female (Morris, 1992, p. 158). The political position assumed by some quarters of the US Deaf community brings this implicit denigration into sharp focus. Thoryk, Robers and Battistone (2001, p. 191) explain the objection of this quorum to being described as "hearing impaired", rather than the preferred "deaf", exclaiming that "we do not label a black person 'white impaired', and we would not call a man a 'female impaired' person". The interaction of value-laden judgments of disability with those of gender may position disabled women at one further remove from the "normate", although impairment has been shown to threaten culturally sanctioned performative aspects of gender in both sexes (Asch & Fine, 1997, p. 242; Sandahl, 2003). Modern social life, it seems, is formulated around difference, and a difference which is inseparable from value.

## Artistic and literary representations

Turning briefly to the aesthetic world, literary and cinematic representations of disability tend to reflect and replicate the hegemony of the "normate", in a manner which distances and objectifies disabled characters from the audience (Shakespeare, 1999, p. 164). Typically, it is the character's impairment which is his or her central feature, forming the symbolic fulcrum of a moral fable or tale of redemption. The disabled figure is, in short, a "means to an end" (ibid.); a mechanism whereby writer or film-maker may evoke identification and the discharge of emotion, drawing the audience into a narrative which appropriates impairment as an existential signifier (Thomson, 1997b). Cinema stereotypes such as the "noble warrior", the "charity cripple", the "curio", the "freak" and the "Pollyanna" abound, whilst the appearance of a disabled person whose impairment is not symbolically relevant to the plot, is highly infrequent (Darke, 1998, p. 181; Shakespeare, 1999). Movie scenes in which disabled persons are seen as extras or background characters, far from depictions of "normal life", are "intended to heighten an atmosphere of exoticism, perversion, evil or fantasy" (Shakespeare, 1999, p. 164). With wonderful aptness, this "over-signification" of the disabled figure has been termed "narrative prosthesis" by Mitchell and Snyder (Davidson, 2003, p. 58; Mitchell & Snyder, 1997; 2001). Continuing the metaphor, the disabled body "serves as a crutch upon which literary narratives lean for their representational power, disruptive potentiality, and analytical insight" (Mitchell & Snyder, 2000 cited in Davidson, 2001, p. 58). More conspicuous still, is the fact that the overwhelming majority of disabled film characters are performed by nondisabled actors and actresses (Marks, 1999a, p. 128). Marks muses that this

may be so in order that, whilst the "disability drama" offers a passing catharsis to the viewer, it is reassuring for him or her to know that "it's only pretend" (ibid.). Disabled characters, thus, are appropriated as receptacles for projections of the psychic conflicts of viewers, who are maintained at one further remove from their own "realities" by the fact that Al Pacino is "not really blind" and Daniel Day Lewis is "not really paralysed" (ibid.). For Marks (1999a, p. 160), if the actor or actress "remained" disabled after the performance, his or her "continued" existence would cause discomfort, as evidence would remain of the fear states originally evoked by the impairment. This ambivalence, arguably, mirrors the positioning of disabled people across society; spurned, yet needed – the objects of both aversion and prurience. In *The cinema of isolation*, Martin Norden (1994) identifies various cinematic disability stereotypes, and traces their prevalence to historical eras in a manner which demonstrates links between political realities and forms of prejudice (Darke, 1998, p. 182). A comparison, for example, of post World War II and Cold War era images of disability is illuminating. The earlier representations show a "rehabilitative" and "normalising" view, relating to the high number of impaired veterans returning home – with actual screen writers and directors forming part of their number. Decades later, the legacy of McCarthyism and fears of the Soviet threat recreated disability in cinema as a "freakish", dangerous symbol, a contaminating threat to cherished social norms (Darke, 1998, p. 182; Norden, 1994). Davis (1997c, p. 66) observes how, more often than not, a disabled character will be "cured" by the end of the drama. What is brought to light by this is the perennial, resonant salience of the tension between the "erotic, complete body" and the "uncanny, incomplete body", rendering the need to re-evolve, and repeatedly resolve, its associated conflicts (ibid.).

Perhaps most troubling is the fact of a more or less constant stream of television programmes and films which carry the most blatant, egregious stereotyping of disabled people, but raise no audible objection from society at large (Davis, 2002, p. 150). The common-sense belief, according to Davis (2002, p. 139), is that there is little or nothing to be learnt about disability which an "ordinary", "sensitive" person would not simply intuit. The notions of "oppression", "politics" or "systematic disadvantage", within colloquial representations, bear no relation to what disability "is". Disability has yet to be established within the broad social consciousness as an issue which requires interrogation, and, most especially, self-reflection. Within photographic genres or criticism, disabled persons are, quite simply, virtually absent (Hevey, 1997, p. 332). Hevey (1997) interprets this absence as based upon a reading of disabled persons as "socially dead", and "not having a role to play" which merits their documenting in visual representations of society. When they do appear, disabled persons are almost

exclusively present as symbols of otherness (Davis, 1997c, p. 63). One particularly haunting resonance observed by Hevey (1992) is that between medical photographs of disabled persons and colonial, racialised images. In both, the "patients" and the "blacks" stand frozen and passive, awaiting an experience of being "done to", whilst doctors and "whites" fill authoritative, self-satisfied and coolly confident attitudes (Hevey, 1992, p. 53). The striking absence, across all media, is that of the disabled person presented as a nuanced, normatively complex individual, simply living life and negotiating human struggles; a person with hopes and disappointments, fears and strengths, who falls in and out of love, finds and loses faith, and so forth. In short, the disabled figure in literature, film or the other visual arts is appropriated as a symbolic commodity, as a portent which gives fleeting and safely vicarious life to the unthinkable, before being reassigned to invisibility. Avery (1999) summarises:

...our novels and films, religion, art and myths are replete with images of the tortured body, the body distorted by pain, the Picassoesque figure that cries out in anguish and terror. But less often explored is the psychic pain caused by the disability experience, the effects of the social construction of stigma that situate the anomalous body as subaltern.

(Avery, 1999, p. 116)

## Charity discourse

Across most nations, a tradition of charitable "support" of disabled persons, at times informed by religious doctrine, is an ever-present contributor to cultural ascriptions about disability. Organisations and institutions have undertaken attempts at providing for disabled persons excluded from much of social and economic life, and abandoned by the state. But – it is argued – in the process of "providing", the discourse of charity has increasingly entrenched the oppressed position of disabled persons, via their reconstruction as passive objects of benevolence, rather than legitimate, entitled citizens. Pity and kindness, thus, become the unstable grounds upon which disabled persons' "rights" are provided for, with the concomitant implication of lives falling evermore under the control of "expert", "professional" – and "philanthropic" – decision-making (Rioux, 2002, p. 214). Whilst potentially providing appropriately for some basic needs – inappropriately for others – charity typically does little to alter the status quo regarding the ideological positioning of disabled persons; it may, in fact, perpetuate such distortions (Coleridge, 1993, p. 3; see also Jack, 1995). If development is equated to the notion of individuals assuming control over their own lives, much charity-

based "disability work" probably militates against this (ibid.). A crucial point is that charity organisations, for their very existence, are dependent upon the reproduction of images of disabled persons which evoke pity and altruism; that is, on stereotypes such as dependency, damage and abjection (Marks, 1999a, p. 167). This imperative to demean disabled persons within the ken of the general public routinely confirms and buttresses prejudices, thereby continuing the cycle of exclusion (ibid). The "fetishising" images of charity advertising have been linked to the role which pornographic imagery plays in gender oppression. In both cases, close focus on the somatic "locus" of difference is present (the breasts, the impairment), in a manner which evokes an othering response. Further, in both cases the circumstances in which the images are created, interpreted and dispersed are beyond the influence of the subject, and are located within broader relations of oppressive power (Barnes & Mercer, 2001, p. 521). The act of giving, comment Murphy et al (1988, p. 236), is not a gesture of unity with the receiver, but a symbol, and act, of separation. Ravaud and Stiker (2001, p. 496) locate charity organisations as one further means – beyond the organs of the state – whereby identity distinctions are established and maintained. One must "qualify" for "charity support", via the appropriate assigning of a disabled identity, along with the donning of the host of wordless ascriptions which this entails (ibid.). All such institutional categorising of citizenship, they add, calls forth social forces which militate against the possibility of "acceptance" of the other "in his or her irreducible difference", resulting in a loss of the rich benefits of exposure to multiple ways of being human (ibid., p. 496).

As argued earlier, if disabled persons do, indeed, serve as ciphers for the disavowed, shameful existential parts of others, it is likely that instinctual impulses toward this group will be of a hostile nature. At a conscious level, and via reaction formation, sadistic drives may be experienced as guilt, along with reparative, altruistic intents (Marks, 1999a, p. 167). The "pay-off" of this psychic manoeuvre is considerable, allowing the guilt-ridden responsibility for hostility to resolve into an act which positions one as both powerful and generous (Shakespeare, 1994, p. 287). Young (1994, p. 131), considering the political functioning of projective identification, writes of the "mapping" of internal processes onto groups, institutions, and organisations, in a manner which allows us to "experience the virulent as though it is benign and part of the definition of a good social order". Charity organisations certainly fill this reassuring role, comforting us with the knowledge of social cohesion and generosity to the "unfortunate", whilst obscuring the abhorrent origins of preventable oppression. The public is treated, via these indulgences, to the reaffirmation of a paternalistic assumption that disabled people are generally treated with kindness (Davis, 2002, p. 155). I

term this very familiar stereotype the "fantasy of filled needs"; an idea that "things are in place" in our society to provide for "those in need", or "those who cannot provide for themselves". The brutal, global truth of the indignity and naked suffering of disabled lives remains as unbelievable as it is obscure.

Within the primal splits which characterise the Kleinian model of the emotional world of infancy, aggression and hatred are ever-present forces (Klein, 1959, p. 252). In fact, it is the anxiety surrounding aggressive impulses which gives rise to the earliest defences of the ego (Klein, 1948, p. 27). The familiar idealisation of disabled persons, as plucky, spiritual, "inspiring", or otherwise gifted, may embody the reformulated essence of aggressive impulses, with charity discourse providing the convenient, sanctioned means for their discharge. The need to reshape internal hostility into the practice of public virtue, is captured in the American cultural phenomenon of the disability charity telethon. Longmore (1997, p. 140) describes the telethon as a moral allegory, a ritual of "cleansing and renewal". This "moment" of generosity forms the (psychically) essential, defensive counterpoint to the looming knowledge of self-interest and conspicuous consumption, rendering the need for "equally conspicuous contribution". The "unfortunates" here assume centre stage, "ritualistically enacting a reversal of everyday reality" (ibid., p. 136). Whilst the material, evident aims of the telethon ritual are "the physical repair of those socially invalidated by disability", at a latent level the ritual performs the purpose of moral restoration for those who give, or simply observe (ibid. 140). Needless to say, the intrinsic meaning-system regarding disability which is at play across the charity spectrum is one which identifies impairment as the cause of suffering and lack, making impaired persons available as helpless unfortunates in need of succour. The message is that *disability equals impairment* (Hevey, 1992, p. 50), thus setting the scene for the wholesale splits of projective indulgence, and entirely circumventing any interrogation of society, let alone self. It is at the telethon that temporary redemption is found, from the guilty, egocentric excesses of consumption, as well as the deeper, more haunting co-existence of "freedom", "opportunity" and "equality" with the horrors of social suffering. To encapsulate, David Hevey (1992) writes:

Charity advertising...represents the highest public validation of the isolation of disabled people. It presents a solution to the "problem" of disablement by a disguised blaming of the victim. It fails to find a solution because *it is itself the problem...*

(Hevey, 1992, p. 51 – my emphasis)

Having over the past segments reflected on aspects of modern, Western cultural responses to disablement, we return now to the more traditionally psychological terrain of the family. Here, we shall examine the potential impact of culturally condensed disability meanings within the dynamic, relational context of psychological development, with a view to unpacking elements of disablist ideology within the socialisation of disabled subjectivity.

## **Disability and the family**

### **Attachment and infancy**

If we are to usefully make sense of the development of disabled subjectivity, it follows – certainly within a psychoanalytic frame of reference that the nature of early attachment relationships which involve disability should be central to our investigation. This discussion is necessarily restricted to the systemic effects and management of congenital impairment, which certainly limits easy generalisability. Yet, I believe there is much that can be learnt regarding disablist ideology broadly via an examination of the titrated, sensitive familial environment surrounding birth of a disabled infant.

Within the limited psychoanalytic contributions to thinking in this area, a preponderance of writers utilise concepts borrowed from grief and bereavement theory, in understanding the responses of parents to the birth of an impaired child (e.g. Burlingham, 1961; Drotar, Baskiewicz, Irvin, Kennell & Klaus, 1975; MacKeith, 1973; Pinkerton, 1970; Solnit & Stark, 1961). These writers draw on Freud's (1923) work on mourning, viewing such a birth as an experience of object loss; that is, the loss of "the longed-for, healthy child" (Solnit & Stark, 1961, p. 524). The expectation, thereafter, is that the parents must traverse a stagewise mourning process, towards some sort of emotional resolution, if there is to be any hope of healthy relating to the child (Drotar et al., 1975, p. 711). Drotar et al (1975, p. 711) describe some of the features of these stages as overwhelming shock, irrational behaviour, uncontrollable tearfulness, helplessness, denial, disbelief, sadness, anger, and anxiety. During the course of this process, in their view, distressed mothers may experience violently negative

feelings towards self and baby, including hatred of the infant's malformation, extreme self-blame, and a feeling of "not caring if the baby dies" (ibid.). The "discrepancy" between the imagined unborn child, and the actual, disabled child, is so great as to embody an experience of trauma, which has the power to substantially disrupt early relating (Solnit & Stark, 1961, p. 524), and lead to the family becoming "enveloped" in a state of "chronic sorrow" (Drotar et al., 1975, p. 710). MacKeith (1973, p. 133) describes two primary types of maternal reaction – protection and revulsion – which may exist in complex relation to one another, singly or alternately showing in consciousness. In her psychoanalytic work with mothers of blind infants, Burlingham (1961, p. 122) describes feelings of "injury, of hurt pride, of guilt, and of ... depression", which may cause her to withdraw emotionally from the child, and, sometimes "irrationally wish for his [*sic.*] death". Within a more psychiatric research frame, Fisman and Wolf (1991, p. 213) describe how the birth of a child with a pervasive developmental disorder has "a significant effect on family members", with disrupted parenting and marital discord rooted in maternal depression being a primary node of difficulty.

As we shall see later, this "bereavement model" has also been used by psychoanalytic writers in conceptualising the process of "adjustment" to adventitious disability in later life. In both situations, this attempt to "map" and "predict" the psychological sequelae of disability has been rejected in the most strenuous terms by disability studies authors, notably those supporting the social model view. These authors argue that the "grief model" reduces complex, socio-political difficulties such as those rooted in discrimination and inappropriate service provision, to the "psychological problems" (such as "denial") of those who have failed to "come to terms" with their impairment (or, that of their infant) (Lenny, 1993, p. 234; Abberley, 1993; Finkelstein & French, 1993; Oliver, 1995). Familiarly, experienced difficulties thus are attributed to individual factors growing out of bodily difference, ignoring, for example, the broad lack of understanding and appropriate social services geared to meet the complex needs of families with a recent, congenitally disabled addition (Ferguson & Asch, 1989, p. 113). Consequently, the "traditional" body of psychoanalytic and psychological theorising in this area has been relegated, by mainstream disability studies authors, to the rubbish-heap labelled "medical model". Writers such as Ferguson (e.g. Ferguson, 2001) regard this "traditional" psychoanalytic view as malign, in its persistent "pessimism" regarding the outlook for families of impaired children (Ferguson, 2001, p. 375). Parents tend to be constructed, almost without exception, as overwhelmed by shock, disappointment and revulsion at their disabled infant, which Ferguson (the father of a congenitally impaired son), finds deeply offensive, and a destructive, misleading and

disrespectful distortion of the nature of real lives (see also Tregaskis, 2006). For Ferguson (2001, p. 381), parents were placed in impossible double-binds by professionals, who tended to read a pathological meaning into virtually any form of response. It is, indeed, clear that the observations of prominent early researchers such as Solnit and Stark (1961), were made in an academic environment virtually oblivious to the politics of disability construction. The recommendation, for example, that parents not be forced to see their "defective" infant – before his or her certain institutionalisation – should they not want to, is both odious and, now, anachronistic. Such a view betrays a disturbing ignorance of, or passivity towards, internalised disablist feelings within parents, as well as society at large, whilst the broad orientation over-validates negative parental responses to the exclusion of all else.

It was argued earlier (see *Psychoanalysis and disability: A brief history*, p.73), that psychoanalytic thinkers have tended to approach the disability phenomenon via attempts at forging causal links between bodily impairment and (typically pathological) personality structure, in a manner which circumvents an interrogation of culturally condensed, oppressive responses to impairment (Watermeyer, 2002; 2006). This orientation, in one important way, is mirrored within the "bereavement" accounts of childbirth summarised above. In both cases, impairment is everything, foregrounded in a manner which tends to create immutable social "givens" attributable to unchanging bodily "realities". The concerted exploration of social factors in mediating and shaping resultant lived realities is, *in effect*, eschewed. Whilst some writers may object to this ascription, my view is that a passing reference to the potential impact of cultural or intersubjective factors is grossly insufficient. An analysis which is almost entirely preoccupied with intra-individual, "impairment" factors (the "constancies" of loss, or grief), and displays no meaningful initiative in exploring ideological, systemic circumstances, in effect denies the profound attributive significance of those circumstances. Note, though, that this observation does not in any way imply a denial of the felt experience of any given parent of a congenitally impaired child, or of any individual's experience of his or her own impairment. The route, from body to psyche, is negotiated within this "traditional" psychoanalytic paradigm via the concept of the "body ego", which is formulated as the earliest representation of ego functioning, arising as a "reflection" of bodily structure and sensation. Freud (1923) writes:

The ego is first and foremost a bodily ego; it is not merely a surface entity, but is itself the projection of a surface.

(Freud, 1923, p. 636)

Orbach (1994, p. 166) writes that, while it is clear that the body and the incremental unfolding of instincts are essential to Freud's model of the developing psyche, the body ego remains a "rather undeveloped" notion. It is this "undeveloped" construct which is elemental to positions which, in effect, excise the impaired body – be it that of an adult or infant – from the world of ideology. "Disability", in this view, is an immutable, depersonalised constant; the "reality" of a "broken body" in the life of an impaired adult, as in the grief of parents at the birth of an impaired child. Yorke's (1980) stated position is an informative example:

If...we had considered cases in which early disabilities, such as congenital blindness, deafness, or deformities leading to early restrictions of motility, had continued into later life we would have found that deviations, defects, and arrests of development were intimately interwoven with the disability itself and ensured, inter alia, that the ego which the patient brought to the analytic task would be an abnormal one.

(Yorke, 1980, p. 191)

The predominance of conceptual space made for the grief of parents construes the "meaning" of infantile impairment, the "reality" of "loss", as an entity largely independent of cultural factors, including, notably, the nature of interactions with health care professionals (see Dreger, 2006). Whereas intra-psychic, historical factors within parents may be considered as mediating the degree of "pathology" in responses to an impaired birth, the "reality" of "what must be dealt with", remains construed as a constant. The deep assumption at work here, is the irresistible equating of a "defective" body with the consistent "reality" of a maladjusted, or wretched, existence. Writers drawing on Freud's (1923, p. 636) utterances on the formation of the body ego in buttressing this position may, however, be insufficiently aware of his later shift in emphasis toward the importance of the mother's physical care in enhancement of the body ego (Freud, 1933 cited in Raphael-Leff, 1994, p. 16). Raphael-Leff (1994, p. 13) describes psychic representations of the somatic self (or "the imaginative body"), as something which "does not just spring from within"; instead, it is "a psychosocial product of its time and place". The experience of the body is thus never a solipsistic process, divorced from the social milieu. On the contrary, "we 'learn' our bodies through the hands, faces and minds of significant carers and their bodily ministrations" (ibid., p. 16). In this "intra-psycho-

somatic" world, representations of the body are also multiple and fluctuant (ibid., p. 14, 16), as social saliences shift. What is being created here is a conceptual picture of disability-meanings which is far more fluid, and fundamentally shaped by intersubjective experiences borne of overt and invisible cultural assumptions. Raphael-Leff (1994) elaborates:

Indeed, right into adulthood, a web of associative connections link the flesh of our permeable bodies in our most intimate moments to the bodies of others. Even in the privacy of masturbatory acts and within the secret realms of bulimic activity or self-mutilating solitude, their imagined responses guide erotic fantasy or relentlessly dictate cruel standards.

(Raphael-Leff, 1994, p. 17)

She goes on to reiterate the point, stating that the bodily self of fantasy is shaped and bound by cultural meanings and aesthetics, which are "as effective to psyche as Chinese foot-binding is to flesh" (ibid.). The "malformed" body of the infant, within this view, only becomes imbued with meaning – with difference – via the mirroring afforded by a world of responses tainted, or distorted, by the feelings and anxieties which routinely compose the social milieu surrounding impairment.

Lussier (1960; 1980) acknowledges his own erroneous assumptions regarding the compellingly credible "functional" relationship between bodily impairment and disturbed psychic development. He recounts a psychoanalytic psychotherapy undertaken with a boy – Peter – who, from birth, had lived with underdeveloped and functionally useless arms. Lussier (1960) entered the therapeutic process with the assumption that it was the negotiation of loss – the loss of a "normal", healthy body – which would form the crux of analytic work, hence calling forth both the bereavement model of disability, and the concept of the body ego as a relatively asocial, functional product of soma. As the therapeutic process wore on, however, profound social (in particular, parental) factors influential in the aetiology of his distress began to come to light; social stressors located largely within culturally condensed, systemic responses to the nature of his impairment. It became clear that Peter's mother was deeply ashamed of his impairment; and thus, manifestly, of him (Lussier, 1980, p. 179). As a baby or young child, Peter's mother would carefully cover his arms when they were together in public, and was unable to openly comfort him on the regular occasions when he was stared at (Lussier, 1960, p. 433). Within the transference relationship, Lussier (1980, p. 180) began

to understand that Peter was showing him that he was "a physically complete human being", and that his body was "a complete unit, self-sufficient, integral, not mutilated". Instead, it was his experience of maternal mirroring which was deficient and pathogenic, resulting in a stunting of his potential for growth and separation. Movingly, Lussier (1980) concludes:

...the boy, as shown throughout his analysis, seemed to have been much more in need of the confidence of his mother in him than in need of normal arms.

(Lussier, 1980, p. 179)

Peter, it seems, had from somewhere – someone – received a fragment of validation which allowed him, through the course of the therapeutic process, to re-find his "whole" (bodily) self, thereby separating his own being from his mother's malignant ascriptions. In an interesting parallel, Balikov (1960) reported a case of three sighted children born to blind parents, who had lived an extremely insular, isolated family life. Remarkably, the children grew into seeming, and behaving, as if blind; for example, feeling their way around nursery school with their hands and feet, and reporting "not seeing" an object before it was explored with touch (Balikov, 1960, pp. 236-7). Of course, this is an extreme example, with complex overtones of behavioural modelling as well as the possibility of unreported comorbid disturbance, yet the implication of an experience of the body, of its function, which is *learned*, remains. Surely, cases such as these should sharpen and prioritise our exploration of the specifics of familial, cultural and resource-related circumstances in our formulation of accounts of the psychic sequelae of impairment.

Let us return now to the disability studies critique of psychoanalysis' "grief and bereavement" model surrounding the birth of an impaired infant, and examine its positions more closely. Linderman (1981) plaintively voices the perspective of those affronted by the assumptions of psychoanalysis:

How can we call such a daughter a 'burden'? On what basis do textbooks repeatedly claim that parents of children with disabilities 'cannot make an honest attachment to their real child until they have withdrawn their affection from the normal, wished-for child'?

(Linderman, 1981 cited in Olkin, 1999, p. 92)

Specifically quoting Solnit's (1989) description of the "sad, resentful, discouraged" reactions of parents to the child they "did not expect", Yuker (1994), implores us to simply "stop studying the presumably horrible negative effects of a child with a disability on parents and siblings" (Yuker, 1994 cited in Olkin, 1999, p. 92). Ferguson (2001, p. 375), likewise, pours scorn on such assertions, forcibly emphasising that parental reactions are "inescapably embedded within a sociohistorical context". He regards the "persistent pessimism" and "horror stories" of psychoanalytic (and other psychological) writers as nothing short of slanderous to parents, and reflective of a profoundly destructive intellectual attitude (2001, pp. 375-6). The "logic" of these accounts, for Ferguson (2001, p. 379) reflects a simple reversal of an earlier, even more crude view: whereas religious or superstitious beliefs previously viewed disabled infants as "damaged" by the prior misdeeds of their parents, in the new schema it was the disabled child who brought "damage" and suffering to the family (see also Barnes & Mercer, 2005a, p. 6). The alleged "tragic connotations" of such births, Ferguson (2001, p. 376) argues, remain "consistently presented as inherent and immutable". Whether family researchers in the second half of the last century chose to focus on attitudinal categories (such as guilt, denial, displaced anger, or grief), or behavioural aspects (including role disruption, marital discord, or social withdrawal), the consistent assumption was that disability necessarily "distorted the connection between child and parent in ways that were both intrinsic and harmful" (Ferguson, 2001, p. 379). With specific reference to the psychoanalytic literature, Ferguson (2001, p. 380) notes how, if parents expressed dissatisfaction with health professionals, perhaps regarding a lack of support, this would be interpreted as displaced anger, which was, in fact, directed at the "defective" child (see also Heifetz, 1980; Turnbull & Summers, 1987). Such interpretation represents the withdrawal, from parents, of the opportunity to express whatever justifiable grievances they may hold toward an inadequate health care system (ibid.). Harris and Wideman (1988, p. 117) concur, lamenting what they view as the use of theory by professionals as a mechanism for distancing disabled clients and their families; a mechanism for "lulling" the clinician's anxieties, rather than for illuminating experience.

What writers such as Ferguson, Gill, Olkin and many others are responding to, is the tainting construction of disabled children and families as necessarily miserable, disturbed and unstable. These representations re-make, in turn, stereotyped and irresistible assumptions about the souls within "marked bodies"; assumptions which settle in, unbidden and unseen, as lived, uncontested truths. Their response is one of vociferous objection, seeking,

understandably, to evict stereotype. But there exists, in their critique, a paradoxical danger arising from the need to forcibly – *contrarily* – re-author the gloomy, intellectual accounts of familial desolation. Consider Olkin's (1999) words:

Although initial reactions to the birth of a child with a disability may be stressful and negative, parents often quickly exhibit coping behaviours.

(Olkin, 1999, p. 95)

Of concern is the following: it is, as we shall see, a hallmark of disabled life within a prejudicial society, that constructions of experience, identity and self may, of necessity, be made in opposition to dominant stereotypes. The question of exploring the shaping of subjectivity within congenitally impaired children is simply too crucial, too vital, for us to risk overlooking (for example) the potentially profound impact of unconscious conflicts within parents evoked by the experience of bearing an impaired child. Ferguson and others object to the assertion that an impaired child brings disruption and struggle to the family; what is imperative for our purposes, is that we do not let this understandable need to rebutt denigrating assumptions about such families distract us from the business of investigating how the disruptions and struggles which may – do – occur, impact upon early relationships, and the delicate coalescing of selfhood. The words of Miller (2006), an achondroplastic man, provide an interesting, first-person contrast:

The birth of a disabled child to able-bodied parents is often met with disappointment, or even anger, due to the loss of the idealised child...The birth of a disabled child often leads to a period of grief.

(Miller, 2006, p. 218)

The simple authenticity of Miller's (2006) words rings true, as does the proposition that adjustment to the birth of an achondroplastic infant would, to most couples, represent a complex, evocative and difficult experience. For Ferguson and others, this simple observation is difficult to allow, as it represents a confirmation of a host of deeper, constrictive stereotypes used to justify ongoing stigmatisation, ostracisation and discrimination suffered by disabled individuals and families. Not least, to much of the disability studies academy, it also

represents an endorsement of the reviled "medical model". Yet, the need to overtly "value" families renders such critics unable to look directly at the (potentially) substantive unconscious emotional currents and distortions which surround infantile disability.

By way of exemplifying the dispute between these academic factions, let us consider the following: Ferguson (2001, p. 382) refers to the abovementioned study by Drotar et al (1975) as one telling example of the blatant pathologisation of parents, whose emphasis upon their child's capabilities is summarily dismissed as "denial", rather than constructive adaptation (Drotar et al., 1975, p. 711). But whilst his critique is certainly accepted, there remains much that is moving and authentic in the accounts of the twenty couples interviewed by these investigators. Further, in comparatively reading these opposing streams of theory and research, it is clear that the psychoanalytic model, with (if thoughtfully applied) its remarkable capacity for the fine description and investigation of emotional states, bears the promise of particularly precious knowledge regarding the conscious and unconscious psychic milieu within which disabled children develop. As is so often the case, the unconscious conflicts evoked by disability have produced a potentially paralysing split; that is, between the "pathologising" and equally ardent "de-pathologising" of families, in a manner which will inevitably silence something of subjective reality. In other words, the "de-pathologising" position risks disallowing parents from consciously acknowledging feelings which may be politically inconvenient or unpalatable, hence obscuring awareness of the intersubjective roots of disabled subjectivity. There is, I believe, a precious baby in the psychoanalytic bathwater.

Donald Winnicott (1947) provides a conceptual space for difficult feelings towards an infant which, I believe, places the foregoing in a new and important light. He writes:

I suggest that the mother hates the baby before the baby hates the mother, and before the baby can know his mother hates him [*sic.*].

(Winnicott, 1947, p. 200)

With these rather dramatic words, Winnicott (1947) introduces the idea of parental ambivalence towards an infant as a wholly normative, *even necessary* part of child-rearing. The presence of antipathy within the mother of a new-born, within this view, is nothing short of instinctually and rationally appropriate. Amongst much else, the baby has been "a danger to her body in pregnancy and at birth", "an interference with her private life", a cause of pain to her nipples, the reason for immense fatigue; in short, the baby has replaced her needs and comforts with the prioritisation of her or his own (ibid., p. 201). In many important senses, parenting involves making oneself available to be "used" – exploited – by the ever-demanding needs of a child; to Winnicott (1947, p. 201), the mother is treated as "an unpaid servant, a slave", who must love her child "excretions and all". This crucially important corrective to the unidimensional, romantic idealisation of motherhood draws appropriate, empathic attention to the needs and struggles of mothers, in a manner which aims to provide an accepting "space" for her entirely natural hateful, resentful and disappointed feelings. Importantly, within the immense, guilt-ridden cultural evaluations of "good" motherhood placed upon women, such feelings are very often repressed, disallowed, or experienced as evidence of failure. The implications of such cultural, and consequently intra-psychic, repression are powerful and potentially dire.

It remains a reliable psychoanalytic axiom that feelings which cannot be consciously allowed and acknowledged will tend to be "acted out", in unconscious, symbolic ways. Thus it is that, for Winnicott (1947, p. 202), the vital need for a culture of acceptance and tolerance of "unpalatable" feelings about parenthood has direct, even measurable implications for the psychological well-being of children, and hence of adults. Ferguson (2001) and others, through the need to disavow pathologising ascriptions to the families of disabled children, risk silencing or de-legitimising the actual, felt experience of parents in situations of crisis. Their focus on the resource-needs of parents is entirely appropriate, and an incidence of the contravention of citizenship rights to access, which requires urgent attention. Further, the identification of overt or hidden "hateful" feelings towards a new-born disabled infant by Solnit and Stark (1961), Drotar et al (1975), MacKeith (1973) and others almost certainly carries the biasing influence of an approach to disability which fails to direct even basic attention at the world of systematic disadvantages under which disabled persons – and parents – suffer. Yet, it is essential to recall that, across society, exposure to disability reliably evokes the projection of primitive parts of self; for parents additionally destabilised by the potential crisis of the birth of an impaired child, there is no reason why this should be any different. The mother-infant dyad, so fundamentally important in the coalescing of selfhood, exists as a

delicate state of merger, in which unconscious exchanges are as important as conscious ministrations. There can be little doubt that, in this precarious relationship, the powerful, often primitive conflictual material evoked by the notion of bodily "defect" carries potentially profound, influential implications. Set against the backdrop of these serious concerns, it is an odd and unfortunate paradox – for disabled infants as well as parents – that, in terms of the (largely understandable) political proscriptions of the disability studies consensus, we are "allowed" to feel ambivalence regarding our "normal" children, but not about those who happen to be disabled. More paradoxically, this creates a situation in which, potentially, we actually selectively deprive the parents of disabled infants the legitimacy, the space, to process the extremely difficult, often conflicted feelings which are likely to be evoked around such a birth. If our hypotheses regarding the nature of unconscious evocations relating to disability are remotely correct, it is likely that, within the disavowing milieu sketched above, these will be associated with extreme levels of guilt and self-recrimination, setting up dangerous and unstable splits which must impact upon relating. Ironically, the position of Ferguson (2001) and others bears a resultant effect of *diminishing* our compassion for these troubled parents.

It is useful, in elaborating this discussion, to further contextualise the debate within psychoanalytic theorising on normative aspects of child-bearing. Sinason (1992, p. 258) describes how pregnant women naturally carry a range of fantasies regarding their bodily state, and the imminent birth, which may be completely forgotten afterward. Reminiscent of our earlier discussion regarding psychic fantasies of monstrosity, it is unsurprising that the drastic bodily changes of pregnancy evoke rich fantasy. A woman may have fears about "what" she is carrying, anxieties regarding how she will be represented by "whatever it is" that comes out of her, uncertainties regarding her entitlement or ability to perform as a mother, the effects of that "extra" glass of wine or cigarette, and so forth (ibid.). Embedded within these fears may be primitive projections of the mother's split-off archaic aspects, such as shameful or subjectively heinous parts of self. When a healthy baby is born, all such fears may be readily forgotten, *as they have been disconfirmed*. However, when a "defective" child appears, he or she may, conversely, be experienced as a confirmation of the darker pre-natal fantasies carried by the mother; relating not only to the child's value, but also to her own (ibid.). Besides the very real, stressful and trying challenges of learning about and accessing

the material needs of an impaired child, the result may be that parents are additionally confronted with, and destabilised by, their own archaic struggles to do with the "meaning" of their having produced such an infant. Raphael-Leff (1994) describes the rich, archaically laden emotional bond between mother and infant:

A mother's palpating hand, charged with affect, reflects her relation to male and female bodies, as well as the positive or negative forces unconsciously invested in her baby and feelings towards her own feminine bodiliness and fecundity, her unconscious representations of maternity, sexuality and gender...To a mother, the baby may at first signify completion of her own fertile identity; alternatively, representing some facet of her internal world she or he is greeted as a beloved or hated reincarnation for a significant figure in her emotional life. She or he may be invested with an idealised female baby-self or ascribed repudiated aspects of the mother's self-image depending on her unique psychohistory.

(Raphael-Leff, 1994, p. 23)

The ability of parents to tolerate and contain painful feelings, rather than exposing these to their infants, has been shown to be a crucial variable in supporting healthy development (Rustin, 1991, p. 46). In order to do this, it is essential that parents do not deny the reality of their feelings, but instead are provided with an accepting relational place for their expression and digestion. The concept of "maternal reverie" (Bion, 1962a) describes the intense, heightened and "tuned in" preoccupation of mothers with their infants, which is central to the development of an integrated sense of self (Rustin, 1991, p. 46). The role of the mother here is one of willingly receiving and containing the infant's difficult or anxious feelings, whilst remaining as a secure and stable, caring figure (Holmes, 1996, p. 31). Rather than deflecting or rebutting the child's difficult emotional material, it is held inside by the mother, acknowledged, and detoxified on the infant's behalf (ibid.). In order to perform this critical containing role, the mother must be sufficiently supported and contained herself to be able to "allow" the baby to feel – to be – whoever he or she is, in a given moment. If the mother retains anxious, projected fantasies about who her baby is, such as those described above, her capacity for acceptance and containment will, almost certainly, be reduced. In addition, part of the achievement of "reverie" involves the mother's empathic imagining of the child's experience and needs, which is dependent upon positive identification. The potentially anxiety-ridden "differentness" which some mothers of disabled infants may feel toward their baby may substantially disrupt this process, resulting, too, in an undermining of the mother's trust and confidence in her intuitive "knowing" of what her baby needs (Harris & Wideman, 1988, p. 128; Lussier, 1980). The intention here is in no way to pass judgment on mothers; very much the contrary. Rather, it is to assert that, in a world in which profoundly negative,

often shame-ridden projections surrounding disability are our shared cultural legacy, it is unsurprising – even "normal" – that mothers of impaired infants should, if anything, grapple more than others with these difficulties. These mothers are placed in an impossible double-bind, between archaic fears, guilt-ridden maternal imperatives, the demands of political expediency, misattuned messages from health professionals, and probably very much besides. They need and deserve space, acceptance, support and empathy, in an environment which recognises that to be fearful or feel shame surrounding disability, is a *normative point of departure for all*.

The paucity of psychological concepts within mainstream disability studies leaves the discipline sadly limited in its capacity to interrogate that most crucial of concerns – the socialisation of its constituency. In understanding the links between generations, and consequently the links between the individual and the social, the theory of attachment must assume a central role (Kraemer & Roberts, 1996b, pp. 5-6). Although attachment theory begins with the mother-infant dyad, its logic extends readily to include relationships between children and all other influential figures, with implications for the experience of self and other which extend throughout the life course (ibid.; Erskine & Judd, 1994). Self-worth, insight into personal pain, the ability to articulate subjective states, and the capacity to work and love are all intimately related to the attachment framework. Any political movement seeking to understand the oppression, internal as well as manifest, of its people, surely should expend resources in the investigation of this area. At many stages of the unfolding of the early attachment relationship, common ("normative") anxieties and projections surrounding disability may, if not openly considered and thoughtfully addressed, threaten to disrupt healthy development. For example, the importance of the appropriate allowing of early omnipotence, later dampened by the emergence of proprioceptive boundaries (Harris & Wideman, 1988, p. 128), may interact closely with the familiar, disability-related anxiety regarding the tension between agency and dependency. It is natural, under the circumstances of current cultural mores, for a mother with a new, disabled infant to wrestle with fears regarding his or her later capacity for "independence", for "ability" to cope and survive in an unwelcoming, materially self-interested world. The progressive, faithful allowing of growth toward a more bounded state, interacting evermore independently with objects in the world – that is, the incremental business of separation – may well present very particular difficulties for such mothers. The role of the mother in mediating her infant's growing contact with the "outside" world is elemental here, and a difficult, evocative challenge for all mothers, involving negotiating the very delicate balance between care and intrusion. A second

example pertains to the especially important infantile experience of the world, the mother, surviving the child's expression of aggression or destructiveness (Harris & Wideman, 1988, p. 128). The child needs to express aggressive impulses in an interaction in which the parent survives in an accepting, undefended way, thus showing that the object (the mother, the world) is robust enough to contain, to accept, the infant's darker emotional aspects (ibid.). A key theme of the present work is the proposition that the de-realisation of experience, borne of the continued rebuttal and un-acceptance of subjective reality by an anxious and unready world, forms a central aspect of the social predicaments of disabled persons of all ages. It should not be difficult to see how the roots of this alienation may develop within the early family milieu, with parents understandably struggling to contain complex feelings regarding their infant, who, like all babies, needs them to feel deep acceptance of him or her. For much of the disabled population, I suggest, experiences of another who is truly able to "stand" one's subjective reality, thus providing moments of the precious resource of the attuned validation of self, are, perhaps at best, rare.

In order, with new purpose, to begin to illuminate aspects of the experience of parents who discover that their new baby is congenitally impaired, let us reflect upon a handful of such accounts. Rinaldi (1996) sensibly and succinctly directs our attention to the ubiquitous presence of cultural images which prize the "unmarked-beautiful-healthy-intelligent-'regular'" child, constantly reminding parents of the inequality, discrimination and struggle which is likely to be their child's social destiny (Rinaldi, 1996 cited in Avery, 1999, p. 116). The very real, and rational, anxiety of many parents with children who are visibly different is that such difference will lead to painful interpersonal experiences which injure the self, and upset fulfilling psychosocial functioning (Parens, 2006, p. xiv). The task, for a parent, of finding internal resources of trust which allow for healthy separation under such circumstances, is a deeply challenging one. Abelow Hedley (2006) provides a moving account of the early stages of family life after the birth of her achondroplastic daughter:

Everything was confusion: how to react, how to proceed, what to do. As the frantic days unfolded it seemed that all we could focus on was how to repair the flaws, and we would listen to anyone from a faith healer to a surgeon if we thought there was a 'fix' for her in it...There are dangers both social and emotional in being different and a certain amount of safety in being normal.

(Abelow Hedley, 2006, p. 43)

An aspect of parental experience described in a range of early psychoanalytic accounts which is regarded as especially offensive and loathsome by the disability studies consensus, is that of the fantasy of an unborn, "whole" and "healthy" child, existing as counterpoint to the real child. Yet, it seems that evidence for this phenomenon is to be found elsewhere. Sinason (1992, p. 131) relates the story of Steven, a congenitally impaired psychotherapy patient. She describes how Steven's mother spoke of him "not as a boy", but rather as a "shadowy representation of the not-properly-mourned healthy twin of himself he should have been". During one session, Sinason commented on how Steven had grown over the holidays; his mother responded sadly, saying "Yes, he would have been so tall"; she notes: "Her real speech was for the other Steven, the healthy one who has never lived or died and has not been put to rest" (ibid.). Considering the heated and emotive controversy surrounding the issue of mourning sketched above, it is highly likely that many parents would be afforded – or would afford themselves – very little freedom to allow for emotional expression of feelings of loss surrounding the birth of an "unexpected" child. The lack, or "circumvention" of such mourning may leave disabled individuals adrift in an identity-limbo, continually (perhaps unconsciously) aware of their presence as a disappointment, as an "accident", and of the consequent need to obscure the reality of their existence (Bowlby, 1979, p. 407). It is in interaction with such lived, intersubjective dynamics that the "expressivist critique" described in an earlier section attains credibility and gravity. An issue which deserves substantial attention is, quite simply, the nature and extent of exposure which new parents have had to disabled persons. The ideology of segregation ensures that it is very much the exceptional individual who has experienced the privilege of contact with disabled individuals living whole, integrated and fulfilling lives. Consequently, the imagined "future-space" of their new, impaired child, may only be filled with anxiety-ridden fantasies, of predominantly archaic and irrational origin. In each of the situations touched upon briefly above, parents deserve to have their experience thoroughly normalised, in a manner which allows for honest reflection, towards the processing of anxieties, losses and projections, such that their children do not become the unconscious bearers of these.

An important implication of the development of a clear, entitled, articulate and honest voice amongst parents of congenitally impaired children, will be the embedding of research paradigms in human development which make provision for a range of "non-normative" developmental pathways. Most psychological theorising on child development is based upon data collection which excludes disabled children (Asch, 1984, p. 534; Watermeyer, 2002).

Conversely, research concerned particularly with congenital impairment tends, within the biomedical orientation, to focus excessively on "physiological factors", to the exclusion of an adequate consideration of intersubjective concerns – beginning with the maternal dyad – in shaping selfhood, as well as cognition. Elsewhere, I demonstrate this point via a critique of Kenneth Wright's (1991) contribution to our understanding of the role of vision in early attachment (Watermeyer, 2002). Wright (1991) is operating within a psychoanalytic paradigm, yet nevertheless falls into the "medicalising" snare of viewing congenital blindness, and its purported impact on selfhood, as a presocial "given" (for another example of this error with regard to blindness, see Omwake & Solnit, 1961). Further, he traces the role of sight in the development of a "normal", "healthy" and "integrated" self, within the assumption that all who cannot traverse this path – say, due to congenital blindness – will necessarily carry a fragmentary and immature constellation of internal objects (Watermeyer, 2002). With the best intentions, such research falls into the snare of not only exploring how development *may* occur, but inadvertently dictating how development *should* occur, in a manner which, a priori, condemns those with differing somatic pathways to a pathologised exile. The emergence of a candid literature which describes the experience of parents of congenitally impaired infants – experiences both internal, and between – will, I believe, add to the impetus to develop more integrated, equitable and inclusive models of psychological development.

In drawing this discussion to a close, the words of Harris and Wideman (1988, p. 119) capture the tone of my position. In reviewing the subjective accounts of parents who have given birth to congenitally impaired infants, what they found was "an absolutely human mix of love, grief, sadness, hatred, depression, and hope..." It is such honest, nuanced, "real-life" representations of life around disablement which are so sorely missing in Hollywood movies; it is essential that we ensure that disabled persons, and parents, are offered the opportunity for the authentic expression of subjectivity, without sanction or silencing from medical or disability movement quarters. Amongst other things, we need to enquire, as deeply and openly as possible, how early interactions of an impaired infant with his or her primary caregivers are shaped and affected by the anxious evocations of disability, in a manner which does not collude with the alienating pathologisation of parents, but *also* does not shy away from the reality of trauma and ambivalence (Harris & Wideman, 1988, p. 118). A common yet profoundly regrettable scenario is that in which the silence and withdrawal of support that so often surrounds an impaired birth is reflected, even tacitly justified, by the social modelist moratorium on personal, emotional expression. There is no question that the potential disruptions to early development arising from the unconscious currents evoked by disability

may carry grave effects for the emotional development of the congenitally impaired (Watermeyer, 2002). Recognition of this is possible without the imputation of blame; rather, an empathic, and richly rewarding discussion of the emotional realities of parents may ensue, to the benefit of families, the disability movement, and society as a whole. Harris and Wideman (1988) encapsulate the crucial importance of an examination of parental experience:

To minimise this process, along with its trauma and its transcendent aspects, is to diminish the large and substantial emotional work of which parents of disabled infants are amply capable.

(Harris & Wideman, 1988, p. 120)

The dangerous binary which is reflected repeatedly throughout this work, is that between the social and the intra-psychic. Here, too, it seems that the social modelist view is prepared to eschew the psychological, in a manner which may threaten the availability, and usage, of much needed psychological care by the parents of congenitally impaired infants. We must, of course, manage to hold both material and existential levels, with the exploration of the unconscious meanings of impairment forming a central area of concern. It is in this realm, I believe, that the aspects of disablism that most resist and retard change, are to be found.

### The body, ideology and surgery

As health sciences advance, and the intersection of medical procedures with the dictates of a social world of narcissistic strivings and capital interests deepens, a range of surgical procedures aimed at "normalising" congenitally different children have arisen. Surgeries such as limb-lengthening (for achondroplastic children), gender assignments (for children with a range of intersex conditions), and cranio-facial procedures (for cleft lip and palate conditions), are now increasingly available to children and parents (Miller, 2006, p. 212). These are procedures which are not performed out of medical necessity, such as the saving or prolonging of life. Instead, these interventions are undertaken for purely aesthetic reasons, aiming to shape a child's body into one which appears less different, or "less disabled" (ibid.). Thus, we are confronted with situations in which it is "body-ideology" alone – the prevalence of intolerance toward those with unusual bodies – that must be considered in weighing up the

thorny question of whether or not to opt for surgery. The hope for many parents is that medical intervention, leading to a more "normal" appearance, will facilitate better psychosocial adjustment in their child. Yet, the slippery and subjective nature of these concerns, rooted so frequently in inaccessible, intra-psychic realms, means that it is often difficult for all involved to ascertain precisely whose needs are at stake. To recall a theme of the previous section, there is evidence to suggest that visible bodily "abnormalities" as well as sensory or intellectual impairments within infants and children, may disrupt the process of attachment, and offset the likelihood of full and fulfilling familial relationships (Asch, 2006; Burlingham, 1961; Fisman & Wolf, 1991; A. Freud, 1952; Lussier, 1960, 1980; Sinason, 1992; Watermeyer, 2002; Wright, 1991). With particular reference to the current discussion, studies involving children with cleft palate, cleft lip, or other cranio-facial differences, have demonstrated a reduced level of parental play, touch, and smiling interaction with their children, as compared with control parents of nondisabled offspring (Rogers-Salyer et al., 1987; Walters, 1997; both cited in Asch, 2006, p. 238). "Marked and troubling" differences were noted in maternal responses towards infants with cranio-facial deformities, leading to the conclusion that these mothers, on the whole, were not as "comfortable", involved with", or "bonded to" their babies as the control mothers (Asch, 2006, p. 240). In a six-year study involving in excess of 1200 Israeli families of children with atypical bodies, Weiss (1994) found that four-fifths of parents overtly rejected their children, isolating them from the family, or abandoning them altogether (Weiss, 1994 cited in Asch, 2006, p. 238). Adrienne Asch's (1989; 2001; 2006) position on research such as this seems fluctuant. In the later publication just cited, she gives substantial credence and relevance to research which shows up parental-relational distortions arising from bodily anomalies. Earlier, however, we find her position in a publication co-authored with Ferguson to be one which tends to reject such work, as a destructive, pathologising sleight on struggling parents. Ferguson and Asch (1989, p. 115) critically categorise this area of familial research as tending to endorse some combination of stereotypes, such as the idea that parents shelter children from the world, parents deny, pretending that nothing is wrong, or parents seek ways to "fix" or minimise the bodily difference. Ferguson (Ferguson & Asch, 1989, p. 114) remains infuriated by research paradigms which are suspicious of the pathogenic motivations of struggling parents. He writes:

As a father, I do not love my son in spite of his handicaps, as some abstracted, idealised version of reality. The object of my affection is the flesh and blood Ian whom I dress every day, put in a wheelchair, and struggle to talk to in words he can understand. Disability complicates the relationship but does not necessarily damage it.

(Ferguson & Asch, 1989, p. 114)

Operations such as limb-lengthening surgery and cosmetic interventions to reshape the genitals of persons with intersex conditions, are typically "intrusive, painful, time-consuming, emotionally wrenching, minimally helpful in improving the body's functionality ... and expensive" (Kittay, 2006, p. 90). In the case of genital surgery, the intervention is regarded as creating "only a crude simulacrum of normalcy" (Frank, 2006, p. 80), and may in fact impede function (Kittay, 2006, p. 90). Limb-lengthening surgery, aimed at (partially) "normalising" achondroplastic bodies, is a notoriously long-term and harshly invasive procedure. Sanford (2006, p. 29) tells of having her first operation of many at eleven years of age, beginning a six year process of surgery, which would result in her gaining eleven inches of height, and a more normatively proportioned body. In addition to these effects, she also sustained surgical complications leading to bilateral tears in her tibialis tendons, and no less than sixty scars (ibid.). After finalising the agonised decision to undertake the intervention, Sanford (2006, p. 34) experienced the immediate onset of excruciating pain, which was to be chronic for much of the duration of the treatment. In addition, her legs were suddenly severely weakened, leading, with painful irony, to the onset of a period of substantial physical impairment (ibid.). She writes:

After being subconsciously aware of the world's practical preferences for people of average size, I was now acquainted with its intolerance for the nonambulatory.

(Sanford, 2006, p. 34)

The tone of Sanford's (2006) very candid and thoughtful account tells of the intervention as a process which subtly under-valued the richness of her identity, reducing her to someone unable to feel whole without a "normate" body. She endured immense pain, remaining uncertain, in various respects, whether the benefits of the surgery had outweighed its personal costs. In the case of intersex conditions, the decision to undertake genital surgery is often made by parents and doctors before the child concerned is old enough to be consulted (Frank, 2006, p. 79). As noted above, the intervention typically creates only cosmetically "normal" structures, thus creating a situation in which individuals remain marginalised from the society of "normal genitalia", yet have been surgically alienated from their own, familiar body (Frank, 2006, p. 80).

Considering psychological aspects and implications of limb-lengthening, Sanford (2006, p. 29) warns that parental decisions to implement the surgery in order to ameliorate the effects of bodily difference upon their child's self-identity, are "dangerous". She implies a scenario in which the intervention becomes framed as a panacea, which draws the child away from the development of his or her own intrinsic identity, thus leaving him or her "ill-equipped to face the challenges posed both by the procedures and by the rest of her life" (Sanford, 2006, p. 29). Efforts should, instead, be directed toward developing a strong, internal sense of self-identity, groundedness and entitlement within such a child, whether or not surgery is later opted for (ibid.). In some cases, professionals may advocate surgery to reduce maladjustment within parent-child relationships based upon the child's "deformed" appearance (Asch, 2006, p. 240). Surgery, in these instances, may form a deeply harmful, concrete realisation of unconscious fantasies regarding unacceptability within the child, thus inflicting damage upon the very self-worth it was intended to foster (ibid.). Across a range of "cosmetic" interventions, it is likely that surgery will often unwittingly undermine a child's capacity to trust in his or her being loved and lovable (ibid.). The implications of this, within a self already chronically subjected to the projections and denigrations of a world preoccupied with "surfaces", are potentially deeply hurtful.

In an earlier discussion, the proposition that ego functioning is, via the distortion of the "body ego", necessarily warped by the presence of bodily "disfigurement", was problematised and disputed. One position on this debate holds that, notwithstanding the disgust or disquiet which, for example, an intersex condition may evoke in family members or the broader community, the child concerned has only ever had a single – and hence normative – experience of embodiedness. To the child, thus, it is any other experience of bodily shape or function which would be felt subjectively as "unnatural". The intention here is not in any way to "deny" the reality of difference, but merely to show up the origins of *subjective differentness* as a social accomplishment. Lussier (1980) was, it seems, taught this by his patient Peter. His conclusion:

The body one cathects from birth on, as it is and as it is perceived by the child, not the body as it could or should be, is what matters psychologically. Any child is destined to invest, to cathect the body he has, as it is, which will soon become a basic part of who he is and this is the body that the mother has to acknowledge, to incorporate, to fuse with, in order to grant it psychological existence for the child, a safe, secure, existence. Mental health grows on this soil.

(Lussier, 1980, p. 181)

The anxiety and aversion instinctively felt by some adults towards "malformed" children may obscure the realisation that changing a child's body, especially in the early years of cognitive development, will alter the most basic patterning of familiarity in experience; that is, sensory experience of the body (Asch, 2006, p. 241). Young children may be bewildered, frightened or confused by the unexpected change in shape or appearance, with the assault on bodily integrity rendering unconscious fantasies of punishment or sadism. In Peter, an older child, Lussier (1980, p. 180) detected what he understood as castration anxiety arising from the threat of surgery to fit him with prosthetic arms, thus "mutilating" the body he had known since birth. In a world where "normalcy" is unquestioningly assumed to be desired, virtually above all else and by all, the recognition of normalising surgery as a castrating attack on the integrity of embodiment provides an important counterpoint. This is particularly true considering the familiar association of impairment (especially of sight) with castration in psychoanalytic work (Watermeyer, 2002). Lussier's (1980) insights direct us to look toward medical and cultural demands for the normalisation of impaired bodies for the origins of fantasies of castration, rather than in the intrinsic experience of those bodies by the individuals concerned. The critique of narcissistic culture, and its henchman, neoliberal "for-profit" medicine (Smart, 2003), implied by this recognition is glaring and considerable (Smart, 2003 cited in Frank, 2006, p. 70).

Turning to a more specific examination of the ways in which decisions surrounding elective cosmetic surgery for congenital malformations are made, we return to the account of Sanford (2006). She tells of her parents suggesting limb-lengthening surgery to her at age ten. Her response was that she was "not interested", expressing the feeling that there was little point in changing who she was. However, extended family members, teachers and acquaintances – all of "normal stature – quickly became very enthusiastic, describing the development as "a great opportunity" (ibid., p. 30). Sanford describes how she felt that her achondroplasia could not be cured, as it was *not a disease*; to "cure" her of it thus, would be to "remove all physical evidence of an enormous piece of my identity..." (ibid., p. 33-4). As we have seen, she later changed her mind. Besides the voluble persuasions of friends and family, the authoritative manner and degree of scrupulousness with which surgical "possibilities" are presented by health professionals, is of immense influence (Mouradian (2006, p. 133; Engel, 1993). As practitioners traditionally – philosophically – preoccupied with "cure", physicians may be personally animated or overly impressed with the emergence of new technologies or techniques, fostering medical encounters where the "correction" of difference is assumed as a universal priority (Morris, 2006, p. 11). The incremental flowering of subjective meaning

surrounding being born "different" may not be conceived of in such interactions; nor the potential of surgery to invalidate these aspects of self (ibid.). Instead, when a difference is "diagnosed" as "severe", the question is typically not "should something be fixed?" but "*when* should it be fixed?" (Aspinall, 2006, p. 15 – my emphasis). As discussed earlier, surgeons are trained to "perform" interventions, not, lamentably, to reflect upon the psychosocial implications of the operations they perform (Marsh, 2006, p. 122). Across a host of "disability interventions", including surgery, occupational – and physiotherapy, prosthetics, psychotherapy, the use of assistive aids, drugs, and much else, children are routinely subjected to life-shaping decisions made by well-meaning parents and professionals, who do not consult them (French, 1994a, p. 110). Many disabled adults look back on the loss of childhoods spent in relentless hours of (at times militaristically applied) activities such as physiotherapy, to the detriment of healthy and fulfilling social and scholastic development (e.g. Oliver, 1996, p. 107). The promise of (even partial) cure assists in the management of personal anxieties evoked by "disfigurement" or "incapacity", with a seductive attraction which is difficult to resist. The case of intersex-related surgery is one littered with incidences of adults who have grown up unaware that, as children, their genitals were surgically altered. In many cases such individuals were never informed of their congenital condition at all, with accounts describing young lives imbued with a haunting, indefinable sense of difference. Later, perhaps upon the advent of first sexual activity, these persons would discover that their reproductive organs were vastly different to those of others, and begin, often with rage, horror and immense pain, to piece together the story of how parents had "chosen" their biological form and gender identity (Frank, 2006, p. 79). Parents, despite these later recriminations, undoubtedly act in what they *believe to be* their child's best interests. Yet, what is demonstrated is the daunting complexity of the combination of intra-psychic responses, malignant cultural imperatives, the confusing directives of professionals, and the simple hope that their child may grow into a happy and well-adjusted person. As argued previously, parents in such circumstances urgently need the support of accepting and non-directive psychological care, in order to sift through the multi-layered meanings and anxieties confronting them. Abelow Hedley (2006) describes her quandary:

I am a mother see-sawing between the nagging desire to alleviate some of my daughter's difference, to feel we are doing something – and the strong belief that I have to protect my daughter against those marauding, seductive, and unattainable notions of normalcy.

(Abelow Hedley, 2006, p. 44)

Bioethical dilemmas such as this position parents squarely in the crucible where bodies meet culture; where subjectivity and embodiment are imaginatively sculpted by the invisible, yet exacting dictates of a culture masquerading as "human nature". Before them is the impossible task of deciding whether to bow to broader society's inability to re-own its indiscriminate disavowals, or to somehow find sufficient trust that their child will withstand the relentless torrent of unwanted abjection ascribed to him or her. Tugging parents towards the former is a cultural phenomenon that exists all around us; the unspoken, yet palpable hegemonic sense that differentness is self-evidently intolerable, that we all *just want it to stop*. And that the impossibility of a fulfilling life for those with unusual bodies is an intrinsic, constitutional reality, rather than a regrettable cultural accomplishment. Asch (2006, p. 228) urges, in response, that all surgical procedures which alter appearance be delayed until children are old enough to participate meaningfully in decision-making. She believes that such a course of action models to children the morality that "character, not outward form, is what ought to count" (ibid., p. 237). Sanford (2006) articulates the conundrum at the heart of a parent's predicament:

...the lines are so blurry, where cosmetic meets psychosocial meets medical necessity...she would bloody well get the very message I know we must never send: we love you, you're perfect the way you are...*now change*.

(Sanford, 2006, p. 46 – my emphasis)

## Guilt

The association of disablement with guilt – within disabled individuals, as well as "in the air" wherever images and ideas of disability prevail – is a familiar one in cultural as well as psychodynamic accounts of impairment. Lane (1992, p. 11) describes how American mothers reliably experience "inexplicable guilt" upon discovering that they have given birth to a deaf infant. The origins, implications and "relational exchanges" of this guilt are complex. A persistent cultural belief, at times associated with religious doctrine, holds that illness or disablement is a punishment for moral laxity (Lane, 1992, p. 11; Avery, 1999; Barnes & Mercer, 2005b; Sontag, 1997). We considered earlier how, within the unconscious metanarrative of cultural symbols, bodily impairment often recalls anxiety-ridden notions of "loss of control". There is, of course, a logic to this, as the "crippled" image defeats our cherished, much-needed belief that our bodily destiny is controllable. The flipside of this

routine, defended position is the implication that, when bodily function begins to "fail", it must be due to our own action; or, *inaction* (Murphy, 1987, p. 51). As in any experience of trauma, it is often (unconsciously, psychically) "easier" to accept blame for, say, the birth of a child with a congenital impairment, than to entertain the fearsome alternative that events in the world – including malevolent ones – are essentially random and beyond our control (Turnbull & Summers, 1987, p. 289; Sontag, 1997). Returning to Lane (1992, p. 12), he muses that finding a self-blaming reason why one's child was born deaf may not only restore a sense of "cosmic" control, but also carries the critical, justifying means whereby deaf persons in broader society are ostracised and poorly treated. That is, this logic provides a mechanism for "blaming" impaired persons for their "predicament", in a manner which deflects guilt over palpable social inequalities.

MacKeith (1973, p. 134) – a psychoanalytic family researcher of the ilk much maligned by disability studies – asserts that guilt within parents relating to "causing" or "being responsible for" infantile impairment, exists in a complex tension with guilt arising from feelings of hostility or revulsion towards their infant (see also Klein, 1948, p. 26). It is not difficult to see how this could be so; morally intolerable feelings of aggressive aversion transform into forced motivations to care, via reaction formation which carries the unspoken knowledge that the parent "brought this upon herself". At this point, though, it also seems fair to acknowledge that Ferguson's (2001) protestation that any and all parental behaviours in such situations may be reframed as unconscious signs of pathology, is, indeed, an important ethical and empirical concern. As was argued previously, however, the unspoken assumption, perhaps shared by parents and practitioners, that feelings of antipathy toward an infant are unnatural, perverse or blameworthy, is a misapprehension. Furthermore, it is an assumption located at the core of the sexist denigration of women, mothering, and the work of motherhood, which afflicts many societies, and perpetuates forces of guilt and culpability which distort parental relating everywhere. The too-often inadmissible conflicts faced by parents in such situations are demonstrated, sadly, by the fact that impaired children are reliably at higher risk for acts of violence and abuse (e.g. Friedrich & Boriskin, 1976). In my view, the point here is in no way accusatory of parents; it is very much the contrary. Such parents, as argued above, are in urgent need of support, acceptance, and the opportunity to process and understand the complex, often frightening, feelings evoked within them by the arrival of their infant. Yet, in an ironic twist of "political correctness" which, by now, should be not unfamiliar, Ferguson (2001) and others, in their attempt to defend parents against the persecutory pathologisation of the medical model, may instead impart the imperative to a collective code of silence. It

should be noted that it is not simply the more "florid" of negative feelings towards an impaired new-born which, in broad contemporary culture – as well as the disability studies consensus – are likely to evoke guilt within parents. Many parents may subjectively view the common-sensically "normative" responses of loss, disappointment and grief as unacceptable signs of their "bad parenting", or, simply, their *bad-ness*. The critique of Ferguson (2001) and others will, it seems, only add to the incipient guilt here. The experience of a subtle awareness, perhaps only discernible via unconscious expressions, of a sense of growing up as a "disappointment" or a "trouble" to one's parents, is highly familiar within the disabled community. Surely, it is the lack of the opportunity for entitled, normalising recognition of such feelings within parents which is at the root of the inadvertent projection which locates them within disabled "selves". Whilst, after Ferguson (2001) we recognise that all parent-child relationships are unique, and in some sense sacred, clearly it is not heresy to assert that the overwhelming majority of adults would not – in advance – choose the stress, anxiety, uncertainty, emotional pain, and physical work that may accompany the rearing of a disabled child. Of course, the emotional landscape is vastly different when regarding real-life, ongoing relationships between individuals; that is, real parents, and their equally real "already born" disabled children.

Guilt which remains unprocessed, or "un-understood" by parents may give rise to subtle forces which distort relationships, notably with regard to the development of healthy, robust psychic boundaries (Watermeyer & Swartz, 2008). In social systems surrounding impaired persons, the prevalence (conscious or otherwise) of feelings of "survivor guilt" over the perceived lack of functionality of "the disabled" is elemental (Sinason, 1992, p. 43; 1989). In Sinason's (1992) view, this guilt may cause an avoidance of the recognition of difference, due to the painfulness of the "damage" which is at (subjective) the heart of this difference. She provides the example of a residential setting for intellectually impaired persons, where the "guilt" of a care worker at not being impaired, becomes enacted as a collusory identification with the omnipotent self of a disabled resident. Some variant of this scenario must pertain in parental relationships influenced by suppressed guilt, impacting upon separation – a process which, at the best of times, is thorny and emotionally taxing for all concerned. As shall be argued later (*Disability and the distortion of personal and psychic boundaries*, p.260), the ambivalence engendered by guilt may set the tone for a life, within a broader social world steeped in similar disability-related evocations, of confused and confusing relational boundaries. Robert Murphy (1987, p. 92), from his own experience, remarks thus:

Indeed, a mutuality of guilt is the very life-stuff of the paralytic's family, just as it is, on a smaller scale, central to the cohesion – and turmoil – of all modern families.

(Murphy, 1987, p. 92)

Sinason (1992, p. 43) construes the "loss" at the heart of the guilt of the other as a real representation of lived difference; an inequality which denotes the painful experience of the "afflicted". In other words, the issue for her surrounds our inability to bear looking upon actual suffering, rather than a difficulty with the fantasies we carry about those viewed as impaired. This position, in my view, represents a slight regression to the "modernist" trap of social model orthodoxy; that is, construing "impairment" as an uncontested, "presocial" reality. Of course, it is not my intention to use this observation as a further means of "denial" of impairment-related struggle, but instead to focus attention on the *centrality of fantasy* in such interactions. It is the unconscious evocations surrounding the idea of, say, intellectual impairment, which are at play in the intersubjective field. This recognition is important, as it forms an essential stepping stone toward the principle of the self-definition of experience by disabled persons. The fact that the archaically-informed "imaginings" of the observer may coincide with aspects of the disabled individual's self-defined experience, is merely the result of (culturally informed) coincidence. As has been noted, it is the defining of subjective experience from without which is at the heart of all forms of human oppression. Thus, it is essential that fantasies – perhaps guilt-ridden – surrounding "what it's like" to have an impairment, are explored, re-owned, understood, and withdrawn from the intersubjective arena, thus allowing the space for the self-definition of "disabled subjectivity". The deeply charged, highly identified and diverse unconscious investments we all have in the "destiny" of our disabled imago, ensures that the pull toward wordlessly – thoughtlessly – "deciding" what disabled life is like, is virtually irresistible. We need to empty our minds, as a human society, in order to begin to "hear" the experience of those we see as carrying such disquieting difference; in order to allow ourselves to be astonished, and to learn.

The assumption that "to be disabled is to suffer", renders, ironically, a pressure upon disabled persons to display signs of pleasure, in order to "rescue" the observer from the clutches of his or her ominous fantasies. Sinason (1992) relates the words of the mother of a multiply impaired son:

I try to keep him happy...Because I brought him into the world with all of his difficulties, so if I can't keep him happy what is the point?

(Sinason, 1992, p. 141)

Here, the guilt-ridden struggles of a mother enter the intersubjective field as imperatives for her son to appear "happy". He is, it seems, made consciously or unconsciously responsible for protecting his mother from her internal culpability – and perhaps guilt over feelings of antipathy – regarding him and his impaired body. One finding of Drotar et al (1975, p. 714) – another "pathologising", yet not valueless study – was that a substantial proportion of maternal relationships with a disabled child remained "fraught with anxieties which caused some mothers to establish what they described as 'closer than normal' relationships with their children". The allegation that this observation is "pathologising" will no doubt be heard, and probably has some substance. But at our peril do we ignore the very real fact of situational stressors, discrimination, and impairment-related anxieties in such relationships which, surely, must have visible effects upon the negotiation of separation. To eschew this recognition, as some disability studies critics would have us do, is to position parental relationships involving a disabled child *outside* of the realm of family mental health concerns toward which professionals are obligated to maintain awareness and sensitivity. The question of relational boundaries, intimately interwoven with dynamics of guilt within familial socialisation, as well as the "real world" of socially created dependency emanating from a barrier-ridden living environment, must assume centre stage in an assessment of the social sculpting of disabled subjectivity.

Thus, parents, family members and others may instinctually feel guilt because, in fantasy at least, they can do, share in, enjoy, perform or otherwise have access to things of which the disabled individual is denied. They may, too, feel guilt arising from split-off, culturally inadmissible feelings of anger or resentment at the ways in which the disability impacts upon them, including both practical and emotional levels. The malignant effects of sibling selves unconsciously forged upon "survivor" identity, manifesting in obsessive, reparative, or self-punitive excesses, equally deserve our attention. Conversely, the disabled individual may feel guilt over being burdensome and in need of assistance, requiring the occupying of a stilted role which is constantly grateful and beholden to others. Or, guilt because he or she does not

"sufficiently" feel these things, but is in fact at times overcome with resentment and anger over the palpable reality of unnecessary and avoidable systematic exclusion from social processes. In the lives of disabled persons occupying modern society, unfairness – that is, the experience of being needlessly, unjustly and hurtfully excluded – is a constant, axiomatic reality. The need to be adequately "grateful" for the assistance, or mere toleration, one receives, very often reduces the capacity of disabled individuals to honestly and assertively express more "negative" feelings. The protection of others from the rage, hurt or frustration of exclusion becomes a deeply socialised habit which is hard to break, recreating patterns of enmeshed, "un-real" relating, which militate measurably against the development of an articulate and entitled disability movement (Watermeyer & Swartz, 2008; Watermeyer, 2009). In short, be it in the family, the school, the workplace or the community at large, disability is a hothouse for the distortions, silences, repressions and manipulations engendered by guilt. The implication here is not one of typecasting, but rather the stimulation of a rigorous investigation of the very real ways in which the "disability complex" may hijack love, kindness and tenderness, in a manner which fosters the chronicity of anxiety-ridden internal splits in all, and the distortion of relationships and socialisation.

Some sense of the inevitable process of internal meaning-making which accompanies experiences of deprivation and othering is provided by the late Mairian Corker (1994), as she describes how the world responded to her deafness. She demonstrates, I believe, that contrary to materialist orthodoxy, such experiences necessarily take up some form of residence internally, shaping selfhood in – probably – predominantly unconscious ways. She writes:

To stand a chance of furthering myself I was told that I had to be prepared to climb the precipice, suffer the cuts and bruises to my sense of humanity in silence and cope with my broken ears. Only then could I attain the prize awaiting me at the top. I dutifully climbed, feeling hollow inside, and was hurt...I realised that I was being offered the stick without the ice-cream "for my own good" (Miller, 1987). The precipice became a different kind of symbol. It meant that I became my broken ears and that there was nothing in between. The chasm which had opened up between who I thought I was and who I actually was, was of such enormity that my roots had become shrouded in the mists of the past. I had, in effect, lost myself.

(Corker, 1994, p. xvi)

The heady, bewildering and toxic brew of deprivation, guilt, duty, atonement, repression, stoicism and imputed shame described by Corker (1994) is surely not exceptional (see also Hogan, 1999). At the heart of such accounts is often to be found the intolerable, threatening unconscious fantasy that one is, by one's very birth, a cause of pain to others, a disappointment, a trouble; someone who brings distress and sadness, not joy, energy and hope. Again, this assertion does not stereotype or simplistically blame families; such a suggestion is borne of a poor understanding of the psychoanalytic model. The pernicious force of the repressive silences surrounding disability in families lies not so much in their "content" (although this is also important), as in the shroud of silence in which these are clothed. It is in the very act of repression, of silencing, that disability-fantasies and evocations are rendered, for all practical purposes, "reality" in the intersubjective arena, with no possibility of the honest exploration within which such imagery may be disconfirmed. The fantasy of being "unwanted" (or "conditionally wanted") for example, exists, without question, in all children. What the snares of disability fantasies and silences provide for is the fuelling of such dark suspicions via, inter alia, the enforced cultural disavowal of normative parental ambivalence surrounding disabled children. It is in the "disallowing" that such fantasies find ready purchase and traction, at times fostering their lifelong enactment.

Within the psychoanalytic model of selfhood, it is the incest taboo – Oedipal impulses – which form the unconscious template for guilt, inadmissible motivations, and the fear of punishment. Murphy (1987, p. 93) regards the "transmutation" of impairment into guilt as a "neat inversion of the Freudian Oedipal drama". In other words, here, within the world of primary process, the "castration" – the "punishment" of a "damaged" body – is the *already-accrued* wages of a prior sin; the sin of desire for the disallowed. Oedipus, after unknowingly killing his father and wedding his mother, blinds himself as punishment. The literary-symbolic and psychoanalytic resonance of blinding with castration is well established (e.g. Watermeyer, 2002). It is significant that, in an act of the brutal self-recognition of undeserving and prohibition, Oedipus blinds himself, providing the resonant notion of an association between impairment and the deep internalisation of authoritarian disempowerments; prohibitions probably borne of unspoken familial projections and well maintained by the constant stream of evidence from an excluding society that one "does not belong", and certainly, "does not deserve". It is often forgotten, as Murphy (1987, p. 94) points out, that Oedipus' father, after being informed by a soothsayer that his son would one day murder him, "crippled" the young Oedipus as punishment. Murphy (1987, p. 94) provides ethnographic evidence of the broader incidence of this further association of "crippling" – as well as

"blinding" – as an appropriate punishment for incest. In closing our discussion, Murphy (1987), never short of a startling, even daring assertion, concludes:

Incest, or even the unconscious wish for it, is a dangerous game, and I would hazard the guess that the unconscious, diffuse sense of guilt that so often bedevils the disabled arises in the first place from the chimerical notion that the crippling is a punishment for this repressed, elusive, and forbidden desire. There may be no such thing as Original Sin, but original guilt lurks in the dark recesses of the minds of all humans. These ashes of our first love are the basic stuff of the indefinable, unarticulated, and haunting sense that the visitation of paralysis is a form of atonement – a Draconian penance.

(Murphy, 1987, p. 94)

## **Identity politics and the movement**

One highly significant area in which the constructions of self and other of disabled persons play out is that of efforts directed at the mobilising of a politicised group affiliation, for the purposes of united advocacy. Gains in this project have been, at best, variable; although the disability lobby has become a relatively visible and vocal one in a range of nations, few would disagree that a large proportion, probably a comfortable majority, of the world's disabled population either is not aware of the politics of disability, or chooses not to self-identify as a member of the movement. In what is to follow, we shall examine possible reasons for this, and make a critical assessment of the strategies of minority politics which the movement has embarked upon, with a view to identifying the strengths and pitfalls of these. Finally, we will chart future terrain, in terms of the re-conceptualisation of disabled "groupness", and the contribution which the "awkward" identity of disability has to make to the philosophy of identity politics.

Watson (2002, p. 509) describes the key distinction between "essentialist" and "constructionist" approaches to identity within the social sciences. As we have seen, the former provides for "natural" or "intrinsic" meanings to an identity, arising from shared social experience, shared origins, or shared physical nature. This orientation is familiar in one area of feminist theory, which aims to promote the notion of a female subject, and hence a female identity, as the bedrock of its politics (ibid.). Much disability studies writing, aiming to

develop group identification and solidarity within the disabled community, does so by taking such an "essentialising" position. The latter constructionist view denies the "real" existence of any identity based upon shared, truly "held" characteristics. Instead, identities are regarded as constructs which only find shape and meaning through binary relationships with their opposites; these illusory "identities" are thus not fixed, but temporally shifting, and composed of multiple superimpositions (ibid.). In this paradigmatic world the idea of "female" as a free-standing, self-circumscribing identity is unfeasible; "femaleness" only finds meaning in opposition to the multiple ways in which we construct "maleness" (ibid., p. 510). The propagation of, for example, a "disabled" identity would be regarded here as a self-defeating illusion, serving only to shore up the very categorical assumptions which are at the heart of disablist oppression.

The dilemma for the disability movement, though, is a thorny one. Presenting a "united front" in advocacy battles for equitable inclusion dictates the need for a relatively essentialist model, which, whilst helpful in the mustering of political sway, inevitably masks the very substantial diversity of experiences and struggles within the group (Priestley, 1998, p. 85). Conversely, an approach which aims to respect the uniqueness of individual experiences of impairment as well as oppression, inevitably dilutes the impact of a political drive for the addressing of collective needs (ibid.). Prominent social model theorists, such as Colin Barnes (e.g. Barnes, 1998) and Mike Oliver (e.g. Oliver, 1990) have, over the course of many years, expressed a deep concern that constructionist approaches reduce the substantive, material effects of disablism to the ephemeral level of thought processes (Priestley, 1998, p. 87). Thomson (1997b, p. 22) has reasoned that the essentialist view is, notwithstanding its reifying difficulties, a necessary stage in the marshalling of a cohesive disabled minority. Whilst the constructionist logic is powerful in its capacity to deconstruct, and hence destigmatise, categorical stereotypes such as those surrounding race, gender or disability, in doing so it works to erase the very categories which social scientists claim as significant markers of disadvantage (ibid.). Thus, in freeing, say, disabled individuals from the "narrative of essential inadequacy", the approach simultaneously risks "denying the particularity of their experiences" (ibid., p. 23). It is for this reason that the position of a "strategic essentialism" (as described earlier – see *The vanishing – and reappearing – body*, p.50) is advocated (Thomson, 1997a, p. 283). This conundrum, though, may provide initial clues as to why the garnering of support and self-identification amongst the disabled community has been a sluggish and hesitant business. Many disabled persons, in terms of group identity, seemingly find themselves between a rock and a hard place.

A range of factors militate against the successful shaping of the disabled community into a cohesive political sector. Members of other marginalised minorities, such as racial or ethnic groupings, often share geographical, linguistic, occupational, cultural or religious associations, laying essential groundwork for the process of political conscientisation (Scotch, 1988, p. 159). The disabled community, by stark contrast, has a history of the most severe forms of social and political isolation, with the majority of individuals growing up in families as the single disabled member. What this means is that, for those not subjected to the even greater material constrictions of institutional settings, most will live out entire lives surrounded almost exclusively by nondisabled persons (ibid.). It is noteworthy, as the movement seeks political allies, that this isolation is an experience closely mirrored within minority sexual orientation groups (Samuels, 2003, p. 234). Throughout the world, disabled persons are over-represented amongst the most impoverished, the poorly educated, and the unemployed – that is, those whose voices are heard most seldom within neoliberal society (ibid.). The "social construction", thus, of disability as a secluded, profoundly individual experience, is a hegemonic reality to most, deeply socialised within disabled subjectivity. But beyond this, even those disabled people shown the opportunity for political mobilisation often eschew this route, baulking at the movement's requirement that they "self-identify" as disabled. Charlton (1998, p. 78) reasons that we should not be at all surprised by the fact that oppressed people of all kinds do not typically choose to identify with their oppressed status, since "all the signposts in their lives point them away from this kind of consciousness". Who would choose to overtly adopt an identity which had been, and remained, the fulcrum of one's spurning by society? A central effect of disablism upon the individual is the imputation of the conditioned shame of inferiority which, logically, implies a "survival" response of disidentification with the contaminated disabled identity. For individuals who are faced with often overwhelming odds in the fight for a liveable existence, the "inviting" of victimisation which such an identification may imply, may seem absurd. In many parts of the world, the "disabled community" exists only in the imagination of a handful of activists; there is no history, no identifiable "culture", and a constituency which is geographically scattered, and often hard to reach (ibid., p. 79). Exclusion from education, as well as community concealment, are massive obstacles to the development of a "web of affiliations" (ibid.) between disabled persons, with variations in impairment further obscuring the key commonality, which is discrimination on the basis of bodily difference. Davids (1996, p. 221) states the situation bluntly, as it pertains analogously to race: "...no one wants to be black, because to be black is to take on unwanted, desperate, and terrifying aspects of the white self".

As I have discovered as a disability researcher, it is common for disabled persons to assume a position which is critical, disliking, or avoidant of others with impairments (Low, 1996, p. 244). Self-descriptions may be given in a form which is overtly distancing, such as prefacing remarks with the qualifier that one is "unusual", or "not like other disabled people", who may be "too dependent", or "malingering" (ibid.). Such "blending in" positions surely must obstruct the development of a united, articulate voice describing the inequalities disabled people suffer. Lane (1992, p. 88) observes simply that colonised people tend to seek to fit the categories stipulated by their colonisers, as social subjugation has become internalised. Tragically, feelings of hostility or rage, thereafter, are directed at one another, rather than at the oppressive majority (ibid.; Glover, 2006). The "pride" so essential in the forging of a minority front, is "no easy thing to come by", as disability has been "soaked in shame, dressed in silence, rooted in isolation" (Clare, 1991 cited in Sandahl, 2003, p. 44).

The challenge of presenting the disabled community as a grouping which possesses real, relevant commonality, is not to be underestimated; the category is, at best, an unstable one (Davis, 2002, p. 23). Social oppression, writes Susan Wendell (1997, p. 260), may well be the only thing that disabled people have in common. Whatever the commonality, what is certain is that it will exist in constant tension with extreme diversity, in experiential, political and physiological terms (Vernon & Swain, 2002, p. 78). Convincingly making the case that a category which contains this level of diversity – from attention deficit disorder to diabetes, obesity to facial scarring, achondroplasia to chronic fatigue syndrome – actually has an internal, essential coherence, is all but impossible (Davis, 2002, p. 24). The disdainful resistance of social model proponents to the exploration of diversified, "situated" knowledge of disability – that is, of its more personal and experiential layers – is rooted in the fact that it was just such investigations which led to the "de-massifying" of the feminist movement, ending the era of unified hegemony (Thomas, 1999a, p. 102). Such authors fear – and quite justifiably – that a too-close examination of disabled lives will show up more difference than commonality, dangerously setting back the development of united demands. Like women, disabled people are certainly "not all the same". But, as we have seen, the alternative of an "arid" and depersonalised materialism imposes a silence and orthodoxy from within, which confounds developing self-awareness, entitlement, and personal integration. The need to defend an "essentialist" disabled category in opposition to a (equally essentialist) "nondisabled" category carries a host of contradictions (Tregaskis, 2004, p. 4). To name but one, we return to Zola's (1988) timeous and wise observation that the universal nature of ageing forms an inescapable – even desirable – link between these two "groups" (Zola, 1988

cited in Williams, 2001, p. 139). Yet, if disabled people are an identifiable "minority group", it is indeed a peculiar minority that putatively includes all of us – if not now, then at some time not too distant (Williams, 2001, p. 139).

It is again the voice of Tom Shakespeare (2006, p. 80) which provides the clearest critique of social modelist attempts at forging disabled solidarity. He writes:

A strong political identity, which should be a means to an end, has become an end in itself. Rather than looking outward, the disability movement has often turned inwards. Rather than building bridges with other groups or seeking the integration of its members within society, the vanguard of the disability movement has often been separatist, promoting a notion of 'us' disabled people against 'them' non-disabled oppressors. (Holdsworth, 1993; Branfield, 1998; 1999). [We must]...offer an alternative to the prison of identity politics, which leads to the politics of victimhood and the celebration of failure.

(Shakespeare, 2006, p. 80, 82)

Shakespeare's (2006) position is characteristically provocative, providing a welcome foil to the at times repressive directives of the social modelist vanguard. Yet, I believe that he underestimates the gravity of the predicament so eloquently outlined earlier by Thomson (1997b). Conscientisation *and* the validation and acknowledgment which emanates from group solidarity – from a recognition of shared struggle – both appear as equally crucial elements in the emancipation of minds and lives. The identification of similarity, and the experience of accurate, empathic mirroring of subjectivity are indispensable ingredients in the fostering of the self-acknowledgement and psychic integration which are at the heart of individual, and thence political, change (Finlay & Lyons, 1998, p. 39). Swain and French (2000, p. 569) present what they term an "affirmative model" of disability; they describe their model thus:

It is essentially a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of life style and life experience of being impaired and disabled.

(Swain & French, 2000, p. 569)

Swain and French's (2000) "solution" to the stereotyping denigration of disabled persons is

the fashioning of an alternative "positive" image of disabled life, presumably in the hope of attracting the identification of disabled persons, as well as debunking destructive myths. The difficulty with such an approach lies in the fact that, like so much of disability movement "orthodoxy", it seeks to overturn an oppressive binary by *colluding with it*. Such attempts at "social engineering" risk replacing demeaning imputations with stoic imperatives, leaving the disabled community, as well as society as a whole, no closer to an integration of the authentic, nuanced voices of the silenced. What emerges is a drama of conflicting stereotypes, or politically motivated phantasms, potentially tugging already battered individuals still further from personal "existential truths". Those taking an "anti-essentialist", or social constructionist, view, meanwhile implore all to "undermine" the perceived voracity of concepts such as disability and impairment, showing these up as "empty and constructed" (Corker, 1999 cited in Watson, 2002, p. 510). A compromise view, which makes provision for the existence of a self, albeit one composed of multiple and changing layers, is proposed by Charles Taylor (Taylor, 1989). This "self" is shaped and modified as we continually locate ourselves (primarily unconsciously) in social narratives; narratives which are typically not of our own making (Somers, 1994 cited in Watson, 2002, p. 511). This concept of self, embedded in what Taylor (1989, p. 36) terms "webs of interlocution", has the capacity to re-introduce ontology into the – by now – bleak terrain of sociological thought; not least, that concerned with disability. Representations of being, rather than an epistemology concerned only with action and materiality, are now brought into view, allowing self and identity to be both existential and political, with the body at centre stage (Somers, 1994 cited in Watson, 2002, p. 511-12; Taylor, 1989). The "disabled self" is here not restricted to definition in terms of impairment ("medical"), in terms of oppression ("political"), or in terms of a subjective account of ontology; as binaries are dissolved, all are included. The process of openly integrating previously disparate, or devalued, aspects of ontology for disabled persons has been compared to the "coming out" process described by gay and lesbian people (Swain & Cameron, 1999, p. 68; McRuer, 2003; Samuels, 2003). Swain and Cameron (1999, p. 68) define this process as "a declaration of identity outside the norm, or 'against the stream'", which demonstrates the integration of difference into a healthy self-concept. This model seems helpful and appropriate, as long as it does not become reified into constrictive orthodoxy, or appropriated as a symbol of self-congratulatory multiculturalism, which is held up in denial of persistent inequality (McRuer, 2003, p. 97).

Nancy Fraser (1995; 2000) incisively observes that political groupings in search of recognition – that is, aiming to galvanise identity and solidarity – may in so doing unwittingly "marginalise, eclipse and displace" the drive for redistributive justice (Fraser, 2000, p. 108). The political routes undertaken by minorities such as the disability movement, she argues, often do not serve to "promote respectful interaction within increasingly multicultural contexts", but instead tend to "drastically simplify and reify group identities" (ibid.). What is created in this melee of othering and counter-othering is a culture of separatism, intolerance and chauvinism, which ironically recalls the very patriarchal and authoritarian styles of engagement which the movement originally set out to topple. To Margaret Somers (1994), the new categories spawned by minority interest "create a new shade of universalism that contains its own inevitable exclusions" (Somers, 1994 cited in Thomas, 1999a, p. 103). Fraser (2000, p. 108) refers to this untoward state of affairs as the "problem of reification", which results from "the politics of recognition" inadvertently displacing the "politics of redistribution". Social model theorists, apt to their orientation, certainly set out with the clear priority of material redistribution, but viewed the route to this end as requiring the adoption of "recognition" strategies in the cultivation of groupness. The result, in the words of critics such as Shakespeare (2006), has been the pitfalls of group reification delineated above. In response to the impasse described by Fraser, some have chosen to abdicate from identity politics or cultural struggle altogether, viewing the enterprise as doomed to a perpetual and conflictual clamouring for legitimacy (ibid.).

Fraser (2000, p. 108-9) does not advocate the wholesale abandonment of identity politics, nor does she assert that "recognition struggle" is always destructive. Some approaches to the garnering of recognition are less pernicious, and represent attempts at emancipatory action surrounding injustices not amenable to redistributive remedies alone (Fraser, 1995, p. 69). If "properly conceived", says Fraser (2000, p. 109), struggles for recognition can aid the redistribution of material resources and power, and "can promote interaction and cooperation across gulfs of difference". But these outcomes are contingent on the careful rethinking of recognition strategies, in order that the snares of reification and displacement are avoided. It would appear that, certainly within the orthodox, materialist "centre" of the disability studies academy, the mode of seeking – or demanding – recognition, is one which stridently reifies not only disabled, but also nondisabled "groupness". In my view, the key reason for this divisiveness is the misguided, depersonalising resistance of the social model vanguard to the integration of more human, lived accounts of disabled struggle, carefully oriented to forge bonds of human commonality between the erstwhile deeply (conceptually) alienated

"disabled" and "nondisabled" constituencies. In Fraser's (2000, p. 109) view, what is required is an account of recognition sufficiently flexible to accommodate complex, layered identities, rather than the enforcement of prescriptive values on in – and out-group members (see also Bickenbach, 2001, p. 565). A thematic underpinning of the current work holds that the route to the integration of disabled subjectivity into the shared jumble of the human condition, is via the construction of bridges of commonality which surround suffering. Disabled persons, as argued earlier, do not "suffer" from the existential trials of "disability issues"; rather, these individuals are exposed and subjected to a more direct experience of the universal strains of shame, guilt and abjection that compose the unconscious template of the human condition.

Tracing the outlines of these experiences, whilst retaining a clear and rigorous analysis of the social origins of disadvantage, may serve to re-present disabled lives as not only "normal" and "human", but, in fact, well placed to throw precious light on those areas of human experience which modernity has so plainly sought to conceal. Of course, it is not my intention to idealise this scenario; narcissistic culture is not simply going to "fade away" – probably quite the contrary. Yet, it is my belief that it is crucial that we invest in human, personal conscientisation, and the development of insight into the nature and origins of internal, yet social, struggle. It is this exploratory, rather than adversarial, attitude which will lead towards the flowering of a clearer voice less disrupted by internalised ambivalences, guilts and shames, and will grow the movement in the direction of burgeoning human commonality. It is precisely within this niche of need that psychoanalysis must be readmitted into the disability fold, harnessing its unique capacity for the tracing of links between ideology, socialisation, and subjectivity. This moment offers much to psychoanalysis as a discipline, embodying an opportunity to develop more solid, persuasive theoretical foundations which interweave political economy with psychological functioning. From a very "non-psychoanalytic" frame of reference, Fraser (1995) outlines the task for which I believe psychoanalysis is well equipped:

...we should see ourselves as presented with a new intellectual and practical task: That of developing a critical theory of recognition, one which identifies and defends only those versions of the cultural politics of difference that can be coherently combined with the social politics of equality...how to conceptualise cultural recognition and social equality in forms that support rather than undermine one another.

(Fraser, 1995, p. 69)

Drawing on Hegel, Axel Honneth (1995, p. 14) envisions a "post" identity politics society, in which ethical cohesion and human solidarity are not found in the clamouring of an ever-increasing welter of minorities, but in the principle of the recognition of the individual freedom of all citizens. This is an imagined society which embarks from a "framework of ethical bonds", rather than the "acts of isolated subjects" (ibid.). Honneth (1995) paints the vision as follows:

As he [Hegel] puts it, the 'existence of difference' is what allows ethical life to move beyond its natural initial state and, in a series of rectifications of destroyed equilibria, ultimately leads to a unity of the universal and the particular...For only if the world-historical course of the 'budding of ethical life' can be conceived of as an interpenetration of socialisation and individuation can one assume that the organic coherence of the resulting form of society lies in the intersubjective recognition of the particularity of all individuals.

(Honneth, 1995, p. 15)

Surely it is the theoretical "stewardship" of psychoanalysis which is best placed to explore, document, and facilitate such an "interpenetration". The "healthy" form of political recognition advocated by Fraser (2000, p. 113) is, rather analogously, one based upon the principle of social status. In other words, what requires "recognition", and our shared human investment, is not "group-specific identity", but the status of individual members of all groups as "full partners in social interaction" (ibid.). Misrecognition, within this schema – and most importantly – does not imply a defamation of group identity; instead, it points to a universal experience of social subordination, or the experience of being "prevented from participating as a peer in social life" (ibid., p. 113). It is within this realm, this direction, that the commonality of human experience is to be discovered.

Contrary to the earnest, identity-reifying efforts of the social model vanguard, Davis (2001; 2002) recommends that the disability lobby *embrace* its existence as a porous, contingent and shifting category (2001, p. 536). The destabilising threat to the "minority identity community" posed by the "woolliness" of disability is, for Davis, evidenced by the conspicuous reluctance of other minority lobbies to form links with the disability movement. In some sense, disability risks "spoiling" the contrived neatness of minority categories of victim and perpetrator, through showing up the built-in self-destructiveness of identity politics

(*ibid.*). The growthful direction ahead for the disability movement, to Davis (2001, p. 537), is not aiming to increasingly join the ranks of the burgeoning number of marginalised identity groups, but instead to use its unique position to drive a critique of identity studies, *and identity politics*, as a whole. The dream of "inclusiveness" for this growing mass of minority interests is, to society, a forlorn one, since the list will always and inevitably grow longer, leading finally to the meaninglessness of particular identities (*ibid.*, p. 537). As "alterity" becomes increasingly subsumed under the rubric of "identity", surely identity must become ever-more meaningless, becoming "so broad a category that it cannot contain identity" (*ibid.*). As "identity politics" comes increasingly to explain everything, it will tend ultimately to explain nothing (*ibid.*; see also Thomson, 1997c). Simultaneously, the "identity endeavour" tacitly endorses the unquestioned "ideal" of white middle class roles; the perpetuation of the hegemony of liberal principles, and the dream of a modernist utopia.

The notion of group identity has, perhaps surprisingly, remained the single area not assailed by the deconstructive intents of postmodernism (Davis, 2002, p. 12). No-one has dared to launch such an attack upon the sanctity of one's existence as, say, black, lesbian, or a woman (*ibid.*). Now enter disability, the identity par excellence which invites such critique; a critique which will begin to reframe the notion of identity, as its contagion spreads and erodes the orthodoxy which is at the heart of the social affliction of separatism. Disability may thus become the identity which ultimately links all other identities, and replaces postmodernism with what Davis (2002, p. 14) calls "dismodernism". It is the very instability of the disability category upon which it must capitalise, through recognising that it is this character which will allow disability to transcend the pitfalls and shortcomings of mainstream identity politics (Davis, 2002, p. 23). The instability of disability, then, becomes viewed as a subset of the instability of identity as a whole; it is this recognition which ushers in the "dismodern" era (Davis, 2001, p. 25). It is the exclusivity of the "traditional" identity model which contains the roots of its own demise, via the paradox of ongoing proliferation of clamouring identity groups (*ibid.*, p. 26). With profound irony, it is the very "problem" of the category of disability being too large, too indistinct, which directs attention toward the corresponding reality with regard to identity more generally (*ibid.*, p. 26). Here is an identity able to confound – to baffle – convention by holding out a hand to humanity, saying "all are welcome", or, perhaps more correctly, "*all are here*". An intriguing, even provocative synergy exists here between Davis' critique of the pull to an ultimately vacuous identity, and the Lacanian view of identity as an escape from intrinsic fragmentation. The "manic optimism" placed in identity – that our inner fragments are in fact coherent, and able to be

bound into an authentic integrity (Frosh, 2006, p. 185) – seems analogous to the proliferation of identity politics, and equally (self-destructively) avoidant of the fearsome uncertainties which the recognition of commonality may hold. If we are, indeed, "the same", then what is it that inheres in our "sameness", our "humanness"? Of course, for Lacan, the answer to this question is by its very nature unthinkable; yet, by contrast, I believe there may be cause for optimism. In the knowledge of truly shared struggle, there is immense potential for the identification and positive mirroring which engenders real inclusivity.

To close this discussion, Davis (2002) captures the spirit of these daring times:

The universal subject of postmodernism may be pierced and narrative-resistant but that subject was still whole, independent, unified, self-making and capable. The dismodern era ushers in the concept that difference is what all of us have in common. That identity is not fixed but malleable...That dependence, not individual independence, is the rule...The watchword of dismodernism could be: *Form follows dysfunction.*

(Davis, 2002, p. 26 – my emphasis)

## **Psycho-emotional aspects of disability**

The key assertion, around which much of the current work revolves, is the proposition that the disability studies movement, under the "auspices" of social modelist thought, is severely impoverished by its lack of any substantive theory of the psychological. The materialist orthodoxy of the movement is preoccupied with the public world, and baulks visibly at the self-evidently truthful suggestion that disability and disablism have a private, internal and emotional narrative. Take, for example, Gill's (2001) observation of the prominence of psychological struggle in disablism oppression, drawing on French (1993a) and Zola (1982):

One does not venture far into an exploration of the disability experience before noticing that isolation, invisibility, tension, and struggle are recurring topics whenever and however disabled persons are asked about their lives.

(Gill, 2001, p. 351)

In its neglect of these realities, the social model approach has, I believe, tacitly endorsed the concealment of pain, illness, emotional struggle, shame, and every other aspect of subjective experience not plainly reducible to the materiality of "disabling barriers". In this way its approach is painfully resonant with the silencing of disability-related struggle which is a hallmark of the social predicament of impaired persons in modern society. Wendell (1997) describes this "social silence" as follows:

Coming into the public world with illness, pain or a de-valued body, we encounter resistance to mixing the two worlds; the split is vividly revealed. Much of our experience goes underground, because there is no socially acceptable way of expressing it and having our physical and psychological experience acknowledged and shared.

(Wendell, 1997, p. 266-7)

In beginning to describe the multi-faceted silencing of disabled subjectivity, I introduce the concept of "emotional oppression". Through the enforced "repression" of disabled experience within and outside of the disability movement, the stifling of voices in the "real" world may imply a corresponding imperative to the smothering of self in the internal realm. As we shall see, the socialisation of disabled persons is routinely steeped in imperatives towards the silencing of "disability-related experience", of which an anxious world, racked with projections, is typically deeply apprehensive. The slippery question, if we are to begin to conceptualize the intricacies of embodied, impaired subjectivity in a disablist world, is where this ongoing social silencing meets the internal, where "individual" psychoanalysis meets ideology; where socialisation meets subjectivity. A theoretical framework for thinking about the internal, psychological nature of contextual and embodied disablement is surely essential, if we are to begin to understand disability and disablism not as simple, structural "entities", which operate on "dumb", homogenous persons, but as dynamic processes within which subjectivities undergo formation, interpellation, resistance, and probably much else.

Whilst the "traditional" social modelist aversion to any analysis of the psychological has been clear and vociferous, a small number of authors operating from this materialist paradigm have sought to integrate some sense of the psychological into their model. Most notable of these is Carol Thomas (Thomas, 1999a; 2002a), who includes her construct of "psycho-emotional

aspects of disablism" within her "extended" social model view (Thomas, 1999a, p. 46). She defines this "psycho-emotional" layer of oppression as follows:

...other dimensions of socially imposed restrictions...those which operate to shape personal identity, subjectivity, or the landscapes of our interior worlds and work along psychological and emotional pathways...not only a concern for 'what we do' and 'how we act' (are prevented from doing and acting) as disabled people, but also a concern for 'who we are' (are prevented from being), and how we feel and think about ourselves.

(Thomas, 1999a, p. 46)

Quite correctly, Thomas (1999b, p. 48; 1999a) argues that such "personal" aspects of disability should not be viewed as the "natural" consequences of impairment, or as "private troubles" of disability which do not carry political relevance. Two examples which she provides of these aspects of oppression include spending most of one's time at home because one feels ashamed of a facial disfigurement, or not disclosing one's epilepsy to a boyfriend or girlfriend due to the fear of a hostile or rejecting response (ibid.). As discussed earlier (see *Prohibiting the personal*, p.42), Thomas views such struggles as "mixed in" with impairment effects, which may, as well, have psycho-emotional implications (ibid.). These aspects combine in her "social relational definition of disability" (Thomas, 1999a, p. 156), which seeks to incorporate something of the intersubjective, emotional forces operating upon the disabled individual, while still holding firm to the structuralist "core" of the social model. Following Thomas (1999a; 2002a), Reeve (2002; 2006) aims to operationalise these developments in studies which focus explicitly on "psycho-emotional" phenomena. Her approach (Reeve, 2002, p. 498) to these dimensions of oppression is one which begins from a Foucaultian position, preoccupied with the "gaze" and "surveillance" which disabled persons suffer, presumably from within and without. The intention to examine and theorise psychological experience spearheaded by Thomas (1999a; 1999b; 2002a) is highly commendable, and represents a significant break from social modelist orthodoxy. But the undertaking simply lacks the basic conceptual instruments with which to begin to theorise observed phenomena (e.g. Reeve, 2002; Veck, 2002); in order to embark upon a psychological analysis, one requires the application of psychological constructs. These, seemingly, are either unavailable to these authors, or located beyond reach by virtue of ideological contamination. In describing, in approving tones, Thomas' (1999a) approach, Colin Barnes and others (Barnes et al., 2002a, p. 10) refer to her focus on "practices that

undermine the psychological and emotional well-being of people with impairments". What is noticeable about this description, is how it expressly locates the subject of study as wholly "external" to the individual; that is, as something which "comes in from outside". Now, whilst no-one would deny that "oppression" is something which (at least initially) "comes in" from the social world, what requires conceptual space and attention is the personal, psychological effects of such factors. That is, we require a theory which sets out to construct a model of psychological personhood in the face of disablism; one which has the courage to examine disabled subjectivity in a manner which does not eschew the internalisation of a distorted and distorting social world.

Analyses such as those of Reeve (2002) and Veck (2002) create a conceptual structure which leads us *to* the individual, but then stops short, consequently constructing the internal worlds of disabled persons as homogenous, with no personal narrative, no conscious and unconscious (Marks, 1999b, p. 611) meaning-making, and no temporality. As a result, these accounts present as shallow, blandly ideological and lopsided, with no model of function *within* the individual able to "hold up" the argument. Instead, Foucaultian "passives" are created, faceless individuals trapped in ideology and discourse, who are unable to bring resonant life to the lived, internal and intersubjective reality of embodied and contextual disability. Disability studies writers are, to some extent, understandably concerned about the danger of psychological pathologisation, which theorises internal realities in a manner which de-emphasises oppressive social origins. Yet, the result is inherently partial and unsatisfactory; Goodley & Lawthom's (2006b) edited volume on "psychology and disability" is a clear case in point.

Veck's (2002) contribution concerns the experiences of a visibly physically disabled mature student, Ray. The author's stated aim is "connecting relational and psychological processes of exclusion"; but again, the psychological is largely absent. Ray's behaviour is regarded by university staff as difficult; the author calls for a need to "understand" psychological responses, but seems reluctant to apply psychological concepts. The crux of this reluctance, I believe, relates to the "danger" of a recognition that Ray may, indeed, present to the world as a "difficult" person. Further, and perhaps more provocatively, that interpersonal difficulties surrounding Ray are not reducible to prejudiced responses in that moment, but also relate to the nature of his socialisation, and relational dynamics of which he is a part. If anyone is surprised that lives of relentless denigration, senseless exclusion, distorted socialisation and

countless forms of discrimination shape and affect personalities, possibly in maladjusted ways; well, I am not. What the authors cited above fail to recognise is that it is in the nature of subjectivity, of personality, of complicity, that a crucial swathe of the *sequelae of social abuse* is to be found. We need to get to close grips with Ray's "difficultness", trusting, as per a critical application of the psychoanalytic model, that sufficiently layered internal exploration will reveal quite clearly the "sense" in his behaviour, including unconscious communications, self-destructive enactments, repetitions, double-binds, disturbed introjects, and the like. The key to this new direction of study is that these psychological phenomena are, at every stage, explicitly connected to aspects of the social world; to socialisation, identity, discrimination, and every other part of society's responses to the impaired body. In this respect, such analyses will differ qualitatively from the "traditional" body of psychoanalytic research critiqued earlier. The reactionary representation of disabled persons as a homogenous group of hapless, well-intentioned, misunderstood, necessarily "good" people carries, for me, sinister resonances of paternalistically idealising racial stereotypes. Getting to the heart of complex subjectivities, conversely, means getting to the heart of oppressive social forces, be they structural, symbolic or interpersonal. The route thence is one which manages to develop psychological concepts which, whilst individual in nature, are expressly linked to the mechanisms of ideology operating via socialisation; from the family, to the school, to the society at large.

Shakespeare (2006, p. 57) argues that Thomas' (1999a) position is "fatally flawed", as it fails to re-orient the disability-impairment binary, instead remaining locked into a perspective which is unable to comprehend the "socio-cultural experience of impairment". Paterson and Hughes' (1999, p. 602) unrelated theoretical contribution attempts to address precisely this difficulty, with the notion of the "dysappearing body"; here, the invisibility of the normatively functioning body, due to factors such as discomfort, pain and disease is disrupted, and the body instead becomes "unceasingly present in experience, albeit in an alien and dysfunctional manner". This concept aims to locate the experience of impairment as something which is "heavily culturally loaded", and shaped by socialisation (ibid. 603). The specific, heightened consciousness of one's body as it "dys-appears" in the context of dysfunctional interfaces with the material and social world, is a consciousness imbued with meaning, *with culture*.

Returning to Shakespeare's (2006) critique, in his reading of Thomas (1999a) he sees no conceptual provision for the ill-effects of illness and impairment upon psycho-emotional well-being (Shakespeare, 2006, p. 36). I concur with Shakespeare (2006, p. 55) as he proposes the adoption of a model which views disability as *always* being an interaction between individual and structural factors. The challenge before the disability studies discipline, and a central concern of this work, is how to begin to theorise this interaction in a manner which is rigorous, critical, nuanced *and* emancipatory. Paul Hoggett (1992) has, at great length, theorised the importance of *engagement*, arguing that authentic relating to the world, and to self, is only possible if we are able and willing to acknowledge our limitations and disappointments. It is this capacity to allow for recognition of confusion, darkness, and a lack of knowing, which is the great strength of psychoanalysis.

Taking this fragment of psychoanalytic "wisdom", I now, over the course of the following three sections, briefly examine topics relevant to the development of a contextual psychology of disablist oppression, beginning with the oft-quoted but very poorly developed concept of "internalised oppression".

## Internalised oppression

For what is being suggested is that the real persuasive power of the social environment, its most enticing hold over our lives, resides not in what it explicitly says to us, but in the way it enters unbidden and unnoticed into the foundations stones of our psychic structure.

(Frosh, 1991, p. 2)

Stephen Frosh (1991) here locates the influence of unconscious internalisations as primary in channelizing how we "choose" to live our lives. It is the refractory "code" of the lenses through which self and other are perceived which carries ideological capital, and produces a world in which oppressive distortions may present as self-evident, natural truths. In his international research involving disability activists, Coleridge (1993, p. 212) arrived at the truly startling finding that, for the overwhelming majority of his respondents, social change was first and foremost contingent upon disabled persons achieving some form of emancipatory *internal* transformation. This finding is particularly remarkable – even

refreshing – given the broad global influence of the materialist view, and reflects a clear recognition of the taut, constrictive hold which internalised disablist assumptions have upon the world's impaired community. Within the disability arena, the concept remains sadly under-utilised and poorly developed, having initially emerged in theoretical approaches to the study of race. Consider the words of assassinated anti-apartheid activist and black consciousness writer Steve Biko (1978):

At the heart of this kind of thinking is the realisation by blacks that the most potent weapon in the hands of the oppressor is the mind of the oppressed. If one is free at heart, no man-made chains can bind one to servitude, but if one's mind is so manipulated and controlled by the oppressor as to make the oppressed believe that he is a liability to the white man, then there will be nothing the oppressed can do to scare his powerful masters.

(Biko, 1978, p. 92)

Like Coleridge's (1993) respondents, Biko (1978) urges that we recognise that attending to the structures and materiality of oppression, whilst imperative, is not sufficient to dislodge the stubborn disease of racism. As argued earlier, prejudices surrounding race or other identity markers remain continually invigorated through the personal meanings with which they are cathected, creating a potentially infinite, energetic drama of individual archaic repetitions played out upon the societal – the global – stage.

For Frantz Fanon (Fanon, 1952; 1963), the political occupation of colonialism embodied a horrific, vicious enactment of the deeper, psychic invasion of black minds by the worm of self-hatred. "Colonialism", he wrote, "forces the people it dominates to ask themselves the question constantly: 'In reality, *who am I* ?'" (Fanon, 1963, p. 203 – my emphasis). The familiar experience of the contaminating force of projective identification – that is, a creeping uncertainty as to what is and is not me – is clearly in evidence here. To escape this, Fanon argued that political and inner liberation must necessarily go hand in hand; the black man or woman must wage war on personal and social levels, always aware that these arenas are in no way interdependent (Fanon, 1952, p. 13; Davids, 1996, p. 205).

The central tenets of Fanon's (1952) argument, are the following: through life under colonialism, the black individual comes to internalise the black-white political relation as part of his or her inner world. Yet, at an unconscious level, he or she identifies strongly with whiteness – that is, with all that is valued and aspired to within a racist regime. The "black self" is thus rendered an unwanted outsider (Davids, 1996, p. 214). Fanon (1952) expresses this bitter truth thus:

However painful it may be for me to accept this conclusion, I am obliged to state it: For the black man [*sic.*] there is only one destiny. And it is white.

(Fanon, 1952, p. 12)

Disabled persons, as we have seen, live lives steeped in cultural and symbolic messaging which fervently values the "whole", "well", "perfectly proportioned" and "functional" body, to the silent, shaming denigration of all else. The de-legitimation of difference, through subtle cultural as well as overt, medicalising or "rehabilitative" mechanisms, direct the impaired body exclusively and inexorably toward the only hope of partial salvation; a closer approximation of the shape and ways of being of the "nondisabled" body. Like Fanon's black subject, the disabled individual's incipient selfhood grows in a world bathed in division; or, more clearly, in exclusion, in which the experience is one of being "shut out", and being required to strive for qualification – via normalcy – to be "let in". Figures of identification – from comic strip heroes to television personalities, sporting stars to film and fashion icons – all come with "nondisabled-ness" as "part of the package" (Davids, 1996, p. 226), giving rise to the unconscious belief that the internal ideal is not the embodied, disabled self, but a nondisabled "prior" or "*truer*" self. Conversely, the gaping lack is that of an experience of accurate, validating mirroring of the embodied, existential self; an authentic, nuanced experience of being valuable which facilitates the opening and integrating of rejected swathes of the internal world, with the concomitant uncovering of the ideological traps which obscure the ingestion of toxins of self-loathing. Instead, all that is "good", all that is desirable, "normal", and something a child wants to be part of – a game, a school, a social group, a sports team, a bodily ideal; all that is aspired to in the labile, heady processes of self-formation, exists at the opposite pole of a closely guarded binary. The racialised picture, according to Davids (1996, p. 226) is further rigidified if the black individual is allowed some limited participation in "white" activities and the "white world". This leads to other blacks – those who cannot participate at all – being denigrated as the bearers of "true" inferiority – the

internal split has become enacted, as self-hatred is lived as hatred of others who are like the disavowed self. The familiar, dissociating attitude of some disabled persons (see *Identity politics and the movement*, p.191) is very resonant here, recalling phrases such as "I don't see myself as disabled". Similarly routine is the experience of feeling complimented if nondisabled "others" forget that one has an impairment. The ubiquitous devaluing of disabled persons thus, via internal channels, manifests in the destructive closure, separatism and hostile attempts at positive distinctiveness which are characteristic of all demeaned out-groups.

Lane (1992, p. 32) sees "profound commonalities" between the cultural oppression inflicted upon colonised peoples, and that suffered by deaf communities. He quotes psychiatric accounts of the "nature" and "personality" of the "deaf individual", which include "superstitiousness, paranoid symptomatology, impulsiveness" and "aggressiveness" (ibid., p. 33). These descriptions present as eerily reminiscent of colonial accounts of racist essentialism, pointing to the need for the institutional and professional "management" of "primitive tendencies". In an analogous fashion, Sandra Lee Bartky (Bartky, 1990) traces the relationship between androcentric narcissism, alienation, and the internalisation of shame in the oppression of women.

Marks (1999a, p. 24) asserts that the development of the concept of internalised oppression is essential if we are to better understand the relationship between the social exclusion and denigration of disabled people, and the experience of psychological difficulties – with the latter, as noted above, representing a particularly politically sensitive area. Shakespeare (2006, p. 62) shrugs off all shreds of this constrictive orthodoxy, in stating that since disabled people are affected by physiological, psychological and external problems, any theory which chooses to address only the external is patently "an incomplete response to the challenge of disability". In my own view, the theoretical construction of internalised oppression as pertaining to disability should begin, as with Fanon's (1952) work, with the internal splits and consequent projections which emanate from immersion in a world of social divisions. The internalisation of self-denigration, simultaneous to identification with the nondisabled ideal, fosters unconscious collusion with relations of subordination, and the obscuring of avoidable injustices. Until such internalisations, and the experiences of trauma with which they originally became unconsciously cemented, are consciously digested, there is little hope of escape from the clutches of repetitious relational enactments, serving only to recapitulate the legitimacy of the status quo. It seems self-evident that the object constellations internalised

by many disabled persons carry the seeds of unconscious, self-sabotaging repetition. A cursory examination of the distorted relational systems in which perhaps the majority of disabled persons undergo psychological development should verify this – from the guilt – and anxiety-ridden unconscious currents of families in distress to the controls and exclusions of forced rehabilitation, from the denigrating responses of schoolmates to the pathologising imputations of well-meaning parental figures, from the perplexing exile of special schooling to the confusion of a ubiquitous, yet unspoken shared shame, from the anxieties of parents regarding one's finding a mate, to the sinister institutional discourse of "realistic expectations"; the list is probably endless. In such worlds, evidence of the splitting engendered by the existential conflicts which exposure to disability evokes is literally everywhere, making the avoidance of complicity extraordinarily difficult, especially in the absence of alternative views proffered by credible authoritative figures. The business of "finding" the contradictions inherent in disablist self-oppression is an intricate, thorny and lifelong task, which involves somehow extricating oneself from systems of meaning which often surpass hegemony (Shuttleworth, 2001, p. 85). Zola (1994, p. 65) identifies incisively that a critical feature of oppression is not only the loss of voice, but of "*the tools to find it*" (my emphasis). Discovering what has been lost, in terms of selfhood, is typically a slow and an arduous process (ibid.). Micheline Mason (Rieser & Mason, 1990) expresses with raw clarity what she began to discover through the unpacking of her socialised sense of self:

A message clearly and firmly slipped into my unconscious saying that people would prefer it if I died...I am now 30 years old. Only now am I beginning to realise that I do not have to smile all the time, and that I can achieve mediocrity without feeling someone will come along and 'put me out of my misery'.

(Rieser & Mason, 1990 cited in Sinason, 1992, p. 143)

The scale and nature of distorted and abusive social worlds inhabited by disabled persons must point us toward an analysis of defence mechanisms employed in the business of psychic survival (Marks, 1999b, p. 614). Such defensive strategies, or, put another way, the repetition of archaic object constellations, may take the form of excessive dependency and compliance, self-pity or self-hatred, hostility and entitlement, colluding with social denialism, persistent blaming of self or other, and the like. Of course, it is utterly fundamental that such "behaviours" not simply be "interpreted" as defensive manoeuvres in a decontextualised way; our analysis must vigorously point toward social origins at every stage, beginning from the (psychoanalytic) premise that behaviour is inherently "sensible" and communicative.

Drawing on Marx, Charlton (1998, p. 35) describes the process of the internalisation of oppression as twofold. First is the capacity of the dominant social class to instil its values within the broader mass of the population, through methods such as "double-speak", "misdirection" (or victim-blaming), "naturalised inferiority" and "legitimated authority" (ibid., pp. 35-6). These aspects together are termed *hegemony*. The second arm of oppression is the psychological suffering and devastation inflicted upon, in this case, disabled individuals. This active demeaning creates stagnant self-pity or self-annihilation, but more crucially, makes awareness of oneself, one's peers, and one's needs measurably more difficult. This Charlton terms *alienation* (ibid.). It is this constriction of self-awareness, often wrought through the necessity of employing the rigid defences required to survive extremes of deprivation and mistreatment, which is the fulcrum of the chronic subordination of disabled persons. It is this recognition which, in my view, locates the materialist aversion to internal inquiry as most dangerous. The estrangement of disabled individuals from one another, precluded by the alienation which denigration brings, disallows identification and the growth of solidarity.

Against the backdrop of the medicalisation of society, disabled persons may grow to project damage and defect into "dysfunctional" parts of the body, or the imperfect body as a whole. At the heart of the medical model is a logic which states that, for disabled people, the "source" or "cause", of difficulty, struggle and distress lies in the nature of the body. Thus, it is the misshapen limbs, the poorly functioning eyes, the inarticulate speech centres, the inert muscles, which are the "problem", the rude intrusion which inherently precludes an equitable life. Biomedicine teaches the dissection of the body into discrete, Cartesian functional systems, clearly circumscribing those which are an insult, an impingement and a nuisance to the dignity of normalcy. Cultural messaging interfaces crisply, communicating that "of course" no-one would want a body part like this. The "damaged" part, consequently, may become alienated from or "disowned" by the individual, and increasingly the location of projected psychic conflicts of all sorts. Focus on the impairment as the exclusive "problem", thus carries a twofold function in the chronicity of subordination. First, it deflects attention from the societal origins of disadvantage; and second, as noted by Charlton (1998) above, it provides a defensive pretext which tends to militate against the self-awareness which emanates from an examination of the authentic, internal concomitants of struggle. In this way the internal rootedness of oppression remains obscured, and cultural accountability correspondingly obviated. Coleman (1997, p. 225) observes that "stigmatised individuals sometimes blame their difficulties on the stigmatised trait, rather than confronting the root of their personal difficulties"; which, very often, will be of substantially socio-cultural origin.

Again, the oppressive fostering of splitting here is dangerous and profound, rendering such identity struggles as those of individuals sufficiently disidentified with their rejected body to regard themselves as "*nondisabled inside*". There is no pathologisation implicit here; what must be confronted is the grave reality of struggle for individuals "occupying" a body that society, and consequently self, has come to hate. Michalko (2002, p. 64) reflects upon his blindness in such a vein, recognising in retrospect how he had experienced his impairment not as part of himself, but as an intrusion upon, or a disruption of, his "true" being (see also Wilson, 2003, p. 29). He warns of the destructive effects of ever-present constructions of disablement as a difference to be "prevented", rather than "lived-in" (*ibid.*, p. 103). Ussher (1989) has presented a comparable analysis of the ways in which oppressive gender constructs conspire to evoke splits within the growing female subject. The adolescent girl separates self from body, the pregnant woman splits sexuality from motherhood, the archetypes of motherhood and menopausal redundancy threaten and deride the unique expression of self; everywhere are harsh dictates which derail individuation (Ussher, 1989 cited in Erskine & Judd, 1994, p. 2). Disabled persons, similarly, are required to successfully occupy a world of irreconcilable dissonances between ideals and experience. The tone is set, in such lives of ongoing persecution, for the resultant persecutory objects to be projected into parts of the body, the society, or the self, thus drawing the individual into the re-creation of oppressive relational systems.

In the case of race, dislodging one's shame-ridden unconscious material and projecting it into one's black skin is not an efficient mode of psychic defence (Davids, 1996, p. 229). Successful projection locates the unwanted "psychic dirt" in another, thus bringing respite and equilibrium. The "nondisabled" cultural consensus, then, projects its disavowed parts of self into the disabled community, who perhaps then individually project their split off psychic material into their own bodies. As with racist projections, there is thus little reciprocity, with the oppressed minority left "swallowing" what has been successfully disowned by the dominant group, whilst redoubling efforts at approximating the ideal of normalcy, and re-projecting shame and defect into those "more disabled" than he or she. The choice, for those who form targets of projected shame, is either the employment of such frantic splits and deflections, or living with the intolerable mental pain of a deep narcissistic wound.

## Mirroring

Winnicott (1974) traces all apprehending, and consequent coalescing, of self back to the mutual gaze shared between mother and infant. It is in the mother's face – her responsiveness, expression, warmth and physical attitude – that the infant begins to "see" and "feel" whom he or she is. For Winnicott, what the mother "looks like" to the infant depends on what she is seeing, as she observes her baby (Winnicott, 1974, p. 131). The "good enough" mother validates the infant with her gaze, confirming and shoring up the child's being, aliveness and value (Erskine, 1994, p. 49). But conversely, if the mother's face shows distraction, distress, bluntedness or sadness, the baby, instead of self-apprehension, is confronted with a premature experience of the nature, and *needs*, of the other. The consequence is a disruptive impingement upon the child's incipient selfhood, replacing affirmation with self-consciousness (ibid.). In this non-loving look is the seed of the shame of objectification – of being "looked at", rather than kindly "looked after" (Erskine, 1994, p. 50; Wright, 1991 – my emphasis). What may occur, if the disjuncture between mother and infant is sufficiently catastrophic, is that the baby "joins forces" with the mother's tacit view, turning upon, splitting off and rejecting his or her growing self. The disowned self thereafter becomes experienced as a threatening and unwanted "other", regarded by the infant as per his or her fantasies of the mother's rejecting attitude (Wright, 1991, p. 46). The infant has begun to assume what Winnicott (1960, p. 142) terms "the false self", which presents to the mother a synthetic pastiche of responses aimed at securing her positive regard, whilst becoming increasingly alienated from the internal source of spontaneous personhood (Erskine, 1994, p. 50).

This early experience forms the basic template for assumptions regarding one's relation to the world, to the *other*; one's place and value in the social milieu (Honneth, 1995, p. 173). Of course, Winnicott's (1960; 1974) model is not intended as a crude categorical descriptor; all have aspects – moments – of selfhood which have been enlivened by attuned validation, and, in darker recesses, other parts of being which are shrouded in the disavowal born of maternal rejection. The "false self" mode of functioning is one in which the major proportion of what is "shown" to the world is not continuous with internal, spontaneous being and responding. But my own view is that the basic capacity for the "reading" of social cues as evidence of the recognition of something shameful exists within all; that is, all have had the (formative) experience of being shown the self as unwanted, valueless, disgusting, or unworthy. Now, what is significant about life with impairment within a disablist society, is that whatever the

more archaic experiences of rejecting misattunement which one carries are, these may be unceasingly *recapitulated*, *confirmed* and *re-aggravated* by the nature of ongoing "social mirroring". The seeds of self-doubt regarding our worth and entitlement – there in all – are enlivened by a world which "carelessly" and unseeingly excludes, deprives and demeans. It is, consequently, not simply the materiality of deprivation which disabled individuals must contend with, but as alluded to earlier, the personal meanings which are (consciously and unconsciously) made of this, emanating from the nature of formative relationships. It is not hard to see how the "false self" persona (Winnicott, 1960) is evoked by lives of disentanglement and marginality, shaping disabled persons as appeasing, silently smiling, self-deprecating, accommodating, and the like. The pernicious confirmation of one's most insecure, unentitled psychic parts may repeatedly batter and destabilise the clarity of thought and self-regard which is so necessary for self-advocacy. This, too, is above and beyond the very real consideration of confused, anxious or subtly hateful maternal responses which are regularly a part of the unconscious currents of some mother-infant relationships involving congenital impairment (Lussier, 1980; Watermeyer, 2002). In Lussier's (1980, p. 182) words, "One starts by loving oneself according to the love one has received in the pre-ego phase of life"; in particular, a child will relate to his or her body in the way that it was – consciously and unconsciously – related to by parental figures. The extent to which internal reality, the "true self" (Winnicott, 1960, p. 143), is able to be authentically realised corresponds to one's capacity to express creativity; that is, to act creatively upon the world. Conversely, "false self" functioning implies an attitude of compliance, which views the world as something which must be "fitted in" with (Hoggett, 1992, p. 10). Within the disability arena, the deadening, dehumanising influence of lives of institutional control, or guilt-ridden deferring to the needs of others, are, I believe, well described by these concepts. Here, creativity is stifled, passivity fostered, and narcissistic wounds re-infected by the projections and controls of the "normate" majority.

As shall be apparent, Winnicott's (1974) view of the role of mirroring in the forging of the self contrasts starkly with the Lacanian theoretical picture, in which all the mirror may offer is a narcissistic self-delusion (Frosh, 2006; Lacan, 1977b). In Winnicott's (1974) view, the mirror is the route to psychic wholeness, maturity and healthy self-expression; for Lacan (1977b), the subject simply fools him or herself that the seemingly cohesive identity image in the mirror is real and authentic, in a manner which provides refuge from the knowledge of certain fragmentation. For Lacan, the coherent identity seen in the mirror is in fact a social construct, created via the collusion of a society preoccupied with surfaces, and desperate for narcissistic

indulgence. But all know, at some deep level, that the self's cohesive image is a sham, barely disguising the disturbance and chaos beneath. If Lacan's view is correct, and all coherent selfhood is an illusion, what the theoretical picture implies is a situation in which disabled persons are, by virtue of a demeaned social identity and gross material deprivation, simply more exposed to the universal "reality" of the fragmented ego than are others. The narcissistic "props" and "benefits" of an in-group world bent on the collusory furthering of its own defended ends are far less available to those situated outside of the world of ideal bodies, or the trappings of wealth. Further, according to Kernberg, what lies beneath the empty, materialistic facade of the narcissistic personality is primitive rage of the most crude, paranoid-schizoid nature (Frosh, 1991, p. 76). This hidden "dissolving self", composed of projected aggression and violence, and profound splitting (ibid.), is (arguably) what the social "mirror" of the disabled body alerts the grandiose self to. Disabled people, as harbingers of what lurks "at the edge of the mirror", may both evoke, and serve as projective targets for, the dark human truth of the fragmented, vicious, and loathsome self.

As noted earlier, the fact that most (though not all) disabled people live out their formative years and beyond surrounded exclusively by nondisabled persons, must have profound implications for the fostering of entitled selfhood (Gill, 2001, p. 365; Michalko, 2002; Wendell, 1996). Consequently, prejudices, values, expectations, and vocabulary (Ramlow, 2003, p. 107) carrying meaning about impairment may be propounded without dispute by nondisabled persons, especially in the absence of a destigmatising disabled subculture (Wendell, 1996, p. 59). Isolation and typecasting may be the only reality for such individuals, as the "spontaneous", creative, and "real" self becomes ever more obscured under layers of internalised self-denigration. Preece (1995, p. 97) found a clear distinction between individuals impaired from birth or early childhood, and those sustaining impairment in later life. The former showed markedly less confidence, with the experience of special schooling being associated with poor assertiveness and limited capacity for independent thought (ibid.). Disturbingly, activist groups representing a range of other political minorities manifest a pattern of dissociation from the disability movement, failing – or refusing – to recognise political commonalities (Gill, 2001, p. 366). Disabled women, for example, have reported that a range of "progressive" women's organisations who lobby aggressively against sexism, racism and homophobia, nevertheless "openly convey defamatory views of life with disability" (Klein, 1997; Morris, 1991; both cited in Gill, 2001, p. 366).

Michalko (2002, p. 22) describes his early life as saturated with constant reminders of his status as "unfortunate"; as perpetually located on the wrong side of a raft of immutable dichotomies, as member of a vigorously "othered" outgroup of one. Mairian Corker (1994) portrays her experience as similar, describing how she found refuge from imputations about her deafness in fantasy. She writes:

I subsequently retreated into and gained solace from a fantasy world peopled by characters who were more companionable than those who occupied the real world. In this world, it did not matter what I lacked, because that could always be imagined and allowed to assume its proper place in the identity that was attempting to shape itself in spite of the wiles of the adult majority...I can remember feeling really confused, even angered by the dichotomy between the messages of the verbal and the more subtle communication of bodily language and facial expression, by the depth of a glance that could warm or freeze.

(Corker, 1994, p. xv)

She describes how such "freezing" looks and other subtle forms of denigratory mirroring are often performed without awareness, and may be invisible to onlookers (*ibid.*, p. 4). Deaf persons growing up in such a social milieu may "become" the hearing person's behaviour towards them, and reciprocally (unconsciously) position all hearing persons as *similarly prejudiced*.

Closer examination of patterns of communication of nondisabled persons towards disabled people reveals a picture of interactions which are abbreviated, and include: less eye contact, but more staring; less smiling, but more indicators of anxiety; less information seeking about the other, and more distancing speech patterns (Fox & Giles, 1996 cited in Gill, 2001, p. 359). Further, assessment of nondisabled individuals' expectations of disabled people reveals an image of social introversion, emotional instability, depression, and hypersensitivity (Emry & Wiseman, 1987 cited in Gill, 2001, p. 359). What is described here appears as a world of responses not unlike those of the anxious, distracted, ashamed or depressed mother, speaking (at both conscious and unconscious levels) to those parts of self where certainty and trust are scant, and self-criticism never far away. The institutional discourses of tragedy, medicalisation and otherness within which disabled children are so often immersed, writes Priestley (1999, p. 92), are in turn "reproduced through daily encounters with other children,

with adults and with a variety of institutional contexts" (see also Todd, 2006). With emotive clarity, Mutua (2001, p. 107) describes the psychological impact of moving, as a physically impaired person, from a highly inaccessible to a more accessible environment (from Kenya to the United States). Inaccessible public spaces provide for an unrelenting experience of wordless negation of one's experience and existence; as the world goes about its business, the built environment whispers "why are you here?" This is a world devoid of cultural representations of one's narrative, clearly calling the legitimate inclusion of one's subjective life in the broad trawl of the human condition into question. Because the experience of illness, pain or physical or intellectual impairment are so violently devalued, there is "little cultural representation which creates an understanding of their subjective reality" (Morris, 1992, p. 1). One oft-avoided area of denigratory mirroring is what has been termed "the discrimination of love" (Rossiter, 2001, p. 97). The hegemony of the bodily ideal, in concert with the unconscious symbolic loading of the disabled body, lead to the construction of some (particularly visibly and intellectually) disabled persons as asexual, and beyond consideration as sexual or life partners (ibid.; Shakespeare et al., 1996). Far from a recognition of such rejection as culturally condensed and partly based in prejudice, the unspoken consensus is one which visits the mental pain of such narcissistic wounding entirely upon the individual, as a "natural" and unalterable outcome of chance tragedy. I end this discussion with the words on this topic of a severely physically impaired man, which demonstrate the superimposition of cultural oppression and the individual psychological narrative:

My mother was also fearful that I might get hurt in pursuing romantic relationships. She was so fearful that she told me 'don't even think about women'...I was so angry inside I sort of forgot the girl's rejection and focused on my own mother's rejection.

(Rossiter, 2001, p. 98)

## Disability: What is development?

An assessment of international development policy surrounding disability reveals that, notwithstanding the spread of the social model perspective, the majority of interventions remain locked into an individualistic, welfare approach which has limited promise in the furthering of a human rights agenda (Albert, 2005, p. 132). The question of what, precisely, embodies "development" for disabled persons relates directly to the vexed issue of "needs", and how, and by whom, these are defined. A fundamental principle, surely, is that a

programme cannot be regarded as "developmental" unless disabled persons are central in the processes of design as well as implementation (Coleridge, 1993, p. 7). Whilst the "welfarist" approach is both oppressive and anachronistic, a key and recurring thread of the current work holds that the structuralist priorities of the social model are equally lacking, in failing to recognise or provide for more personal aspects of empowerment and growth amongst its constituency. Quoting Lyotard, Fraser and Nicholson (1990, p. 22) celebrate the "postmodern condition" within development studies, as an era in which we are no longer convinced or subdued by monolithic, sweeping narratives of social "truth", such as the Enlightenment tale of progress, or the Marxian ideal of proletarian revolution. Instead, development theory must re-create, observe and acknowledge individual subjectivity and embodiment, in a manner which foregrounds the self-authoring of culture.

In a most illuminating and emancipatory social work text, Thompson (2003, p. 40) states bluntly that "existential freedom is a prerequisite for political freedom", and that "to deny the former is to foreclose the latter". In opposition to the social model's at times vehement dictates, these words direct us specifically toward the personal, subjective realm. Jenny Morris (1993b, p. 106) is equally unequivocal, stating that disabled persons' liberation from prejudice will never succeed if it is viewed as "solely a matter of changing *others*" (my emphasis). As alluded to earlier, the social model view may, along with its unquestioned "enlightening" influence, have failed to recruit a portion of the disabled population to the struggle through the alienation engendered by its rejection of aspects of their experience (Thomas, 2001, p. 51). Oliver (1999, p. 185) remains steadfast on this issue, commenting forlornly that "the decline of Marxism and the rise of postmodernism has enabled researchers to solve their theoretical and individual difficulties at a stroke", freeing such workers to continue producing "stilted", post-structuralist, ideologically impotent knowledge with impunity. But ever-more, the notion that "development" can occur in the absence of concerted efforts at human existential transformation becomes implausible. Honneth (1995, p. 164) regards engagement in political action and the internal development of entitlement to recognition as inseparable, combining in the journey toward a new, more positive "relation-to-self". One of the major respondents in Coleridge's (1993, p. 13) exploration of the views of disability development workers stated simply that "if people feel good about themselves, they can begin to create change". Courageously addressing the reality of dynamic relations of oppression, Coleridge (1993, p. 36) argues that "discrimination and prejudice create the sense of being disabled that leads to further discrimination and prejudice". Of course, the ideological danger is that this correct assertion be used to support the prejudiced belief that

disabled persons are responsible for their own oppression; it is this considerable concern which has underpinned the excessive, and diversionary, caution shown around the issue of collusory relational dynamics. Coleridge's (1993, p. 36) respondents emphasise repeatedly that the process of transforming attitudes must, at its core, incorporate the issue of the self-regard and self-concept of disabled individuals. He writes:

The harsh reality is that if disabled people see themselves as victims, they will be treated as victims; if they are sunk in self-pity, they will be perceived as pathetic; if they are hostile towards non-disabled people, they will be shunned; but if they refuse to see themselves as victims, if they claim their own dignity, see themselves as positive and able to contribute, they will be seen as positive and able to contribute.

(Coleridge, 1993, p. 36)

This is indeed a "harsh reality", which places severe and unfair demands upon disabled people, as upon members of all oppressed groups. Significantly, all disabled activists interviewed insisted that their work is primarily with disabled persons; this in no way denies the reality of discrimination and prejudice – very much the contrary – but it does reflect the belief that those committing acts of discrimination will not change unless the process is begun by the oppressed minority (ibid., p. 39). Finally, Coleridge (1993, p. 52) delineates what he considers to be the personal characteristics which signify the arduous movement from a position of "disempowerment" to one of "empowerment". The "empowered" individual is:

...open to change, assertive, pro-active, self-accountable, self-directed, uses feelings, learns from mistakes, confronts, lives in the present, realistic, thinks relatively, has high self esteem.

By contrast, the person who has not yet moved to this "empowered position" tends to be:

...closed to change, aggressive, reactive, blames others, directed by others, overwhelmed by feelings, avoids, lives in the past or the future, unrealistic, thinks in absolutes, has low self-esteem.

(Coleridge, 1993, p. 52)



In my view, the distinct danger to be avoided here is a misunderstanding which holds that, since it is the disabled individual's "task" to "achieve" a state of empowerment, the behaviours and ways of being listed as "un-empowered" are senseless, unjustified, irrational, excessive, or otherwise inappropriate. Such individualising and pathologising views of the behaviour of disabled persons routinely rest upon a crass ignorance of the nature, the scale, and the complexity of social suffering under which disabled individuals may labour. Instead of launching an investigation of these, stereotypes are employed which portray the individual as "another" dependent, embittered or manipulative "cripple". Coleridge's (1993) position is courageous in that it shows up the harshness of disabled life, in which there is simply no choice but to work with struggle, despite the fact that capitulation, embitterment and hostility may well be no more or less than natural and human responses to the madness of oppressive predicaments.

Paolo Freire (Freire, 1970) introduced a notion of empowerment via what he termed "conscientisation". Freire's (1970) objective was the socio-political and personal emancipation of the poor of Latin America which, he believed, could be achieved through a process of critical reflection on everyday realities, in a manner which exposed the strands and mechanisms of oppression (Mercer, 2002, p. 231; Kalyanpur, 1996). His approach stressed a "dialogic method", which facilitates self-understanding and the development of personal narratives (ibid.). Freire (1970) describes conscientisation as "learning to perceive social, political and economic contradictions, and to take action against the oppressive elements of reality" (Freire, 1970, p. 19). This enterprise fostered not only political mobilisation, but an internal emancipation from the self-blame and self-doubt engendered by relentless subordination. I concur with Peters (1999, p. 103), in the belief that Freire's (1970) model has much to offer the disability movement. At the heart of the concept of conscientisation is *praxis*, which combines both critical reflection and political action, emanating from a group-based exploration of experiences of struggle (Peters, 1999, p. 104). The gravity of the process of "reflection" required here is not to be underestimated; undertaking a direct examination of one's losses, experiences of trauma, and personal subjugation is a necessarily painful and gruelling challenge. As the pain is uncovered, it is shaped into narrative which, through the action of group-based political struggle, begins to be amalgamated into the cultural discourse of the populace. Disabled people, of course, are located at the epicentre of this model of development, growing in personal power and entitlement as the words are found to articulate the buried struggles which cement inequality. It is the Freirian model which, in combination with the principles of psychoanalytic group psychotherapy, informed the philosophical

approach of the present study. As already noted, though (see *Identity politics and the movement*, p.191), a key question within such a development agenda surrounds the conditioned wariness of many disabled persons to "disability-identity" affiliations of any sort (Low, 1996, p. 244). This, and a host of other operational challenges in implementing such a model, will be discussed later.

## Disability and psychotherapy

Of specific import, in light of the previous section's reflections upon the relationship of personal transformation to social change, is the place of psychotherapy in the unfolding story of the disability movement. To say the least, psychotherapy has "a bad reputation" with large swathes of the materialist-dominated Western disability sector (Marks, 2002a, p. 2). Mental health interventions are viewed as tending toward a pathologising and individualising attributional logic, which grossly underestimates, and largely fails to theorise, the realities of systematic exclusion and discrimination (ibid.). Simi Linton (Linton, 1998, p. 294) points to three respects in which her reading of the basic tenets of psychology run counter to the core currents of disability studies. First, psychology is viewed as responsible for the theoretical constructs and research conventions which circumscribe the notions of "normal", "deviant" and "pathology", which have impacted so massively upon the lives of disabled persons. Secondly, psychology's largely negative response to standpoint theory, and emphasis on empiricism, have militated against the undertaking of the sorts of analyses necessary for a vigorous interrogation of disability as a social construct. Lastly, the discipline tends to train professionals to intervene at the level of the personal, the intra-psychic, in a manner which obscures the social contradictions implicit in unequal life circumstances (Linton, 1998, p. 6). Clinical experience, in my view, would tend to support these assertions, as awareness of disability as a marker both of oppression and complex prejudice remains extremely scant amongst psychological professionals.

An initial, distinctly fraught question for our consideration is whether disabled people "need" psychotherapy. It should be no surprise that a range of social modelist voices respond to the suggestion with deep suspicion. Reeve (2004) asserts that, although psycho-emotional aspects of disablement operate at an emotional level, a visit to a psychologist is more likely to "add to", than resolve, such difficulties (Reeve, 2004 cited in Swain et al., 2006, p. 158). The

need for therapy, within this logic, implies a "psychological problem" which requires addressing; hence, the expectation is that normative, even healthy responses to dehumanising living circumstances will be understood as the manifestations of a constitutional pathology, which requires treatment (Lenny, 1993, p. 233). This concern is certainly realistic – as noted earlier (see *Disability and the medical encounter*, p.138), appropriate disability-related training, and the need for disabled representation within the body of mental health professionals, are issues which require substantive and urgent attention. For example, McKenzie (1992) found that disabled persons who had been under the care of psychologists and psychiatrists found these professionals to have little insight into the lived realities of life in a disablist society (McKenzie, 1992 cited in Oliver, 1995, p. 263). However, in terms of the "attitude" of the disability movement to the idea of psychotherapy, of note is the social modelist predicament of forceful disidentification with human experiences which approximate stereotypes about disabled people. As we have considered at length, to recognise emotional struggle, publicly or simply to oneself, may be experienced as a confirmation of deeply held fears that one "is" what the stereotypes dictate: dependent, broken, ashamed, self-pitying, or whatever. The split-off position of internal, emotional experience within the social model philosophy surely must create mirrored splits within individuals, which may position an enterprise like psychotherapy as evidence of failure.

It is the profoundly compelling nature of impairment that causes psychotherapists, as all people, to be drawn to it as a central variable in the construction of meaning, and the drawing of attributions. In other words, an interpretive trap which mental health professionals very routinely fall into is that which views the nature of impairment as the key – and often, the only – precipitant of emotional distress. So unprocessed are our unconscious projections surrounding disability that it requires substantial, focused attention to counter-transference responses in order to disentangle fantasy from the lived reality of struggle. The social model response to this very real difficulty has been at times to "deny" that impairment ever leads to emotional distress. In one sense this response is understandable, as it is cognisant of the very real risk that attributions which begin with impairment inevitably remain locked into this explanatory view, hence eliding social factors altogether. The result is the perpetuation, often within patient and practitioner alike, of an oppressive, self-blaming perspective on disablement, where "personal tragedies" need to be "dealt with" via processes of grieving (Abberley, 1993, p. 108; Swain, Griffiths & French, 2006). Social model writers, consequently, remain adamant that psychological distress is caused exclusively by disabling environments (Swain et al., 2006, p. 161). The fact that this statement is implausible, though,

does not negate the very substantive reasons for its propounding; that is, that all within disablist society, mental health professionals included, are unceasingly pulled toward an oppressive view of disability which locates impairment as the definitive variable. Joy Oliver (1995) found that disability counsellors schooled in the social model approach viewed environmental factors as pivotal. She writes:

It is evident that, in many cases, by removing the disabilities caused by the practical and social environment, the physically impaired person would have no more need of counselling than any other person.

(Oliver, 1995 cited in Swain et al., 2006, p. 161)

Finkelstein and French (1993, p. 31) note that disabled persons may experience depression through having absorbed negative attitudes about disability from the cultural world, as well as struggle pertaining to the ongoing business of life in disabling environments, including poor access, prejudicial treatment, unemployment, and poverty. This position is incontrovertibly true in its need to foreground oppression, yet falls squarely into the familiar impairment-disability binary which is the Achilles' heel of the social model. Impairment, consequently, is written out of the script.

Some "rehabilitationist" theoretical offerings present a model of disability psychotherapy which aims to "manage" emotional distress via, for example, cognitive behavioural interventions, in a manner which potentially dampens or sidelines recognition of the oppressive origins of the difficulty (e.g. Vash & Crewe, 2004). The critique of such work is directly analogous to the feminist interrogation of mainstream psychotherapy (e.g. Hollway, 1998; Priestley, 1998), in the re-formulation of politically-based struggle as neurotic responses which require "re-shaping". Here, "treatment" may be prescribed for the modification of "maladaptive" responses to environmental factors, in the absence of direct mobilisation toward the interrogation of such factors. The error here is often one of emphasis; political action may not be excluded, but it is typically not sufficiently foregrounded. The deeply socialised and unconscious self-blaming of some disabled individuals may interact

with such tendencies in creating a therapeutic discourse which is simultaneously supportive (rather than critical), individualising, and depoliticising. Vash and Crewe (2004), in their influential volume entitled *Psychology of disability*, now in its second edition, exemplify the problem of emphasis, in writing the following:

Contemporary understanding of disability, however, requires comparable recognition of the social dimensions of emotional distress.

(Vash & Crewe, 2004, p. 269)

The identification of a need for "comparable" recognition of social factors implies, logically, that the initial analysis is predicated upon a foregrounding of impairment factors. As noted above, my view is that accounts of disability which begin with impairment seldom "move on" to environmental concerns, instead becoming "obsessively" preoccupied with the irresistible notion of bodily "defects" inscribing presocial "damage" upon the emotional world. Reeve (2000, p. 669) is correct in observing that, whilst mental health practitioners are often appropriately aware of the need to address racial or gender prejudices which they carry, no such intent is visible regarding disability. She describes disbelief within some psychotherapists regarding the centrality of environmental factors, which probably manifests regularly in a "diagnosis" of "denial" (ibid., p. 673).

Perhaps the most well-read text on the vexed relationship between disability and psychotherapy written from within disability studies is Olkin's *What psychotherapists should know about disability* (1999). Due to its broad influence, I comment upon its approach in some detail. Olkin's (1999) approach is one which strives to foreground environmental factors in the understanding of mental health difficulties amongst disabled people. Whilst the perspective she takes is certainly critical, it also embodies a "modernist" position, in terms of outlining "methods" and "models" for "managing" disability. Perhaps the need for these is inevitable, but their presence nevertheless somewhat confounds a vigorous tracking back of attributions to ideological sources. A rigorous encounter with social difference requires a degree of thorough-going interpretation which leaves no stone of convention unturned, instead welcoming and exploring different ways of being, even in the face of the disquiet which these may engender. A mode of engagement which supports disabled persons in strategies for "coping" with life in a disablist society, despite its emancipatory intentions, may

lead to prioritising the development of perspectives and lifestyle choices which carry the least disruptive effects when interfaced with broader cultural mores. If meticulously applied this is the great strength of the psychoanalytic model, which aims not only to criticise, for example, cultural readings of disability, but to reach "underneath" toward an understanding of their psychic origins, with profound deconstructionist implications. The disability phenomenon presents the opportunity for a mammoth critique of the "ideology of the body"; of course, a work such as Olkin's (1999) could not be expected to perform such an interrogation, yet it must be possible to create applied therapeutic principles which continually foreground the analytic imperative of subversion.

Amongst much else, Olkin (1999, p. 67) reviews research which explores factors which mediate more positive attitudes towards disabled people. These include similarity of appearance to the nondisabled majority, lesser severity of impairment, attractiveness, competence, and good social skills (*ibid.*). Her intention in quoting such work is not to justify the attitudes evidenced; but conversely there is little overt problematising of these either. Instead, what is created is a mood which begins with the "cooperative" attitude shown by socially and occupationally successful disabled persons, necessary in offsetting the prejudices of others. It will be clear that she concurs with Coleridge (1993) in this assertion, as well as the disability activists he surveyed; yet, in the clinical setting such principles carry a subtly different ideological valency. As noted earlier, the recognition that some responses of disabled persons to the social world may be "maladaptive", and ultimately self-destructive, does not imply that such responses are not rational, meaningful reactions to the "madness" of society's multi-layered oppressions. The observation that such responses are unhelpful must be accompanied by a close investigation of their social origins and communicative intent, such that meanings are not elided, but integrated. In other words, whether or not a clinician regards it as "well adjusted" for a client to manifest a certain style of behaviour, the "sense", and unconscious "fit" of the behaviour with the predicaments and messages afforded by distortions of socialisation and mirroring must remain a central and salient focus of therapeutic work. The applied nature of Olkin's (1999) work, seeking as it does to create models and principles for dealing with the likely "problems" of disabled lives, renders a form of "psychiatry of disability", which inevitably reconstructs subtle essentialist differences between disabled and nondisabled groups (see also Crisp, 2002). This is entirely inadvertent,

and part of a critique of "categorisation" which may equally be directed at a range of psychological interventions, which cannot avoid reconstructing the "ill" and their "needs" in over-simplifying ways. And yet the cultural hegemony of the devaluing of disabled lives is such that it is crucial that social critique be a constant companion to "interventionism".

Psychotherapy which justifies the assignation of "subversive" should unpack the hidden contradictions of social oppression in a manner which harnesses new entitlement, and the "giving back" of hitherto unconscious negative imputations (Marks, 2002a, p. 5; Samuels, 1993, p. 51). Quoting Jean Laplanche, Frosh (2006, p. 175) observes our tendency to regard the presence of a coherent life-narrative as evidence of mental health; but herein lies the great contribution of psychoanalysis. The sculpting of a coherent life story out of one's perpetual subjection to the slings and arrows of a hostile, self-interested society, may typically carry a defensive function (ibid.). Psychotherapy which lacks the subversiveness of rigorous social critique may smooth over the contradictions of oppressive social life, creating a narrative which dampens cognitive dissonance, and hence relegates the causes of injustice to the shadows (ibid, p. 176). Conversely, the psychoanalytic project aims to disrupt the ease of narratives borne of ideological sleight-of-hand, revealing, instead, the "necessarily fragmented" nature of psycho-social experience. It is the fault-lines in the narrative which draw interest and curiosity, leading towards the uncovering of the trauma which underpins the chronicity of inequality. Samuels (1993, p. 52) sees the scope for political mobilisation inherent in psychoanalysis vividly, regarding the analytic setting as "a bridge between depth psychology and politics". One particularly stimulating observation Samuels (1993, p. 55) attaches to his view, is the assertion that it would be greatly to the benefit of political organisations to pay more close attention to the psychological development of their members, for reasons as much to do with "effectiveness" as with "humanitarianism". Samuels (1993, p. 66) calls upon psychoanalytic psychotherapists to alter their interpretive "thrust", away from an exclusive, insular focus on the "analytic dyad", toward a view which more overtly connects the patient's conflicts to the political world. This, he notes, would be "a modulation of feelings *outward* as well as inward..." (ibid. – my emphasis). It is such a model, which provides thoroughly for an ontological history, but is equally curious regarding the interpretive significance of prevailing political realities, which is required in facilitating the personal and ideological conscientisation of disabled patients.

## CHAPTER FIVE

### Research methods and issues

#### Introduction

In the course of this chapter I will describe the empirical study which forms the data-basis of the present work. As shall become clear, the research endeavour within disability studies and, perhaps more especially, the health sciences concerned with disability, is an extremely politically sensitive and often controversial enterprise. The political complexities of ascribing "needs" and deciding on the real nature of "problems" goes directly to the heart of disability oppression; questions of the legitimacy of research aims and methods, as well as researchers, abound. These issues will be examined in some detail, forming something of a theoretical "tangent" from the main methodological narrative. Part of my aim is making myself – as a researcher, a clinical psychologist and a disabled person – more visible to the reader, as befits a research orientation which allows and values the interpretive. Consequently, I later provide a quite detailed description of my own orientation toward the collection and processing of the data. The journey begins with some reflections on the role of qualitative research in political struggles, such as that pertaining to disability.

Norman Denzin (cited in Jones, 2005) signposts the imminent era in qualitative research thus:

The next moment in qualitative inquiry will be one at which the practices of qualitative research finally move, without hesitation or encumbrance, from the personal to the political.

(Denzin, 2000 cited in Jones, 2005, p. 763)

It is precisely with this tone that the current work embarks upon an investigation of intra-psychic and relational dynamics surrounding the social experience of disability. As shall be evident, it is my position that any theory which aims to describe, account for or combat prejudice and discrimination must recognise fully that the roots and consequences of this scourge reach deep into the realm of the psychological functioning of all participants. A materialist-structuralist account of disablism oppression provides essential impetus for the reshaping of societal institutions, and the application of the principles of citizenship rights to those unjustly deprived and mistreated. But a vision which addresses only the materiality of oppression will always fall short of *fully* illuminating the causes of the stubbornness of disablism prejudice, as well as eliding an investigation, and integration, of the human phenomenology of "otherness" which social disability affords. The ironic and regrettable silencing of the personal experience of disablism has created a deep lacuna in the social theorising of the disability phenomenon. This vacuum is not filled or mitigated by the largely decontextualised and solipsistic disability accounts characteristic of the tradition of medical sociology. The key failing of this work lies in its inability to maintain theoretical threads which link the social with the intra-psychic; which view experience as rooted in subjectivity, and connect subjectivity to ideology. It is with this challenge that qualitative research aims to move, with purpose and logical continuity, from the personal to the political.

## **The study**

The present study aimed, via qualitative data collected within a group psychodynamic psychotherapy context, to explore the socially situated psychological experience of a sample of persons with severe physical impairments. The intention was to gather data which would assist in the work of beginning to develop concepts which illuminate what have been termed the "psycho-emotional dimensions of disablism" (Thomas, 1999a). Whilst my position differs somewhat from that of Thomas (1999a), who embraces an "extended" materialist social model account, I employ her term loosely to delineate a generalized category of yet un-theorised psychological and relational phenomena which surround disablism and impairment. Some of the questions which motivated this study are listed below. These questions are intended not as "problems", to which one anticipates finding "answers", but rather as areas of import and interest, which require the development of conceptual ideas for their further investigation. The aim of this study is, first and foremost, the *initial shaping* of such conceptual ideas. The value, or otherwise, of the concepts reached will be identified in the degree to which disabled persons find these ideas helpful, and illuminating of the often highly

confused and confusing subjective sequelae of systematic disadvantage. Thus, key questions motivating the study included:

- What are the conscious and unconscious processes which shape the often distorted relational dynamics which surround disability?
- What cultural meanings regarding disability are at play in shaping the forging of identity of disabled persons in a prejudicial society?
- What psychological pressures do disabled persons live with in a disablist world?
- What is the relationship between individual and social factors in the experience of disability?
- What are the lived effects of pressures to "normalise" upon disabled persons?
- What are the effects upon disabled persons of the anxiety and avoidance which impairment often evokes in others?
- What are the psychological mechanisms underpinning the perpetuation (or enactment) of stereotypes surrounding disability?
- How do we develop a psychology of disability which theorises the individual, yet remains profoundly, rigorously contextual and political?

## **The research process**

### **Background**

In a society where awareness of disability as a civil rights issue is in its infancy (Watermeyer, Swartz, Schneider, Lorenzo & Priestley, 2006), the systematic disadvantage afforded to South African students in higher education institutions remains extreme (Howell, 2006; Watermeyer, 2000). Whilst access facilities vary greatly across nations and continents, accounts from many countries concur in describing the severe social and educational struggles experienced by disabled students (e.g. Low, 1996; Viney, 2006). Everyday life for disabled students involves the rejecting of imputed negative identities, the experience of a myriad of forms of structural and procedural exclusion, the negotiation of prejudiced or hostile responses from others, the management of poor learning access, and very much else (Low, 1996, p. 235; Watermeyer, 2000). A key finding of Charlton's (1998, p. 4) international study

was that the experience of lived disability was remarkably similar for individuals across a broad range of cultural and political-economic environments. It is my position that the anxiety-ridden evocations of disability (Marks, 1999a; 2002a; 2002b; Watermeyer, 2006) shape excluding or prejudiced responses to disabled people which, notwithstanding variation in cultural "content", have much in common.

## Setting and origination

### *The research story*

The study was undertaken at a prominent South African university, where I was employed as professional clinical psychologist within a student counselling unit. Management at the university's department for disability service and advocacy had, over several years, become aware of the lack of development of a relatively unified, visible and vocal disabled student population on the campus. Disabled students were, instead, a fragmented group, who showed significant ambivalence regarding association with one another, or with disability-related staff. Further, it was clear to staff at the university's Disability Unit that disabled students suffered a range of severe difficulties during the course of study, as well as campus life more broadly, of the nature of those listed above. Yet, much-needed united action towards group advocacy for the needs and integration of such students had not materialised.

Discussions surrounding this situation, as well as the stated need of some disabled students for a supportive group process, led to the decision to explore amongst students the desirability of establishing a group-based psychological intervention. My own theoretical backdrop to this endeavour combined an awareness of the Freirian model of political conscientisation through critical literacy, with a strong personal belief in the incisive power of psychoanalytic concepts in interrogating social responses to disabled persons (Marks, 1999a; Watermeyer, 2000; 2002; 2006). First, disabled students were invited to voluntary individual interviews with myself, before the broaching of the proposed group process. A group of 28 students responded. In these interviews I chose to disclose my own status as a disabled person (partially sighted), and the fact that I had myself previously been a student on the campus. Further, I expressed a curiosity regarding the predicaments of disabled students at the

university currently, making careful provision for students to choose their level of disclosure. A small minority opted not to discuss such issues at all, or stated that no difficulties pertained. The majority of students, however, responded very positively, and had much to say regarding their position. With this group, I then mooted the possibility of a group process aimed at jointly exploring students' experiences, towards a combination of greater self-understanding, and the interrogation of modes of exclusion to facilitate advocacy for improved access. Up until this point, the group intervention had been merely an idea; it was the students' responses which would define its existence.

After completion of the interviews, and the establishment of a core of students who expressed an interest in taking part in the group intervention, a venue and first session time was established. However, between the interview period and this time of initiation, which included a short university vacation, I hypothesise that the ambivalence which I sensed in many students began to surface, and many chose later to forego the opportunity to participate in the group process. After beginning with seven students, the final, stable group process comprised five members, and met for a total of 24 ninety minute sessions.

During the initial interviews I took a position of trying to convey to students the foregrounding, in this initiative, of disability as an axis of discrimination and systematic inequality. For example, I stated that I am aware that disabled students on the campus are subject to multifarious and complex disadvantage, which contributes to very high stress levels, and sometimes leads to students dropping out. I added that it is in the nature of organisational discrimination of this sort that individuals tend to take on (or be saddled with) personal responsibility for the difficulties they face. I took this somewhat directive stance in order to clearly differentiate myself from any semblance of "institutional authority" which may be viewed as regulatory or disciplinarian. This was a tactical decision, which, I believe, did set up a certain transference dynamic surrounding my perceived political investment in the empowerment of disabled students on the campus. The dilemma here speaks very directly to a fundamental difficulty with the harnessing of group solidarity amongst disabled persons (see *Identity politics and the movement*, p.191). That is, it is extremely difficult to create an investigative space for the voicing of disabled experience which does not, in some way, carry the imperatives implicit in a perceived or overt agenda. I discuss the problem of my "political countertransference" later (see *Political investments and therapeutic boundaries*, p.378).

## Participants

The participants in the group psychotherapy process by which the data was collected were five adults, of whom three were male and two female. All had severe physical impairments (quadriplegia, paraplegia, hemiplegia and degenerative ataxia), and all had acquired their impairments in mid or late childhood, or adulthood. This may be significant, as some evidence suggests that persons with adventitious impairments may be less vulnerable to the internalisation of disablist ideology than congenitally impaired individuals (Preece, 1995, p. 97). The candid and often highly insightful discourse of the group may be partly due to the fact that all members fell into the latter category. We may speculate that the experience of "contrast" in how one is responded to by society before and after sustaining an impairment may show up the distortions of disablism more starkly, in a manner which enables clearer, more entitled articulation. Three members were registered for postgraduate study, and two for undergraduate.

## Procedure

The group sessions were facilitated according to the non-directive principles of psychoanalytically informed group psychotherapy (Corey, 2005). All sessions were audiotaped and transcribed. In addition, I kept a journal of "field-notes" (see *An "interpretive" auto-ethnography*, p.245), in which I recorded my own assessment of group process, transference dynamics, the development of unconscious themes, and my own hypotheses regarding the unconscious meta-narratives of life in a prejudiced environment. These reflections were supplemented by fortnightly supervision with a senior psychodynamic group psychotherapist. As the process wore on, my field-notes began to render crystallizing themes which, in final coding and data analysis, formed the skeleton of my resultant conceptual contributions. The conceptual ideas I will put forward are meant in no way as exhaustive; rather, it is my intention to begin a process of the refining of salient themes which will be added to and modified, as per the extent to which these are regarded as relevant in the lives of disabled persons. Some of the themes I critically examine are familiar in colloquial culture in relation to disability (e.g. see *Disability and loss*, p.302). In such cases my aim is to examine the often oppressive meanings associated with such ideas, and perform a re-formulation of their relevance in terms of what is shown up by the data. Other ideas will

present as unfamiliar, and represent original thematic clusters which were shown up repeatedly during the group process (e.g. see *Disability and the distortion of personal and psychic boundaries*, p.260).

Due to situational factors, including two group members finishing their time at the university, and the tragic passing away of another member, the process was ended after a period of approximately eighteen months. As is so often the case with clinical psychological interventions at higher education institutions, the university's calendar serves to truncate the working process, which is punctuated by breaks for examinations and vacations. After combining the products of thematic analysis of the data with my own field-notes, the resultant conceptual ideas were then "re-presented" to group members in individual interviews six months after conclusion of the group process. The interpretive approach which I chose to take (Hollway & Jefferson, 2000), reaching beyond overt discourse to more unconscious processes, meant that the conceptual ideas which I arrived at were, in part, some "interpretive distance" from the manifest discourse of the group. In order to assess the salience, the resonance, of what I had extracted from the group discourse, I thus interviewed each group member, gleaning responses to my conceptual ideas (Mercer, 2002, p. 243). Interestingly, the overwhelming experience for me here was one of all having moved towards very similar understandings. The "auto-ethnographic" mediation of my interpretation (discussed later in this chapter) presents the very real risk of "self-fulfilling prophecies", in which my personal view is grasped, even enacted, by group members seeking to make sense of what is often a bewildering and traumatic world. This, though, is a concern which besets all forms of psychoanalytically informed work, and demands rigorous self-reflection and counter-transference analysis.

## **Ethical considerations**

### **Disability studies: Research and emancipation**

Research into disability has over recent decades been steeped in controversy, as the growth of the disability movement across society has become reflected in critical assessments of traditional models of researching disability. Important questions have been lodged, including

the issues of who should perform such research, what its aims should be, and what ethical considerations should be borne in mind. At times this encounter has had a distinctly vitriolic flavour, as a "traditional" body of researchers, located largely within medical and rehabilitative disciplines, have come to be seen by segments of the disability lobby as complicit in the perpetuation of oppressive, individualising models of disability (Mercer, 2002, p. 228). In response to this perceived lacking, the disability studies academy has ever more vociferously demanded the creation of a paradigm of research into the lives of disabled persons which expressly foregrounded societal barriers and discrimination as the key causes of disadvantage (Oliver, 1992, p. 102). Too much existing disability research, according to this argument, fails to reflect disabled people's experiences accurately, and is alien to the needs and lived struggles of the community (Mercer, 2002, p. 229; Shakespeare, 1996). The picture created of disability research was one of the exploitation of oppressed, often impoverished and marginal persons, whose life situations were in no way altered by the research outcomes (ibid.; Oliver, 1992, p. 105; Barnes et al., 2002b; Morris, 1992; Ward & Flynn, 1994). Ever the Marxist, Oliver (1992, p. 102) conceptualises the issue of power in disability research via what he calls "the social relations of research production", of which a central tenet is the "firm distinction" between the researcher and the researched. This distinction locates the researcher as a "specialist", who has "expert skills" in the area of disability, and consequently determines the topics to be examined and the methods to be used (ibid.). The implication here is that such research, often located within health sciences or the maligned field of medical sociology, will produce accounts which serve to buttress and justify the continued medicalisation and control of disabled lives. Discourses of rehabilitation and normalisation are closely associated with the "disability industry", which relies on the reconstruction of disabled persons as constitutionally flawed, and thus "in need of intervention". For Oliver (1992), these "relations of production" must be challenged, in order that disabled persons may assume control of what is deemed relevant and influential in the shaping of experience; viz. physical and cultural barriers to equitable inclusion.

Oliver (1999, p. 184) is searingly critical of what he frames as the ruse of "objectivity" in social research; this, in his view, is simply a justification for a self-serving abstention from the moral imperative to assume a partisan approach in championing the interests of the marginal citizens being "researched". Exasperated, he concludes: "I no longer wish to operate within a research discourse which prioritises investigation over emancipation" (ibid., p. 184). The alternative he demands is a "new epistemology" of research, which replaces the discourse of investigation with one which recognises research as a cultural phenomenon which actually

*produces the world* (1999, p. 188). In Marxian terms, the point being made is quite clear: the class that owns the means of production – of research, in this case – is consequently the class empowered to create "mental", and hence social, reality (ibid.).

The protestations of Oliver, Barnes and others to the dominant current of disability research related to what they viewed as an excessive focus on the "personal" (see *Prohibiting the personal*, p.42), believing that it is the structural elements of societal exclusion which are at the heart of disablist oppression. By contrast, to feminist disability studies authors, the palliative required to re-create disability research into a more emancipatory influence, was something approximating the converse (e.g. Morris, 1992; Thomas, 1999a). Whilst these writers objected to the decontextualised solipsism of much existing disability research, in their view it was in the critical explication, not the avoidance, of the "personal" realm that liberation was to be sought. For Morris (1992, p. 157) and others, disability studies stood to gain much from feminist discourse, notably with regard to the sensitivity of feminist methodology in showing up the landscape of the "personal". The crux of this approach, in the words of Dorothy Smith (1988), lies in its creation of space for an "absent subject" that, during the research process, is filled with the actual presence and lived experience of the individual (Smith, 1988 cited in Morris, 1992, p. 159). Further, the feminist approach aims to overtly connect the nature of subjective experience with the politics of everyday life – with the unequal, oppressive and discriminatory positioning of women, and disabled persons, in relational as well as structural systems. As Morris (1992) comments, most of the legacy – and ongoing production – of medical and rehabilitationist research on disability fails in this regard (ibid.).

The history of disability research, rooted as it is in the biomedical model, is overwhelmingly a history of nondisabled "professionals" researching disabled "subjects". The "mutiny" at the Winnipeg conference of Rehabilitation International in 1980 (see *Disability: The international development context*, p.14) may be viewed as an expression of the outrage felt by a quorum of the disabled community at this reality. For some, the principle is simple: "...if a researcher is to empathise with those being researched, then it follows that their life history must be as near as possible to that of the people being studied..." (Barnes, 1992, p. 117). My personal view is that sharing a marginalised identity with the subjects of one's research enterprise may carry silences as well as illuminations, and requires substantial effort paid to reflexivity. Conversely, there is little doubt that prejudicial and oppressive

constructions of disabled people have been propounded via the extraordinarily common phenomenon of decontextualised and uncritical disability research. Furthermore, the inherent role split between nondisabled researchers and disabled respondents may serve (even inadvertently) to create and reify the illusion of constitutional, existential differences between the human "conditions" of these respective groups (Livia, 1996, p. 34). Barnes (1992, p. 117) does mention the risk of a disabled researcher "going native", in un-reflexive over-identification with the research subjects, which scuppers any claim the outcome may have to objectivity. Further, he makes the extremely important point that having a disability does not at all imply solidarity with the struggle of disabled persons against oppression; nor does it "equip" one to perform quality research (ibid.). The entire social modelist critique of disability research, nevertheless, bears a tone of subtly deriding the empiricist tradition of researcher objectivity and the requirement of a solid evidence base. Instead, as we shall see, political commitment is ushered into centre stage, as the primary trait of a worthy researcher.

What was beginning to emerge was the so-called "emancipatory model" of disability research (e.g. Barnes, 1992; Mercer, 2002; Oliver, 1992; 1999; Zarb, 1992). This model centrally involves "a confrontation with power which structures the social relations of research production", locating the priorities of the "researched" as pivotal (Campbell Brown, 2001; Oliver, 1992, p. 110; Zarb, 1992). Research, in this approach, becomes a goal-directed part of the development process, aiming to show up the landscape of disadvantage in stark relief, for the purposes of lobbying and advocacy. Research and radical politics, thus, are deeply, deliberately intertwined. Further, the process is conceptualised as one in which the self-understanding of researchers as well as subjects is in the offing (Oliver, 1992, p. 112). Whereas prior research was construed as the study of disabled people, here it is disabling society which is "in the dock" for interrogation. The move from a discourse of "research as investigation" to one of "research as production" involves embarking upon a study with a clear, political motive, which aims to present data directed at social change (Oliver, 1999, p. 183). This orientation fits into what Mercer (2002, p. 229) terms a "critical social theory" perspective; the "third wave" of social research philosophy, emerging in the wake of positivism and interpretivism. Positivism, according to this framework, "had become so obsessed with objectivity that the critical potential of the 'sociological imagination' to expose entrenched power relations was downgraded" (Mills, 1959 cited in Mercer, 2002, p. 229). The precepts of critical social theory, thus, include anti-imperialist, anti-racist and feminist attacks on the reductionism and depersonalising reification of positivist, and, to a lesser extent, interpretivist research models (Mercer, 2002, p. 232). Within the arena of disability

research, critical theory interfaces both with the theorising of the social model, and latter feminist approaches seeking to temper its materialist emphasis with a "politics of the personal". As disability research became increasingly politicised, methodological criteria were downplayed (ibid.), in a manner which may have served to sacrifice rigour in the cause of pluralism and broad participation. Combining the requirements of an "emancipatory" research philosophy with the stipulations of disciplinary evidence protocols began, it seems, to prove difficult (Stone & Priestley, 1996, p. 706).

Examination of the "emancipatory" research movement's precepts does, however, seem to uncover evidence of contradiction. The structuralist roots of the social model suggest direction towards an orientation which favours a positivist, evidence-based approach, particularly in view of Oliver's (1999, p. 191) gloomy exhortations of us to reclaim the critical edge of sociology from the "postmodern ruins". The resistance of the social model vanguard to the incorporation of feminist research principles foregrounding the politics of the personal also seems to contradict their vehement rejection, expressed elsewhere, of research as "objective". What emerges is a school which appears to seek structuralist truths by pluralist (or populist) means, whilst simultaneously placing an embargo upon the nature of the "realities" which its constituency may articulate. Research based upon the "discourse of production" would, according to Oliver (1999, p. 188) evoke an "intellectual backlash"; he was not to be disappointed. In speaking of his difficulty in managing the conflicting accountabilities one feels, as a researcher, to the disability movement and the academic community, Shakespeare's (1996; 2006) view on the "emancipatory" paradigm has become ever more critical. He quotes Einstein in encapsulating his view, who instructed us to "Make everything as simple as possible. *But not simpler*" (Shakespeare, 1996, p. 118 – my emphasis). Later, he becomes more belligerent, stating that he simply "doesn't care" if his research is rated as "emancipatory" or not, professing to follow his own ethical standards, rather than bowing to orthodoxy (Shakespeare, 1996, p. 185). Kicking against the political imperatives of the social modelist consensus, he rejects accountability to anyone except himself, his conscience, and his publisher (ibid., p. 186). Becoming ever more critical, Shakespeare retrospectively evaluates the "emancipatory" social modelist research approach as having largely failed to produce good empirical work, due to the problematic reifications of its social model basis (Shakespeare, 2006, p. 10). What we are confronted with is a hostile paradigmatic encounter between the political necessities of a movement justifiably desperate to change the miserable living circumstances of its constituency, the constraints of methodological theory, and the tempering influence of moderate researchers understandably

concerned about the distortions afforded by political expediency. Clearly, the undeniably oppressive and individualising nature of the vast majority of pre-social model, medically oriented research into disability presented the necessity for the instigation of an adversarial assault based upon oppressed lives, rather than institutional discourses. The challenge is to arrive at a model which combines a concerted recognition of the social origins of much of disabled reality, with methodological rigour, and the foregrounding of subjective concerns.

The principle of feeding research findings back to respondents for verification (as performed in the present study), is an undoubtedly useful contribution, which is widely regarded as an important marker of an equitably conducted study (Mercer, 2002, p. 243). The question of objectivity is more difficult, presenting the confrontation between positivist imperatives, and feminist rejections of the notions of value-free research and the "neutral researcher" (Mies, 1983, p. 122; Wall, 2006; Barnes, 1992; 1996). "Conscious partiality", in the form of vigilance regarding the presence of unequal or oppressive layering within the social fabric being explored, must be combined with a sober and humble readiness to be proven wrong, and surprised by emergent data. Writing in the field of human development, but with a broader applicability to the behavioural sciences, Bronfenbrenner (1977, p. 513) describes our research predicament as being caught in an ambiguous landscape, "between rigour and relevance". Narrowly scientific, empiricist work may render little direct social relevance, whereas research of a more discursive and feminist nature may offer limited defensibility (ibid.). He comments on the short-sightedness of the indifference or brazen rejection directed at research rigour, which often leads to a reliance on exclusively existential analyses (ibid.).

## **Data analysis**

### **Qualitative and interpretivist**

Having thus traced the cross-cutting political and intellectual investments in disability research methodology, I turn now to a statement of my own position. Pivotal to the analysis are the tenets of an interpretivist approach, which construe reality as "created and social" (Ferguson, Ferguson & Taylor, 1992, p. 4 cited in Low, 1996; Berg & Smith, 1985). However, I view it as essential that a means be found whereby cognisance is simultaneously

maintained of the very real structural frame of constraints within which disabled persons dwell. To add a further, complicating layer, as has already been argued it is my position that a substantive proportion of the psychological reality of subordinated social positioning is lived via unconscious channels (Marks, 1999a; 2002; Sinason, 1992; Watermeyer, 2002; 2006). The import of this in the context of the oppressive history of disability research is quite momentous, viz. the ("unthinkable") idea of interpreting meanings of respondent discourse which lie *beyond consciousness*. It is these disparate strands and intents which I seek to weave into a coherent methodological orientation. I deal, now, with each aspect in turn.

The unifying belief of the interpretivist approach centres on the uniqueness of subjective reality, which is viewed as intersubjectively socially constructed (Mercer, 2002, p. 231). Versions of this reality, thus, are multiple; the "pluralism of ontology" (ibid.; Campbell Brown, 2001). Located within the feminist tradition, the approach is curious regarding the discursive origins and meanings of every day experiences in the social milieu, rather than intent on the establishment of functional explanations (ibid.). Within the field of disability research specifically, Ferguson, Ferguson & Taylor (1992, p. 295) regard the particular value of the interpretivist approach as lying in its emphasis upon the "inescapable contextuality" of knowledge and beliefs, creating an unencumbered space to be filled with the subjective realities which grow out of discursive immersion. Disability, here, is construed not as a fact or an entity which awaits "discovery", but rather a socially situated experiential meaning set, which awaits description (ibid., p. 296). The "interpretation" of data within an interpretivist framework is, in the influential words of Norman Denzin (1998, p. 317), "an art", for which there is no ready formula or mechanical method. Like storytelling of any sort, it can only be learned *through its doing* (ibid.). Consequently, the researcher – the teller – is in no way invisible. Instead, he or she is carefully, overtly situated in relation to the data, with this identity structuring the relationship between researcher, text, and reader. The "writing self" presented by the researcher is one which, by virtue of its positioning, experience and reflexivity, claims a degree of insight and authority vis-a-vis the research material (ibid.; Wall, 2006). But the knowledge is produced collaboratively, and thence refined through the interactive building of consensus between researcher and participants (Schwandt, 1994 cited in Mercer, 2002, p. 231). Rather than hypothesis formulation and subsequent testing, the emphasis is on an inductive generation of concepts (Mercer, 2002, p. 231), which are reflected upon and repeatedly elaborated.

Richardson and St. Pierre (2005, p. 961), with rich irony, describe qualitative research writers as "off the hook"; that is, relieved from the impossible task of writing as "disembodied and omniscient narrators claiming universal and atemporal general knowledge". In short, they are rescued from being required to "play God" (ibid.). Implicit in the recognition of this role is an experience of being both humbled and empowered; one is positioned in the seat of co-creation, but simultaneously made visible as a creator, with a unique view, history and bias. The encounter with "data", thus, is as much an *encounter with self*. My own "standpoint" will be described and considered in the following section.

In an earlier section (see *Disability and psychotherapy*, p.222), I cited Samuels' (1993, p. 55) astute remark that political movements would do well to make provision for the psychological well-being of their members. Such movements are conceived in suffering, often exist in circumstances of ongoing trauma, and accordingly are composed of a human constituency which carries the wounds and fatigue of struggle. One early position on the relationship between politics and social research held that those struggling for political rights had no need of research, because surely people who are "oppressed" *know it*, and hence continually battle against subordinating social forces (Bury, 1996, p. 111). Such an assessment bears the hallmarks of a structuralist analysis which, by its nature, lacks and eschews psychological concepts. A consideration of the psychodynamic model of mind, which incorporates normative, continual tensions between consciousness and the unconscious, along with an awareness of the psychic implications of trauma, must bring one to a view which recognises that it is arguably *especially difficult* for those in the midst of struggle to fully comprehend their predicament. When trauma is ongoing – when life in a hostile society must continue to be lived – the subjective nature of struggle often precludes the conscious processing of emotional material, as human energies may be all but exhausted on the business of survival. Thus it is that oppressive social splits will tend to create internal splits, as defences are erected to protect an already stretched and demoralised ego from the unconscious tide of personal meanings attached to experiences of trauma or deprivation. Patricia Hill Collins (1990) expresses the point simply: "Groups unequal in power are correspondingly unequal in their ability to make their standpoint known *to themselves and others*" (Hill Collins cited in Morris, 1992, p. 159). But the question then, as posed by Frosh (2006, p. 13), is *who* is able to own the knowledge required in order to confidently pronounce on the nature of the unconscious processes of others? This question raises both psychological issues and far-reaching political ramifications. Surely, at the heart of all prejudice, all dehumanisation, is the consistent feature of individuals being coercively defined from without; that is, having some

combination of one's identity, worth, ability, nature, or needs determined by a dominating "other". And yet, the "reality" of that very dehumanisation may be well obscured within members of the subordinated group, due to the necessity for occupying a psychic reality which is liveable. This, then, is the conundrum that faces us.

With surprising ease and clarity, given the political sensitivity of the area, Hollway and Jefferson (2000) approach this difficulty via their notion of "the defended subject". For these writers, all members of subjugated groups encountered in research (or elsewhere) are constantly engaged in conscious as well as unconscious meaning-making surrounding their social predicament (*ibid.*, p. 26). In other words, as defended subjects, all are differentially invested in the assuming of positions in available discourses, in order to protect vulnerable parts of self from the corrosive or overwhelming knowledge of demeaning treatment. The defensive need to disrupt psychic links for the purpose of self cohesion (Bion, 1959) may lead to subjects not knowing the meaning or origin of experienced feelings (Hollway & Jefferson, 2000, p. 26). Unconscious motivations, thus, are harnessed in the disguise or reformulation of deeper responses to social suffering, in a manner which may obscure the clear apprehension of injustice. Similarly, the meanings or triggers of action may be poorly understood, as multiple narratives, both conscious and unconscious, continue to relate to experiences from the outer and inner worlds.

In light of the "hidden" nature of important aspects of social suffering, including the internalisation of oppression, it follows that brief data collection methods, which allow little space for the observing of psychic processes, will be distinctly limited in showing up such phenomena. The psychoanalytic method, in both individual and group contexts, provides for an observation of psychic functioning through the course of an unstructured process, within which unconscious symbolic communications, as well as manifest utterances, may be heard. The duration of time available for such observation is a key issue which distinguishes such data collection from, for example, a semi-structured interview procedure. But, perhaps more importantly, the analytic relationship which develops between psychotherapist and patient, and between co-members of a therapeutic group, allows for the cumulative growth of a sense of safety and familiarity which renders the more aversive reaches of self, beyond consciousness, increasingly available for exploration. A key aspect of interpretive awareness maintained by the psychoanalytic psychotherapist pertains to the nature and functioning of defence mechanisms, which provide clues as to the structure of the ego, and the ways in

which everyday struggles are psychically managed (Hollway & Jefferson, 2000, p. 33). By creating an environment for free association, the psychotherapist is eliciting a narrative which is not structured simply in conscious, didactic terms, but also according to an unconscious "logic"; a pathway of symbols and associations directed by emotional motivations (ibid., p. 37). As a psychoanalytic psychotherapist and a researcher, I thus aim to maintain an awareness of the socially constructed nature of the disability phenomenon, whilst simultaneously "holding" in my mind the incipient, structural "realness" of barriers and hostility which the research subjects face daily. My over-arching attitude, lastly, is one which is thoughtful and curious, but also careful, surrounding my hypotheses with regard to the ways in which suffering "settles" within psychic space, and is unconsciously defended against, enacted, discharged, or otherwise integrated into self and identity. My aim is the development of a strongly politically, socially and temporally situated psychology – rather than psychopathology – of disability. Such a psychology is necessarily intersubjective, because as has been argued, it is in this realm rather than upon some mythic foundational plane that disability derives meaning, and thence shapes identity, self, and further engagement. Selfhood is forged in the intersubjective space, and disability, first and foremost, alters, distorts, mediates and shapes the character of that space, in terms of cultural as well as unconscious-developmental meanings. Logically, then, it is within this realm, where the significations of incipient selfhood are lodged, that we should begin.

## Researcher's orientation to data

In light of the foregoing, it should be amply clear that my presence in this work – as researcher, psychoanalytic psychotherapist and disabled person – is one of clear "visibility", built on a belief in the need for rigorous self-reflection upon the evocative issues at hand (Hertz, 2006, p. 539). My background in disability studies research and advocacy certainly locates me with a political agenda; the implications of this will be considered later (see *Political investments and therapeutic boundaries*, p.378). This orientation intersects with my own extensive self-exploration, via more than a decade of psychoanalytic psychotherapy, of the unconscious meanings, relational distortions and real-life dilemmas of disability. The issue of commonality of experience deserves a further moment's attention here. It is my position that, notwithstanding the extraordinary diversity in the embodied nature of impairment, a commonality of the experience of difference and discrimination is to be found

across such variation between disabled persons. Charlton's (1998, p. 4) international study, as we have seen, provides singular, but dramatic evidence of this postulation. To some extent, the reliability of this assertion will be tested by the current investigation, and others like it, as a shared "*psychology of disablism*" begins (I hope) to take shape.

The extensive knowledge, academic, anecdotal and experiential, which I carry regarding socially situated disability may serve to show up hidden aspects of experience within participant narratives, but also may serve to obstruct my clear "hearing" of the unique nature of individual standpoints. The "emancipatory" model of disability studies research, this time expressed in the words of Colin Barnes (1996, p. 110), charges researchers to espouse "commitment", not "value", "freedom" and "engagement", not "objectivity", and "solidarity", rather than "independence". The stage, in my view, is set in assuming such an orientation for the mis-hearing of subjects whose conscious experience *does not* fit this description of political intent. It is essential for a researcher, whose antennae may well be helpfully augmented by political awareness, to retain the "not knowing" mental space required in order to allow the coalescing of accounts which are politically inconvenient, or otherwise novel (Casement, 1992). The post-structuralist view of research writing, in addition, serves to free the researcher from the impossible – though nevertheless nagging – imperative to "conclusively" circumscribe and account for the subject matter at hand (Richardson & St. Pierre, 2005, p. 962). Along with this freedom, it is the great strength of the psychoanalytic view that it provides theoretically and technically for uncertainty, for silence, and for a lack of knowledge. I thus attempt to position myself as open to the resonance of familiarity, but equally ready for that which is not yet knowable. It is both the manifest accounts of participants, and the unconscious metanarrative of process, which is a focus of study. This metanarrative includes speculation on the psychic structures and assumptions underpinning statements, the mode of relating and social positioning which prevails, and the unconscious views of selfhood which are subtly described as the substrate to real life, everyday events. My aim in this awareness is to apprehend something of the ideologically obscured forces which socially position individuals in complex, often unconscious ways. My position thus, is (again) carefully, but also unapologetically, interpretive.

## The use of data

Due to the strong, stated influence of my own theoretical background, personal insights and political bent, it is clear that the "idea clusters" which are the subject of the balance of this work are a combination of data and "intra-researcher" factors. I consider this in the following section (see *An "interpretive" auto-ethnography*, p.245). We have considered at length why the area of psychological aspects of disability and disablism is as poorly conceptualised as it is; what this reality implies is that the current work is by its nature exploratory, as I attempt to create useful ideas "from the ground up". As I attempt to synthesise ideas from psychology and psychoanalysis, philosophy and politics, my conceptual discussions will track back to, and be *demonstrated by* the data, but not be reducible to it. As alluded to earlier, the validity (or otherwise) of the contribution will be shown up in the extent to which the resulting (growing) conceptual picture is experienced by other disabled persons and researchers as illuminating, and stimulating of further investigation, writing, and development.

## An "interpretive" auto-ethnography

Auto-ethnography is defined by Ellis (2004, p. xix) as "research, writing and method that connects the autobiographical and personal to the cultural and social", including such features as emotion, embodiment, self-consciousness and introspection. It is generally comprised of self-narrative, but an account which, in telling one's own story, forms a critique of the "situatedness" of self within the social milieu (Spry, 2001 cited in Jones, 2005, p. 765). The genre aims to express multiple layers of consciousness, in a manner which describes connective threads between the internal and the cultural; that is, the *ideological* (Ettore, 2005, p. 536; Ellis & Bochner, 2000). Now, my approach in the current study does not involve writing in the first person, or writing about my own experience, save in the special area of researcher reflexivity. My introduction of this methodological format is, instead, to draw clear attention to the manner in which my reading of the data, notably with regard to the interpretation of unconscious processes, is enriched by my own experience, and my own analysis. What I am referring to is not discontinuous with the principle of self-awareness and constant self-examination required of any trainee or practitioner psychotherapist working within a psychoanalytically oriented frame. Through this method I hope, to some degree, to bridge the gap between the intra-psychic and the social, via the careful employment and modification of my own formulations surrounding the interplay between subjectivity and social positioning. As has been discussed (see *Psychoanalysis and social critique*:

*Depoliticisation or subversion*, p.61) the "pull" of analytically informed work tends to be oriented toward sense-making with an intra-psychic attributive bias. Through the use of my personal conceptualisations of the mutually constitutive relationship of inner and outer realities, I hope to avoid the pitfalls of both psychological and contextual essentialism, in the understanding of the experience of disability. The "findings" of the study are thus as much mine, in the sense of being artefacts of my own psychological reality, as precipitates of the realities of the participants. I thus draw upon the extensive interrogation of my own socially situated experience not as a data set, but as interpretive tool in unpacking possible underpinnings of the respondent data. The juxtaposition of my own insights, I believe, contributes greatly to the "thickening" of interpretive formulations, which may then be "tested" and modified through further discursive exploration. It is through "reaching inside" my own narrative that I seek clues in "reaching into" the narratives of participants.

Through the keeping of regular field-notes (Warren et al., 2000, p. 185), I continued my own "researcher narrative", in which concepts were born, elaborated or rejected. These notes were composed of an amalgam of my own thoughts, clinical material, counter-transference responses, and a record of process interpretations. The "free writing" of these notes created a rich thought-environment of associations, which contributed to the data set, and often uncovered meaning-links hidden within the material. Ellis (1991) suggests that a social scientist who has personally "lived through" an experience, and carries subjectively important, unanswered questions about it, may usefully "employ" his or her own introspection as a data source (Ellis, 1991 cited in Wall, 2006, p. 3). Whilst the risk of an "individualising" and "decontextualising" bias is one requiring strong vigilance (Bochner, 2001 cited in Wall, 2006, p. 9), the rich specificity of a closely analysed narrative account also holds great promise in tracking socialisation's shaping of subjectivity (Muncey, 2005, p. 7).

## **Limitations**

Over the course of the preceding sections, many of the limitations of the study have been described, as these form central aspects of the method and philosophy employed. It is not the intention of the investigation to "produce findings" of a necessarily generalisable nature. Nor is it stipulated that the small sample group, augmented by my own experience, is necessarily a representative one. Rather, in a field as yet un-conceptualised, the intention is to begin circumscribing idea-clusters which, over time, will be refined into useful, illuminating

concepts. As has been argued, it is in the nature of disablist oppression (as in other forms), that the effects and management of struggle are often obscured. Further, the intersubjective distortions and subtle social situating of disabled persons are often difficult to identify, and may, through familiarity, be mystifyingly disguised as normalcy. The challenge confronting this area of research revolves around whether it is possible to "unlock" some of the hidden dynamics of oppression at the interpersonal and intra-psychic level, in a manner which facilitates the growing consciousness, and hence "separation", of disabled persons. My concern, thus, is with the mechanisms of oppression; notably, the "emotional oppression" mentioned earlier (see *Psycho-emotional aspects of disability*, p. 201). The disability studies literature shows a range of accounts of awakening consciousness pertaining to how one has been oppressively positioned, how one has colluded, and how marginality has been reproduced. Developing an understanding of the mechanisms whereby ideological forces are "real-ised" in the lives of disabled people, it is hoped, will assist in the escaping from such snares, toward the growth of a more entitled, integrated, creative and valued self.

## CHAPTER SIX

### Group psychotherapy with severely physically impaired adults:

#### Conceptualising aspects of clinical material

##### Introduction: Disability and anxiety

*F: ...the difference is then how people manage that anxiety...There are some people who come and confront it by sort of revealing their anxiety, but I think they would probably be the smallest minority. And some people who...try and disarm it in some way...we feel a little bit like we're tiptoeing around something. And...then some which are far more rare for me...is a more confrontational way of dealing with it...where people come and...need to...understand why I'm disabled ... the conversation moves to trying to find the blame for being disabled. And that, often times, either is God or the disabled person...and there's obviously the other which is just avoidance, when people try not to talk to you and try not to engage.*

Within the social-relational spaces surrounding group members on campus, in social settings, or in public places, dynamics of anxiety were ubiquitous. The experience often described was one of being surrounded by a social world of individuals feeling awkward, subtly hostile, embarrassed, "at a loss", or "off balance" in the business of relating. Melanie Klein (1948, p. 40), in her investigation of the psychic underpinnings of anxiety in young children, found that anxiety was only alleviated through an analysis of sadistic fantasies and impulses. It is thus aggression – or, more accurately, the fear of its consequences – which are at the root of a proportion of manifest anxiety. Freud's (1933, p. 253) association of altruism with repressed sadism (see *Reaction formation*, p.104) fits well with this analysis, and clearly, if disabled persons do indeed "carry" our most shameful parts, the impulse to obliterate these individuals, and what they signify, should not surprise us (Watermeyer, 2006, p. 38).

The implications of the capacity of visible disability to evoke anxiety are multifarious and significant, and form a socio-cultural backdrop which mediates much of the relational phenomena described in the present work. To begin this discussion though, it is useful to contemplate the personal, experiential implications of "carrying" with oneself the "cause" of the fear and unease of others, as one moves through the world, forced to continually occupy a milieu in which easy, trusting, robust and authentic relating is rare. There is meaningful "messaging" regarding the nature of the self implicit in the experiences of mirroring at work here, ranging from disgust or pity, to the communication that one is "unmanageable", "uncontainable" or "too much to bear". The self, in such circumstances, lives under a more or less consistent assault from overtly deriding, or subtly devaluing imputations, as one is forced to "field" the psychic "excess" of others. One clear "demand" which emanates from such treatment, is the imperative to diminish – to silence – evidence of the projected psychic pain which is imputed to the "soul" of a "damaged" body, to which issue we now turn.

### **Imperative to silence**

*J: One thing that I have found, though, with my past peers ... I get a very standard response. It's like, how are you doing, a standard response, and like, I'm fine. And when you say you're fine it's got absolutely nothing to do with how you're actually feeling. And, you know, conversation generally doesn't go past that...There's only one person that knows me the best, and that's myself. Every other person... gets a sliver, but they never get a big piece.*

As individuals all subject to the inevitably bumpy process of development, inner aspects of selfhood which carry shame are a universally shared legacy of our humanity. As corollary, the conflict between disclosure and disguise of those parts of ourselves we deem less admissible is an ongoing aspect of social life. Is what is "inside us" palatable, tolerable, acceptable, loveable to others? Assessments of this are related to the extent to which we are prepared to take risks in relationships, towards the garnering of validation and acceptance – the experience of being "seen" – which is so crucial to psychic integration. This universal "challenge" of being human is, I argue, substantially amplified and rendered more salient by cultural constructions of disability.

As quoted earlier, Wendell (1997, p. 266) describes how, in her experience, "coming into the world" as a disabled person involves encountering profound social resistance to the "mixing" of "worlds"; the "normal" and the "not normal". The result of this resistance is that much of disabled people's experience may go underground, due to the fact of there being no socially sanctioned means of giving it expression; the chance of having one's physical and emotional experience acknowledged is, by virtue of this fact, foregone (ibid., p. 266-7). The threatening loss of control symbolized by the suffering of the body is, for Wendell (1997, p. 267), "despised, pitied, and above all, *feared*" (my emphasis). The urge, consequently, to protect others from this "danger", but also to protect the self from the responses of others, is constant, and extremely hard to resist. Group members described a "disability narrative", composed of the continuous stream of everyday experiences within which disability was a salient variable. These included experiences with a positive, negative or neutral valency, with the common denominator being that, in anecdotal accounts, impairment would cease to be the "elephant in the room". Of course, experiences of struggle such as discrimination, social shunning or other demeaning treatment, systemic exclusion and struggles for access, impossible inconvenience, and impairment impacts such as pain or fatigue are ever-present parts of life in a disablist society. This "metanarrative" to engaged social life continued upon a subterranean path, ever-present and changing, but to an overwhelming degree, unspoken. Even the starkly limited admission into the "mainstream" afforded to group members, was regarded as contingent upon this constriction of expression; not remaining silent would clearly make an already highly taxing set of circumstances measurably "worse". The hidden "disability layer", it should be noted, is not composed of experiences which are in any way qualitatively different or "set apart" from the "everyday" subject matter of common small talk. Rather, this is the very material, lived "fibre" of ongoing engagement with life, entirely analogous to discourse regarding the daily experiences and tribulations of nondisabled persons. Murphy (1987, p. 87) remarks on this code of silence in his own life with the simple observation that no-one has ever asked him "what it is like" for him to live with quadriplegia. The reason for this Murphy cites is that to do so would "violate all the rules of middle-class etiquette" (ibid.). He seems to be alluding here to the "normative" constraints upon personal disclosure which are a general feature of "polite" conduct, thus applying to all. Yet, what is noteworthy about the predicaments of disabled persons is the fact that so much of life is "excommunicated" by this censure; so much of life is "unspeakable". Olkin (1999, p. 77) regards the "requirement" that disabled persons "regulate affect" as a common aspect of life in modern society – a constraint

which, for Fanon's black figure, was the first hurdle to overcome in the advance to emancipation (Charlton, 1998, p. 74). In Fanon's analysis, it was the "mechanisms of concealment" which alienated the colonised not only from one another, but from their own internal life and potential (ibid., pp. 74-5). To a large extent, the "duty" to remain silent is part of the "normalising" which is a requirement of inclusion.

The capacity to listen to the experience of another is, in practice, a demonstration of the willingness and strength to "tolerate" what one imagines is "inside" the other. In psychoanalytic terms, this recalls Bion's (1962a; 1962b) notion of "containment". In Bion's theoretical schema, the containing, accepting state of "reverie" offered to an infant by a mother with adequate psychic capacity to ingest her baby's unmanageable feelings, consequently buttresses the infant's growth, integration and learning (ibid., p. 36; Rustin, 1996). This early relating provides an important template for later psychic functioning; the concept of containment, and what it provides, has relevance throughout the life course. In fact, Hinshelwood (1991) describes Bion's concept of "container and contained" as a mechanism whereby the notion of projective identification may be operationalised in the analysis of relationships between groups (Hinshelwood, 1991, p. 191; Young, 1994).

Rustin (1991, p. 48) expresses what we need from others as an experience of being *thought about*; that is, having our experience known, accepted and "contained" in a manner which assists the psyche in the development of greater integration – that is, self-acceptance. If we consider social responses to impairment, what emerges is that, as modern society, we are largely unable to "think about" disabled experience. The "un-containability" of such subjectivity, further, seems manifestly demonstrated by society's failure to recognise and address the human needs of disabled persons. Experience must be "thought about", accepted and validated, if the needs and "realities" of that experience are to be rendered real, and thence addressed. Conversely, if, as seems to be the case, perceptions of disabled experience are so saturated with threatening projected fantasies that such "thinking" cannot take place, humanity remains disregarded. In addition, it is important to note that these considerations concern only material deprivation; we have yet to consider the psychological ramifications of being experienced as "un-containable".

The implication here is not that disabled people, as individuals, are "impossible to contain". Rather, I suggest that, due to the archaic unconscious evocations associated with disability, individuals will often struggle to contain and accept others when impairment is visible. These hesitant, furtive responses are probably so familiar to the congenitally impaired individual as to be indiscernible; as the accommodations of the "false self" to an un-containing world are (barely) "second-nature". Disabled persons, in this model, are seldom afforded the experience of being emotionally "held", since this is contingent upon the opportunity for authentic expression; instead, such individuals may constantly be required to perform some of the "holding". Individuals who repeatedly receive the tacit message that their inner life is somehow dangerous or toxic, will tend to internalise that assessment. In other words, it is the containment of others which supports us in the accepting of self, and the inner reclaiming of alienated, shame-ridden parts of ourselves. If – to echo Fanon – disability experience is relegated to these shadowy recesses, the "reality" of the social brutality suffered by this group will, also, remain obscured.

In Bion's (1962a) view, it is not "knowledge" carried by the analyst (or the mother) which facilitates emotional growth, but rather a listening stance which communicates openness, acceptance, and a readiness to be surprised (Frosh, 2006, p. 14). Frosh (1991, p. 77) attributes the violent nature of narcissistic pathology to disruption, in the modern world, of the conditions which facilitate the growth of a secure and cohesive self; that is, the conditions we may call reverie and containment. The nature of modernity, it seems, does not provide well for the presence of a "processing", "containing" other, who is able to recognise and validate (in this case) social distress. The cultivation of such acceptance would seem to contradict much of what neo-liberal, autonomous and narcissistic modernism is comprised of, with the disabled figure arising as the dreaded nemesis to the heart of its project. The (perceived or actual) "chaos" of the narrative of bodily frailty makes the story exceptionally hard to hear to the Enlightenment mind, causing the teller to be relegated to the dehumanised ranks of those devoid of "proper" stories, and hence of "proper" lives (Frank, 1995, p. 97). The positivist bulwarks of modernism and progress are incapable of "containing" these stories, or those who live them, as their very existence flouts the cultural stipulations of the age. In the lives of disabled persons such as those who participated in the present study, the physical experience of exclusion – "nowhere to be" – is mirrored by an ongoing psychic experience of "overflow",

of "being too much", of "not fitting"; of being *matter out of place* (Douglas, 1966, p. 39; see also Kitchin, 1998). The universally human shame of not having a place to contain one's innards, one's products – the secretions of experience – is continually inflicted via the culturally condensed rejection of lives.

In a most unfortunate parallel, the social model, by denying or negating the legitimacy of personal, emotional and impairment-based experience, makes disabled persons themselves fully responsible for "containing" these aspects of life. The imperative of the social model is to vigorously point to material barriers, whilst protecting others from the (possible) emotional implications of, notably, impairment. Disabled people, in terms of the provisions of the original social model schema, must show impairment to be something completely "normal" and "adjusted to", where its only effects are those of prejudice. This is probably true for many impaired persons, but has an oppressive implication for many others, for whom the reality of struggle, in Susan Wendell's (1997, p. 266) words, "goes underground".

## **Trauma and its re-enlivening**

*L: You know, I know these are pessimistic emotions that are not unique to people with disabilities, but I think they're probably magnified to a degree.*

*R: You lose out on the ability to recognise yourself as valuable, as worthy, yeah, and I think that was...a core part of that early [post-accident] process was figuring out a way of... almost like a lexicon, a language...that would allow me to recognise...again who I was. And...the only discourse available to you at that moment is...the survivor. You know, in the early days, the fact that you didn't die becomes...a great achievement [small laugh].*

*F: I think one other thing that has been my experience of being disabled is the ... the huge amount of time you spend on the very mundane things. And just the huge amount of time I spend waiting for stuff to happen...kind of in limbo...and it means that ...it's almost like there's an unhealthy amount of time to chew things over. When you're in, kind of, emotional turmoil, you really have the space to torture yourself. And not to go and do something which would take you're mind off it for a while.*

It is my position that one source of the perennial, splitting conflict between "experiential" and "materialist" accounts of disability arises from the fact that disability so often involves trauma. Life in a hostile, denigrating and depriving world will visit trauma upon those it mistreats. We know too that trauma, almost by definition, is difficult to "think about" (Bion, 1962b), as it confronts us with realities beyond the bounds of our comforting expectations, and hence defences. The prevalence of collective, traumatic suffering amongst disabled persons may present a form of "performance anxiety" (see *Pressure-anxiety*, p.377) to theorists and other writers, who may be constricted by an anxious concern regarding "doing justice" to the gravity of struggle at hand (see Dalenberg, 2000). The psychically destabilising, evocative power of disability, in concert with this "performance anxiety", and the enormous diversity in forms of impairment, may render it extremely difficult to commit generalising descriptive statements about the nature of "disability trauma" to paper. Also of note is the widespread history of disabled persons' experience having been oppressively, discursively defined from without. The high incidence of individual "autobiographical" accounts of disability, which have been heavily criticised, is one consequence of this, which has led to a fragmented literature on "disability trauma" with limited political efficacy. Conversely, materialist accounts have the necessary "categorical power" required for political advocacy, but also embody an enactment of the internal alienation of disabled persons (as other oppressed minorities) from the subjective nature of lived experience. Evidence of the sense that "much is at stake" with disability writing is to be found in the splitting which inheres in the discourse of "acceptance and denial" (see *Acceptance and denial*, p.307), which presents a uselessly limited, binary repertoire of being, into which disabled persons are discursively forced. Either "option" provides no space for the uniqueness of individual lived experience. To summarise, the conflicting forces tugging at one's sleeve as one attempts to produce writing on this issue, include a constrictive "reverence" for trauma (Dalenberg, 2000), the anti-subjectivity orthodoxy of the social model, the categorical and semantic requirements of political expediency, and a concern that one may provide data available for misappropriation in support of stereotyping; together, these are formidable concerns.

In psychoanalytic (rather than psychiatric) terms, "trauma" is defined as any event – of internal or external origin – which one's psychic defence system is not competent to shield oneself from (A. Freud, 1967 cited in Judd, 1994, p. 87). Applying this construct, an experience of "trauma" exists as much in the shifting of meanings as in the occurrence of acute events; thus, a "realisation" may be "as traumatic" as an accident. The word "trauma" is drawn from the Greek word for "wound", and denotes a piercing; in the current sense, of the

psyche's protective apparatus (ibid., p. 88). According to Davis (2002, p. 156), the hegemony of "ableism" creates a systematic silence around the reality of trauma inflicted upon disabled persons by a hostile society. This climate, he argues, makes it "comfortable" for us to regard, for example, systematic violence as merely "accidental". He writes:

One of the reasons why there is resistance to calling attacks against people with disabilities 'hate' crimes is because the general ideology toward people with disabilities rules out hate as a viable emotion. But the 'hate' toward people with disabilities is a much more subtle and ingrained hatred. It is a hatred of difference, or the fact that someone cannot see a clearly posted sign, cannot walk up unblocked stairs, needs special assistance above what other 'normal' citizens need. This kind of hatred is one that abhors the possibility that all bodies are not configured the same, that weakness and impairment are the legacy of a cult of perfection and able embodiment.

**(Davis, 2002, p. 156)**

As we have seen, "traditional" rehabilitationist and psychoanalytic models of "disability trauma" have relied upon an oppressive, victim-blaming logic which tends to view psychological states as the pre-social "sequelae" of bodily impairment (Asch & Rousso, 1985; Watermeyer, 2002; 2006). The challenge, then, is to begin to conceptualise disability trauma in a manner which avoids such simplistic, impairment-based reductionism. This directs us towards the realm of individual psychological development, which carries the familiar snares of pathologisation and decontextualisation; that is, the lack of a critical analysis of oppressive social forces. What is required is an analysis which is able to examine psychological – that is, individual – states, whilst retaining a rigorous, contextual critique of social factors, and hence overcoming the perennial, distorting splits which have so dogged disability theory. Thomas (1999b, p. 47) describes a precisely analogous dilemma as she considers the challenge of developing a psychology of identity development in relation to disability; in other words, engaging with the issue of "personal identity formation", but with a "heavy sociological slant". She offers no ideas regarding how this could be done without falling into an approach which individualises disability.

The model which I propose is one which begins from the (already established) premise that all humans, by virtue of the nature of identity development, and in terms of the Freudian "conflict model" of mind, carry unconscious psychic wounds. As has been discussed at length, any argument for some qualitative difference in psychic functioning or subjectivity between disabled and nondisabled persons is fallacious (Watermeyer, 2002), as such a view inevitably tracks back to a pre-social cause-effect logic which ignores ideology. Instead, all carry phylogenetically equivalent, hidden parts of self which bear the scars of contextual misattunement, of shame, self-loathing, fearful inadequacy, and the like, which have origins beginning with the nature of the most primary of attachment relations. But where we must begin to theorise upon the question of "disability difference" is in the systematic ways in which disablist prejudice and oppressive social positioning *selectively enlivens* and confirms these split-off, malignant aspects of self within the disabled individual. I propose that what cultural formations surrounding disability produce is an experience of systematically perverse social mirroring, which acts to re-evolve, confirm and aggravate the most vulnerable, wounded, or self-attacking parts of the self-identities of persons with impairments. I term this mirroring *systematically* perverse because its "perversion" is unconsciously mediated by precisely the sorts of shame-ridden existential conflicts which its action "speaks to" within the psychological lives of those it targets. Via projective identification, the distorted mirroring directed at disabled persons works to evoke, to enact and realise, precisely those parts of the psychic self which dominant group members seek to disown.

As we saw earlier (see *Psychoanalysis and disability: A brief history*, p.73), Freud's (1914, p. 561) view on disability, though at times somewhat ambiguous, largely construed impairment as something which would be used as a "pretext" by the ego for the living out of what were, in fact, repressed psychic conflicts of a more constitutional nature. In continuing this discussion regarding the purported relationship between physical characteristics and psychic functioning, he writes:

We may be tempted to believe a neurotic woman patient when she tells us that it was inevitable she should fall ill, since she is ugly, deformed or lacking in charm, so that no one could love her; but the very next neurotic will teach us better – for she persists in her neurosis and in her aversion to sexuality, although she seems more desirable, and is more desired, than the average woman.

(Freud, 1914, p. 561)

What Freud (1914) seems to be supporting here is a view which construes the presence of neuroses as common across bodily differences, with situational factors selectively enlivening (as well as creating) disturbance. Such factors, as we have seen (see *Culture and prejudice*, p.147), may exist in the form of differential, limited access to "worldly" narcissistic supports for the containment of incipient layers of disturbance, as well as denigrating imputations inflicted upon the "pariahs" of society. Young (1994, p. 139) describes how research into the psychic effects of catastrophic events demonstrates that the trauma functions like a "homing device", and "ransacks...the history of the victim until it finds a congruent, early experience" (my emphasis). The new event then "latches on" to this psychic part, in a manner which attributes meaning; typically of a type which confirms, solidifies and empowers split-off and destabilising aspects of self. Acute experiences of trauma leading to adventitious impairment are very relevant here, though not exclusively. For complex, systemic and cultural reasons, such emotional trauma may often not be effectively psychologically processed (see *Acceptance and denial*, p.307). The primitive, malignant meaning-position which such an acute experience may take up in psychic space thereafter, may coalesce meanings regarding identity which "set the tone" for the ongoing denigrations of prejudicial mistreatment. In other words, the un-digested trauma may lend credence to social ascriptions of brokenness and damage, which are directed at the body, but felt as the self. Clearly, though, even in the absence of such acute trauma, the ongoing trauma of demeaning social responses will continually "ransack" the psychic space of disabled persons, seeking alliances with mutinous parts of the self.

If we believe that political activity inevitably activates, and is mutually constitutive with, early infantile and developmental conflicts (Parin, 1985, p. 66), then surely the nature of oppressive political relations must equally – if not more directly – engage with individual psychological characteristics. Correspondingly, Raphael-Leff's (1994, p. 14) psychoanalytic work in child-bearing shows up how the "body work" (rooted in cultural meanings) of pregnancy and birth conjure a host of body percepts retained from different developmental phases. The evocativeness of reproductive changes, mediated by the cultural significations these carry, selectively "enliven" various parts of the developmental self, both "healthy" and "disturbed". The social model's circumvention of all things psychological creates a disabled

figure which is artificially homogenous; oppressed, yet unfeeling, without character or unique patterns of response. The key issue is the failure of such a view to recognise that trauma – or "life stressors" – are made sense of psychodynamically in terms of personal meanings. That is, in terms of (probably largely unconscious) pre-existing fears, vulnerabilities, suspicions regarding one's "true" nature, and the like.

The picture beginning to crystallise, thus, is one in which traumatic events are in the essence of the ongoing treatment afforded to impaired persons within a disablist society. But beyond this drone of discrimination, for some impaired persons, perhaps especially those with lifelong congenital impairments, a history of traumatic attacks upon the self is likely to have been even more direct, specific, and hurtful. Consider, for example, the heightened likelihood of parental separation difficulties and childhood "parentification", the incidence of false self pathology, controlling (reaction formation-based) parenting bent on repair, moral and rehabilitative imperatives to be more "normal", exile to special schooling or other institutional care, receipt of familial-systemic projections of damage, and a host of other destructive influences on the development of a robust self. It is then left to a discriminatory world to manifest a consistent pattern of directed re-traumatisation, recapitulating and confirming fears regarding unworthiness and unacceptability, re-opening old wounds and re-evoking malignant self-object experiences. The internal chronicity of battles relating to trying to feel legitimate, entitled, whole and healthy may, consequently, be hard to escape.

Though not assuming a psychoanalytic stance, Paterson and Hughes' (1999, p. 603) notion of the "dysappearing body" intersects well with this formulation. Consider the following extract:

When one is confronted by social and physical inaccessibility one is simultaneously confronted by oneself; the external and the internal collide in a moment of simultaneous recognition. When one encounters prejudice in behaviour or attitude, one's impaired body 'dys-appears'.

(Paterson & Hughes, 1999, p. 603)

As one's lived body "dys-appears", we may assume that the range of differing, fluctuant aspects of the body ego (see *Monstrosity*, p.119 and *Attachment and infancy*, p.162) forged in formative moments of physicality may be selectively re-evoked and enlivened by social experience. In concert with this, impaired modes of being are constantly de-legitimated by the "carnal information" inherent in socially produced embodied norms of functioning (ibid.). Impairment, thus, settles in experience as a blight upon conventions of functioning which are, a priori, hostile to alternate forms of physicality. The impaired body is excluded from making a contribution to shared "carnal information", and is therefore denied a home in the social world (ibid., p. 604). What is rendered, to Paterson and Hughes (1999, p. 604), is a form of "homelessness", wrought of the fact that the "information that animates the world is dominated by a ... specific hegemonic form of carnality, which *excludes as it constructs*" (my emphasis). The parallels between this theoretical formulation and the prior consideration of "containment" (see *Imperative to silence*, p.249) are clearly apparent. The disruptions afforded by bodily "dysappearances" to the possibility of the experiencing of an ongoing, continuous "stream" of self (Winnicott, 1974), seem immense.

To close this discussion, Davids (1996) echoes my position by problematising Fanon's (1952; 1963) analysis of racial oppression, pointing out that he fails to bring to life the unique meanings of social mistreatment in the context of psychological development. "Fanon's", writes Davids (1996, p. 227), "is a passive, idealised child, the innocent victim of a malevolent split permeating down from the social". The passivity of his subject obscures to Fanon the crucial issue of the child's own awareness of colour, and the way that difference is psychically appropriated in the manifesting of unconscious conflicts (ibid.). Fanon's victim of oppression is a unidimensional "uncomplicated" subject, whose form, in my view, separates him or her from the commonality of the human condition. The idea of disablist mistreatment enlivening destructive aspects of the internal world brings disabled persons into the picture as unique, fallible, quintessentially human individuals, not the simplified victims of a uniform oppression presented to us by the social model. The important paradox here lies in the fact that it is in the personal malignancy of oppression – the emergence of human abjection which oppression stimulates – that the universality of human subjectivity is to be found. Instead of separating out disabled people, such an approach directs us toward beginning to value the contribution which an analysis of disabled experience will make to our common appreciation of the human condition.

## **Disability and the distortion of personal and psychic boundaries**

### **Introduction**

Through the course of the group process, the issue of personal and psychic boundaries – their maintenance, and their distortion – began to emerge as pivotal to developing an understanding of the psychological, relational circumstances surrounding disablement. As we begin this discussion, Robert Murphy's (1987) words set the scene:

...it [his paralysis] has visited upon me a *disease of social relations* no less real than the paralysis of the body.

(Murphy, 1987, p. 4 – my emphasis)

Robert Murphy (1987) refers here to his often agonized personal wrangle with relational distortions which emerged with his burgeoning impairment. Much of what I suggest regarding psychological-relational dynamics surrounding disability in the current work point towards the "common denominator" of a distortion of personal and psychic boundaries (Watermeyer & Swartz, 2008). The psychoanalytic critique of disablism (Marks, 1999a; Watermeyer, 2006) relies heavily upon the notion of psychic material moving between individuals, through such processes as projective identification, and via the "perforation" of the "psychic skin". Accepted cultural norms of etiquette and respect for privacy are, in the case of disability, routinely flouted. It is, for example, difficult to find a visibly disabled person who has not had the experience of being asked the question "so ... what happened to you?" by a stranger (Slack, 1999, p. 33). The level of intimacy and shared history in a relationship required to ask a correspondingly personal question to a nondisabled person would be considerable; yet, such intrusions occur routinely, and may go unproblematised. There are clues, I believe, in such anomalies which alert us to the subtext of control and defensive psychic appropriation of the disabled figure as a counterpoint to dominant narcissism. The respectful maintenance of clear boundaries would preclude such appropriation, by blocking the ascriptions required to "create" disabled persons as the custodians of shame and damage.

Disability discrimination is by its nature subtle and nebulous, creating subordinating meanings which may be so disguised as kindness, or some other "normative" intent, as to slip into an oppressive "home" in the self unnoticed. It is slippery and difficult to see, and consequently, difficult to resist. Gill (2001, p. 366) observes with keen insight how disabled persons "rarely encounter the clarity of contempt associated with racism and homophobia", as such sentiments are typically actively repressed by others. Furthermore, undermining ascriptions made to disabled persons are, until critically considered, not as clearly "illogical" as racist rhetoric, as the presence of impairment imbues such ideas not only with a "rationality" (ibid.) but, more sinisterly, with an *admirable empathy*. It is, in Gill's (2001, p. 366) view "more difficult to refute a distortion of fact than an outright fiction". Lastly, and perhaps most importantly, it is often extremely difficult for disabled persons to grasp the political reality of their predicament, as subordination emanates not from "prejudiced villains", but from persons with whom they may identify deeply (ibid.). Family members, friends and other "good people", who believe in justice, may, confoundingly, be the source of only subtly visible devaluing attributions.

In a paper entitled *The Exceptions*, Freud (1916) presents reflections on a profile of psychological functioning which he believes to be closely associated with physical impairment. In patients with a congenital impairment, or an incapacitating illness of early childhood onset, Freud (1916, p. 591) noted a conspicuous resistance to acceptance of the reality principle. These individuals took the position that they had "suffered enough", and thus should be allowed to remain un-subject to such rules; they should be allowed the status of "exceptions". In analytic work, such patients showed marked resistance to relinquishing the pleasure principle, rejecting the delayed gratifications which follow the painful embracing of psychic reality. Of this group, Freud (1916) writes:

They say that they have renounced enough and suffered enough, and have a claim to be spared any further demands; they will submit no longer to any disagreeable necessity, for they are exceptions and, moreover, intend to remain so...Their neuroses were connected with some experience or suffering to which they had been subjected in their earliest childhood, one in respect of which they knew themselves to be guiltless, and which they could look upon as an unjust disadvantage imposed on them.

(Freud, 1916, p. 591)

The figure Freud (1916, p. 593) chooses to animate this discussion is Shakespeare's *Richard III*, who believed that nature had done him a "grievous wrong" by denying him the physical beauty which is required to win human love. This "wrong" led Richard to believe himself entitled to reparation, whilst simultaneously exempting him from the responsibility of treating others in a scrupulous manner (ibid.). His logic, thus, was one of "I may do wrong, since *wrong has been done to me*" (ibid. – my emphasis). As is by now familiar in psychoanalytic accounts of disability, Freud (1916, p. 593) then conflates psychological phenomena purportedly of "bodily" and "cultural" origin, by locating Richard III's "neurosis" as an enormously amplified version of a universal human struggle. He reasons that all of us, at a pre-conscious level, demand reparation for the ways in which we have been short-changed by nature, with bodies and minds that are replete with imperfections. The fact that we were not born beautiful or of exceptional intellect inflicts wounds upon our narcissism, and creates within us the firm conviction that "*it's not fair*". Freud (1916) asserts that women, due to their "universal" fantasy experience of having been mutilated and hence diminished in infancy, are particularly prone to the assuming of the position of "the exception", and the consequent claim to exemption from "the importunities of life" (ibid.). The embitterment, holds Freud (1916, p. 593), of so many daughters in relation to their mothers emanates from a deeply held reproach at having been brought into the world as female rather than male.

Rosemarie Garland Thomson (Thomson, 1997b, p. 37) slates Freud's (1916) essay as rank essentialism, reading that, for Freud, "deformities of character" are the results of physical impairment, rendering a universal psycho-pathologisation of disabled people. Lennard Davis (2002, p. 123), equally critical, regards Freud's (1916) formulation as a malignant reinforcement of stereotyping, not least that applied by United States judges and jurors in cases of litigation surrounding the Americans with Disabilities Act (see *Disability: The international development context*, p.14). The overwhelming proportion of failed attempts at using the provisions of the ADA reflect, for Davis (2002, p. 148), a prejudicial suspicion amongst legal authorities regarding disabled persons who want "a free ride", "special treatment", or recompense of some form for the rude "injustice" of impairment. The anxiety-ridden logic at work here surrounds the fear that one "exception" allowed will lead to a tidal wave of others, resulting in the inundation of officials, the draining of resources, and a fantasied descent into generalised chaos. Seeming to support Freud's (1916) "essentialism", Jacobson (1959, p. 139) provides a psychoanalytic account of her work with impaired persons who regard themselves as "exceptions". Drawing expressly on Freud's (1916) essay, she asserts that women, and disabled people, will tend to possess "defective" superegos, which

fail to fully subject them to the laws of morality and fairness. In addition, this lack occurs in association with a masochistic need for punishment, based upon unconscious self-hatred (ibid.). This hatred toward the self may be cloaked, or warded off, by "unconscious rebellion and scorn of the laws which others must obey" (as in Freud's [1916] picture), or may be utilised as a defence against such rebellion, manifesting consciously as a sentimental belief that one was "chosen" to suffer (ibid.).

Clearly, what Freud (1916) is referring to, is a distortion of boundaries; in particular, the purported demands of disabled persons to be exempted from the moral limits set on others. As identified previously, and as in so much of his writing, Freud's (1916) position on this issue seems indistinct; whether so by inadvertency or design is an important question for our consideration. Freud (1916) begins by referring explicitly to disabled persons as manifesting of what I shall term "exceptionalism", but then positions such neurotic phenomena (qualitatively, if not quantitatively) as a universal artifact of development. What remains unclear, though, is whether Freud (1916) necessarily intends eschewing the influence of discrimination and politics in shaping the experiences of self of disabled people.

In the face of the virulent feminist critique of the Freudian notion of penis envy (Freud, 1925), Juliet Mitchell (1974) reinterprets Freud's intention as diametrically opposite to that attributed to him by such criticism. For Mitchell (1974, p. 54), the "penis" of penis envy was a symbol of the political reality of male power in a patriarchal world. The body – that is, bodily differences between men and women – was being *interpreted*, as a mode of making sense of political realities. Freud was, in fact, positioning himself as a critical social commentator, pointing to the particularity of gender inequality he saw around him. The "envy" felt by women was thus not so much of an organ, as of a social status. And further, the psychological realities of women were not viewed as a product of the nature of bodies, but of the manner in which such bodies were socially positioned. Thus, it was politics that imbued the female form with incompleteness, and rendered masculine anatomy the object of envy. As a corollary, the "exceptionalism" of women was not an artifact of body shape, but a response to the *asymmetric nature of gender relations*. The demand to be indulged was therefore borne of a combination of, firstly, the (largely unconscious) recognition of structural unfairness, and secondly, the sedimented nature of gender culture and socialisation, which – we may surmise – created a field of "spongy" limits around the assumed "frailty" of the female ego and physique. Now, if we apply an analogous logic to Freud's (1916) utterances

on the topic of disability, what emerges is a picture of selves whose "difference" has been imbued with psychic meaning via the systematic distortions in treatment characteristic of disability oppression.

In the sections to follow we will examine at some length the relational distortions – the distortion of personal and psychic boundaries (Watermeyer & Swartz, 2008) – which prevail around physical difference. If, as Lussier (1980, p. 181) would inform us, the body is increasingly cathected by the developing child as it is, rather than as it should be, then from where might the shaping of "exceptionalism" emanate, but from culture? If Freud does believe that impairment leads, unmediated, to self-entitlement, or the female "lack" of a penis leads, equally unmediated, to penis envy, then how would he argue this? In order to make provision for such a state of affairs, we would need to revert to a simplistic, essentialist view of the body ego as a pre-social, ahistoric reflection of anatomy. Further, we would have to endorse the, frankly, preposterous idea that body-image in general is not profoundly mediated by culture. If we disbelieve this in the case of the nondisabled body – and I assume we do – then, surely, we should do the same in the case of the congenitally impaired body. My own emphasis in this regard is upon an examination of how unconscious conflicts stimulated by exposure to disability systematically maintain a culture of permeable boundaries in relationships surrounding people with impairments. The question for our consideration concerns what the origins are, in this population, of the belief that one is inferior, and thus deserves a special dispensation. As Jacobson (1959, p. 139) notes, the "entitlement" of the "exceptions" is a conscious disguise for a deeper, masochistic self-loathing. Is the lack of belief in one's ability to "stand up" to the clear limits of social rules not an artefact of the denigration implicit in ascriptions of lack, frailty and damage? The self-hatred of which Jacobson (1959, p. 139) speaks may, in women as well as in disabled persons, be an effect of the construction of both of these populations as inherently incapable, inferior and incomplete, rendering the emergence of narcissistic entitlements which barely cover the miserable internalisations of self gleaned from the projections of the social world. Notably, Jacobson (1959, p. 139) refers to the presence of a "defective" superego as a concomitant to the psychic attitude of the "exception"; yet clearly, the "defect" of which she speaks is not one of insufficient stringency. On the contrary, what we see is an especially punitive, authoritarian superego, which is "managed" via quite crude devices of reaction formation, which may transform self-loathing into prerogative, whilst simultaneously enacting suspicions that the self is fundamentally lacking, and hence must live on "charity". The deeply socialised links to cultural formations such as disability altruism are concrete representations of the hegemonic,

invisible status of such projective dynamics, which take up residence unbidden and, perhaps for lifetimes, unseen in the core of the self. The self-punitive excesses of the superego in some disabled persons (see *On being un-disabled*, p.310 and *Disabled superego*, p.299) bear rich testimony to attempts to evacuate the self of the stubborn imputations of "exceptionalism", inability, and the need for benevolence.

Within Heinz Kohut's (1966; 1972) model of the role of primary narcissism in self development, what the "exceptions" manifest psychologically are the implications of inadequate positive participation of important others in the process of developing self cohesion (Kohut, 1966, p. 68; Frosh, 1991; Greenberg & Mitchell, 1983). Narcissistic entitlements to "special treatment" here are the outcome of disapproval and rejection by early self-objects suffered by a child, whose psychic life thereafter is characterised by a need for escape from the abjection which inheres in the self. The early self, thus deprived, falls under attack; what happens is that its normative, healthy, grandiose and idealising inclinations become repressed, instead of realistically modified (Frosh, 1991, p. 103). What we see here is the lack of provision of adequate narcissistic needs to the young child in order for him or her to fully internalise, and trust his or her capacity for accordance with, the reality principle. Instead, the result through development may be a taut vacillation of the ego between overestimation of the virtues of the self, and intolerable feelings of inferiority (ibid.). Frosh (1991) summarises the psychological picture:

Thus the exhibitionism and grandiosity of the child remain in action in a repressed form, unrealistic and unrealised in any healthy way, with failure and rejection experienced as deeply shameful and disturbing, and with chronic manipulateness and avoidance of dependency the only possible paths to interpersonal stability.

(Frosh, 1991, p. 103)

The salience of this model to the question of the disabled self and the purported incidence of "exceptionalism" is, I believe, profound. It is, as has been argued, very difficult for parents socialised within a segregated, disablist world to have healthy "faith" in their disabled child's capacity to grow, separate and develop. This seems very likely to present difficulties with the nourishing of a child's healthy narcissistic needs, such as the subjective strength required to separate, and to survive disappointment. The distorting possibilities are of unhealthy indiscriminate "indulgence", or, equally, of a reactionary, withholding spartanism. The picture which takes shape, thus, is of disabled persons as a systematically intersubjectively-psychologically disadvantaged group, often deprived of the narcissistic resources all humans need, by force of the disruptive unconscious material evoked in others (including parents) by the presence of bodily difference. Beyond this, and as we shall see, is a world of unreal, "enmeshed" or "patronising" relating surrounding disabled persons, which repeatedly mirrors the implicit message that one is not able to perform in the "mainstream"; that one is

"different", and requires special "support" due to one's inherent "dependency". The crux of the issue is that these undermining meanings exist everywhere – in intersubjective spaces, in cultural representations, in parents and families, and in disabled persons themselves. If reactionary exaggeration of ability or personal value occurs in opposition to cultural denigrations, then this must be carefully separated from the rational, enraged, and hence politically entitled, response to disablist exclusion which must also prevail. There is dehumanisation implicit in one's being constructed as an "exception", as it robs not only one's rightful place within the common stream of the human condition, but also one's belief in the rightful ownership of such a place. What is so fitting, so mystifying and confounding, in the lives of disabled persons regarding the "exceptionalist" logic of "it's not fair" is that, in real lives, and in the most brutal fashion, it really isn't fair. For all human beings, the question of what one deserves, what one is entitled to or may ask from the world, is one with deeply rooted psychic connections, and complex, conflicting answers. In the world of disability, the atmosphere is perpetually thick with cross-cutting and contradictory, yet forceful, projected imputations regarding one's entitlement. Such meanings span the helplessly dependent pathos of the disabled figure in charity advertising, the authoritarian imperatives to normalise of the rehabilitation discourse, the vicious accusations of "freeloading" evident in popular culture, the relentless call to greater "independence" evident everywhere, and the religious or quasi-spiritual disability rhetoric of redemption and "overcoming", amongst very much else. This is a world of chronically, severely, and often perversely, disturbed boundaries.

## The relationship of psychic boundaries and anxiety

When psychic boundaries – within as well as between us – are contravened, or threaten to fail, or become murky and indistinct, anxieties tend to arise, borne of a threat to psychic cohesion and equilibrium. Not being able to clearly "see" the limits of oneself, or the far reaches of reflected internal threats, brings the fear of danger from malevolent forces based upon the indistinctness of power and locality. The power of disability to evoke projections means that exposure to disability often triggers boundary-less dynamics of relating, rendering anxiety, and possibly subsequent needs for control. As a group therapist, I am compelled by disability, as projective identifications are activated in drawing me into the vicarious gratification of needs I ascribe to the other, whilst I simultaneously have a need to subdue, control and protect.

The concept of the "healthy" boundary is that which is associated with the depressive position (Greenberg & Mitchell, 1983: 126), which signposts a level of psychic maturity at which the ego "can define the boundary between what is inside and what is outside, and can control the transactions between the one and the other" (Rice, 1965 cited in Palmer, 2002, p. 162). It is, in my view, precisely such reflexive, "depressive position functioning" which is often prohibited amidst the heady atmosphere of archaic evocations surrounding disability. Anzieu (1985) introduces the concept of the "skin-ego", which is a fantasied membrane separating inner, mental contents from the outside world (Anzieu, 1985 cited in Hinshelwood & Chiesa, 2002b, p. 16). We may speculate that experiences of intrusion upon the physical space of the infant or child are reflected as disturbances or distortions of this membrane, rendering uncertainty regarding the bounds and "ownership" of mental contents and mental space. It should be clear that such a developmental milieu may have significant implications in shaping congenitally disabled persons as psychically receptive to the unwanted emotional parts and social roles of others.

As was argued earlier (see *Monstrosity*, p.119), the "freakishness" of the impaired body has the power to pose an acute threat to internal, conceptual boundaries within the observer, such as those between male and female, sexed and sexless, animal and human, self and other, experience and fantasy, and so forth (Fiedler, 1978, p. 24). This destabilisation raises the threat to internal equilibrium of malignant, split-off parts of the self, rendering the need for "further" boundary contravention in the form of projective identification, as the psyche struggles to regain the sense of control brought by "clear separations". Paradoxically, it is through the need to be "separate" (distinct, different) from the disabled individual, that the observer coerces him or her into a narcissistic form of merger, via the re-creation of the disabled figure as a custodian of projections. Disabled persons, consequently, may chronically be socially located in a confused space as regards where they begin and end, as parts of the self are inserted, extracted, controlled, appropriated, re-defined, and categorized by an incessantly invested social world. There is, thus, a continuum from the spectacle of the show freak to the personal encounter with disability, in which the assumed bodily and psychic integrity of the observer is challenged by a confounding destabilising of the "typical" (Mitchell & Snyder, 2001, p. 210). The subversive force to the psyche of this challenge is often too much to bear alone, as the conflicts it enlivens render psychic compromises unfeasible, and evacuation and control become the only workable courses of action.

## Being real

*L: Yes, it's...authenticity. I mean, I think that's the heart of the problem...I feel like, if there is an answer to that...that would be the holy grail in terms of finding...a normal way of negotiating relationships...Spontaneous...I think spontaneity is the heart of it.*

Group members described moving in social worlds in which they were seldom related to in a manner which felt natural, spontaneous, robust, and real – in short, in a manner not substantially impacted upon by projections. It is a reliable truism that when one party in an interaction slips into relating of an un-real, un-separate nature, the other participant – knowingly or otherwise – is almost invariably drawn into collusion with this. Dynamics of a complex, collusive mutual "protectionism" thus take root, stiling communication and contact; this is a mode of relating particularly difficult to shift. The "silence" around real or imagined "disability experience" may take many forms, and, in the case of the disabled individual, often spreads to constraints upon self-disclosure of a more general nature. Projections occupying the silence may (for nondisabled others) be of the form of an assumption that what is unspoken is a dreadful reality which "we all know about", and thus requires no explication. Nondisabled persons may make pre-conscious sense of their own avoidance via the generally irrational idea of "protecting" disabled persons from something they would clearly not want to be reminded of. Self-circumscription by disabled persons is thus rendered immensely difficult, as this must be performed in the face of (probably) contrary projections, and within a manner which concurrently manages the hyper-vigilant anxiety of others, who may be tremulously awaiting confirmation of their fears. This attribution of meaning, with consequent implications for anxiety in relating, is largely unconscious, yet palpably felt in the moment of contact. The awareness, within that moment of relating, of the need to subtly "reassure", to contain something of the anxieties of the other, militates directly against the "showing" of self and experience, since – as group members described – one will then simply "have to do more looking after". Such a turn of events may lead, for the disabled speaker, to an even greater experience of being "un-seen", as energy and attention turn towards the nature – the self – of the observer, visibly manifest in his or her disability fears. The predicament of disabled persons in this world of non-real relating is, therefore, one of a rock and a hard place. Either one placates and protects the other, colluding

with and reproducing unrealness, and hence remaining invisible; or, one may attempt to show authentic experience in a manner which may evoke splits, manic impulses toward reparation, anxious withdrawal, or even sadistic prejudice (for evidence of the latter, see Cahill & Eggleston, 1994 cited in Gill, 2001, p. 261). The common denominator in both scenarios is that the self of the disabled person remains largely unacknowledged.

Gill's (2001, p. 361) assessment of available research is that, whilst disabled people report that the need to placate others creates a disquieting disconnect between public and private personas, most choose to weather this internal stress rather than continually face manifest confrontation. Frosh (1991, p. 99), quoting Miller (1979), describes how narcissism within parents may lead to "false self" (Winnicott, 1960) psychic structures within children, resulting from the domination of the intersubjective space by parental needs for recognition and gratification. As has been described (see Mirroring, p.213), conformity, inauthenticity, and barriers to true intimacy are the result. The picture of interactions in the "mainstream" world described by disabled group members was one strongly analogous to this, where accommodation and silence became second nature. Interestingly, evidence from group members also concurred with research literature in portraying young children as far more likely to relate to a visibly impaired person in a "refreshingly" robust, real and honest way (Coleman, 1997, p. 220). Children do not typically eschew physical differences, but also do not avoid attending to them, often responding with interest and questioning curiosity, but not stigmatisation (ibid.). Hahn (1997) found that, in order to "read" the attitudes of others, visibly disabled persons tended to develop a particular proficiency in discerning non-verbal cues (Hahn, 1997 cited in Gill, 2001, p. 361). Observation, by Braithwaite (1999), of nondisabled persons in the presence of visible impairment rendered much evidence of discomfort, expressed through such behaviours as fidgeting, minimal eye contact, staring, physical distancing, expressions of sympathy, avoidance, or acting as though the impairment does not exist (Braithwaite, 1999 cited in Gill, 2001, p. 361). In response to this "affected" treatment, disabled persons employed a range of strategies to promote acceptance, including making conversation about "normal things", sensitively managing curious questions, and "taking control of helping behaviours in ways that signal their full personhood" (ibid.). Similarly, Fox and Giles (1996, p. 266-7) summarise research assessing the "unusual" aspects of nondisabled non-verbal interaction when in the presence of visible disability; these include shorter interactions that end prematurely, increased physical proximity, less smiling, and heightened galvanic skin response. With regard to verbal behaviours, nondisabled persons often expressed opinions relatively unrepresentative of their own, which were more similar to

those of a disabled interactant, or used lower verbal immediacy (a measure of psychological distance indicated by word choice) in such interactions (ibid.; see also Hordon, 1994). In Sinason's (1992, p. 139) clinical experience, "fake cheerfulness" is the most common means whereby disabled persons deal with the silencing exclusions of everyday interaction – a strategy which is "often encouraged and rewarded as a sign of genuine good humour". Disturbingly, it is abused and disabled children who are the only two statistically significant groups who produce "big smiles" on their drawings (ibid.). What this points to is the extent to which the relational defences of the intersubjective world must extend into the psychic lives of disabled people, where a systematic lack of containment (Bion, 1962a) and accurate mirroring (see Imperative to silence, p.249) must serve to limit the psychic resources required in order to maintain contact with the more traumatic or dysphoric aspects of experience.

*R: Yes,...because I'd cultured my own behaviour in a way of...pretty much whatever the nondisabled students I was around felt like doing, I'd sort of modify my behaviour so that it gels with what's going on...we are the minority, and so we just sort of gel in. It's not something that I question, really, it's something I've done all my life.*

Murray (2006, p. 39), in a first-person account, describes how the "deep pain" of disablist exclusion lies in "the denial of access to 'ordinary' relationship". Murphy (1987, p. 121) concurs, referring to the prevalence of a "forced artificiality", involving "joviality", the "pretense of humour", and "effusive friendliness", all of which rob the disabled individual of real social engagement, along with the realisation of self which this brings. The essence of authentic relating lies in the capacity to "feel real"; to have, in the presence of another, a reasonably continuous access to one's internal stream of being (Ashforth & Tomiuk, 2000). It is the safety – the containment (Bion, 1962a) – of trusting relationships which allows subjectivity to come into relief, in order that it may be recognised, processed, and integrated. If this is to occur, the intersubjective milieu must be relatively free of silencing, or any form of protectionism, so that attention may be focused inward. The (hypothesised) systematic lack of such relating in the lives of disabled persons, with the "de-realising" implications this brings for subjectivity and psychic integration, must embody a substantial obstacle to the development of a clear and articulate voice of the experience of disablist exclusion, which is so important to the business of advocacy for social change. Undoubtedly, such relating is dynamic and may be deeply socialised. As a result, it is participated in – and hence perpetuated – by all concerned, as in the following:

*F: ...kind of hyper-managing your relationships like this, means that you create the room to have...'normal'...relationships, but only up until a certain point, and then...people...they realise that they don't have access to parts of you that they would with other people...I feel it creates a certain...glass ceiling to relationships. Yeah, you hit...a line in the sand.*

In order to "break the spell" of disability projections, it is "robust friendships" which are (universally) needed, not "kid gloves" (Coleridge, 1993, p. 39). Simi Linton (2006, p. 17) viscerally captures her experience of this need for realness. She relates how, soon after an accident in which she suffered a spinal cord injury, she was telephoned by an old friend. "I'm OK", she said, to which her friend loudly exclaimed "You're fucking paralysed!" After everyone had "been so nice", this friend's honest, real response to her experience was a profound signal of inclusion; of "normalcy". A similar sentiment is expressed in the following, in which a group member describes an incident in a "disability awareness" seminar which he chaired:

*R: Then one guy put up his hand, and he says, 'I avoided you last year because I'm terrified, not just scared, I'm terrified of what you represent'; and that was refreshing, so I could just take it from there. That was real. I said 'great', this is the kind of response I want. You're expressing what you, and probably what a lot of other people feel.*

Over-politeness, as much as outright discrimination, is a signifier of difference, which imposes silences around the illusion of intrinsic human otherness, whilst in so doing prohibiting the form of contact which is the only route to the de-mystification of projections. "Stifling pity", as much as overt hatred, has the capacity to be "murderous" to the "very nature" of the objectified individual (Byrom, 1999, p.

## Being seen

*F: For me it would be quite a simple thing for a person to do...you know, take a functional limb, say, if you're right handed, tie it behind your back. Spend a day with it like that...just one day...Get some kind of idea of, you know, the life that*

*I've been forced to lead...You wouldn't even have to have an impaired leg like me, or be treated weirdly by people. But just for a day, and you know, what's the big issue...in twelve and a half years I haven't got one person to try.*

Sally French (1999, p. 21) describes how, as a disabled person, an ongoing social experience is that of having to explain oneself, or "re-present" oneself in a form more manageable to others, whilst rarely having one's experiences seen, validated or confirmed. The constant corollary of not being allowed or able to be "real", is the experience of not being "seen". Underpinning the quotation above is the ongoing experience of an often highly salient layer of subjective narrative being unspeakable, and hence going unseen and remaining un-integrated into one's social persona. Even before considering human relating, the physicality of occupying a built environment which presents constant, maddening and cruel barriers to participation in essential, everyday affairs renders the unspoken, yet palpable message of unwelcome; of *not belonging*. The non-validation of internal experience, in this way, is recapitulated by a material world which was all-too-clearly constructed with only the needs of others in mind. Susan Wendell (1997) expresses this symbolic experience of the world thus:

Much of the world is also structured as though everyone is physically strong, as though all bodies are 'ideally shaped', as though everyone can walk, hear and see well, as though everyone can work and play at a pace that is not compatible with any kind of illness or pain, as though no one is ever dizzy or incontinent or simply needs to sit or lie down.

(Wendell, 1997, p. 266)

The "carnal information" (Paterson & Hughes, 1999, p. 604) of the experience of impaired embodiment thus occupies a shadowy, illegitimate status; it is, in terms which are deeply cultural, yet experienced as instinctual, simply "not OK" to not be fully able to see, hear, walk, speak, or whatever (Watermeyer & Swartz, 2008). The experience of the impaired body's "dysappearance" (Paterson & Hughes, 1999) triggers cultural mores bent upon concealment, as material and social worlds combine in creating an environment for (in this case) physically disabled individuals which embodies a failure of "containment" (Bion, 1962a) which reverberates through all levels (physical, relational, intra-psychic). As we have seen, even in academic and public discourses of identity and civil rights, disabled people remain largely an "ignored population" (Mitchell & Snyder, 1997, p. 11); in a host of ways,

the world – the Other – remains unresponsive. In the face of the Other, writes Michalko (2002, p. 93) the carnal difference of impaired embodiment is constructed not as an *addition* to the human condition, but as a *distortion*. It is the fact that disability "difference" does not "count" as "real" embodied subjectivity that relegates it to the shadows, leaving disabled persons to dwell, at least partially, in an unseen borderland. Experience, here, is not by its nature novel and salient, but rather a sullied, depersonalised analogue of an unseen ideal; to Michalko (2002, p. 93) the difference of disability is difference that "*does not make a difference*" (my emphasis; see also Magee & Milligan, 1995). Against this backdrop, the universally daunting developmental challenge of securing the resources to "gather up" one's experience towards psychic integration and wholeness, seems most especially thorny for this population. It is, bluntly, extremely hard to find one's way to feeling whole if one has spent one's life steeped in signs denoting that one simply is not, and cannot, be so.

Axel Honneth (1995, p. 174) regards "freedom" or "lack of coercion" as far more than the absence of external forces or influences upon behaviour – a position in which he seemingly differs from the social model orthodoxy. Instead, to Honneth (1995, p. 174), a key signifier is the absence of "inner barriers", "psychological inhibitions" and "fears". Further, and most interestingly, he construes these latter aspects as "a form of *trust directed inward*", which lends individuals a confidence in the articulation of needs, and the exercise of abilities (my emphasis). This "confidence", or, as he puts it, "these unanxious ways of feeling with oneself", are parts of a positive self-relationship which can only grow upon the foundations of experiences of recognition (ibid.). What Honneth (1995) is suggesting – a position with which I concur – is that it is essential for individuals to receive an accurate experience of being seen if self-knowledge and psychic integration is to follow, leading, most significantly, to the self-definition of one's experience, and hence oneself. The impetus of prejudice and discrimination is contingent upon social forces which have the power to define the nature of individuals from the outside. As long as social formations deny such individuals from experiences of apprehending and validating the self, the successful countering of stereotypes will be limited. In short, we need to be seen, in order to see ourselves more clearly, such that we may make ourselves more seen.

Whilst it is clear to see at a manifest political level why materialist authors advocate that the disability movement not show or articulate the internal, personal experience of disability and impairment, it is possible to speculate upon the more latent underpinnings of this policy.

Here, I dare to make a simple interpretation of this position. As we have seen, there is good reason to believe that those who do disclose such culturally "unpalatable" subjective material will not be "met" or "accepted" by the cultural majority, but instead are likely to be subjected to heightened exclusion, disqualification, or stigmatisation. The question emerges, then, as to whether the social modelist position reflects something of the nature of the "emotional oppression" of disablism (see *Psycho-emotional aspects of disability*, p. 201). Shame and concealment of the self is, as has been argued, part of what is engendered by oppression. Is there, in the social model moratorium on the "personal", something of the knowledge that one's already precarious societal belonging is contingent upon the continued protection of others from the "complicated", "messy" and "ill-fitting" vicissitudes of impaired life? Perhaps proponents of the social model seek to construe the world as "less complicated" for the benefit of the dominant groupings in society, as a necessary stage in gaining political rights before the possibility of being known, and feeling an authentic sense of belonging, becomes even remotely feasible. Of relevance to this discussion is the seldom-recognised fact that the pathologisation of disabled people has been *as much* of a psychological as of a bodily nature (see *Written on the body*, p.10). This, surely, is a key reason why psychological concerns have been entirely elided within disability studies. The psychological dimensions of oppression, in the form of a litany of assaults upon the self, are less articulated, but ever-present, and particularly harmful in their silently hegemonic nature.

## Manic defence

In the quotation below, a group member compares himself to an acquaintance who also suffered a spinal injury. Whereas for the group member such an injury led to permanent quadriplegia, that of his acquaintance proved, in time, to be minor, and resulted in no permanent impairment.

*R: ...so he was fixed, and I can't be fixed. And I think that's a big thing for people; and I think sometimes there's a collective feeling in society that...it's a failure, because we couldn't fix you. And we're sorry, and because we couldn't fix you we don't know what to do with you...*

The anxiety associated with disability phenomena – or more accurately, with fantasies about the nature of disability phenomena – often tends to evoke responses which may be described as manic defences (Watermeyer & Swartz, 2008; Watermeyer, 2009). The essence of a manic defensive response involves managing what feels like an emptiness, a frightening lack or void, with a "doing" response. A familiar situation is that of a disabled person being gently coerced into receiving – and appreciating – unwanted and unsolicited assistance with an everyday task, such as crossing the road or pouring a cup of tea. What may have occurred here is the rearing, within the observer, of an anxiety-laden sense of perceived lack, of a shameful inability or deprivation, which must be filled. The feeling is managed through action. The action, in this case, embodies a contravention of psychic and personal boundaries – the observer has not engaged with the disabled person to ascertain clearly what the nature of his / her experience is, but rather has assumed that experience, and furthermore has annexed responsibility for its "remedying".

In various ways, members of the group communicated the oft-learned lesson that, if disability experience is shared, others *cannot retain psychic boundaries*. In other words, as described above, when an experience which relates to disability or impairment is spoken about, resulting anxiety elicited within the observer tends to lead to pre-conscious feelings of helplessness, which in turn may be managed through unsolicited actions, or "helping" responses. Where such responses are not feasible, or cannot be construed as helpful in a manner which renders the defence a watertight one, the strong feelings at play may instead be managed via withdrawal, subtle blaming, dissociation, or a range of alternative modes of distancing. In short, it appears through these interactions that it is extremely difficult, within a society such as ours, for individuals to "see" disability, without needing to intervene upon it; to alter, remedy, obscure, or repair it. What is crucial here, is that this "doing defence" tends to leave the experience being described – lived – by the disabled person unrecognised and unheard.

To exemplify some of the dynamics surrounding this "flight into action", I provide the following anecdote from my teaching on a postgraduate university programme in clinical psychology (see Watermeyer & Swartz, 2008). A very insightful student, C, told of how she struggled to manage her partially sighted housemate's transport needs. C had a car and a driver's licence, while her friend Z could not drive due to her impairment. C described Z as

always very polite surrounding her need for lifts, but also worried that Z harboured other feelings, perhaps anger, behind her courtesy. Simultaneously, C was aware of having difficulty being "real" in her responses to the situation; she found it difficult to say "no" when it was inconvenient for her to provide a lift, and at times felt resentful. Interestingly, neither of C and Z's other two (nondisabled) housemates had cars, and they regularly also called upon C for lifts. However, the emotional valency, the meaning and evocations, surrounding these favours felt entirely different – and innocuous – to C. Class discussion surrounding the situation led to consideration of the dynamic of a "doing defence". This response – providing lifts even against one's own needs and wishes – tends to address the pragmatic difficulty, and circumvents or forecloses discussion of what is below; that is, what it is like for Z to occupy the space of someone who must be constantly polite and courteous as she asks for access to a structurally unavailable, unreliable, yet essential resource. Clearly, what is primarily at fault is the prevailing social order in South Africa which fails to provide accessible, efficient transport to all of its citizens, but examination of the impact of this discriminatory backdrop on personal relationships is informative. Of course, it is not my intention to cast blame on C – she is, with the best intentions, caught in the midst of unreal relating along with all other participants. Rather, I wish to highlight how practical, discriminatory, inter-personal and intra-psychic factors combine in leaving Z's experience of her world, of herself, relatively silenced. The key to relating which is more informed, in which the needs and predicaments of all participants are more fully present, lies in being able to know about and discuss disability experiences without needing, as a first port of call, to intervene upon them; to be able to hold clear boundaries. Such discussion would then form a more solid, a more whole and respectful, platform for later decisions regarding such issues as assistance, mutual support, and the business of ongoing relationship. Very often, in accounts of group members, the work of caring for, examining and nurturing relationships through honest and real communication became lost or distorted under the weight of ongoing, cross-cutting pressures to do with the boundary confusion which surrounds help and assistance. Such relating may leave disabled people feeling split and uncertain regarding the realness of the relationship, the honesty and trustworthiness of positive regard, and lead to further hesitancy regarding real communication.

It seems that allowing the lack to be real in the interpersonal space, and openly confronting the insolubility of so many situations of contextual disability, simply feels unbearable. Rather, what is harnessed is a need, in the face of our fears of disability, to maintain a fantasy that things are soluble, that the world is fair, that the lack can be filled; what I term the *fantasy*

*of filled needs.* This is a familiar cultural phenomenon, composed of vague, and quite illusory, yet firmly held beliefs to do with "special" services, facilities and provisions "out there" in society for those who are "less fortunate" by virtue of impairment. Again, the resultant experience for the disabled person is that the layer of disability and impairment experience which simply is – and will probably remain – an insoluble lack, is rendered invisible by attachment to the notion of the "just world", and consequently goes underground. Further, accepting assistance, or reassuring the other when it is not available, may, to the disabled person, accompany feelings of a subtle form of self-betrayal, through a tacit collaboration around the fantasy of difficulties being soluble, of needs being "fillable". French (1993b, p. 75) describes the irresistible nature of this fantasy of solubility to the broader population, in her account of her experiences as a partially sighted student having to negotiate a course in statistics. After her many requests for additional tutorial assistance from her university had been disregarded, she undertook to obtain tuition elsewhere, at personal and financial cost. After she finally passed the examination, her lecturer commented "in a jocular and patronising way", that her worries had "clearly been unfounded" (ibid.). She comments: "Our successes serve to reinforce the erroneous assumption that we really are 'just like everyone else'" (ibid., p. 74-5). What French had met during this experience was a social system highly attached to a fantasy that whatever difficulties may confront her were soluble, and by implication, that her concerns and worries were of her own making. This delegitimising, even demeaning response left her not only unprovided for in material terms, but also alienated and invalidated as an individual.

At the heart of the broader population's inability to cease acting or resisting, and begin listening, is a combination of two sets of factors. The first, as referred to above, is a complex of projected fantasies regarding what impairment experience is like; the spectre of universal anxieties to do with damage, adequacy and defect. The other intolerable knowledge set surrounds the appalling reality of unnecessary, arbitrary and unjust deprivations inflicted on disabled people by a brutally unconscious society. This knowledge lurks unexplored within the pre-conscious, never far from triggering an avalanche of guilt-ridden implications, to do with complicity in the humiliation of others, who might, again in the pre-conscious, simply be hapless victims who share the same humanity we do. Using this picture as a point of departure, it is not difficult to make sense of the vast range of defensive responses we apprehend surrounding the reality of disability-related disadvantage, be they quizzical, questioning, diminishing, victim-blaming, denying, confused, angry, hostile, impatient or patronising.

There are, in my view, notable parallels between "assimilationist", normalisation and rehabilitation discourses and policies, and the manic defences of everyday interactions around disability sketched above. Both attempt to provide resources toward "making normal", intentions we may represent symbolically as "filling a void". But in doing so, both also may silence the lived reality and elaboration of "being different". By their nature, these forces militate against the voice of "irreducible difference" (Ravaud & Stiker, 2001, p. 496), or, the right to "be as one is".

## Solutions, entitlement and passivity

*L: You know, the reality I see is that I pose some...opposition, to these solutions, because, it feels like this person doesn't know what it's like to...spend a day in my shoes.*

*F: ...a lot of the way that people who really care about me interact with me is to offer those [solutions]...a way of showing that you care is to provide answers. Which, of course, ends up in this strange cycle of...needing to thank people for caring, and for providing the answers, and explaining why you...don't or can't make that choice...it becomes more work if people try and provide you with answers than if they didn't.*

*J: ...you get the problem-solvers. Well, some of them have valid points. But often you see people listening, and they're trying to say 'well, what about this?'; and as you talk they're trying to work out how to overcome it [laughs]. And so I've had this conversation with people, and they go 'Yeah, but, but, but', and I go 'Yeah, but, but, but', and they say 'well what about...'; and then at the end of the day they sort of go 'Yeah, OK', [sighs]. And they're kind of...deflated.*

A key assumption underpinning the postulations of this section is the following: when people suffer chronic deprivation of needed resources which are readily available to others, the material nature of the situation may be internalised, causing it to become increasingly difficult for such individuals to feel deserving. In the case of disabled people, socialisation surrounding the issue of deserving – of what one is, and is not, entitled to – is likely to have been distorted in some way. The reality of senseless exclusion, the reactionary permissiveness of family members and others, awareness of the stereotype of the "entitled" disabled person; all such issues impact upon the clarity with which one holds the question of

deserving. It should not be surprising, thus, that at times we see conditioned distortions of deserving amongst disabled persons, including self-denial, spartanism and the acceptance of marginal and impoverished lives, as well as the stereotype of passivity and entitlement (as in Freud's "exceptions"). At an unconscious level, entitlement often carries a substantial degree of reaction formation, in terms of presenting a response which intra-psychically acts to manage looming, internalised and malignant forces of self-deprivation, and of "not deserving". The stereotype of the "passive victim" is closely associated with that of the "entitled" disabled person. The stubborn resilience of this particular prejudice is surely not surprising, considering the fact that most disabled people live lives of continuous discrimination and deprivation, in which there is little prospect of change. The form which such deprivations take, in the experience of group members, is often one of an "insane", seemingly casual and arbitrary, yet brutally policed distinction between the "haves" and the "have nots". Consider, for example, the distinction between those who may go to a club, restaurant or bar, onto a beach, to the home of a friend, to a theatre or cinema, and those who, due to the discriminatory nature of the built environment, simply cannot. The experience here is one of a numbing, senseless eviction from access to sharing in that most basic of human resources, social contact with others. As with any trauma, this experience is not simply "integrated" in a sterile fashion, but rather is made sense of in ways which shape entitlements of the self. Meanings are found which relate to individual history and, in particular, if our experiences are of being deprived and demeaned, such are the interpretations of events to which we will be drawn.

Finkelstein and French (1993, p. 32) point out that, due to immersion in disablist cultural meanings, disabled persons "frequently" think of themselves in ways similar to that of the dominant ("narcissistic", "normotic") majority. There is, consequently, immense potential for the "self-fulfilling prophecies" of internalised cultural scripts (ibid). Passivity and acquiescence, according to Marks (1999a, p. 44), may be a defence against rage at the constant experience of being unseen, excluded or negated. But as expressed in the quotations which opened this section, the experiences of group members uncovered a dynamic relationship, both overt and intra-psychic, between the manic, "reparative" needs of others, and the withdrawal of disabled persons into a passive, and at times rageful position. In the lives of disabled persons an extremely familiar, seemingly consistent experience is that of "solutions" to practical difficulties being mooted by nondisabled others. "Why don't you try this?" or "what about doing it this way", and "haven't you thought of that", are the ongoing, mild "confrontations" of others. To begin, these questions often carry the unspoken

assumption that in the life of the disabled person concerned options, resources and possibilities are not, as a rule, being explored or utilised adequately. Group members described how, unseen to this observer, life was saturated with a daily onslaught of intractable dilemmas, exclusions and discomforts. Against this backdrop of constant, numbing and insoluble barriers to inclusion, the "hopeful" or "cheery" assertions of the nondisabled observer represent a defensive affront, which unconsciously attends to internal narcissistic needs, rather than practical ones. Such "solutions" may be experienced by the disabled individual as an exhausting further sign of the chronic un-recognition of struggle in a disablist world, compounding despondency and evoking rage. The lives of group members were punctuated by a barrage of constant challenges to "make the impossible possible", to find ways of doing what needs to be done without the necessary resources. Further, whilst some suggested "solutions" were, in fact, feasible, the careful planning, organisation and preparation which these would require was utterly unrealistic in light of the massive, time-consuming and physically taxing demands upon everyday life afforded by disablism and severe impairment. The psychic crux of the "solutions" discourse is control, which must be exercised in the face of the destabilising evocations which disability brings. One group member compared his feelings regarding "solutions" to the response of black consciousness to "white liberalism", as in the following:

*F: You know, the notion of black consciousness, the attack on white liberalism ... It's like 'you guys, I know that you're trying, but you...reaffirm everything that the harsh oppressor says about us by trying to be positive...but [small laugh] in this deeply patronising way'. It's a...deeply disabling experience. Like of somebody coming to the townships and explaining to you how to ...solve your problems.*

The psychic "flipside" of the "positive" imperatives to action of the "solutions discourse" relate, we may hypothesise, to a base fantasy of despondent inactivity, of "deathly inertia", or capitulation to depression. The imperative to action and normalisation is a manic response to this universal imago. The feeling – perhaps associated with Freud's death drive (Freud, 1920) – is one of wanting to simply "lie down and give up". The looming, even inviting spectre of this capitulation creates the need, within the observer, for disabled persons to realise its opposite. Winnicott (1963, p. 181) describes a dynamic within the attachment dyad in which the gratification of instinctual needs – such as through feeding – actually embody a defensive, silencing elision by the mother of apprehension of the infant's experience. In association with this idea, Winnicott (1963, p. 181) relates how, within the therapeutic dyad, satisfying patient

needs may "eliminate" the object for the patient, and hence *obstruct relating*. In the current discussion, what this points to is how the positing of "solutions" – that is, illusory "satisfactions" – may, for disabled persons, embody a moment of having contact between internal life and the social world severed, as the out-flow of experience is inundated and repelled inward by the blunt weight of "solution". Burlingham (1961, p. 131), in her work with congenitally blind infants, found that guilt and signs of withdrawal within mothers rendered a withdrawal and passivity amongst infants "way beyond" that which might have resulted from impairment. She also noted a strong relationship between physical dependency and the concealment of aggression (see also Sinason, 1992, p. 21). A hostile "giving over" of control, rendering a passive stance, may also form an enactment of control continually being "taken away" by the realities of a disablism world. Anger, therefore, may be expressed in one locale, although accumulated across a range of unseen sites of discrimination, leading to such expressions being branded as irrational, maladjusted or disproportionate – what Olkin (1999, p. 77) refers to as "decontextualised rage". Some early accounts viewed catastrophic episodes of rage amongst institutionalised persons with cerebral palsy as a function of organic, neurological damage (Sinason, 1992, p. 226). However, Sinason (1992, p. 226) re-interprets such rage as a rational response to the control, guilt-ridden permissiveness and over-protection to which such persons are often subject, within families as well as institutional settings. Passivity, within this view, may be understood as a defence against the repercussions which such rage may evoke from a social milieu unable to view "disabled behaviour" as coherent, goal-directed and rational. This surprising, unconsciously motivated reluctance to "read" the behaviour of disabled persons as sensible was pervasively experienced by group members, expressed in the ready directives of "problem-solvers". The appalling contradiction of the social suffering of disabled persons would, perhaps, be brought dangerously near consciousness by such a recognition, leading instead to a style of psychic compromise which locates the disjunction of rationality within the disabled individual.

## The reality of limited choices

*M: But, I think, in terms of disability and managing being disabled in society, there are very stark prices to be paid no matter which fork of any road you take. You make a choice, but it's kind of...between evils. Most of the time you're on ... the losing side, and the choice is just...what form of losing you're going to be doing. It's constant compromise...although often times I recognise what the choices are in terms of being in those relationships.*

As has been argued, a defining environmental factor underpinning all of the relational phenomena under discussion is the lack of access to adequate and appropriate resources and services for people with impairments. What this may create in the lives of disabled people is a range of compromising situations in which the way relationships are managed becomes affected by the reality of needs for assistance, or other essential resources. Murphy (1987) comments on this from his own experience, referring in particular here to transport-related dependency:

In all this, they [people with mobility impairments] are passive recipients, waiting for the world to come to them – in its own time, if at all.

(Murphy, 1987, p. 77)

Later, and in more general terms, he describes the distorting effect of physical dependency upon social relationships:

[dependency is]...a condition that warps all one's other social ties and further contaminates the identity of the dependent...[dependence]...assails and tests even some bonds that we hope are impermeable, such as those of marriage.

(Murphy, 1987, p. 199)

The need for assistance – rooted in inequitable social process (Berg, 2005; Briggs, 1993) – may position disabled people in the role of having to manage multiple relationships, particularly in terms of monitoring, understanding, negotiating and preventing controlling or enmeshed modes of relating, which tend to emerge around disability. That is, disabled people often may find themselves receiving assistance which also affords a level of gratifying control, or "psychic pay-off" (Marks, 1999a, p. 22) to the "helper". Such patterns of relating, if not addressed, may tend to become amplified and entrenched over time (see Shaw, 2001). A natural response to this situation may be to regard the disabled person concerned as responsible for drawing boundaries, for assertively framing the relationship appropriately, in a way which suits him or her; conversely we may regard the disabled person as to blame if he or she finds the relationship problematic. But what this view fails to recognise adequately is the reality of very limited material choices which disabled people live with. In the example

cited earlier (see *Manic defence*, p.275), someone in the position of the disabled person Z may well be forced, to some extent, to "go along" with a relationship (or way of relating) which does not feel right to her, simply because functioning in her life requires that transportation to (in this case) her university is utterly essential. Disabled people inhabiting an inaccessible environment may regularly find themselves in situations where help and assistance are so needed, so indispensable, as to substantially compromise the work of understanding, modifying or choosing relationships. In a world of universally accessible and available public transport, Z's ability to see, interrogate and understand the nature of her relationship with C would be greatly enhanced, as she would be operating and thinking from a position of equal power. But the overwhelming majority of engagements between disabled and nondisabled persons are markedly asymmetric in terms of social, educational and vocational status, as well as access to material resources. This continual state of affairs serves to structurally "muddy the waters" of bounded and assertive relating (Eberhardt & Mayberry, 1995, p. 630).

As we all know, relationships are bewilderingly complex at the best of times. Also very relevant here is the reality that in an uncertain (that is, discriminatory and inaccessible) world, in which constant hard work and creativity are required to simply manage, and in which consequently little time and energy is surplus, one cannot reasonably be expected to be capable of exercising the sophisticated levels of insight necessary to unpick such relationships. The picture which emerges is one of interlocking social forces drawing disabled people away from realness in relating, away from the psychic centre, and an ongoing dialogue with internal experience. There is a sad irony here. Disabled people who, because of the necessity of assistance from friends, family members, health practitioners or carers, have a particular and critical need for skills surrounding the management of bounded, clear and assertive relationships, tend to have undergone experiences of socialisation which fly directly in the face of these needs. In short, disabled people find themselves in complex, often intrusive relational situations, and have classically been socialised in a manner which obscures this, instead fostering placation and accommodation, leaving the self under constant threat of being undermined, or even annihilated. One need not look beyond the charity and volunteer cultures surrounding disability to apprehend weighty evidence of this. The tacit or overt imperatives exercised upon many disabled people throughout the life course require appeasement and accommodation; it is not difficult to see from here how the stereotype of "manipulative" disabled people has coalesced. In a world of minimal or unreliable access to a resource as essential as transportation, disabled people may be drawn into a mode of relating which incorporates pragmatic trade-offs. For example, one may decide to tolerate, even

affirm, a relationship with a controlling and intrusive figure – these sorts of responses are never unfamiliar in the lives of visibly impaired people – in order to maintain access to a resource which that individual may be able to provide. Such trade-offs may be conscious and deliberate, or occur more unconsciously, as products of lengthy processes of socialisation in which the intersubjective space has been perverted by demeaning ascriptions, narcissistic investments, and self-fulfilling cultural prophecies. Morris (1993b, p. 102), from a non-psychoanalytic perspective, describes how treatment by the nondisabled world may leave one feeling enraged or undermined, without it necessarily being clear *why* these feelings have coalesced. Such, it seems, is the subtlety and embeddedness of demeaning representations and dynamics, that strong emotional responses may seem unreasonable not only to others, but to the disabled individual as well (ibid.). There is testament here to the rank, unprocessed nature of culturally conditioned prejudicial responses to bodily difference.

## Collusion and complicity

Whilst the foregoing underscores the reality of limited choices available to disabled persons, which may force individuals into collusion with oppressive relating, such relationships are also reciprocal at an intrinsic level. To begin with, it must be said that unpicking the complexities of the relational distortions surrounding disability is as – if not more – bewildering a task for nondisabled as it is for disabled people. It is pivotal, if we are to make inroads in understanding the psycho-emotional and relational complexities of the disability phenomenon, that we begin by firmly eschewing the oft-cherished (often materialist) assumption that disabled people are simply passive recipients of a unidirectional "force" known as "oppression". Temperley (1984) describes feeling a distinct "unease" at the tone of some feminist writings, which seem to endorse this populist maxim. Temperley comments as follows:

It seems to me fatally easy for a group that has been disadvantaged or exploited to idealise itself and to believe that, once the privileges of the oppressors are removed, the hated qualities associated with those oppressors will cease to be the social problems they were before.

(Temperley, 1984, p. 25)

A theoretical view which fails to make provision for the role played by disabled people in relations of oppression serves only to reproduce the malignant, dangerous illusion of an essential separateness or difference between disabled and nondisabled people. In addition, it demeans disabled people by constructing them as victims, whilst simultaneously arguing that their victimhood and trauma has not wrought any effects on their personhood and capacity for, or style of, social relating. This, of course, is a nonsense. Relations of oppression, be they between race groups, men and women, or disabled and nondisabled people, are inherently bi-directional and dynamic in nature. Furthermore, these modes of relating incorporate ideological mechanisms of socialisation, interpellating individuals into (partly) unconscious perpetuation of relations of power. Young (1994, p. 127), in describing projective identification, which is at the very heart of social oppression, emphasises the unconscious "collusion" of the recipient. Rather than a feeling or attribute being "put inside" another, the dynamic involves eliciting something from the recipient's pre-existing repertoire of psychic materials, which is then exaggerated, with the product being experienced as of internal origin. The uncertainty regarding the origins and meaning of emotional responses experienced by some members of oppressed groups (e.g. Morris, 1993b, p. 102) seems helpfully accounted for by this. What has occurred is that projected materials have found a home inside the recipient, where these may become intermingled with disallowed emotional responses, guilt, and superego imperatives for control. It is the ambivalence and uncertainty engendered by such projective identification which renders members of oppressed groups available and vulnerable to the sickening imputations of a proportion of the dominant majority. What the foregoing informs is the reality that all must change if change is to come about. As corollary, all are complicit until that change occurs.

The threatening spectre of this hitherto unexplored complicity has been a key factor in provoking disability studies' careful circumvention of the personal and psycho-emotional. As argued above, a substantial tract of disabled reality – of disablist oppression – has thereby remained obscured. Part of hearing the experience of disabled people is hearing the internal conflict, the ambivalence, the collusion, the confusion; exploration of these aspects is essential in the process of giving disabled people back their alienated, colonised experience. Understanding and integration of this experience will embody a fuller and more compassionate apprehension of self, incorporating the clearer emergence of the universality of human suffering, loss and hope. If psychoanalysis, and, in particular, object relations theory is to take an invigorating part in this process, the means must be found whereby clear focus is directed not only at the difficulties underpinning the ability of the individual to "have", but

also those which buttress the unwillingness of the world to "provide". Our analysis of the phenomenon of disability oppression must interrogate both sets of variables, constructing a model of dynamic interplay between the intra-psychic and the socio-political, which integrates the reality of deprivation with complexities of self-punishment, reaction formation, un-containment and the enactment of projected fantasies.

## Disability and transitional space

As we have seen, the power of disability to evoke primitive unconscious conflicts may trigger and rigidify narcissistic defences within the observer, involving regression to a paranoid-schizoid mode of functioning characterised by splitting, projection and projective identification. Within this mode mental space is limited, emotional responses may be felt as overly immediate intrusions, and separateness, or the unknown, are intolerable. Splits between self and other are marked, with the other being forcefully controlled, through the defining inherent in projections. The fact that unconscious, perhaps shame-ridden conflicts have been brought to salience and light by the trigger of disability imagery, means that the projective recipients of these materials must be related to as disavowed and othered, yet "un-separate", utterly controlled extensions of the psychic structure. Any self-definition of the other under such circumstances will threaten the utility of the projective defence, and this must consequently be decisively quashed. What is occurring here is that the observer has been thrown back into the ambiguous, fraught world of a disturbed and unpredictable transitional space (Winnicott, 1974), in which threatening psychic materials enlivened by the omen of disability urge a return to the omnipotence and omniscience of a unitary, un-separate world. The realness of the outside world, along with the relatively clear boundaries which this informs, have become extremely difficult to tolerate, rendering psychic reality ever-more an admixture dominated by the dynamic consequences of the emergence of infantile psychic experience. Transitional space, during early development, is an arena in which parent and child engage in the work of constituting the child-self and the self-in-relation, through play, communication and growing symbolization (Harris & Wideman, 1988, p. 129; Winnicott, 1974, p. 3; Young, 1989). The integration of ego during this process is necessarily partial, rendering psychic elements which exist on a continuum from those defined wholly internally, to those substantially mediated by the nature of external reality. We have already considered the susceptibility of the congenitally impaired child to the development of a "false self" (Winnicott, 1960 – see, inter alia, *Mirroring*, p.204; *Imperative to silence*, p.259), arising from a strong subjective discrepancy between the "active, constructing self" and the

diminished, stigmatised view of disabled life communicated to him or her (Harris & Wideman, 1988, p. 129). The defensive carapace of the false self which may arise as a result of relational disturbances surrounding infantile impairment is, it seems, likely to be confirmed, elaborated and further embedded by the psychic regressions which disability may evoke in the other throughout the life course. Reversion of the other to the ambiguous transitional world of early life embodies a need to expend new energies upon the negotiations of inner and outer reality, perhaps leading to a predominance of apperception over perception, to the detriment of the likelihood of the disabled other being "seen" as unitary, separate, and self-defining (Winnicott, 1974, p. 3). In short, boundaries between self and other are distorted, opening the way for psychic colonisation, and consequent silencing.

## **The discourse of independence**

*L: ...I think it's also a psychological...fear that we all have, that we're...less than...we want to be. It [dependency] speaks to that basic insecurity...And I would term my disability...hyper-dependent...that hyper-dependence I think becomes like the high water mark of our insecurities...you really are stripped back to an infantile state, and so...everything that gives you value in society is stripped away...in a moment...but I think it also speaks to a very deep fear we have...that we've...failed in a very profound way...that we've failed full stop.*

*R: ...after a lot of work I manage to transfer myself onto my bed and then back onto my chair, which is an incredibly difficult process for me...it took me...about six months to get that right. Well the problem is when you're getting out of bed into your chair, and by the time you get into your chair you feel like getting back into bed. And I realised that actually...it's not where I really need to put my energy every day.*

*T: And so as part of my rehab as well I had to learn to take off and put on my shoes, but I obviously don't have any hands and so I had to use my mouth. I had to use my teeth to undo my shoes, to put them on again. It was just insane, I was literally completely exhausted after doing that.*

It is a commonly held assumption that disabled persons value, and hence strive for, independence above all else (French, 1993c, p. 44). Whatever the expressed position of disabled people on this issue, what is clear is that the construct of dependency is a highly contested one, and the psychological reasons – across society – for its forceful eschewing, are

complex and layered. As has been noted in the previous section (see *Disability and the distortion of personal and psychic boundaries*, p.260), one reason why disabled persons may seek physical independence relates to the manner in which the power differentials which may inhere in assistance distort and confuse relational boundaries. Examples of such potentially malignant distortions include the patronising gratification of needs for control, the imperative to cheerful gratitude, and the silencing of anger or hostility. Disabled persons may be thoroughly socialised into the experience of self as dependent on the benevolence of others, through the discourse of charity, as well as the cold reality of lives of deprivation and voicelessness (Charlton, 1998, p. 3). Treacher (1989, p. 140) demonstrates how the notion of the "independent" subject is a culturally specific one, mobilised by a range of discourses, including neoliberal autonomy, some strands of feminism, and much of the theory and practice of the humanistic psychology movement. Dependency, in many of these thought environments, is viewed as "toxic" and destructive to the human spirit (ibid., p. 142). Noted anthropologist Clifford Geertz (1993) underscores just how clearly culturally situated the discourse of the independent subject is; he writes:

The Western conception of the person as a bounded, unique, more or less integrated motivational and cognitive universe, a dynamic centre of awareness, emotion, judgment and action organised into a distinctive whole and set contrastively both against other such wholes and against its social and natural background, is, however incorrigible it may seem to us, a rather peculiar idea within the context of the world's cultures.

(Geertz, 1993 cited in Hughes, 2001, p. 25)

As expressed in the last two participant quotations above, the disability studies literature contains a number of experiential accounts of the "normalising" drive to rehabilitate leading to punitive and excessive strivings for "independence", often in the performance of everyday personal tasks. Health care discourses within rehabilitation settings, it seems, may direct overly fervent attention towards an illusory "independence ideal", in a manner which may obscure or marginalise psychological needs for quality of life, fulfilment and balance. French (1993c, p. 44) cites examples including some strikingly similar to those above. In such cases, a basic task such as removing one's socks, for a severely physically impaired person, may become a "rehabilitative goal" which requires the expending of large amounts of physical and emotional energy, to the detriment of time and resources being available for the developing of more subjectively meaningful pursuits. Corbett (1989) presents the picture as follows:

The basics of self-help, which are second nature to the able bodied, might be an intolerable chore to some people with disabilities. Why should they bother with them? A narrow focus upon basic skills impedes the quality of life and inhibits self-expression.

(Corbett, 1989 cited in French, 1993c, p. 44)

The question arises, especially in light of the foregoing sections, as to whose psychic needs are being filled by the, at times, manically driven securing of fragments of "independence"? The rehabilitation model inevitably informs an orientation of both practitioner and client to "trying" ever harder to effect personal physical adjustment to impairment, whilst the cultural imperatives towards such "betterment" are seldom interrogated (Phillips, 1985, p. 48; Ingstad & White, 1995). In pervasive cultural representations as well as the rehabilitation discourse, the ability to walk, perhaps with crutches and immense physical exertion, is often prized above adjustment to wheelchair use (ibid., p. 50). What emerges is the operationalisation of culturally informed anxieties regarding difference, which manifest, inter alia, in health care policies which regard alternative lifestyles as at best a final port of call; at worst, as evidence of failure. Some writers have argued that the insistence upon striving toward such independence embodies a form of oppression of disabled persons, which inherently devalues lives characterised by difference (Shearer, 1981; Sutherland, 1981; both cited in French, 1993c, p. 45).

Within the social model perspective, dependency does not exist in an ahistoric sense, but rather is a product of systematic distortions in the management and distribution of social resources (Oliver, 1993b, p. 50; Marks, 1999a, p. 105). Further, the inherent *inter-dependence* upon which society rests is held as proof that "independence" is a relative, rather than categorical, concept (Lonsdale, 1990, p. 81). The view thus propounded by French (1993c) and others, is one which rejects the proposition that nondisabled persons are "independent", instead arguing that, against the backdrop of universal inter-dependence, it is the specific "dependencies" of disabled persons which are selectively disallowed by a prejudicial society (French, 1993c, p. 46). As a partially sighted person in an occupational setting, French (1993c, p. 46) describes how it quickly becomes evident that all employees have various "limitations", and consequently require assistance, advice and support from one another. But there is one "crucial difference"; she writes:

...able-bodied people's problems are regarded as normal and acceptable, and thus they can ask assistance of each other without feeling guilty or inferior. Disabled people can ask for help too as long as they steer clear of any problems directly associated with disability...thus disabled people are often expected to cope with their limitations in a way not expected of other people.

(French, 1993c, p. 46)

Asch (2001, p. 313) notes wryly that all in modern societies are dependent upon a range of service providers to perform tasks for which we are ill-equipped – from car mechanics to computer technicians, plumbers to lawyers; yet, the normative status of these needs renders them invisible as evidence of dependency. However, the need for qualitatively indistinguishable services such as assistance in dressing or washing required by physically impaired persons is construed as a shame-ridden signal of failure (ibid.). The lack of access to such personal assistance is a contravention of human rights, bringing into relief the socially inflicted dependency of individuals unjustly deprived of free choice in the management of their lives (Litvak & Enders, 2001; Shaw, 2001). The rise to prominence of the modernist notion of individuality has, as has been argued (see *Narcissism, normalcy, modernity, and the market*, p.147), carried a particular significance in the marginalisation of disabled persons. As we grow and develop, the imperative of modernism stipulates the progressive achievement of the trappings and deportment of an illusory autonomy (Taylor, 1989, p. 36), against which the disabled figure is situated as a demeaned counterpoint (Watson, 1998, p. 148). Popular psychology has enthusiastically taken up the vision of "self-reliance" as a cornerstone of psychic health, which is regarded as integral to successful and responsible adulthood (ibid.). All such propositions, however, fail to recognise the relative and constructed nature of achievement of the independence "ticket" to societal legitimacy. Of course, clear recognition must be given to disabled individuals' desire for independent functioning, with the provision of equitable access, universal design and appropriate, client-driven rehabilitation forming central aspects of an anti-discriminatory societal response to impairment. However, the independence construct must be applied with critical care and vigilance, surrounding the oppressive and controlling potentials of the normalisation discourse.

Tom Shakespeare (2006, p. 146), watchful as ever regarding the replacement of oppressive social structures with constrictive political orthodoxies, regards the reasoning that all are vulnerable, dependent and in need of some form of care as somewhat disingenuous, even trite. The "conventional dependency" experienced by all is, in his assessment, "very different" from the pervasive dependencies of some severely impaired individuals (ibid.). For Shakespeare (2006, p. 146), the disability movement, by taking a largely deconstructionist position on this issue, risks eliding a recognition of the very real personal experience of extreme dependency, including the inescapable reality of inequalities in the giving and receiving of care. Group members in the present study provided a strong and layered account of the often exhausting interpersonal complexities of negotiating relationships with employed care workers, with concomitant implications for quality of life. As was seen, the imperatives to "normalise" – not simply during rehabilitation, but implicit in ongoing cultural discourse – were very familiar irritants, which at times presented difficult challenges to the maintenance of robust self-worth.

Marks (1999a, p. 93) interprets the cultural view of dependency as repellent, as an artifact of a narcissistic drive to disavow split off, unmet dependency needs experienced during infancy. Disabled persons may enliven unconscious fears of a return to an infantile state of precarious dependency, mobilising the often shame-ridden, manic imperatives to control. Frosh (1991, p. 98) echoes the assertion that underlying the "glitter" of narcissistic society is an extreme fear and loathing of being dependent upon others, as such dependency would open the way for a repetition of the experience of maternal rejection which – threateningly – occupies the psychic shadows. The language of autonomy and independence, in this schema, represents a desperate attempt to escape the dread of infantile vulnerability (Treacher, 1989, p. 143). In Klein's (1957, p. 181) theoretical system, the profound destructiveness of infantile envy is intimately bound up with the hatred of dependency. The impulse of the infant is to mutilate and destroy the breast, expressly for the "powerful" ease with which it provides, and holds control of all that is good (ibid., p. 183). The demeaning attacks upon the "dependencies" of disabled people by society may, ironically, reflect envy of the fantasy of an idealised dependent state, in which primitive needs are accepted, and filled. Of course, this envy also incorporates hatred, directed at internal, split off infantile dependency, as well as that projected into the disabled individual. Hoggett (1992, p. 23) explains envious hatred as stimulated by a sense of absence or longing, which resonates with infantile emotional needs. Thereafter, envy may be interpreted as "both a desperate attempt to deny this sense of lack and an attack upon the things which prompt it" (ibid.).

Due to the anxieties evoked by the dread spectre of impairment, assistive technologies for impaired persons may, at times, be culturally construed as a "disability panacea", which happily "makes the problem go away". Whilst there is no doubt that a range of technologies are of immense value to many people with impairments (Seelman, 2001) – to begin, the adapted personal computer with which I compose this text – such "interventions" are too often used as evidence of an illusory "equality", which denies both difference and the material impact of discrimination. Typically, the latest device is heralded as the "new saviour" of disabled persons, whilst the applied practicality of usage, as well as the general availability of such products, is inadequately and uncritically assessed (Roulstone, 1993, pp. 243, 247). French (1993c, p. 44) recounts her experience of the library at the university where she was a student acquiring specialised computer technology, which would provide sight impaired persons with access to the cataloguing system. She sketches a familiar scenario in which, with much fanfare, the university publicly celebrated its achievement of "equal access". In actual fact, the paradoxical – but equally familiar – reality was that the system provided only partial, and highly laborious, access (ibid.; Litvak & Enders, 2001). Of greater significance, though, was the experience, reported by a host of contributors to the disability studies literature, of such interventions *de-legitimizing* the needs for personal assistance which inevitably remained. French (1993c, p. 44) describes the imperative to "gratefully" make use of such technology, as it has "been bought for the purpose at great expense" (ibid.). It is clear to see how, at an intra-psychic level, disabled persons are here invited into collusion with a fantasy which denies difference, whilst simultaneously circumventing social accountability for the stubborn reality of inequality. Assistive technology, for many or most disabled people, will never replace the need for personal assistance; instead "it can isolate the disabled individual, and firmly locate the problem of disability within the individual, thereby inhibiting societal change" (ibid., p. 46). Further, according to Shakespeare (2006, p. 49), the social model approach has colluded with such accounts through reinforcing the "fantasy" of a barrier-free and completely equitable Utopia, in which impairment exists, but not disability. The reality underscored by French (1993a) and others shows that there is a manifest materiality to the functional limitations of impairment, which is not always amenable to intervention; to reject this formulation is to elide the challenge of interrogating (and personally processing) our cultural discomfort with the universal human traits of dependency and difference.

## Control

*F: The thought of never being secure...and maybe I'm generalising here a bit, but that is one of the characteristics of what it feels like to be disabled. It's never having absolute security...and so to live your life having experienced, you know, complete security, probably means you now fill...quite a different space.*

*L: It's...predictability...there's just a higher level of predictability about your place in the world and your interaction with the world when you're not disabled.*

A profound, shared aspect of life with disability for group members was the experience of endlessly being required to relinquish control. Being embedded in complex systems of assistive relation, as well as dealing with the daily myriad of entirely unpredictable, stress-inducing difficulties presented by a prejudiced and barrier-ridden environment, meant that managing the inner experience of "un-control" was a constant challenge. Oliver (1995, p. 261) found that it was this lack of control over the physical and social environment, rather than the experience of impairment, which was at the root of manifest emotional difficulties amongst disabled respondents. Group members described the issues of control and management of personal and psychic boundaries as deeply interwoven, as the measure of control available was often contingent upon successful relational negotiation. Often, however, a chronic lack of the experience of mastery of one's environment was described, leading to the aggravation of culturally imputed self-judgments regarding the demand for autonomy. The lack of an accessible built and cultural environment, at times unreliable access to personal assistance, and the exhausting physical work of life with a severe impairment, was experienced as severely foreshortening opportunities for the expression of identity. Such expressions as personal lifestyle options, spontaneous choices regarding how to proceed with one's day, preferences in the pursuit of relationships, and much else, were overcome by the pragmatic needs of functional survival in an unready and un-containing social world. Murphy (1987) describes this deadening of ongoing self-expression in his life:

This loss of spontaneity invaded my entire assessment of time...It rigidified my short-range perspectives and introduced a calculating quality into an existence that formerly had been pleasantly disordered...

(Murphy (1987, p. 76)

Echoing group members, Murphy (1987, p. 76) mentions such everyday activities as going outside for fresh air, getting a snack, going shopping, or to visit a friend; all such enterprises now required careful planning, substantial effort and, most of all, the cooperative support of others.

The immense emphasis on autonomous control in the modernist western world shows in clear relief the subjective struggle for selfhood which is implied for those deprived of access to the trappings of narcissism required to bolster the social self. Again, we see how disabled persons may be appropriated as bearers of a consciousness of the universal struggles disavowed by others, through the denial of access to the material means of narcissistic defence. Mutua (2001, p. 112) highlights this extreme contrast in access to what we may term the "materials of narcissism", by comparing how disabled persons are often expected to be thankful for "just" having some form of basic access, whilst products, technology and living spaces are meticulously, indulgently designed in terms of not only the needs, but the *wants* of the nondisabled majority. Offering a contribution that fits interestingly with these reflections on disability and social narcissism, Hunt (1998, p. 11) remarks that disabled persons have a "special insight" to offer the human world, through the experience of living the "passive aspect that is one half of the human reality". He writes:

*Those who lead active lives are perhaps especially inclined to ignore man's [sic.] need to accept passivity in relation to so many forces beyond his control. They may need reminding sometimes of our finiteness, our feminine side in the hands of fate or providence.*

(Hunt, 1998, p. 11)

Finally, like Toombs (1994, p. 342), group members described life with a severe physical impairment as maddeningly truncated, slow and laborious. The sheer physical demands of embodied life with, for example, quadriplegia, mean that immense time and energy is expended upon the banalities of existence, such as dressing, washing, eating, routine physical procedures including toileting, and the like. In the words of Toombs (1994, p. 342), disability "truncates the forward directionality of time, pulling one back to an enduring present". Given the substantial impairment-related physical demands of life for group members, the inaccessibility, hostility and overwhelmingly excluding nature of the physical and social worlds presented to me as disturbingly brutal manifestations of the "careless" unconscious hostility of dominant society.

## **Depression and suicidality**

*F: I think my own journey is particularly lonely because...I feel I see the dynamics that other people...don't, and often times choose not to. It's the Pandora's box kind of moment, of kind of recognising...the real unhappiness of what's going on, rather than the surface unhappiness of it all.*

*M: ...and I think there's something there as well in terms of us developing an alternative, collective voice. You know, it's the same reason...why the long awaited for revolution never happened, that that level of passivity becomes expressed in...the least destructive form of self-hatred you can find...whatever that expression might be...I don't think that disabled people are even that enabled, I don't think we've even been able to express in material ways...or.... through beating people up...There's no...literally no lower power person to take it out on.*

*G: ...and then...we won the case, my mom was fine which was my big concern and I sort of decided that I would give it five years and then I'd call it a day, I don't want to live like this. And I was pretty adamant about that...And so my mom arrives home and she's been at the shops, and sees me floating in the pool. And I'm like thinking 'oh well that didn't work'. And that it's quite ironic that I'm so disabled I couldn't even kill myself [everyone laughs]. But she arrived and she was totally freaked out.*

The despair experienced by group members at various times of life tracked back, for the most part, to an excruciatingly painful awareness of a lack of authentic, real relating from others, in concert with the constant othering of denigrating imputations. In the first quotation, F reflects on his understanding of how the relational space around him has become profoundly distorted since he became impaired, starving him of un-affected, honest contact. Living in the teeth of a gale of projections requires the constant re-girding of self, especially when one is afforded limited access to the distractions, escapes or materialist opportunities for dissociation available to those not disadvantaged by exclusions based on disability or class. In the second excerpt, reference is made to this material deprivation, which may sideline disabled persons sufficiently as to render even simple expression of one's experience of injustice through social action impossible, or inaudible. In her view, the proneness of group members to depression and suicidality (all had experienced this), emanated from the constant need to be "nice", whilst internally managing powerful feelings of rage and loss at relentless experiences of denigration and exclusion. As argued earlier (see *Lives not worth living*, p.123), it was the imputed meanings implicit in such exclusions, as well as overt experiences of discrimination, which tended to evoke despair. However, and most malignantly, what such experiences would lead to was a vulnerable uncertainty regarding self-worth, as the mirroring of society served to confirm and resonate with psychic parts hostile to the self, paving the way for a growing confusion regarding the "real" meaning of impairment; that is, whether it did *indeed* (as per society's prejudices) imply an inherent devaluing of the self. Material aspects of the social experience of disability were thus, subjectively, very difficult to decisively separate from archaic internalisations regarding personal worth and entitlement. There was, thus, a litany of practical "exclusion issues" to deal with, but each of these also carried an emotional weight of meaning, which demanded time and energy in its addressing. The bioethics debate surrounding whether disabled lives are "worth living" represents a highly amplified version of the cultural contestation of meanings of impairment which continued daily in the lives of group members. What is referred to here is the battle to interpersonally, as well as intrapsychically, subdue or evict projected meanings which portray one's life as inevitably abject. As has been discussed, a "damaged" body does not lead in an unmediated fashion to a defective body ego. But damage to the body – in a cultural context of meanings – does have the capacity to disrupt one's ability to defend the self against universal anxieties regarding the value, nature and beauty of the self. Coleridge (1993, p. 37), in no uncertain terms, recounts his experience that rejection, in the lives of many disabled persons, has "catastrophic" results. Dismissal by a subtly or bluntly recoiling social world, he writes, "provokes despair and retreat, which in turn widens the gap and produce[s] further rejection and stereotyping" (ibid.). In my subjective view, the robustness of self displayed by group members in the face

of discrimination was remarkable; yet it was the very consistency with which all had to deal with (often subtly) perverse mirroring, which rendered the experience at times intolerable. What I perceived was the difficulty of maintaining a battle fought on two fronts, inner and outer, in which the re-aggravation of denigratory inner voices was an ongoing source of instability to personal identity.

Clearly, the under-diagnosis of depression (see *Lives not worth living*, p.123; Olkin, 1999, p. 47), as well as the pervasive pathologisation of anger amongst the disabled community both represent risk factors pertaining to mood disorder. In addition, some impairments (such as dementia or Parkinson's disease) may produce depression-like symptoms leading to difficulty in diagnostic differentiation, and consequent under-diagnosis of mood problems (ibid., p. 210). Research into the "quality of life" of persons with severe physical impairments such as quadriplegia too often makes little or no reference to the contravention of citizenship rights, nor to the crucial variable of the degree of political conscientisation of respondents (e.g. see Bach & McDaniel, 1993; Ingstad, 1995). Within such research, it is "adjustment to injury" which is incorrectly regarded as the appropriate primary focus of attention, rather than "adjustment to marginalisation". In my vicarious exposure to the responses of social networks to the onset, and chronicity, of severe physical impairments amongst group members, it was very clear to see how a logic which attributes subjective struggle to "naked" impairment, rather than a depressive illness, may readily obtain. Further, the implicit meanings of social mirroring, couched within the invisible hegemony of the medical model, repeatedly sow the seeds of a hateful self-blame, engendering the pull toward depression and inertia. With particular reference to disability, Charlton (1998, p. 77) names nihilism as a key aspect of oppression; in particular, a form of "alienation in its most desperate stage". Its range of social manifestations, including suicide, crime, domestic violence and substance abuse serve, via externalisation, to conceal the reality of one's oppression from the self (ibid.). However, in the experience of M above, she reflects that disabled persons may be so socialised into self-blame as to lack any external channel for such "acting out" of aggression upon others. In summarising her position, Adrienne Asch (Asch, 2001, p. 315) asserts that, in a world where all human life, regardless of health status, was appropriately valued, disabled persons would be no more likely to consider suicide than any other portion of the population. With characteristic vehemence, she then adds:

In a world that still systematically reduces the life chances for people with disabilities, the disability rights movement should fear a right to physician assistance in dying when there is so little medical or social assistance *in living*.

(Asch, 2001, p. 315 – my emphasis)

## Disabled superego

*L: But that doesn't change the fact that you've got a conditioned mind. You know, you say something, and all of a sudden, you're hearing yourself, and starting to judge yourself...it's like, you're just not good enough, you don't deserve to have good experiences.*

*R: I've got a mind that likes to try and solve problems. I think up problems just to solve them...And then I find myself confronted with my disability, and trying to work out, how can I actually solve the problem, and I would just beat my head again and again against the wall, because there was no logic...It's like...a conundrum.*

*J: I don't want to just be an equal human being or a...good disabled person... For a disabled person being exceptional, not just because they're disabled, but because they're exceptional, is kind of read as...a larger feat. But it means that the things I ask of my self are that much more intense, the road I walk is that much more...steep. There's very little room there for...fallibility.*

*F: But you see, where I'm coming from...I always feel I have to achieve, achieve and achieve, and I'm never happy with who I am...The disability makes it worse. I feel like...I'm never good enough. And that I have to not have ataxia in order to be good enough...That's how I feel, but I'm trying to change it.*

As touched upon earlier, one reading of Freud's (1916) essay on "the exceptions" views impairment (or femaleness) as leading to "defective" functioning of the superego, based upon the "inapplicability" of laws of morality and fairness (Jacobson, 1959, p. 139). My own impression from the data collected in the present study is, if anything, the converse. The multi-layered cultural imperatives placed upon disabled persons, incorporating a host of demands to normalise, change, "improve", and otherwise strive for the "overcoming" of impairment, seemed to consistently feed and revitalize the most stringent internal controls upon the self. The language of "solutions" (see *Solutions, entitlement and passivity*, p.282)

served to invigorate the superego, through always directing attention at "what is wrong", or should be done differently – that is, reasons why subjective struggle is *ultimately the fault of the individual*. Similarly, a familiar, colloquial discourse concerning disability presents a hegemony of ideas such as the moral directive to strive for independence, to "not make excuses", to transform "adversity" into "challenge", and to "refuse" to be "held back" by impairment. In a world which reliably ascribes disability-related struggle to individual factors it is extremely difficult to escape the nagging sense that: if one just goes about it the right way, is adequately assertive, asks in the proper manner, plans things more carefully, is more strategic, works harder at maintaining relationships, is more grateful for what one receives, and doesn't complain or be negative – amongst much else – one might find that one's difficulties are, in fact, largely of one's own making. The malignant potentials of such ascriptions of blame to the self, especially in the context of substantial, ongoing subjective trauma, are considerable to even the "healthiest" mind. The oft-quoted, even hackneyed notion of "victim-blaming" comes here into disturbingly vivid relief. Narcissistic culture creates an impossible ideal – the illusory state of normalcy – as a baseline criterion for legitimate, inclusionary personhood, drenching those who fall conspicuously outside of the curve in failure. In the face of damning unconscious and overt imputations, it may be immensely difficult for disabled persons to find the "thought space" to separate from these projected accounts of the self, being drawn, instead, into fulfilling the dynamic of projective identification by attempting to actively (even manically) "disprove" denigrating ascriptions. As should be clear, I regard it as elemental that this punitive superego structure be viewed not as a "pathology of disabled persons", but as the internalised psychic consequence of lives of damaging exposure to discrimination. Although, of course, it should be held in mind that all such self-punishment tracks back to abuse of some form, recapitulated by the internalisation of the authoritarian other. In addition, this particular juncture is one which shows up the ideological dilemmas of psychoanalysis as it is currently, predominantly, "enacted" – that is, the question of whether its operationalisation upon the current subject matter would effectively yield nothing but "individualisation", or whether some real subversion of the heinous cultural hegemonies at work here is feasible. One part of such hegemony is a positioning of disabled persons which militates against the capacity for self-compassion, through the inhabiting of a world which is bent upon obscuring and denying the reality of deprivation through discrimination or exclusion, or even the lived experience of impairment. This is internalised oppression; that is, a scenario where ideology has become internal, in a manner which maintains an interior surveillance which prevents the breaching of codes of silence surrounding the proximal, undeniable reality of symbolic and manifest violence. To the extent to which such internalisations predominate in the inner world, a full, authentic, self-acknowledging and nuanced experience of self will be precluded.

According to Davids (1996, p. 231), projected "psychic dirt" almost inevitably contains psychotic aspects of the projector, with the consequence being immense resistance to social change, as such change is contingent upon the "taking back" of disowned psychic materials. If psychic, and hence social, change is to take place under such circumstances, it will necessarily involve "great pain, anguish, and upheaval" (ibid.). If this account is correct, the investment of the dominant majority in the "retention" of received projections by the disabled community is immense; the alternative being a threatening onslaught upon psychic equilibrium. What this state of affairs points to is the "psychic payoff" accrued to the dominant majority by its (predominantly unconscious) ensuring of the maintenance of internalising forces of self-blame amongst the disabled minority. The individualising ideology of the medical model serves to shore up frontiers which force, and keep, unwanted psychic matter "inside" the target population, as waves of denigration and self-blame destabilise internal defences, leading to the perforation of boundaries. It is manifest oppression which renders disabled persons continually available as projective containers for the abjection of others; demeaning material circumstances pave the way for the gratification of narcissistic needs for self-exculpation and aggrandisement. The continued "functionality" of the projection depends upon the collusion of all in a fantasy that "some" humans, by virtue of "constitutional factors" carry such inherent, internal shames, whilst others do not (ibid.). Recognition of the universality of shame or wretchedness upsets the split, unfastening these fragments of experience from their psychic moorings, and "re-levelling" the intersubjective space, in a manner which exposes narcissistic structures to the marshy underpinnings upon which they are founded. Christopher Lasch's (1978; 1984) model of narcissistic culture bemoans the erosion of the "traditional" superego, founded upon paternal authority and the moral centrality of the family (Frosh, 1991, p. 66). But as already noted, there is a case to be made for the heightening of superego imperatives within narcissistic culture, in terms of the ever-more stringent requirements of the normate ideal. Yet, perhaps what we see is the disavowal – the projection – of superego imperatives into those who so palpably fail at the business of approximating the idealised human phantasm; viz. the disabled community. What disablism does, against the society-wide backdrop of viciously authoritarian obligations to "measure up", is turn on incipient failures, as a proportion of any population will do when fighting for selfhood under siege by a debasing, punitive authority. Within a social world dominated by a cultural hegemony which disrupts containment of its own humanity, it is inevitable that someone will have to be found to carry the humiliation of the collective.

## Disability and loss

### Introduction

Within medical and rehabilitation approaches to disability, the idea that disablement is necessarily associated with the psychic experience of loss is at least implied, and generally apparent (e.g. Solnit & Stark, 1961; Vash & Crewe, 2004; Siller, 1969). Similarly, public discourse and media representations of disabled people remain firmly attached to the construct of disabled life as incomplete, lacking, and constantly aware of what is lost, or was never had. As we have seen, psychological accounts of "adjustment" to disability have drawn on bereavement models, involving the expectation of stage wise progression through processes of "mourning" after onset of an impairment (Gill, 2001, p. 357; Oliver, 1995; Olkin, 1999; Watermeyer, 2009). Subsequently, the individual concerned is regarded as "needing" to move, within a process of psychological "working through", to a point of overcoming his / her "denial" of the "reality" of impairment, to a place of "acceptance", which allows for development towards creation of a new mode of living (Lenny, 1993, p. 234). The gaze of an anxious and unready world upon the lives of people with impairments, carrying as it does waves of disowned and projected human vulnerability, is steeped in assumptions surrounding the intractability and misery of loss (Watermeyer, 2000; 2009). The logic of disability loss seems no logic at all, but rather a self-evident "reality" emitting from the juxtaposition of culturally condensed (illusory) in-group bodily and performance ideals with unconsciously mediated, often sordid fantasies of what disabled life may be like (Marks, 1999a; Shakespeare, 1994; Watermeyer, 2009). It is unsurprising, thus, that this "disability loss" has been largely rejected by the disability movement, and notably by writers within the social model perspective (e.g. Abberley, 1993; Finkelstein & French, 1993; Lonsdale, 1990; Morris, 1989; Oliver, 1990; also see Watermeyer, 2002). All too familiar to swathes of the disabled community is the exploitation of assumed loss in the sentimentality and othering publicly exercised by certain disability-related charity organisations. Rituals of public benevolence such as the telethon (see *Charity discourse*, p.159) are, for their own existence, necessarily bathed in presuppositions regarding the "losses" of the "unfortunates" presented as stimuli for the generation of "much needed kindness" (Longmore, 1997, p. 140; Michalko, 2002; Thomson, 1997b).

The disability movement's vehement rejection of the ascription of loss by broader society emanates from an awareness of how the loss discourse situates disabled people as vulnerable and incomplete, feeding and justifying segregation and other forms of social control. Media representations of disabled lives nearly always – and often spectacularly – miss the opportunity for presenting accounts and images of disabled people simply going about the business of life, full, as it is, of the universal ups and downs of muddling through. Instead, the spectre of "tragic", numbing loss is never far away, regardless of whether the account is overtly concerned with deficits and dependency, or the "courageous" and "inspiring" overcoming of "adversity" (see *Artistic and literary representations*, p.157). The perceived loss seems to seep through the essence of the life under scrutiny, not limiting itself to particular instances of inaccessibility or impairment effects, but rather saturating the whole individual in a manner which colours subjectivity and identity completely. Disabled people, in contemporary culture, have become the personifications of loss (Marks, 1999a; Shakespeare, 1994). Being utilised as receptacles for the projection of feelings of loss involves being positioned as having "something missing" and in need of intervention, benevolence or consolation in order to mitigate the inevitable emptiness and desolation which attend such a life (Watermeyer, 2006). As shall by this point be clear, it is not my intention to support a dissociation of disabled persons from experiences of selfhood such as those pertaining to loss; rather, it is to critique the selecting out of disabled persons from the rest of humanity as the, ostensible, *primary custodians* of loss. The phenomenon of loss with which we are dealing refers to a ubiquitous, even essential, aspect of the human condition. To be alive, to grow and develop, to hope and relate, means inevitably to experience loss. At issue here is the manner in which access to that part of human experience in which one's losses dwell is distorted and perverted in the lives of disabled persons, through the deeply prejudiced constructions and controls exercised upon this group by a defended society.

## The loss discourse

*R: It's like with old friends of mine I used to know, and they'll see me at a party or something, and they can't relate. To them it's ... the whole tragedy. And so they ask me how are you doing and how's your work and stuff, and they want reassurance from me that I'm OK, which I'll duly tell them, and that's kind of that.*

*F: Oh, yeah, people pray for you. I've been prayed for so many times it's a miracle I can't walk. And people can be...incredibly rude and invasive about it.*

*G: I think, in my case, if I could move my arms, I could be seen to be doing something, but what I can do, people just don't see...they have no idea what I'm capable of or not capable of. All they see is me being fed and watered...not...doing anything else. Like a big...baby...I guess that's how they see it.*

Evident throughout accounts given by group members was the ubiquitous presence, in the social world, of powerful ascriptions of loss. The cultural imago of disability is one inseparably cemented to human loss, in a manner which opens the intersubjective space to waves of unmitigated projection, richly evident in the sentimentalising, "indulgent" tone of much popular disability discourse. Most of the history of psychology has, inadvertently or not, concurred with these representations, foregrounding the purported loss of the healthy body, of perfect function, or of the "wished-for child" (Olkin, 1999, p. 78). Insightfully, Olkin (1999, p. 78) identifies that the "repertoire" available to disabled persons within this structure of projected assumptions is one of "suffering, loss and mourning", or "continual pluckiness". The hegemonic construction of disability generates a view of impairment as the "negation" of the natural, allowing little or no conceptual space for an "additive" subjective difference. For example, apprehension of the world as a blind person, for Michalko (2002, p. 27), embodies a qualitatively different, novel and valuable addition to the store of human experiences of social life; in his experience, it is, however, construed simply as lack – of knowledge, of normalcy, and of ability.

An instructive example of the application of psychology's loss and mourning model to disability is provided by Thomas and Siller (1999). Drawing directly on Freud's *Mourning and melancholia* (Freud, 1917), these authors assert that patterns of emotional response to disablement "frequently" follow "identical lines" to those of losses such as bereavement (Thomas & Siller, 1999, p. 186). Key aspects of the adjustment process, in this view, include "shock, expectation of recovery, mourning, defence (either healthy reality formation, or neurotic use of defence mechanisms), and adjustment" (Kerr, 1977 cited in Thomas & Siller, 1999, p. 186). The trauma of the onset of disability thus is framed as demanding the performance of the "work of mourning" by the afflicted individual, in order that object loss may be absorbed, and a positive experience of self reconstituted (ibid., p. 187; Castelnuovo-Tedesco, 1981).

After more than two decades of research designed to validate models such as that of Thomas and Siller (1999), however, little evidence has emerged of any orderly or characteristic sequence of unfolding psychological reactions to disability (Gill, 2001, p. 358; Finkelstein & French, 1993; Oliver, 1995). Instead, disabled persons have been found to follow largely unique and individual styles of managing their life situations (Oliver, 1995, p. 261). Notwithstanding the time elapsed since writing, Oliver's (1995, p. 261) observation that psychological support for disabled people not rooted in a stage-wise grief model is relatively rare, remains overwhelmingly true. Deeply interwoven with the assumed need for grieving is an individual, medical account of the "real problem" of disability; one which, familiarly, largely elides contextual factors. Crucially, the grief model facilitates interpretations regarding an individual's internal state, or relations with others, in terms of the degree of "successful" or "adequate" progress made through the pre-ordained stages of adjustment (Gill, 2001, p. 357). Needless to say, the groundwork is thoroughly laid here for victim-blaming and pathologising attributions of what are – in all likelihood – profoundly *social troubles*. As we shall see, the denigrating and deeply individualising label of one who is "in denial" awaits those who intrude upon social harmony with signs of poor adjustment.

The disability studies literature contains, in a range of forms, adversarial responses to the imputation of loss. Amongst these are empirical studies which have produced evidence that many disabled people do not identify the onset of, or life with, a disability, as loss (e.g. Campling, 1981; Finkelstein & French, 1993; Lenny, 1993; Morris, 1989). Disability may be experienced as an enrichment of life, possibly leading to the questioning of hitherto invisible assumptions regarding the human condition and the workings of society. As we have seen, many writers have persuasively argued that the voicing of disabled subjectivity carries much potential benefit in the broad creation of a more human, caring and critical society (e.g. Davis, 2002; Michalko, 2002). At the core of the present work is the idea that disabled people must be afforded a silent, unitary and non-judgmental space in which to define and articulate their own subjectivity; a space uncontaminated by the symbolic violence and control of demeaning assumptions. Of course, there could be no justification in questioning the accounts of disability experience in the above studies, but of interest is their emphasis as defiant counterpoints to stereotype. Of concern is the possible extent to which such constructions – politically highly necessary – require an evacuation of accounts of disability which do carry aspects of loss and struggle. As has oft been pointed out, the question of whether such struggle is construed as attributable to impairment or disabling barriers remains of key political significance. But disability research which expressly eschews loss serves to collude

with the perpetuation of a false binary, which – again – embodies a silencing of real lives. Many authors have criticised "phenomenological" or "experiential" accounts of disability as supportive of medical, charity and dependency discourses (see *Prohibiting the personal*, p.42); perhaps these narratives have fallen into the same binary snare, but in the alternate position. The path, though, to a clear, nuanced and measured voicing of disabled subjectivity, surely is not the reactionary emphasising of the "positive" in response to a damning "negative"; what is required is an overturning of the dynamic discourse which underpins both accounts. Quoting the work of Arthur Kleinman and his colleagues, Rod Michalko draws attention to the formidable issue of where the "truth" of subjective "social suffering" lies; that is, the question of whether it is possible to escape suffering whilst steeped in cultural meanings which attach it to the very foundations of the self (Michalko, 2002, p. 67). Kleinman et al write, p.

Social suffering is a feature of cultural representation both as spectacle and as a presentation of the real...how we 'picture' social suffering becomes that experience, for the observers and even for the sufferers' perpetrators. What we represent and how we represent it prefigure what we will, or will not, do to intervene. What is not pictured is not real. Much of routinized misery is invisible; much that is made visible is not ordinary or routine.

(Kleinman et al., 1997 cited in Michalko, 2002, p. 67)

In other words, the representations of disabled life which predominate within society – that is, the grief and bereavement model – create exclusive spaces for the imagining of disabled subjectivity, which, in turn, inform social policy and resource provision responses. The more we "imagine" the suffering of disability within a particular thought paradigm, the less we are able to hear. It is my position that the discourse of loss, incorporating the use of ideas of mourning, denial and acceptance, has functioned culturally as a means of achieving mastery over the dissonant and frighteningly unknown phenomenon of disability (Watermeyer, 2009). The illusion that what has been "lost" can be circumscribed *from without*, to the extent of defining a process which must be negotiated in order to "integrate" this loss, serves as an essential vehicle for observer control needs surrounding disability, towards the stilling of unconscious anxieties raised by disability images. Typically, ideas regarding the overcoming of "denial" pertain purely to the imagined experience of impairment, whilst the lived reality of discrimination remains unconsidered, unnamed. This fact attests to the profound extent to which cultural constructions of disability, incorporating such ideas as loss, are mediated by

irresistible fantasies – projections – about impairment, rather than any grounded sense of the lived nature of disability. The "losses" to be dealt with, thus, are experienced as an affront by the disabled community because they exist in the minds and taxonomies of the observer, and, to some extent, for his or her benefit. The benefit here pertains to a "psychic payoff" (Marks, 1999a, p. 22) which arises out of the opportunity for a simultaneous distancing and indulgence of unconscious losses which are at the heart of the narcissistic mode of being-in-the-world (Frosh, 1991, p. 70). The high valency of resonance between such split-off wounds and the visible and salient "damage" of the "broken body", ensures that disabled persons function as a psychic lightning rod for "unthought" loss (Bollas, 1987). Disabled people's rejection of such ascribed loss, arising as it does out of a recognition that "*this is not mine*", provides a neat and confirmatory enactment of the "denials" which seem self-evidently to accompany such tragedy. Further, the rejection relates to the clear knowledge that any recognition – or *admission* – of loss by disabled people will tend to operate as a confirmation of expectations, serving thus to usher in a pre-existing and highly elaborated stereotype, which may cover, and hence silence, the individual entirely.

## Acceptance and denial

*M: And I think because...there's that desperate search for meaning...everybody around you [is]...desperately trying to find that same thing. Like, 'where's the silver lining here?'...so there's this...sense of desperation to the whole conversation...*

*L: I think, before there was this whole thing of we need to accept it. And then, saying I'd accepted it, when I knew I hadn't accepted it, and fighting with myself to accept something that I know I can't accept, because I can't accept it. Are there to many 'accepts' in that sentence?*

The central imperative placed upon disabled people within the grief and bereavement model is to "achieve" an imagined existential location of "acceptance". If problems, difficult feelings or "poor adjustment" is in evidence, this tends to be attributed to the individual's ongoing "denial", based upon a lack of adequate "dealing" with loss. But as shall become clear, the discourse of "acceptance and denial" (as I shall term it), is an inherently *dynamic* phenomenon, which fluctuates within the intersubjective space, often serving the containment needs of the observer. Sinason (1992, p. 141) teaches us how individuals who witness

suffering, or are witness to experiences which evoke their own suffering, and cannot bear it, will tend to encourage "happiness and smiling". Her extensive experience in institutional settings for elderly and intellectually impaired persons bear rich testament to these manic demands for the disguising of evidence of loss. In a deeply moving account of her experiences as a partially sighted child entitled *Can you see the rainbow?*, Sally French (French, 1993b, p. 69) describes constantly being surrounded by "anxious relatives who were trying to get me to see things". One can well imagine the fretful fantasies of the grown-ups around her, as they struggled to digest the unthinkable idea of their beautiful niece or grandchild being unable to see such things as rainbows. She describes being positioned with great precision, her head tilted by a gentle hand to exactly the right angle, before the adult would point to the sky, saying "Look, there it is; look, there, there...there!" She was acutely aware, even as a toddler, of the intense anxiety which would be evoked if she could not see what was being pointed out (ibid.). Quite quickly she learned that the best option for all concerned was for her to simply say "yes", perhaps exclaim with fabricated delight, and thus allow relations to overcome the impasse (ibid.). In this way, French (1993b, p. 69) was *taught* to deny her disability for the benefit of those around her; in the light of her – certainly not uncommon – familial circumstances, denial of disability was an *entirely rational* choice of action. It is not difficult to see how such pressures extrapolate to the broader society in every sort of relational context, with the disabled individual disguising or denying the lived reality of both disability and impairment in order to protect the feelings of others. In French's (1993b, p. 69) experience, even adults not emotionally involved with the question of whether she was able to see tacitly "required" denial, through a strong tendency towards disbelieving her, or interpreting her "not seeing" as manipulation or mischief. The pressure to deny continued for her throughout adulthood, though becoming steadily (and perniciously) more subtle and difficult to identify (ibid., p. 74). She writes:

Disabled adults frequently evoke anxiety and embarrassment in others simply by their presence. Although they become very skilful at dealing with this, it is often achieved at great cost to themselves by denying their disabilities and needs. It is not unusual for disabled people to endure boredom or distress to safeguard the feelings of others...In situations like these reassuring phrases like 'I'm all right' or 'don't worry about me' become almost automatic.

(French, 1993b, p. 74)

John Bowlby (1979, p. 405) directs attention to evidence that parents may, at times, press their children to "shut off" from the conscious processing of painful information. This may relate to knowledge, or the direct experience of events, which parents wish had been kept from their children. Of course, a key question in such circumstances pertains to *who is being protected* by such silence. In a case such as that described by French (1993b), parents and others may be operating from within a pre-conscious fantasy of *protection* of the child – from loss, failure, misconduct – which, in fact, manifests as an imperative to denial. Familial hierarchies may be substantially disturbed by such protectionism, as children learn to function as containers of the feelings of others. Bowlby (1979, p. 405) describes how situations where a child is subtly coerced into protecting adults from perilous knowledge are strongly associated with a range of psychological difficulties, including chronic distrust of others, inhibition of curiosity, distrust of one's own senses, and an experience of the world as unreal (ibid.). The essence of what he is referring to is the experience of "seeing", or perceiving, one reality, and being told that another reality pertains. In light of what we have seen, the incidence of this "template experience" throughout the life course of many disabled persons seems likely to be pervasive. What this amounts to, at its foundation, is the systemic withholding of containment; that is, a moratorium on what one is "allowed to feel".

In cases of the adventitious onset of impairment such as those of group members, the acute trauma experienced by the entire social system tended to create a similar milieu, of projection, protection, uncontainment and silence. The following excerpt is representative:

*R: Yeah, like this guy came in and said 'you're never going to walk again', and it just didn't sink in at all. He said 'you won't be able to move your arms again'; yeah, right. You can't comprehend that. It's impossible, it doesn't make sense...it just doesn't gel. And then, also the reaction of other people is very strange. And suddenly you're this [horrified sound] tragic figure and people you've known all your life are coming in and walking out crying and you think 'what's going on?' It's very odd. And there you are comforting them...[It's] very paradoxical. One of my best buddies came, he stayed a bit. And he kind of said I want to come and talk to you, I'm battling with this. And I remember being in hospital, my head kind of still in traction, and I'm like 'don't worry Doug, I'm strong, I'll be fine'. And he's cracking up by my bedside...but...you lose a lot of people you're involved with because they can't handle the situation.*

From the first moments of regaining consciousness in his new life as a quadriplegic man, R became aware of the pressures to contain others, as familiar faces above his bed crumpled and turned away. In the midst of the denuded, seemingly boundless and chaotic feelings which reverberate through a social system after a traumatic accident, a tone was immediately set which required him to safeguard contacts by reassuring those around him. In time, though, much of this safeguarding proved ineffective, as others tended to withdraw – this is common in circumstances of the traumatic onset of severe impairment (Braithwaite, 1990, p. 469). Against this background of horrendous, primitive pain, the *individualising* imperatives of the discourse of acceptance and denial are shown up as a ludicrous and atrocious miscarriage of equity. Further, the violent marginalisation of R's own feeling response to what is, in fact, his predicament alone, is all too evident. Health professionals in acute care settings dealing with such trauma have been shown to share deep pessimism and emotional avoidance around the newly impaired, compounding the culture of silence (Basnett, 2001, p. 454).

What these disabled people have been symbolically taught by the shaping of relational dynamics is that their inner experience and nature is intolerable to others. It is upon this marshy, false ground – this most *insecure base* (Kraemer and Roberts (1996a) – that self must somehow develop, and find solidity. Behaviour labelled as individual "denial" is likely, in fact, to be a complex struggle with the "titrated" losses and shames of entire social systems of narcissistic *denialism*, channelled through the bodies and minds of disabled persons by virtue of the cultural meanings of non-normative "carnal information" (Paterson & Hughes, 1999). Above all, such meanings are not solipsistic in their emergence and course, but deeply social, dynamic, and interactively pragmatic (Rapley, Kiernan & Antaki, 1998, p. 809).

## On being "un-disabled"

*L: The problem with this idea of heroes...there's pressures put upon you to be Superman, like 'you're amazing', or like 'I'm your biggest fan', and we've never even met before. And so you do so much, and there's just not a balance. You can't be just a regular guy trying to get on with your life...they elevate it to that status ... And that gets in the way of just...being.*

*G: And so...you work harder to be seen that you can do it. Or you try to. And even in yourself, it's like, 'am I wasting my time, am I not?'; 'am I tired, how tired am I?' You can get quite confused about it.*

*J: ...it's almost a case of if you can't join them you try and beat them... 'if an able-bodied person can climb Kilimanjaro, then so can we'. I think it has...a psychological flavour of 'we're going to do things you recognise', but, because we're doing them everyone recognises that it's fundamentally different...And I think that's a process of trying to find...a positive way of being different.*

In *Moby Dick*, Herman Melville's Captain Ahab lives a life predicated upon the need to resist categorization; that is, to repeatedly, infinitely prove that he has not become what the world expects him to be (Kriegel, 1987, p. 34). As a disabled man, Ahab feels the strong currents of cultural expectation that would construe him as broken, useless, and defeated – his life is thus an exhausting, yet tireless, project of overturning these anticipations. Along quite similar lines, F.D. Roosevelt knew all too well that, if he was to lead the United States, he would have to present a convincing, vigorous "un-disabled" counter-narrative of his life to the American people (Finger, 2006, p. 64). To replace the colloquial attributions of tragedy, loss and shame, Roosevelt formulated a story of triumph over impairment, presenting himself as a man who had been galvanised, not weakened, by his disability (ibid.). In addition, he took great pains to ensure that "disabled" images of himself were tracked down and excised from public view. What Ahab and Roosevelt's stories show up is the phenomenon of disabled persons being made responsible for "undoing" the perceived or real implications of their impairments. In a culture which celebrates the "supercrip" (Marks, 1999a, p. 75), disabled persons are drawn into lives of attempting to disprove that which is contained in the hail of projections launched by society. In other words, one may be drawn away from what is internally real by irresistible, profoundly evaluative social forces which dictate what one should try *not to be*. More specifically, this may mean striving to disown parts of experience or self which in any way hint at, or resonate with, the stereotypes directed at one each day. These are forces which militate strongly against the capacity for self-empathy – against the ability for recognising, in a compassionate and candid way, what one's struggles and experiences mean to the self.

The evidence of an awareness amongst disabled people of a need to avoid being squarely positioned within pre-existing stereotypes is to be found in the sometimes self-punitive excesses of "anti-stereotyping behaviour", often to be found in popular media (Watermeyer & Swartz, 2008). These stories deal with fiercely "independent" disabled people undertaking fantastic physical challenges, in a manner which seeks to overturn stereotyped assumptions

concerning their abilities, or lack thereof. The media experience is a familiar one; viewers' hearts are warmed by the reassuring knowledge that, despite their "challenges", disabled people, in their remarkable resilience, have the character and courage to "overcome" their deficits. What is at work here is, in my view, an amplified version of an everyday predicament which disabled people find themselves in. This position is one ensnared within an absurdly limited, split repertoire of identity ascriptions; the "hero(ine)" who "overcomes", or the helpless invalid (ibid.). Under the rubric of the former, the stereotype-busting behaviour referred to above may be interpreted as a response to assumptions regarding severe vulnerability, dependence, inadequacy, or whatever; in "managing" these, the individual eschews every last fragment of such human fallibilities, in performing superhuman feats. Ironically, it seems likely that such exceptions, reassuring though they may be to the observer, serve more to confirm the rule, the stereotype, than to overturn it (ibid.).

The centrepiece of my approach to psycho-emotional aspects of disability (Reeve, 2002; 2006; Thomas, 1999a) is the notion of being drawn to *define oneself in opposition* (Watermeyer, 2009). The barrage of stereotyped expectations and demeaning assumptions under which disabled people survive, create a climate in which the disproving of negative imputations must, of necessity, often take precedence over the exploration and expression of aspects of the self. If this work of resistance were not undertaken, the extraordinary robustness of disablist prejudices would, it seems, simply cover disabled individuals completely. Instead, it is left to such individuals to strive not only to overturn expectations of, let's say, dependency, but to attempt to ensure that no shred of evidence may be found in their behaviour to support attribution of such a trait to them (Watermeyer & Swartz, 2008; Watermeyer, 2009). Any hint of dependency needs will, most likely, not be fed into a nuanced and integrated picture of the individual concerned, but rather tend to contaminate and colour the full human impression, rendering "dependency" as an essential and enduring part of ascribed identity. Of course, in practicality it's often impossible for disabled people, notwithstanding ongoing efforts and awareness of the implications, to fully avoid displaying behavioural evidence which may touch upon incipient stereotypes. Inhabiting an inaccessible, inequitable world of disablist exclusions makes this so.

In essence, what we see here is a form of oppression in which disabled people are, if demeaning stereotyping is to be contested, precluded from being allowed to show or communicate universal aspects of human emotional life, such as loss. In a deep, yet somehow

familiarly resonant irony, persons forced to occupy positions of material deprivation and ostracisation by a disablist world, are simultaneously disallowed from articulating – even consciously experiencing – the possible emotional implications of their predicament. As in all such situations of identity in which binary tensions are created, a proportion of disabled people negotiate their worlds by capitulating to imputed stereotypes – that is, allowing behaviour and utterances which may re-voke and confirm depersonalising prejudices; these persons "become" "the Disabled" characterised in the stereotyping of society. For these people, perhaps there is some experience of acknowledgement or mirroring buried between the disablist assumptions which may surround them; that is, some experience of real, human struggles being partially "validated", as if by coincidence, through the ascription of a social identity with suffering at its centre. Or perhaps a form of internalised oppression is at work, in which disabled people have, through life-long subjection to distorted and malignant socialisation, come to experience themselves as nothing more or less than the stereotypes dictate. The same distorted socialisation may support the alternative, anti-stereotyping (and often self-harming) position, for reasons that pertain as much to the looming fear of fulfilling internalised stereotypes, as the threat of imputations from the social world. Here, individuals may seek to excise the presumed, demeaning implications of impairment, not only from the minds of others, but also from one's own mind.

Thus it is that a continuum of disabled individuals, from those engaged in the most vigorous "stereotype-busting" behaviour to those quietly smoothing over the jagged edges of interpersonal misattunement, are not attempting to "overcome" their impairments, but instead are attempting to *overcome imputed stereotypes*. The need to do this may, too often, result in the de-prioritisation of more intrinsically fulfilling styles of living. After Kohut (1966, p. 68; 1972), we may construe the cultural milieu surrounding disability as one in which the withholding of appropriate narcissistic ("selfobject") experiences from disabled persons renders potentially tortuous attempts at re-creating a positive self, interspersed with capitulation to the denigrations of the world. I hasten to indicate that this view in no way represents a categorical judgment, let alone "pathologisation" of the life-activities and strivings of disabled persons. Instead, it is simply my intention to direct concern toward the very real, conflicting and bewildering imperatives placed upon disabled persons by the incipient dismissals of society; the authentic – and, doubtless, diverse – nature of individual motivations can only be ascertained by introspection. My application of Kohut's (1966) ideas on early narcissism is intended as drawing attention to the immediate, intersubjective dynamics which shape the positioning of disabled persons, rather than an assessment of more

enduring personality attributions. However, as I have argued (see *Trauma and its re-enlivening*, p.253), my position is one in which ongoing, systemic distortions of relational life around disability afford the selective confirmation of the more disturbed aspects of self which all carry.

In one key respect, then, "identity" within the disability realm operates in a manner inverse to the norm. Instead of carrying points of identification along with elements of othering, "identity" here is predominantly about *rejecting ascribed difference* (Watson, 2002, p. 515); in essence, identity is about "what I am *not*", rather than "what I am". The "adaptation narrative" (Michalko, 2002, p. 139) implicit in "stereotype-busting" serves only – like all "mime" – to underline difference and the internalisation of the attribute of lack (Taussig, 1993, p. 13). Mimesis would not occur without the implicit recognition of inferior difference; in the act of imitation, such difference is re-created and confirmed (ibid., p. 17). So it is that disabled persons are called to "remake" themselves as "able-bodied". In the "inimitable" words of Murphy (1987, p. 20), the "first commandment" of illness or infirmity is "*get well*" (my emphasis). In psychoanalytic terms, Taussig's (1993) ideas reflect the inevitability of the unconscious enactment, in which strivings to evacuate derided aspects of the self incorporate an *in vivo* manifestation of just those characteristics. Freud (1909 cited in Sinason, 1992, p. 42) captures the double-bind as follows: "...the thing which is warded off invariably finds its way into the very means which is being used for warding it off".

## Disability, entitlement and loss

*M: ...what I think...is that if I was more accepted in society, that I wouldn't be feeling the loss as much as I do...because...I would have a lot more support around me. As a community, that would be helping me get through this, but as it is it's just like 'this is your problem, now cope with it'. The best thing would be if I could just like say to some guy, 'you know I really wish I could move today, it's really crap that I can't move at the moment'. And to turn to anybody and be able to say that. To say this is how I feel.*

*R: ...I don't know if I would use the word acceptance. I'd use the word...adapting ...Yeah, and saying, well, this is what I have to deal with and I make no excuses, I have to do this now. And I'm going to do it.*

*J: [on the disabled community]...there's...so much trauma...And it confirms in my own mind a suspicion...that...great people are really forged out of fire, it's really when you're going through those amazingly trying periods in your life...where those people who are phenomenal people because they are forced to make difficult decisions about who they are, and who they want to be. And they become very conscious about that journey. But on the other hand they are broken people, they are scarred people. You know, that's kind of the price you pay for the knowledge you get, you pay the price.*

Throughout the group process, there was seldom doubt regarding the ongoing reality of losses experienced by members. But the losses described were complex; a layered amalgam which incorporated impairment, but was typically flavoured, and given personal meaning, by social ascriptions. The malignant cultural attributions to the impaired individual suffered by group members created a complicated, highly ambivalent relationship with the notion of loss, perverting clear, self-empathic experiencing of subjective struggle. At the best of times, acknowledgment of loss to the self is a painful and risky experience; but it is way more hazardous when such "real-ising" may bring renewed force and certainty to the stereotyping one suffers, as well as heightened, anxious suspicion regarding the *correctness* of such stereotyping.

The essence of the affront, the oppression, of the loss discourse for disabled persons is that, like all humans, these individuals must and do hold loss, but typically not the losses attributed to them. Some losses relate directly to disability, some do not; often disability and impairment are interwoven with identity and experience in a complex narrative which renders separation or identification of "disability losses" meaningless. The very real danger for disabled people is that this sphere of human experience, of self, may be rendered less admissible or possibly banished entirely from view, under the host of moral imperatives exercised by a medicalising society; to overcome, normalise, disguise, defeat, disown, defy, or otherwise void, the perceived emotional trappings of disablement.

Within the Kleinian view of personality, authentic relating centres upon the ability to allow oneself and others to be in touch with, and communicate, loss (Frosh, 1991, p. 75-6). When, in relationship, we are positioned in a manner which permits the conscious elaboration and communication of loss, we become more real and internally whole, fostering a healthy entitlement based on compassionate self-insight. Bringing loss to light and consciousness is

constrained, to a greater or lesser degree, by the conditioned shame which is our universal (human) legacy. A cultural environment in which Western morally coded ideals of autonomy, performance and perfection predominate, serves to cement this shame, in a manner which may feed into a punitive, internalised self-alienation. These constraints confront us all; what is at issue, though, is the extent to which an especially severe sanctioning of expressions of loss – positive and negative – is imposed upon disabled people. The incipient presence of loss-related stereotypes in the social world serves, for disabled people, to heighten the pressures of what is and is not permissible, in terms of the familiar imperative to "successful normalcy". The human struggles are universal, but our anxieties surrounding disablement manifest in the selective disallowing of entitlement of disabled people to have, show and communicate these. In mediating the extent to which any individual feels free to think and talk about loss, an important consideration may be whether he / she feels that the disclosure will contaminate his / her identity in the view of the listener. We need to know, if we are to show difficult, even shameful, parts of self, that we will "remain the same" to the other, and not become viewed as somehow sullied, or saturated with the pain or loss we are negotiating. The courage to describe the experience of loss incorporates a trust that the listener will hold onto the knowledge that "this is not all that I am"; again, these are universal human challenges. For disabled people, however, the risks of this already delicate social situation are often amplified, by the fact that it is not simply the utterances of the disabled individual which are at play in mediating his/her social identity, but also the evocation of pre-existing disability-fantasies of loss and struggle within the listener, which are sparked by a conversation which touches on loss. In short, a range of self-fulfilling prophecies about the experience of being disabled are often waiting, in the mind of the other, to be confirmed. At both a conscious and unconscious level, the position which disabled people may be drawn into assuming is one of defending against welling negative imputations or ascriptions in the other, as a sort of preparatory default. The painful reality is that, as unconsciously mediated prejudices surrounding disability remain largely entrenched and uninterrogated, the constantly attendant vision of the disabled person for whom loss is "all" that he or she is or could be, is never far away, and slips neatly into place unbidden, even unnoticed. Disabled people may consequently be left in a paradoxical and invisible borderland, carrying attributions of (inter alia) "losses" which are not theirs, and living with the invisibility or concealment of experiences of loss which are real, unique and human aspects of identity.

The silencing of social forces is considerable, yet the concealment of emotional experience such as loss may be viewed as a form of collusion with disablism; a pandering to the fears and prejudices of the majority, in a manner which does not track accountability back to oppressive cultural formations which may be implicated in creating the "losses" at hand (Abberley, 1987; Csordas, 1988; Oliver, 1986). Instead, it may be interpreted as a sort of "walking on eggs" around the awaiting threat of prejudiced assumptions. It seems intuitively true that, as long as such self-censorship is maintained, life will continue to be breathed into the dynamics of constructed difference which such unrealness is a response to. It is the mode, the tone, of such social spaces which disabled people may be forced to occupy, which is most disquieting. This is a hesitant and ambiguous place, not truly "being", yet searching for authenticity, whilst anticipating rather than relating; a place of inherent relational compromises. Disabled people coerced into occupying this borderland must surely find it harder to develop a grounded and confident voice; one simultaneously aware of the internal implications of oppressive phenomena, and clear and coherent entitlements to inclusion. Finding such clarity in the midst of the cauldron of cross-cutting, deeply conditioned and unproblematised cultural associations to disability – to which disabled persons are themselves equally subject – must, at the best of times, be challenging. But being required, in addition, to cater to the prejudices of others through selecting out aspects of relevant experience surely embodies a diminution of self, and the losing of ground in disabled people's struggle for an autonomous and audible voice. This, though, in no way elides the reality that moving towards finding such a voice is a very difficult task. Internalised uncertainties regarding justice and entitlement are as much a barrier to the clear articulation of experience as anticipated othering; the two concerns are one, mutually constitutive, and often experienced as continuous. Finding one's way to solid ground in the midst of this gallery of voices, past and present, is the work of an internal reclaiming of self.

In stark contrast to the social modelist call to eschew all evidence of loss, my own position is that personal and group empowerment for the disabled community is to be found via the deliberate and thoughtful *claiming* of loss (Watermeyer, 2009). The notion here is one of disrupting the stereotyped meaning splits between stoic strength and misery, by turning, carefully, to internal referents rather than external constraints. This means embarking on the work of weaving a more overt narrative of personal meanings in which losses and hopes are mingled and interwoven. The identity of "disabled", in this schema, has varying salience, as it relates closely to some losses, less or not at all to others; the enforced attachment or dissociation of loss from disability is rejected. Instead, loss and other painful aspects of our

existence are welcomed back, reclaimed as precious and hitherto colonised, and honoured in one's own words, as disabled subjective life assumes its rightful place within the continuous stream which is the human condition. The project of reconfiguring a world of visible and invisible, active and structural forms of discrimination and exclusion can, surely, only be possible if the nature of disabled life in a disablist world becomes more fully known and described – the present research enquiry is a response to this logic. There are many layers to this experience, and it is both naive and unjust to assert that disabled people simply "know" what is wrong with the world, what it means to individuals, and what ought to be done. There is much that we do know, but there is also much that we all need to find out for ourselves. It seems clear that allowing the development of an understanding of personal meanings of loss must form one crucial arena of this work.

## CHAPTER SEVEN

### Conclusions

*G: ...well, I think it's a process of grappling with meaning, you know ultimately that becomes my way of finding control. It's understanding...the nature of the dynamics which lead to...the way things happen. In many ways it allows me to normalise my life. Because...if you don't understand these dynamics as having these kinds of root causes, you end up being...sucked that much more into them, and...in many ways...I end up feeling more disabled when I don't feel like...I get it. That's been an over-arching experience from the initial injury...initially the ways a lot of people reacted to me just didn't make sense at all. But then slowly, over time, you start to understand the patterns.*

The basic social institution is the individual human heart. It is the source of the energy from which all social action derives its power and its purpose

(Dass & Gorman, 1985 cited in Coleridge, 1996, p. 96)

### Concluding reflections

The essence of the psychological predicaments of people with impairments within disablist society which the study brought to light, may be succinctly expressed as follows: The physical experience of homelessness manifested by a discriminatory material world is mirrored and recapitulated by an experience of *psychic homelessness*; of "nowhere to be". As the physical and cultural misattunements of a barrier-ridden world repeatedly exclude, reject and deprive the disabled individual, so the social world denies the disabled self recognition and containment, the experience of being seen and known, and an accepting place for authentic relating. The experience of bearing signifiers of dreaded human frailty brings with it a constriction, in the other, of psychic space available for the business of human contact. As the insufficiently containing mother, due to her overwhelming internal concerns, cannot make psychic space for her infant, so it is that the dominant cultural milieu cannot make space for disabled life, as exposure to impairment renders the intersubjective field thick with unconscious struggle, projection, and defensive alienation. The distortion of psychic

boundaries in the lives of disabled persons may exist as a broad social system of interlocking constraints on self-expression, which extend across social environments, as well as the life-span. The obscuring of self is common across social groupings which suffer oppression; yet in the lives of disabled persons it is typically people with whom one is deeply identified who may most powerfully constrain one's self-realisation. The extreme evocativeness of the impaired body may render relations – in the family, the school, the workplace, the social world – ridden with the protection, collusion, guilt, reparation and repression characteristic of false self dynamics. Finding clarity on where one's psychic self begins and ends may, in the context of such a milieu, be especially difficult for disabled persons, as parts of self are continually inserted and extracted by a deeply unconsciously invested social world. The silencing censure on disability-related subjectivity – in particular, that relating to oppression – renders a substantial layer of experience, and hence of self, "unspeakable".

Cultural representations of disability have tended, subtly or overtly, to construe disabled subjectivity as somehow intrinsically different, and separate, from the broad trawl of the human condition. As has been argued, such a pernicious misapprehension reflects defensive needs for distance from the looming threat of unconscious materials which the disabled figure evokes. With the universal human commonality of subjective struggle in mind, the picture which begins to emerge is one in which the material discrimination of disablism tends to concretise – to *realise* – human abjection in the lives of the disabled minority which exist, in fact, within all. One may make sense of this postulation as a form of projective identification upon a society-wide scale, in which disabled persons are appropriated as the projective containers of the psychic "excess" of a narcissistic world. In the face of such appropriation, it may be extremely difficult for disabled persons – as for members of all oppressed groups – to locate, realise, process and voice the deep, authentic nature of experience and self. The accessing and integration of self is fostered through accurate mirroring from an empathic and inclusive world; in the lives of the severely, visibly disabled participants in the present study, such attuned responsiveness was chronically thwarted by unconscious "noise" which tended to inundate the intersubjective space. If one combines this lack of acknowledgement, of authentic relational contact, with the constancy of prejudice and denigration (overt, subtle, symbolic) present in the narratives of group members, one apprehends a psychic predicament of the continual internalisation of attacks upon self-identity, in which injustice, unfairness and misrepresentation are commonplace.

Robert Murphy viewed his paralysis as a "splendid" arena within which to study the place of the individual within human culture (Murphy, 1987, p. 4-5). To Murphy it was clear that the relationship between, on the one hand, "society and its symbolic standards for acting and evaluating", and on the other, the "strivings and interests of ordinary people", was one of unremitting conflict. The individual and societal realms, far from being sensitively adjusted (*attuned*) to one another, are inherently at odds, thus typically rendering human history a contradiction of both human intentions and cultural values (*ibid.*). The lives of disabled persons, within Murphy's schema, embody the denuded reality of this cruel conflict; in his view, disabled people represent "humanity reduced to its bare essentials" (*ibid.*, p. 5). The study of the tenuous, perilous position of disabled people on the margins of society will thus reveal much regarding the hidden nature of all social life (*ibid.*). It is, perhaps, in such lives that the brutality implicit in modernist mores comes into haunting relief. Later in the same work, Murphy (1987, p. 157) underscores the centrality of the existential, the intra-psychic, in social oppression, commenting that the "most lasting" benefits of struggle against domination are the "transformations of consciousness of the combatants". Such "transformations", in the lives of disabled people, must incorporate escape from the imperative to live lives devoted to the constant disproving of negative imputations, in which self is lost amid the clamour of conflicting accounts of the true nature of identity.

The *ongoing* nature of material deprivation and symbolic violence sustained by the disabled minority tends to perpetuate the societal status quo, as this constant challenge to well-being militates against the clear recognition of ideologically obscured, although everyday, disadvantage. Most of the energies of the participants in this study were taken up by the business of survival in a hostile world, leaving little for the purposes of resistance and interrogation of lived predicaments. A constant exposure to denigrating imputations will, for any population, at times draw the individual into conscious or unconscious self-injurious ruminations, as the "conundrum" of deprivation seeks resolution in self-blame. Murphy's (1987, p. 4-5) reflections on the conflict inherent in the relationship between individual needs and cultural currents is illuminating, in demonstrating how the intolerance at the heart of the modernist ideal is shown up in the case of the disabled minority. The "societal container" which is co-constructed by dominant cultural forces within society, is receptive to the needs of individuals in a *highly conditional* manner. The carefully designed, technological responses to individual "wants" so characteristic of modernity are, it seems, reserved for those afforded inclusivity by virtue of a temporary ability to avoid flouting the prescriptions of the normate ideal. In turn, it is these "trappings of narcissism" which have psychic utility in

reinforcing defensive systems which disavow the "excesses" of human frailty, of struggle. This combination of othering and material deprivation locates the disabled minority as a docile receptacle for the "psychic dirt" of a mainstream culture seeking, in fantasy, to overturn its mortality. But in the very act of re-creating this hegemony of the normate, dominant cultural forces prepare for themselves the shunning and cruelty that awaits all in the wake of the breakdown of the body. The anomalous cultural location of age-related *disability* as simple "ageing" forms a clear demonstration of pre-conscious awareness of this contradiction. In the case of the disabled community, the (incipient) malevolence which cultural forces hold toward individual interests is brought into dramatic relief, heightening states of paranoia regarding individual abilities to fulfill the conditions of inclusion. Such anxieties, though, will only serve to further rigidify forces of othering, reinforcing the individual's safe distance from the "abject". The "societal container", thus, offers experiences which selectively enliven this abjection in some, whilst providing the means for narcissistic defence, and the disavowal of human struggle, in others. The disabled minority, thus, arguably is required to contain the "excess" of all, whilst offered the *least material and relational means* for the digestion of these existential materials. The "imperative to silence" surrounding the subjective life of disabled persons – that is, their "emotional oppression" – forms a key aspect of this cycle of deprivation.

The picture of subjective life with impairment in a disablist society which was provided by the data in this study, is one which portrays such lives as psychologically gruelling. Constant attacks upon selfhood from the social world, in addition to the everyday challenges of human life, demanded of the individual a great deal of psychic integration, of awareness and flexibility, of tolerance of ambiguity, and of the capacity to independently contain primitive anxieties. For any human individual in such circumstances, being able to live in an open, engaged and hopeful way will require immense personal effort and courage, since little containment is provided by the material and social world. The symbolic experience of being unmanageable – un-containable – by the world was consistent, requiring repeated effort at turning toward inner resources in order to make sense of often painful lived realities. Against this backdrop, the lack, within the social model movement, of any substantive theoretical approach to the psychological predicaments of its constituency represents, in my view, a serious obstacle to the development of a conscientised, articulate and united movement for social change.

With Danermark and Gellerstedt (2004), the findings of the present study suggest that injustices to the disabled minority cannot be adequately accounted for solely by cultural, economic or biological mechanisms, but must instead combine levels of analysis, mechanisms and contexts in the creation of an integrated model of disadvantage (Danermark & Gellerstedt, 2004 cited in Shakespeare, 2006, p. 54). The ubiquitous presence of splitting surrounding a field so ridden with (manifest and perceived) trauma has been discussed at length, and has formed a key determinant of the various modes of reductionism which characterise biological, materialist and cultural approaches to understanding the marginality of the disabled community. The work of Irving Zola is exemplary here, in rejecting the "monochrome" languages of medical or social models, in favour of a broad-based curiosity regarding experience, analysis, and political strategy (Zola, 1982; 1988; 1994; Williams, 2001). Such flexibility, and willingness to incorporate diverse disciplinary contributions, is essential if a coherent "psychology of disability" is to be developed, which rests upon a consensual theoretical base, and is able to "contain" a significant proportion of the lived reality of the disabled community. Surely, such a psychology must be built upon the "bridges of commonality" which connect all humankind; that is, the universal existential conflicts that, according to the present study, are manifested in the lives of disabled individuals via the workings of disablism ideology. As in racism, it is essential that a psychological account of disability foregrounds the universality of human struggle, and thence accounts for dynamics of the psychic appropriation of oppressed groups in its managing. In other words, a "psychology of disability" is by no means restricted to being a "psychology of disabled people".

What a growing recognition and voicing of disabled subjectivity will render is a rich store of existential narrative on the human condition, as well as an incisive critique of the underpinnings of modernist society. The "grotesque" or "carnavalesque" body bears, in its very nature, the capacity for social critique, via the transgressing – the confounding – of dominant social categories. The implications of insights gleaned from the lives of those most directly oppressed by the "ideology of the body" have rich relevance to all, as all are ultimately subject to the prescriptions of the normate. The ("uncanny") instability of the disabled identity is what will allow disablement to transcend the illusory surfaces of dominant constructions of identity, beckoning all to a united humanity which transcends and defies categories. This is the vision of what Davis (2002, p. 4) terms the "dismodern" age; here, "the instability of disability...becomes a subset of the instability of identity as a whole" (Davis, 2002, p. 25). Wendell (1997, p. 267), with a similar tone, notes that "the oppression of

disabled people is the oppression of *everyone's real body*" (my emphasis). The rich potential of the subjectivity of disabled people lies, for Wendell (1997, p. 274) not only in the fact of their having experiences not available to the nondisabled majority, but in their ability to "transcend cultural mythologies about the body, because they *cannot* do things the able-bodied feel they *must* do in order to be happy, 'normal' and sane". Disabled people, thus, must carry and know what lies "behind the mask" of the narcissistic ideal; that is, what of humanity is most routinely lost amongst the hubbub of commodification, competitive autonomy and "normotic" constriction. If disabled people were to become truly heard, this would render "an explosion of knowledge of the human body and psyche" (ibid.), releasing creativity and imagination from the constrictions of normalcy.

At the end of this journey, we return to George Eliot:

If we had a keen vision and feeling of all ordinary human life, it would be like hearing the grass grow and the squirrel's heart beat, and we should die of that roar which lies on the other side of silence.

*(Middlemarch – George Eliot )*

The "roar" of which Eliot speaks is the existential muddle, the hum, of ordinary life within the human condition, which is inevitably characterised by loss as well as hope, love as well as hatred, and disintegration as well as wholeness. The "integration" of the disabled minority, consequently, is one which must occur on multiple planes – material, cultural, psychic – and for all, as lost fragments of experience and self are re-gathered, within a uniting vision of the common fallibility of humanity.

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## APPENDIX

### **Group psychotherapy with severely physically impaired adults: Aspects of process**

In this chapter I explore noteworthy aspects of process which emerged from the psychotherapy group, and attempt interpretations of these which relate to the lived experience of disability described by group members. Later, I pay particular attention to features of my countertransference experience within the group, drawing some tentative conclusions regarding these pressures in clinical work with disabled clients. If disablement does, indeed, carry the powerful unconscious evocativeness I have described, then it follows that issues within countertransference will require central attention in clinical work with this population. But there are a number of other ways in which disability has the power to upset and test the constancies of the psychoanalytic therapeutic frame, as we shall discover.

The italicised quotations provided in this chapter and the next are verbatim utterances of participants – these are more frequent in the following chapter, which will deal with "content" rather than "process" aspects of the psychotherapy group. The initialled "names" I provide to refer to group members are fictitious, and used merely for convenience.

#### **Inconsistent attendance**

*M: So what I was wondering was, is this more or less par for the course in terms of bringing together disabled people, or are we doing particularly badly?*

Attendance at group sessions was unpredictable throughout for, I believe, manifest, practical reasons as well as unconsciously motivated ones. To begin with the former, severe physical impairments, such as advanced ataxia or quadriplegia, may present a life-routine which is highly complex, unpredictable, labour-intensive and often interminably tedious. As a quadriplegic, for example, performing everyday tasks of rising, washing, dressing, eating and otherwise preparing for the day – all of which involve essential assistance from personal attendants – can be exhausting, and fraught with unexpected complications. Fatigue, susceptibility to infection, difficulties with bodily temperature control, muscular spasms and pain, as well as the structural uncertainty afforded by dependence on assistance, are routine and daunting challenges to functionality. The myriad of wholly avoidable structural barriers of life on an inaccessible university campus add incalculably to such difficulties. In terms of facilitating a group psychotherapy process, these realities had to be appropriately recognised and validated, whilst retaining a sense of commitment and accountability to other members to attend, as well as an "interpretive space" to make sense of the multiple determinants of missing a session. Of course, ambivalence is an inherent aspect of the process of group maturation; yet, supervision discussions rendered the assessment that forces pulling members both towards, and away from, attachment to the group process were especially amplified in this case.

My experience of the pattern of attendance was that of a "patchwork", which allowed stories and experiences – particularly of trauma – to be broached, briefly ventilated, and then discontinued. The developing of links, thus, between the materiality and history of life-worlds, and the largely split-off emotional meanings of these, was disrupted (Bion, 1959). The inaccessibility of, I believe, highly threatening internal material was safeguarded by the discontinuities in narrative afforded by shifting attendance, and hence shifting attention. I also felt that I was being unconsciously protected from exposure to what lay below the accommodating silence which disablist society so often demands of disabled persons (French, 1993b). For myself, as well as for participants, a process of what Sinason terms "modulation of trauma" was being performed (Sinason, personal communication; 1992). Later, I shall consider in more detail the issue of the "imperative to silence" imposed upon disabled persons by a social world in the grip of anxiety-ridden fantasies about the "abjection" of disability. But for the current discussion, the relevance of this idea is to be found in the dramatic contrast between an external social environment where disclosure (even to the self) is denied, and the allowing, "listening" space of the group process. The silence of the outside world, which may impute disability-related experiences with shame,

may be internalised, rendering the reactive splitting off of these aspects of self, in a manner which is associated with the pathologising "diagnosis" of disabled persons as being "in denial" (French, 1993b; Watermeyer, 2000; see *Acceptance and denial*, p.307). A "permissive" relational space may, consequently, be experienced as destabilising, even (unconsciously) traumatic. I had the persistent hunch that group members unconsciously felt that I was, even to the point of irresponsibility, naive to what I was "letting myself (and them) in for". The experience, against the backdrop of a deeply avoidant, disregarding world, of someone who "suddenly" wants to know, may feel jarring and incongruous; even obtrusive.

A further interpretation of the "patchwork" attendance surrounds the unconscious communication to myself of the extreme unpredictability, and (external, and consequently internal) lack of control, which pervaded the private lives of group members. These circumstances were vividly described in many discussions. The picture created was one of worlds which felt incomplete, unreliable, unpredictable, slow, and laborious; where one is "let down", forced to "make do", and constantly expects to be accosted by disruptions which cannot be predicted or avoided. The uncertainty of attendance, and how to manage the issue therapeutically, left me feeling anxious, inadequate, and unsure about "what will come next", "how things will be", or "if things will be alright". The attendance pattern, thus, seemed to be both a manifest product of the materiality of life experience, and a symbolic communication (or projective identification) of its emotional evocations. In my "professional" uncertainty, I was reminded of the host of material difficulties which members faced on campus, each of which was able to make a day feel impossible. For example, the question of whether lifts are available and in working order simply dictates the movement possibilities of wheelchair users. One group member – C – an especially tall quadriplegic man, related how the lifts in one campus building he regularly had classes in were unusually small. This being the case, what was required of him several times a week, was to wait outside the lift until the doors opened, and then request that all occupants vacate it, as it would barely contain him alone. C's personal assistant would then squat above him on the arms of his wheelchair, and they would proceed to the upper floor. The absolutely endless number of such stressors, complicated by anxieties to do with entitlement, are additions to the everyday, demanding reality of university study.

## **"Socialising"**

Over the course of the first quarter of sessions, a pattern of light, "socialising" banter intermingled with discussions of more gravity, to the irritation of some members. These same members, though, at other times engaged in similar "lightening" of the discourse. Part of this dynamic was, I believe, a manifestation of ambivalence regarding the contemplation of struggle. Group members expressed a strong, even urgent conscious need for the opportunity to tell of their experience, but simultaneously "spoilt" the opportunity for doing so. The effect of this pattern was, again, to evoke anxiety in myself. I was repeatedly pushed into a position of doubting my professional capacity to perform the work, as well as its feasibility in the abstract. It was extremely difficult to hold onto a "process perspective" in the face of my anxiety regarding whether this was *"really therapy"*. The casual relating, as was confirmed much later, also simply reflected a need for contact; in particular, for relating in a clear, real, uncomplicated and inclusive way. This experience, for group members, was quite rare, with most interactions on campus being deeply coloured by anxiety, projection, avoidance, or other relational distortions arising from the effects on others of visible impairment. The issue of protection (of self, one another, and me) from trauma is also relevant here, with the socialising behaviour creating a "safer", but un-therapeutic environment. Repeated comments regarding my "excellent" memory, communicating both appreciation and a subtle, unconscious apprehension, further pointed to this interpretation. What I heard in these comments was that the experience of having one's unheard narrative listened to carried great import, and was an exceptional, even peculiar, contrast to everyday life.

## **Physical boundaries and the frame**

The thorough maintenance of the clear physical, and hence psychological, boundaries dictated by the psychoanalytic frame may be profoundly challenged by severe physical impairment. Consider, for example, the fact that a quadriplegic person requires assistance in tea-drinking. Each session would begin with tea and coffee being made, typically by myself and D, the one group member with fully functional upper limbs. Thereafter, and during the early part of discussion, D and I would "feed" the two quadriplegic members their drink. Compared to the clarity of distance afforded most psychotherapists by the analytic frame, this is intimate, personal contact. It felt as though, for these moments, I was drawn from the realm of "talking", and into

that of "living", as I confronted my own anxieties about being depended on, "getting it right", and being a "good" therapist. In the act of holding a cup while another drinks, there is uncertainty regarding the amount of time one tips the container, and to what angle. The evocations here regarding feeding, control, intrusiveness and accommodation speak for themselves, with the physicality of this enactment serving to amplify the salience of all.

A further example concerns G, a female member who uses an electric "scooter" for mobility. At the end of a session, and after other group members had left the room, she discovered with sudden and intense anxiety that the scooter's battery had inexplicably run flat during the session. The sessions were held in the late afternoon, and we were thus two of perhaps only a handful of people left in the building. The only solution was for me to push G, on her scooter, out through the building and into the parking lot, where the bus for disabled students awaited her. Later, on reflecting upon the experience, I became aware of the complex and ambiguous nature of the feelings it had evoked. I had felt initially helpless, battling to contain internal anxieties to do with the seeming intractability of the situation, which I partly projected onto her as shame or humiliation. I was struck by the great volume of these feelings, which had, although only for moments, filled the intersubjective space in a manner which had rendered me incapable of clearly discerning their origin. That is, situations such as these, where anxieties are high, make it extremely difficult to see to whom such feelings belong. Further, immersion in a social milieu which is (probably quite consensually) attributing such feelings as shame to one's experience, must render it extremely difficult to retain clarity on the nature of one's own meanings. Scott (1969) describes the point in relation to the projections which abound surrounding sight impairment:

A major component in the experience of being a blind man [*sic.*] is defending the self from imputations of moral, psychological, and social inferiority. For some this defence succeeds and for others it fails, but for all blind men it is another fact of life.

(Scott, 1969, p. 117)

I believe that what Scott (1969) is referring to here is the very difficult task of achieving and retaining contact with the authentic, nuanced reality of one's own emotional experience in the face of an ever-present drone of heavily charged assumptions from the interpersonal milieu. What both examples demonstrate is how I, as a psychotherapist, am not protected by the frame as one typically would be, in a manner which renders it more difficult for me to maintain the distance of an observer. This absence of clear boundaries left me vulnerable to manic, defensive impulses to act (to fix), rather than simply to witness and interpret; of course, I *had to* act, but also aimed to reflect. Psychoanalytically informed psychotherapy is about staying with feeling, with meaning. But the practical dilemmas presented by the physicality of disability tug one toward action, and simultaneously towards merger which may tend to elide understanding. In clinical practice involving disabled children, a very familiar experience is of family systems so racked with the ongoing practical requirements of managing the complex needs of an impairment, that simple conversations regarding "what it's like" to live with disability are seldom, if ever, embarked upon. The boundary-crossing of the situations described above embodies, I believe, an enactment of boundary contraventions that are an elemental aspect of relational distortions surrounding disability (see *Disability and the distortion of personal and psychic boundaries*, p.260). Visible disability tends, as we have seen, to evoke the projection of split-off existential conflicts. The result, in a thoughtless moment, may be the experiencing of a disabled stranger as the personification of one's projections; of dependency, brokenness, shame, or whatever. It is this positioning of the disabled individual which then provokes manic reparative (or "curative") action from the observer – plainly visible in feelings of helplessness, the intrusive providing of unsolicited assistance, and the like. What has occurred here is a boundary contravention, in which internal conflicts within the observer are "placed" within the disabled individual, after which, in a moment of fantasied "merger", the observer begins acting on behalf of the disabled individual, in terms of the fantasied "needs" which emanate from the projected conflict. The "reality" of a need for assistance in, say, tea-drinking, forms an "authentic" template which confirms the validity of the projected assumptions of the dynamic, re-conjuring the disabled figure as 'needy' in the ways we imagine. I argue that, at the level of symbols, visibly disabled persons are constantly penetrated by projected conflicts, which perforate boundaries and justify not only psychic intrusion, but the myriad of material, controlling intrusions ubiquitously visited upon this community.

Shula Wilson (2003, p. 56) believes that fetching any, but especially disabled, psychotherapy patients from the waiting room may "feed the client's helplessness and dependency and delay autonomy". My critical view is that this position may be somewhat short-sighted, and partly a result of the spectre of evocations which surround an un-critiqued stereotype of dependency. Clearly, there will be those clients who are unable to, say, come directly to the consulting room unaided, and there will be others who may require a variety of other forms of physical assistance discontinuous with the dictates of the frame, such as those described above. Surely, it is the notion of – the need for – that most slippery of characteristics we call "independence", which must be vigorously interrogated (see *The discourse of independence*, p.288). If escorting a patient to the consulting room is considered "infantilising", surely, since some patients will need this and much else, we should closely examine the cultural grounds upon which such an attribution rests. Wilson's (2003) approach is, in my view, somewhat mechanical, prescribing "solutions" which do address the physical, but not the psychic roots of potentially malignant assumptions. Of course, it is doubtless true that, for some, the experience of being escorted would amount to inappropriate infantilisation, but what emerges, nevertheless, is evidence of the universally unpalatable flavour of intractable physical dependence. Later, Wilson (2003, p. 56) addresses the "problem" of wheelchair-using clients positioning themselves too closely to the therapist's chair. I do not believe that these practical issues would have the import Wilson (2003) attributes to them if the underlying issue, to do with a more universal anxiety regarding boundary transgressions, was courageously and candidly explored. What Wilson (2003) seems to be trying to create is an anticipatory climate of "kid gloves", in which the "messy" experiences of a lack of control and clear boundary – which, I believe, are at the heart of disabled life in the modern society – are not allowed to be "lived" in the consulting room. Psychoanalytic boundary stipulations may at times militate against authentic, real and robust relating around the lived materiality of struggle and circumstance, whilst simultaneously (unhelpfully) protecting the therapist from "getting things wrong". As has been argued, base responses to disability, manifesting in layered prejudices, are in the very fibre of our societies, and there is no reason at all to assume that mental health professionals are an exception.

## **Interpretation**

The issue of the interpretation of the conscious discourse of members of oppressed groups is, as we have seen, a highly politically fraught one. The risk is of the misappropriation of

psychoanalysis as a frame for victim-blaming, via the attribution of social troubles to intrapsychic origins. What, then, is the position and utility of psychodynamic interpretation in the work of subversive – that is, emancipatory – psychotherapy?

In the early phase of sessions, I was shown a powerful mix of readiness to articulate untold accounts of trauma, and deep ambivalence. These stories included the accidents, illnesses or diagnoses experienced by group members, but always with a strongly psychosocial, meaning-oriented slant. In other words, without in any way denying the base reality of impairment, it was in the context of the reverberations of trauma within the family, the school, and other social networks that stories were structured. The "untold" nature of these stories – we will consider examples later – brought a sense of image-based memories being unearthed, in a manner which I experienced at times as "like a movie". Pictures of a beach, the silhouetted face of a man against the sky, a hospital, the misery of family members, a rehabilitation pool; the image-memories were told and re-told, seeming to become slightly more animate in the telling. These accounts were of an acute trauma (a spinal injury, a stroke) which, for a range of reasons relating to cultural responses to disability and disease, had remained relatively unprocessed. This initial, socially engendered split had, I believe, set a tone for the silencing of disability- (that is, oppression and impairment) related struggle in an ongoing sense. What seemed to be happening as stories were told and re-told, was the beginning of a process of "real-ising" a split-off, silenced tract of experience, locked in trauma, and thereafter muffled by the imperatives of disablist culture. This process of "real-isation" certainly did not call for interpretations of unconscious process; rather, what was required was a simple holding and witnessing. In the face of the defensive "de-legitimation" of disabled experience (see *Disability and the distortion of personal and psychic boundaries*, p.260) in everyday discourse, disabled persons may be required to psychologically swim against powerful conscious and unconscious cultural currents in order to maintain stable contact with the reality of disability-related struggle.

In situations where oppression – trauma – is ongoing, the appropriateness of an interpretation hinges upon whether it is able to allow material elements to remain fully real, whilst including commentary on the nature of unconscious processes. Consider the following crude, yet instructive example: F, a quadriplegic man, telephoned me after missing two sessions, to say that

he would not be able to attend "today" as he was ill. It was Thursday, and our meeting day was Wednesday; F believed that "today" was Wednesday. F was clearly in the midst of severe physical struggle, including intense fatigue and chronic, burning pain in his legs. If not for the fact of F's extreme, ongoing physical difficulties, I would have been drawn to thinking, and acting, interpretively, and making sense of his oversight in terms of ambivalence. Making such an interpretation would, I believe, have embodied a misattuned, non-validation of the physical reality of his impairment. The clinical picture of a combination of the ongoing trauma of exclusion, social shunning and discrimination of every sort, along with such impairment-based suffering, is one in which there is so much experience to be processed at a *surface level*, that it is not yet possible, or appropriate, to attempt moving into the symbolic realm. Put simply, one is required to attune to the (hitherto avoided or silenced) conscious, before beginning to think about unconscious processes. In my view, the legacy of psychoanalytic theorising on disability critiqued earlier (see *Psychoanalysis and disability: A brief history*, p.73) often made this very error; that is, making sense of disabled experience in terms of repressed unconscious phenomena (e.g. denial, shame) in the absence of a rigorous, critical and candid assessment of the everyday, manifest lives of social trauma to which disabled individuals are subject. The crux of the point is that experience must be *seen* before it may be questioned, interrogated or understood in any more depth-oriented way.

However, on the opposite side of this delicate dialectic is the very real risk of the "materiality" of (especially) impairment leading to the creation of a collusory defence which avoids emotion, instead focusing exclusively on physical, pragmatic elements of exclusion. This is the essential failing of the social model as a framework for conceptualising disabled experience. In short, the model makes provision for the interrogation of modes of exclusion (or "barriers"), but not for the layer of personally, historically situated struggle which "naturally" emanates from such factors. The tension is between the *as if* understanding of historical, unconscious factors and the "as" recognition of the reality of material struggle. Of course, this logic pertains to all psychoanalytically oriented psychotherapy; its key significance here arises due to the almost ineffable tendency of cultural meanings surrounding disability to mobilise splits, which typically obscure the situational level. Working prematurely with the *as if* often represents nothing more than fearful defence within the clinician regarding the injustice of continual, demeaning exclusion. As is familiar from clinical experience, psychological formulations of disabled individuals which begin with the neurotic – that is, with the *as if* logic of complicity – result in a

dead-end of victim-blaming. In my experience, it is essential that material persecution be fully acknowledged before internalised persecution may be usefully examined.

## **Psychotherapy with disabled persons: Countertransference considerations**

### **Introduction**

The very substantial challenges in the area of countertransference which face a psychoanalytically oriented psychotherapist working with disabled clients are, in my view, a highly instructive, microcosmic representation of the unconscious patterning of disablist prejudice within society more broadly. Of course, as alluded to earlier, there should be no shame for clinicians in the self-recognition of anxiety and prejudice; this is a universal legacy of segregation, and thus beckons all to self-reflection and growth. The danger of a form of complacent denialism of the reality of such deeply conditioned prejudices is one demanding real vigilance (Reeve, 2000, p. 678). We are only beginning to consider these deeply evocative issues during the current era; as professionals, as society. Thus, therapeutic work may be viewed as a process of the clinician "working through" his or her personal evocations and assumptions surrounding disability, via a concerted, honest, and highly reflective focus on countertransference. As "healing" professionals, clinicians, like members of the broader society, carry needs to know, control, distance, subdue, repair, alter, reject, modify, rehabilitate, disguise, minimise, exaggerate, idealise, or denigrate. The evocative power of disability raises in all an "unconscious profile" of such needs, in response to the deep psychological phenomena with which physical "damage" resonates. If reflected upon enough, what occurs in therapeutic work with disabled persons promises to tell us much about how the psychological aspects of oppression work "out there". In the following sections, I provide a brief discussion of these issues in the present study.

## Pressure-anxiety

From the outset, I was aware of inordinate levels of anxiety within myself regarding the possibility of "harmful" misattunement. That is, my own awareness of disability oppression and politics rendered within me a paradoxical "paralysis" surrounding the fear that I would "miss", or not sufficiently acknowledge, some atrocious experience. What was at work here, I believe, was an unconscious communication of the experience of having suffered silently, within a world of overt and subtle avoidance and negation of the reality of struggle. It should be unsurprising that, in therapeutic work with members of a brutally silenced minority, one finds oneself afraid of silencing. Further, it is in the nature of therapeutic work involving trauma that a certain excessive, even defensive "reverence" or respect for the gravity of (fantasies regarding) what has been suffered intrudes disruptively upon the possibility of authentic empathy (e.g. Dalenberg, 2000). In addition, I hypothesise that the apprehension I carried regarding the risk of "re-obscuring" experiences of suffering pertained to my own unconscious wish to, in fact, *do so*. Whilst my own political orientation towards disability may appear as a defining variable, I do not believe that it is so. Instead, what is of note is the ubiquitous presence of anxiety-ridden assumptions of excess; that is, of splitting. My particular countertransference predicament locates me as one struggling to see emotional resilience in the face of social brutality, whereas other circumstances may render a corresponding difficulty with "seeing" the reality of oppression, or be "obsessed" with impairment in a manner which elides all else. My experience of feeling "not enough" as a therapist, or an empathic listener, bears relation to the loss of boundaries which so often characterises relating to disabled individuals. My own unconscious projections of damage render a "manic defence", involving feelings of helplessness and a need to repair; but by their nature, the conflicts which are the subject matter of my projections are intractable, rendering predictable feelings of inadequacy. As an adjunct to this, the unconscious habituation of just such relating within group members (from the opposite vantage point) is likely to have contributed to this dynamic. Finally, the "unheard" nature of the layer of disability experience which was slowly being uncovered contributed, I believe, to a shared sense of precariousness and danger regarding the material being "held". The cultural avoidance and silencing of the layer of experience which pertains to disability (oppression as well as impairment), must surely manifest in a burgeoning internal sense of that experience being inadmissible. The ongoing experience of an absence of mirroring – of being truly seen and validated – contributes to an entirely sensible expectation of not being seen, which has direct relevance to psychotherapy.

Ironically, though, what was lived out at times within the therapeutic relationship was another form of social silencing, paradoxically enacted via my over-anxious need to hear perfectly, and in effect, to pre-empt, negate, and "speak for". There is a dialectical tension here which deserves our attention. In circumstances in which we work therapeutically with members of oppressed minorities, it is common cause that a working knowledge and a degree of personal, internal reflection regarding the nature of social predicaments suffered by minority members is essential in "opening our ears" to the experience of oppression, whilst simultaneously avoiding or overcoming the snares of our own prejudices (e.g. Marks, 2002a; 2002b). Consider, for example, the wealth of theoretical investigations of feminism into psychotherapy. Perhaps the present work may be construed as a corresponding form of ideological conscientisation, pertaining to disablism, rather than sexism. However, at the heart of the dialectic is a structural tension between "understanding" the shared predicaments of members of a minority, and hearing – allowing – the *unique* nature of an individual's account to unfold. This challenge is at the heart of the countertransference jumble of disability-related therapeutic work.

## Political investments and therapeutic boundaries

*J: I mean is the purpose of the group, to talk, to talk openly and in a safe environment about our own experiences or is it...to have some kind of forum where we actually...try and make a difference to the other person, or are we actually going to...influence things, you know, to better ourselves and for future generations...what is the purpose of this, what are we doing here?*

Now, in my role as a disability service provider at a university, I want to 'share the wealth' with my students – people who have been indoctrinated...Never has even one of our students expressed awareness of such terms as 'social model' or 'medical model'. They believe that their disabilities belong to them individually and it is up to them to 'adjust', 'adapt' or be granted 'special' treatment to support their efforts to 'overcome' their 'challenges'.

(Gordon, 2002, p. 33-4)

As a psychoanalytic psychotherapist working with disabled people, I regard it as essential that I, and others working in the field, have a thorough and critical awareness of disability oppression; how it works, what it rests upon, and how change might take place. However, within my personal tussles with countertransference, what this consciousness – or conscientisation – sets up within me is a confusion regarding the ownership of stories, and the boundaries between patient and therapist needs. The anxiety regarding my need to "know" sketched above interacts here with my (also partly obsessive) investment in particular political "outcomes" within the therapy. These may involve the patient "seeing through" obscured modes of oppression that he / she has suffered under, and, through an "internal emancipation" taking up an appropriately "critical", politically resistant position. Alternate to this inadvertently "controlling" therapeutic stance, the (presumed) commonality of experience between patient (or subject) and therapist (or researcher) who share a marginalised identity, may create a misleading, collusory assumption that "we all know". In other words, a relational defence arises, surrounding shared "in-group" knowledge which, in fact, is *never articulated*. Roman (1993) describes this experience as follows:

This cogent feeling of similarity distanced me from countering their assumptions and distorted realities. This affective pull of sameness blurred my vision. The participants' stories resonated so closely to mine that I maintained a 'racially privileged naivete'.

(Roman, 1993 cited in Hurd & McIntyre, 1996, p. 81)

Whilst the political stances inherent in my personal orientation may be highly defensible, even desirable, at issue is the fact that they are mine, and embody a philosophical position which I have been led to by my own experience. Of course, the "politically correct" position may not – will not – fit with the experience of all to the same degree (if at all), or in the same way. More important still is the fact that if I do not take great care as a psychotherapist, I am at risk of subtly "delivering" a world view, in a manner which obviates or negates an individual's developmental process. In evidence here, I believe, is not just my personal political investment in disability emancipation (considerable though this is), but a further example of unconscious enactment which serves, via control, to allow me to constrain the "free" telling of stories. The usual challenge of the analyst, to wait, to postpone understanding, to not know (Bion, 1988; Casement,

1992), is amplified; instead, I agree too quickly, explore too little, step in too fast – I'm vigilant, manic and anxious regarding the looming threat of re-traumatisation. In the words of Foster (2001, p. 85), my own depressive anxiety has contributed to my forging of "sentimentalised" client relationships. All of the aforementioned pressures militate against simple *listening*, and relate, I believe, to my own anxiety regarding what may emerge should I retire to a neutral, listening stance, and allow patients' experiences to come independently into full elaboration. Analysis of these anxieties which I carry exposes a struggle – not discontinuous with the underpinnings of current bioethics – with simply believing that life with a severe physical impairment is survivable. Taking that purely listening stance would mean assuming a position of "giving back" each individual his / her experience, the right to finding one's own style of redemption; to finding personal truth, and possibly a degree of peace, which all seek. What my difficulty in granting this humanity reflects about what lurks beneath common, everyday anxieties surrounding disabled people, and the way we manage these anxieties, is sobering, to say the least. There is a dehumanisation of sorts at work here, based on boundary contraventions, control, and projective identification, in which disabled people are not so much appropriated for the psychic needs for catharsis and evacuation of others, as used as instruments for the protection of others from their own fantasies about impairment. It seems that it is extremely difficult for us, due to the nature of our unconscious fantasies about disability, to allow people with impairments to possess, to feel, to circumscribe and articulate, their own psychic reality. We need to know, to decide in advance; surely this is the essence of stereotyping, and the myriad of social controls which emanate from it.

The function of our projections, however, is not only to give voice to our own disowned torments, but also to preclude the incidence of open space which may be filled with the experience of the other. What is created in the lives of disabled people is an intersubjective milieu which precludes, obviates, stifles, deflects or dampens the question "*Who are you?*" At the core of any form of prejudice is the predicament of having one's experience, oneself, defined by others. An array of interlocking forces is at work in cultural formations around disability to ensure that self-definition is constrained. Within the psychotherapeutic frame, this may mean that the therapist's difficulty with the idea that disability is survivable, may render him or her unable to entrust disabled individuals with their own healing, with their own path.

And yet it would be foolhardy and self-defeating to simply "put away" one's political investments as a psychoanalytic practitioner. We would, then, be left locating disturbance or difficulty internally, denying the ongoing structural and relational implications of the consistently "mad" nature of constructions of disability in the outside world. Surely it is not the purpose of our discipline to simply "deal with" clinical implications of social reality, rather than assume a more critical, subversive and ideological role in the "real world" (Samuels, 1993). Is psychoanalytic work limited to the business of "taking back projections" and "owning feelings" in a manner which disperses "persecution complexes"; or is it about facilitating the directing of rage toward where it is due? Perhaps it is important to observe that subjugation seldom (if ever) leads to a psychologically sterile subordinacy, but rather to a variety of forms of disturbance, including complex systems of displacement and enactment. It is thus dangerously naive to construe therapeutic work as a simple process of "coming out" to an "empowered" position which "gives oppression back". Indeed, such a view represents a miscarriage of the analytic task of exploration, toward individuation. Thompson et al (1994) offers the following helpful observation:

Conscientisation is not intended to be a crude process of trying to *win someone over* to a particular ideology. Rather, it is a question of *deindividualisation*.

(Thompson et al., 1994 cited in Thompson, 2003, p. 223 – my emphasis)

This process, to Thompson (2003, p. 223), is one of facilitating an understanding of how the position of an individual mirrors the broader cultural and political landscape. Most interestingly, Thompson (2003, p. 224) adds that a "crude approach" to such work is to be carefully avoided, as this may "undermine professional credibility" and lead to "alienation and mistrust". There is, amidst these directives, a clear critique of the "de-psychologising" impetus of the social model approach. Epitomising the misapprehension at the heart of the social model, Swain and French (2006, p. 155) regard the topic of "counselling and disability" as a direct reflection of the

"individual-society divide". For these writers, examining the internal will only – ever – serve to elide the political. Samuels (1993, p. 6) stridently, even scornfully, rebuffs such a position, countering that rejection of the clinical enterprise forecloses what is, in fact, the only real connection between our understandings of individual and cultural spheres of life.

The position I began to reach was one of viewing "intra-psychic" and "political" aims as mutually constituting aspects of a dialectic. A position which prioritises either will often function as a defence against the reality of the alternate realm. Nevertheless, increasingly it became clear that intra-psychic constellations had to change before political contradictions could be clearly, consistently seen. It was thus very important for me to "manage" my own, politically motivated (and defensive) need to point out such contradictions, so as to allow a more personal, internal process of unfolding awareness to take place. My "blundering in" with such observations tended to create an experience for group members of not having their current reality heard, in a manner which diminished exploration, trust, and separate relating. Gordon (2002, p. 36), whose frank description of such "misplaced politics" opened this section, encapsulates the issue thus:

After all, if I assert that his view of himself [*sic.*] as a disabled person is incorrect and that my view of his experience is the accurate one, then I become just another oppressor who considers his ontological frame to be a symptom of dysfunction.

(Gordon, 2002, p. 36)

The difficult lesson for me, thus, was to let the group process "be" what it was; to let individuals exist "where they are", no matter that such a place may be far removed from a politically critical one. An important possibility for contemplation is the idea that political fervency within the clinician may, in part, relate to an appeasing of guilt, which manifests in a drive to bring oppression into relief, hence situating the therapist in defensive opposition to the "heinous" social realities under discussion. "Revolutionary" intentions, it seems, will always fly in the face of a therapeutic stance which – appropriately – values ambiguity, ambivalence, and nuance. Such controlling "merger" will tend to rob the "other" of untethered ownership of his or her internal

experience, hence disallowing this material from surfacing in consciousness in an unaffected, uncontaminated manner. Within psychoanalytic theory, the technical issue of "holding" both personal and political realms, in a manner which remains unintrusive, respectful and affirming of a unique standpoint, is one which requires substantial further attention.

## Our most damaged selves, and the struggle of "not knowing"

Later (see *Solutions, entitlement and passivity*, p.279), we will consider how the anxiety which emerges within an observer regarding the threateningly "uncertain" bounds and implications of impairment, may lead to manic refuge in the positing of "solutions". In the therapeutic environment, similar dynamics, such as the need for subjective control, render the task of "not knowing" for the clinician particularly difficult in the face of images of impairment. At the heart of the psychoanalytic psychotherapy model rests a contradiction which is especially salient in the realm of clinical work with individuals who suffer prejudice. On the one hand, the challenge to the analyst is to "not know" – to postpone formulations regarding the nature of internal life in order to better "hear" the patient in an uncontaminated manner (e.g. Casement, 1992). The capacity to be open to having one's expectations and biases confounded or exposed is an essential element in the "humility" required of the reflexive analytic worker. Uncovering the nature of subjectivity "near its source" involves immense care taken in eliminating disruption of the flow of psychic material. This ability for "allowing" experience to come to light is surely of particular relevance in the realm of disability-related work, where, as in cross-cultural psychotherapy, the presence of (often barely visible) assumptions within the clinician – and consequent need for the conscious suspension of such assumptions – is essential if subjective life is to be heard clearly. And yet, on the other hand, the clinician is expected to "see beyond", to hypothesise, imagine and reconstruct inner reality from the signs implicit in symbols and process. As is by now clear, the fantasy-evocations surrounding disability are of a rich and archaic order, presenting the risk of complex projections based upon the "certainties" of embedded cultural assumptions regarding evidence "written on the body". Anxiety within the clinician is likely to be managed with distorting attachments to "memory and desire" (Bion, 1988). The need to not know, but also the

difficulty of not knowing, are, in my view, substantially amplified within such therapeutic work. It's particularly hard not to know because of our fear of what we will find; yet, with deep paradox, we actually do "know" what we will find, because *it is ours*. Wilson (2003, p. 94) falls somewhat, in my view, into this snare. She writes:

For the therapist, realising the degree of the client's limitations can be likened to a mother realising the limitations of her impaired baby.

(Wilson, 2003, p. 94)

In this passage, it seems as though fantasies regarding the nature or implications of impairment (within therapist and mother) have been "indiscriminately" allowed to colour growing impressions of the nature of subjectivity and potential. Clearly, with empathic good intentions, Wilson (2003) aims to "reach" the "reality" of the experience of her patient, yet her route toward doing so is (potentially definitively) mediated by invisible cultural assumptions regarding the import of impairment. Similarly, in the case of the mother, a "recognition" of the implications of impairment forecloses consideration of the crucial impact of cultural assumptions upon the socialisation and self-formation of her baby. The logic is irresistible, viz. the "condition" is palpable, and the "experience" and the "condition" are conflated. Thus disability renders struggle which renders experience, and since I can "see" the disability, I thus believe that I can circumscribe experience. It is only through an especially rigorous regime of "not knowing" that the realisation of such invisible cultural assumptions, set in place via socialisation and social construction, may be derailed. Further aspects of this process may then involve the conscious consideration, interrogation and neutralisation of such assumptions. Reeve (2000, p. 674), who performs training of mental health professionals for work with disabled clients, comments that: "Unfortunately, my personal experience is that some counsellors believe that they already 'unconditionally accept' all people, and therefore don't need DET [her training programme]". Traditionally, it seems that psychoanalysts working with disabled patients have foregrounded the

"problem" of the patient being able to believe that his or her body was not repugnant to the clinician, with the clinician's actual feelings or presumptions regarding the "living" of such a body going largely unexplored (e.g. Ogden, 1974, p. 431). The evidence that mental health professionals tend to under-diagnose suicidal depression in persons with severe impairments, at times viewing impairment as reason enough to rationally desire death, provides an important perspective here (Herr & Phil, 1992, p. 15).

What emerges throughout the foregoing is a picture of countertransference phenomena which, if unprocessed, will render a mode of relating to disabled people as if "they" were extensions of our *most damaged selves*. Evidence of this mode of relating is readily to be found in everyday constructions of disabled people, typically embodying a binary between the "tragic", "dependent invalid", and the superhuman, "inspirational" disabled person who "overcomes adversity". Remaining separate – resisting control – means not knowing the destiny of our most damaged part, and this is unbearable. Not being able to see the edges of our struggle, because it is continuous with the imagined feelings of the other, as we, in fantasy, drain into the cavernous experience-bodies of those so frighteningly different, yet so similar to us, rouses annihilatory fears rooted in the experience of boundlessness. "Controlling" psychological and psychoanalytic theories of disability (e.g. "rehabilitation psychology", the "bereavement model", and the discourse of "denial") may be understood as defensive responses to the experience of not being able to manage "not knowing". Instead, the oppressive compromise is for us to "know" the worst, whilst merged and colonising, yet publicly disowning, controlling, and subduing. The essence of insight-nurturing psychotherapy is a combination of curiosity and neutrality, both of which are disrupted by the disability phenomenon. The presence of projective identification, which reconstructs the other as the shameful or "bad" self (Klein, 1946) also reduces resources available to the ego, leading to poor reality testing and pathological judgments about self and other (Main, 1975 cited in Young, 1994, p. 130).

At many points during the group process I was aware of my own "growth", occurring via continual reflection on the countertransference, which exposed not only my disability prejudices, but deeper anxieties rooted in my history which were pointed to by disability imagery. As I commented in one supervision session, it felt as though "I am the one in therapy". The protective

hesitancy of group members in describing their traumatic experiences, in combination with this uncovering of my own evocations, rendered a profound reflection (in my interpretation) of the "caring for" performed by disabled persons in the outside world. This, I believe, incorporates the lived, adult manifestation of false self dynamics based upon the neediness exposed in others by contact with disability. Put another way, highly visible impairments, such as those of the group members, have a Rorschach-like evocative effect on the social world, rendering the need for containing management of the unconscious "psychic fall-out". One consequence of this "projective effect" (to be examined more fully later – see *Disability and loss*, p.302), is the motivation group members felt to disguise or otherwise dampen evidence of loss, struggle or difference which would evoke such anxious responses in others. There was clear awareness that, if disability experience was too visible in the interpersonal space, this negative emotion would be returned to the individual as projection, but enormously elaborated with the conflicted or abject unconscious struggles of the other, leaving the disabled person doubly burdened, negated and unseen.

Davis (1997c, p. 54) interprets Medusa, in Greek mythology, as the ugly, malformed, "disabled" counterpoint to Venus' physical perfection. In the narrative, Medusa is punished by Athena for "lying with" Poseidon; Athena transforms her into a winged monster so ugly that she turns onlookers to stone. Later, Athena has her killed by Perseus, who decapitates her, and then contains her remains in a "magic purse" which protects onlookers from the deadly power of her appearance. Medusa and Venus occupy opposite ends of a dialectic, which joins "beauty and ugliness, desire and repulsion, wholeness and fragmentation" (ibid.). For Davis (1997c, p. 54), the Medusa story is an allegory of the encounter of a "normal" individual with the threatening spectre of the disabled body, in which the visual is a central, abominable force. The "normal" person, upon seeing the disabled body, is "turned into stone". The subversive disabled body, consequently, must be decapitated, and then "contained" within a "purse" of rationality, which is the device whereby it is subdued, controlled, and reformed (ibid.). The chaos of the malformed body issues shock-waves which render the ego vulnerable to a terror that its brittle, cosmetic identity (in Lacanian terms) is about to be undone, to be mutilated and perforated by the fragmentary instability at its core (Davis, 1997c, p. 64; Lacan, 1977b). The association of disablement with punishment for sexual deviance also appears clearly here. It is at our peril, in my view, that we as clinical professionals, as well as members of society, underestimate the power of these disruptive fantasies.

## Denied separateness

The "din" of projections which characterise relating surrounding disability embodies, as has been outlined, a contravention of psychic boundaries, in which aspects of the self (of the observer) may come to be experienced as characteristics of the disabled "subject" (Young, 1994, p. 130; Klein, 1946). But what, then, does it mean to occupy – as many visibly disabled persons must – a more or less constant social space of "*un-separate relating*"? Let us consider children experiencing separation anxiety difficulties, rooted in overinvolved, enmeshed and anxious parenting. As will be attested to by clinical experience, the growing sense of selfhood of such children may be stunted by the lack of "faith" in the child's capacity to grow, cope and develop which is implicit in the parent's anxiety surrounding separation. Through the enmeshed nature of relationships with parents, such children lack the experience of being seen and accurately mirrored as separate, unitary individuals. The lack of such validation leaves the child with little to "go on" in the business of girding him or herself for venturing into an unknown world – put simply, everyone need someone to "have faith" in him or her, in order to confront the challenges of growth and change (Salzberger-Wittenberg, Henry & Osborne, 1983). The invisibility of the incipient selves of such children is often mistaken for being very loved and sensitively cared about, whereas it is (to some extent) the projected aspects of self of parents which, in fact, are being "cared for". Being "loved", "cared for" or "looked after", and being *invisible and silent* are things which regularly co-occur. Consider, for example, what is in common between such enmeshed parental relationships and the charity and welfare discourse surrounding the "neediness" of disabled persons. Further, it seems highly likely that, in the lives of disabled people, such experiences of un-separate relating are continuous and superimposed; from the separation difficulties with parents engendered by anxieties regarding whether disabled children will cope and be accepted in the world, to patronisation and control by charity or health workers. The silencing which is inseparable from the imperative to appease, is re-evoked across temporal and socio-cultural contexts. What may be occurring at a deeper level is a form of "enmeshed compromise", where the loss of a clear boundary by the "other" draws the disabled individual into an equally inauthentic, placating role. This dynamic is directly analogous to the manner in which

the enmeshed parent draws a tacit agreement from his or her child to "not be real" (see *Being real*, p.269). The compromise is encapsulated in Skynner's (1991) bleak but incisive critique of the dangerous irrational factors which draw individuals toward mental health professions; the dynamic of projection is, I believe, directly analogous. Skynner writes:

The mental health professional automatically selects the ideal clientele in which to study himself or herself vicariously and discover what is missing...though the knowledge cannot benefit us...until we acknowledge the fact that our work, however useful, has also been an evasion of the truth about ourselves...I'll look after you if you'll look after the bit of me I can't look after.

(Skynner, 1991: xviii cited in Marks, 1999a, p. 109)

Occupying a psychic space in which one is so constantly subject to the intruding emotional "jetsam" of others, must, as in the case of the child with separation anxiety, create immense confusion regarding the ownership of feelings, and consequently, the nature of self. If self, as Winnicott (1974, p. 131) would have us believe, is coalesced in the mirrored constructions of others, then who, or what, we are – or are allowed to be – is defined and constrained by the constructions of others. The question thus arises: is it possible to have a life, a self, which is not saturated with abjection, if abjection is the primary characteristic attributed to one? The intrusion of the "psychic dirt" (Davids, 1996) of others not only coerces the individual into tacit "ownership" of this material, but also engorges psychic space in a manner which renders it impossible to "find" emotional material that truly belongs to him or her. It is, thus, in the very nature of (emotional) oppression, that the interrogation of such oppression, incorporating the exploration and "real-ising" of self, is precluded. The individual, instead, may remain psychically "baffled" by the chaotic, indeterminate amalgam of emotional responses and exogenous attributions, with the (perhaps lifelong) lack of accurate mirroring rendering these indiscernible from one another. This psychic substrate is, needless to say, richly fertile ground for the seeds of self-doubt and self-blame sown by individualising disablist ideology. The options available to disabled persons in responding to this constant hail of projections are probably dictated by socialisation, yet all involve a compromising of the self. The continuous rebuttal of projections is likely to evoke ascriptions of the stereotype of the "embittered", "aggressive", "uncooperative" or "maladjusted" disabled person, bringing isolation, whilst still locating the individual within the

meaning-splits forged by cultural responses to disability. Further, as we shall see (see *Disability and loss*, p.302), the evacuation from psychic space of the "vulnerable" projections of others often leads to a "baby and bathwater" situation, in which much of one's own, unseen struggle – and hence, parts of oneself – are also jettisoned.

Having thus considered elements of my experience of countertransference, and aspects of "process" within the development of the psychotherapy group, I turn in the following chapter to the conceptualisation of "content" material which emanated from group discourse.