# The Communicative Participation of Adults with Cerebral Palsy

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# DECLARATION

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# ABSTRACT

Conducted within a critical disability studies framework, this study explored the experience of communicative participation by adults with cerebral palsy who live with severe communication impairments. The concept of the participation of communicatively disabled people is relatively new, and the theoretical understanding of communicative participation is underdeveloped although participation is increasingly recognised as a central goal in rehabilitation. In addition, there is a paucity of information with reference to the trajectory of lifelong communication disability. Little is known about the communicative participation of adults with cerebral palsy in South Africa.

Nine adults with cerebral palsy, who lived with significant communication impairments, participated in the study. They were between 32 and 49 years of age, and had lived South Africa all their lives. They were observed in social interactions in their daily lives on multiple occasions and took part in serial interviews over a six-month period. Using a pragmatist grounded theory approach, the data were analysed from an interpretive basis.

Four main categories were constructed. The first category was “being misrecognised as a communicator”, which showed that the participants were not acknowledged as having equal moral participatory status in communicative exchanges. The second category, “contexts for communicating”, indicated that the participants lived with significant communication impairments which resulted in their experiencing limitations in a broad spectrum of life’s activities. The third category, “an embedded communicative self”, illuminated that the participants saw their communicative disabilities as embedded within a broader picture of being disabled, and that their communication impairments had a marked effect on their identity development. Through an analysis of lifetime contributions to communicative participation, the final category, “dynamic participation” revealed how communicative participation is a fluid, ever-changing process.

Extending Ikäheimo’s (2010) model of social participation and recognition, a “dynamic recognition-theoretical model of communicative participation” is presented. Communicative participation is defined as a dynamic social process. It is undergirded by the moral recognition of the interactants as communicative partners, and is influenced by time as the dimension through which all communication takes place.

# OPSOMMING

Die studie, vanuit`n kritiese benadering, het serebraalgestermde volwassenes (wie se vermoë om te kommunikeer ernstig aangetas is) se ervaringe met betrekking tot hul deelname aan kommunikasie of situasies waarin daar gekommunikeer word, verken. Die konsep wat fokus op die deelname aan kommunikasie deur diegene wie se vermoë om te kommunikeer ernstig aangetas is, is `n relatief nuwe begrip. Die teoretiese grondslag van die konsep is onderontwikkeld, maar die konsep word toenemend gereken as een van die belangrikste doelwitte van die rehabilitasie-proses. Daar is ook`n gebrek aan inligting wat handel oor die verloop van mense se lewenslange ervaringe wie se vermoë om te kommunikeer ernstig aangetas is. Daar bestaan beperkte kennis oor volwassenes met serebraalgestremdheid in Suid-Afrika se deelname aan kommunikasie.

Nege volwassenes met serebraalgestremdheid, wie se vermoë om te kommunikeer ernstig aangestas is, het deelgeneem aan die studie. Die deelnemers se ouderdomme (gedurende die tydperk waarin data-insameling plaasgevind het) het gewissel van 32 tot 49 jaar, en die deelnemers het nog altyd in Suid-Afrika gewoon. Die deelnemers se kommunikasie-gedrag gedurende verskeie sosiale situasies is waargeneem. Die deelnemers het ook oor `n periode van ses maande aan `n reeks onderhoude deelgeneem. Pragmatiese, gegronde teoretiese benadering (ook verwys na as ‘grounded theory’) is gebruik om die data te analiseer.

Die bevindinge dui op vier hoof temas. Die eerste tema verwys na bevindinge wat handel oor ‘om misken te word as as iemand wat deelneem aan kommunikasie’. Die bevindinge dui daarop dat deelnemers van mening is dat hulle nie as `n gelykke beskou word gedurende situasies waarin daar gekommunikeer word. Die tweede tema verwys na ‘die konteks van kommunikasie’, en dui daarop dat weens die feit dat deelnemers se vermoë om te kommunikeer ernstig aangestas is, word hulle ook op `n verskeidenheid van lewensaktiwiteite ingeperk. Die derde tema verwys na die volgende: ‘die aantasting van die vermoë om te kommunikeer gesetel in die self’. Die tema dui daarop dat deelnemers die aantasting van hulle vermoë om te kommunikeer, sien as deel van die geheelbeeld van gestremdheid en dat die vermoë om te kommunikeer `n betekenisvolle impak op hul identiteitsontwikkel gehad het. Die lewenslange ervaringe van die deelnemers het aanleiding gegee tot die vierde en laaste tema, naamlik ‘dinamiese deelname’. Dit dui daarop dat die deelname aan kommunikasie nie staties is nie, maar voortdurend verander.

Die studie bevindinge suggereer dat Ikäheimo’s (2010) se model van sosiale deelname en erkenning, uitgebrei kan word tot `n dinamiese teoretiese model wat die deelname aan kommunikasie erken. Die deelname aan kommunikasie word gedefiniëer as `n dinamiese sosiale proses. Die grondslag van die model behels die erkenning van diegene wat kommunikeer as deelgenote wat beïnvloed word deur tyd as die dimensie waardeur alle kommunikasie plaasvind.

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Our cherished children, Daniel and Marc, have watched their mom working away, often concentrating on this work and not on them. Sometimes you have not had me there for you, but what we know in our family is that we all have our places to go to and our things to do. You are the centre of our universe, and will always be.

I dedicate this study to the memory of my beloved father and mother, Edgar and Phyllis Esakof, and the memory of my father-in-law and mother-in-law, Philip and Tilly Levin.

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## CHAPTER ONE: INTRODUCTION

### 1. Introduction

This study is about the participation in the communicative world by adults with cerebral palsy who live with severe communication impairments. Communication is central to human function (Threats, 2010a) and yet very little is known about what it means to live with a communication disability (Pound, 2011), particularly in relation to people with lifelong disabilities (Balandin, 2011).

The study was born following an encounter that I had with a communicatively disabled couple. Gina and Mike[1] were both born with cerebral palsy. They were in their early thirties and lived in a residential home for physically disabled people. They were employed in a sheltered work environment, and had no independent income. Gina and Mike were in love and had been for six years. They were not permitted to live together as the residential home provided segregated facilities only. Gina and Mike spent every waking hour together. They wished to marry. However, neither of them had been able to convince their families, or any of the people in their social networks, that getting married was what they wanted, was their right, and that being married would be good for them.  Mike's mother considered it ridiculous that he would want to marry. The social worker insisted they could not marry because this would set a precedent for others living in the home. Gina and Mike were both anxious because Gina's brothers lived overseas and had voiced their desire for her to go and live with them. The brothers wanted Gina to live close by; they did not think that being tied to Mike was viable or necessary. Mike's speech was unintelligible to most people most of the time and so he could not argue, negotiate, demand, or talk things through with anyone without extreme effort; Gina's speech was fairly intelligible but she had difficulty with expressive language.

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[1] I have used pseudonyms to protect the identity of these people

I had seen Mike for speech-language therapy when he was a child, and twenty or so years later his mother contacted me and asked me to work with him because his speech had become increasingly unintelligible over time. When I met with Mike, he had gone on “speaking strike” and was refusing to speak at all. Gina was distressed, and moreover, did not have the language skills to negotiate on behalf of herself or her boyfriend. The social worker had said, “*They’ll get over it*”.

Mike would not talk to me; I was unwanted, in the way, and incapable of doing anything to help Mike and Gina. Nothing in my training, and none of my quarter century of clinical experience as a speech-language therapist with disabled children had prepared me for understanding and managing this situation. I could find very little literature to guide me in my understanding of the adult lives of communicatively disabled people. Working with Mike and Gina, I came to appreciate that the lives of people who have grown up with lifelong communication impairments need to be researched.

I started this study as a way of trying to begin to understand what it is that adults with cerebral palsy who live with severe communication impairments experience in relation to living and participating in society. The end result provides some way to understand the complexity of the lives of communicatively disabled adults, like Gina and Mike.

Scant literature describes the adulthood of people who live with lifelong disabilities (Bigby, 2004). Remarkably, the communication impairments of adults who have lived with lifelong disability are mentioned rarely in any of the texts on communication impairments in adults. There are very few published articles that examine the trajectory of childhood communication disabilities (Levin, 2010a) but there are exceptions such as a small body of work on lifelong stuttering (Bricker-Katz, Lincoln, & McCabe, 2009; Guitar & McCauley, 2009), and lifelong language impairment (Miller & Poll, 2009; Owens, 2012). Despite a large body of literature on adulthood with Down Syndrome (Bigby, 2004; Phelan, 2011) and some other types of intellectual disabilities (Phelan, 2012), there is little attention to the communication difficulties associated with these conditions. There is a growing base of work with lifelong users of Augmentative and Alternative Communication (AAC) (Dew, Balandin, & Llewellyn, 2011; Wickenden, 2011).

In a landmark article, Balandin (2002) called for the communication needs of older people with lifelong disability to be addressed. She made the point that an extremely small body of literature had addressed the communication of adults with lifelong disability in terms of its development and the nature of its impairments. She demonstrated that an emerging literature at the time examined the long term outcomes of people with lifelong disabilities, but that despite this literature, as well as a fairly extensive body of literature on aging, there was limited research interest in lifelong communication disability. This state of affairs remains true a decade later (Balandin, 2011). This study responds to Balandin's (2002; 2011) call for research into lifelong communication disability.

## 2. Cerebral palsy

Cerebral palsy is a condition that arises in the earliest months of life, resulting in a wide range of impairments which, although not unchanging, are experienced throughout the individual's life. Cerebral palsy is defined as

> a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorders. (Bax et al., 2005, p. 572)

During the past 60 years, the prevalence rate of cerebral palsy has fluctuated and peaked at around 2.3 per 1000 in developed countries (Surman, da Silva, & Kurinczuk, 2012). Estimates put the prevalence of cerebral palsy as significantly higher in developing countries (Bhutta, Darmstadt, Babar, Hasan, & Haws, 2005; Blair & Watson, 2006). South African history has had an enormous influence on the lives of disabled people (including people with cerebral palsy) – particularly the adults of today who lived through the Apartheid years. The sub-standard health care system that was available to Black people as well as the conditions of poverty into which many Black families were entrenched, resulted in a high infant mortality and morbidity, including a high incidence of births of children with cerebral palsy (Arens & Molteno, 1989; Epstein, 1960; Molteno, Arens, Marshall, & Robertson, 1980). Many children born with developmental problems, including cerebral palsy, did not survive because of the unavailability of health services (Epstein, 1960; Saloojee & Pettifor, 2005).

In the first half of the last century, few children with significant childhood conditions were expected to survive beyond their childhood years. In developed countries today, over 90% of children with what are described as "special educational or health needs" survive into adulthood (Strauss, Brooks, Rosenbloom, & Shavelle, 2008; Surman et al., 2012). Studies in the USA (Strauss et al., 2008; Surman et al., 2012), UK (Hemming, Hutton, & Pharoah, 2006), and Australia (Reid, Carlin, & Reddihough, 2012) have shown that survival in early childhood has improved over the past two decades, and that those individuals who survive to early childhood are more likely to reach adulthood than in the past. Societies across the world have to deal with more survivors, underscoring the need for research into lifelong disability.

It is possible that more individuals with childhood conditions are surviving into their adult years in South Africa today. However, the current conditions of poverty in which so many disabled people live, as well as the lack of resources and services that resulted from exclusionary and discriminatory Apartheid policies, may render the situation in South Africa very different from international findings (Levin, 2008; Saloojee, Rosenbaum, Westaway, & Stewart, 2009). Survival rates in the developing world are less promising than in well-resourced communities; moreover, there are few reliable mortality data. The most recent information available to date is the 2004 report from the World Bank (World Health Organization/World Bank, 2011), which suggested that there were in excess of 150 million young people between 10–24 years of age living with significant disability in developing countries. There is an exceptionally sparse literature on cerebral palsy in South Africa. There are no data that report how many adults with cerebral palsy live in South Africa.

## 2.1 The communication difficulties experienced by people with cerebral palsy

It is estimated that 50% of people with cerebral palsy have communication impairments (Workinger, 2005). In a record review of 129 cases of cerebral palsy, Nordberg, Miniscalco, Lohmander, and Himmelmann (2013) found that more than half of the children had speech impairments, and 32% were non-verbal. Speech ability was associated with the type of cerebral palsy, severity of gross motor function, the presence of intellectual impairment, as well as the localisation of brain lesions.

The speech of people with cerebral palsy can be affected by their poor control over the motor and sensory components of speech production. Impaired speech production that results from neurological damage is known as dysarthria. In addition to dysarthria, speech can be affected by impaired planning of speech movements, broadly referred to as apraxia of speech. Both apraxia and dysarthria affect the intelligibility of speech production which ranges from mild to extremely severe compromise. For some individuals, AAC may be of benefit. Studies show that it seems that most adults with cerebral palsy use speech to communicate, even if their speech intelligibility is compromised (Van der Dussen, Nieuwstraten, & Stam, 2001).

As well as the motor and sensory impairments that affect speech production, a significant proportion of people with cerebral palsy have impaired language skills which may be due to the brain damage itself, coupled with environmental deprivation caused by their limited mobility and their social isolation (Workinger, 2005). Eight to 18 percent of people with cerebral palsy have hearing impairments (Rapp & Torres, 2000).

An extremely small body of research describes changes brought as a result of aging with cerebral palsy (Brady et al., 2012; Haak, Lenski, Hidecker, Li, & Paneth, 2009). Secondary complications arise from difficulties such as lifelong altered movements, abnormal postures, chronic medication consumption, and poor nutrition (Haak et al., 2009). As people with cerebral palsy age, they experience more general health problems including fractures (Haak et al., 2009), fatigue and pain (Malone & Vogtle, 2010). The hearing losses associated with cerebral palsy are reported to deteriorate, and just as members of the general population experience a deterioration in hearing with age, so too do people with cerebral palsy (Rapp & Torres, 2000). Oral motor difficulties are reported to become worse with age resulting in deterioration in speech and feeding (Brady et al., 2012).

Despite this information about changes with aging, the research that addresses the communication impairments of adults with cerebral palsy is exceptionally limited in breadth and scope. In most contexts, rehabilitation services rarely have a lifelong perspective and as a result, almost nothing is known about adult outcomes. In more resourced contexts, children with cerebral palsy receive treatment until about 18 years of age but rarely does this care continue after school-leaving age (Van der Dussen et al., 2001). This age-related separation of individuals with cerebral palsy from professional services probably contributes to the paucity of literature on adulthood with cerebral palsy. There is a very small body of literature that has explored the impact that the communication impairments related to cerebral palsy have on the lived experience of people with cerebral palsy (e.g. Ballin & Balandin, 2007; Heller, Ying Gs, Rimmer, & Marks, 2002; Kang et al., 2012; Llewellyn, Balandin, Poulos, & McCarthy, 2011). There is therefore a need to develop the literature in relation to the effects of communication impairments on the lives of people with cerebral palsy.

## 2.2 Cerebral palsy and intellectual disability

The root of the difficulty in establishing a unified definition of cerebral palsy lies in its history. Blair and Watson (2006) argued that cerebral palsy is not a diagnosis but a description because it stems from various etiologies and in addition, the expression of the symptoms is remarkably diverse. To this end, Blair and Watson (2006. p. 1) stated, “cerebral palsy is defined by clinical criteria that allow a wide ranging symptomatology” and hence etiology, pathology and prognosis are variable. They posited that the term cerebral palsy was coined to group children who fitted a description of symptomatology in an era before etiologies could be determined. Today, technological advances have meant that it is possible to isolate both etiology and pathology in most cases. Nevertheless, as Blair and Watson (2006) pointed out, even if all people with cerebral palsy were to receive a diagnosis, the term would probably remain because of its longevity, brevity, and uniqueness. Intellectual disability is associated with cerebral palsy, although prevalence figures are very variable which is probably due to the range of causes of cerebral palsy, as well as the broad continuum of severity and expression of impairments. SCPE (2002, cited by Workinger, 2005, p. 9) report one out of every five children as presenting with severe intellectual impairments.

Intellectual impairment interacts with the other impairments which are associated with cerebral palsy. For example, it is worse if epilepsy is present (Hoie et al, 2006a; Odding, et al., 2006).

Intellectual impairment is associated with both the type of cerebral palsy as well as the severity of motor impairment (which is often used as a measure of the severity of cerebral palsy). Dalvand, Dehghan, Hadian, Feizy, and Hosseini (2012) examined the relationship between gross motor function and intellectual functioning in 662 children. Their participants were between 3 and 14 years of age. They tested them on the Wechsler Preschool and Primary Scale of Intelligence and the Wechsler Intelligence Scale for Children-Revised, and rated them on the Gross Motor Function Classification System (GMFCS). They found a strong statistical correlation between gross motor function and intelligence. In a longitudinal study, Smits et al. (2011) described the development of non-verbal intellectual capacity of school-age children with cerebral palsy, and determined the association between the development of non-verbal intellectual capacity and the severity of cerebral palsy as defined on the GMFCS. The assessed 42 children at 5, 6 and 7 years of age, and 49 children were assessed at 7, 8 and 9 years. Using the Raven's Coloured Progressive Matrices, intellectual capacity was significantly associated with the severity of cerebral palsy.

In Smits et al. (2011), children with spastic quadriplegia were found to score higher in non-verbal intelligence than those with dyskinetic cerebral palsy. Majnemer, Shevell, Hall, Poulin, and Law (2010) found that differences in intellectual function were identified in association with different diagnoses of cerebral palsy, with children with spasticity exhibiting more limitations than others.

Over-estimation of intellectual and cognitive impairments in children and adults with cerebral palsy is due to the injudicious use of conventional measures of intelligence which are not valid because of the complexity of the symptomatology of cerebral palsy, as well as the unavailability of appropriate tests (Sigurdardottir et al., 2008).

## 3. Participation

In recognition of the impact that impairments have on the lived experience of disabled people, participation has become a key rehabilitation outcome. However, the concept of participation is complex, and theories of participation are diverse and incomplete (Whiteneck & Dijkers, 2009). The word “participation” is often paired with another word, which explains the diversity of the notion as well as the complexity in its definition. For example, the literature refers to social participation; political participation; economic participation; communicative participation; and civic participation. Words other than participation are used to denote similar or, at times, the same ideas – access; inclusion; community engagement; and civic living.

The study of participation emerges from many academic fields: sociology, philosophy, disability studies, psychology, rehabilitation science and so on. Each of these fields uses terminology in different ways. Moreover, they each bring unique biases and it is exceptionally difficult to arise at understanding based on well-established theory because it seems that participation is defined differently depending on its use. For example, Raghavendra, Bornman, Granlund, and Björck-Akesson (2007) pointed out in their study of people using AAC that different professionals involved brought different conceptualisations of participation depending on their roles and their experiences. The mixed ancestry provides a richness and depth to understanding participation from multiple perspectives, but it also raises questions about the meaning of participation.

As well as this pragmatic issue, it has been very difficult to develop measures of participation, and to decide upon the units of measurement because the components that comprise participation have not been theoretically teased out. The distinctions between activity and participation, for example, as presented in models of disability, have been debated and analysed for many years, but there is still little consensus (Anaby, Miller, Eng, Jarus, & Noreau, 2009; Whiteneck & Dijkers, 2009). In chapter 3, I provide a review of the various conceptualisations of participation and show that despite the lack of consensus, participation of all people in society has become an increasingly important universal concept in rehabilitation and disability (Hammel et al., 2008).

### 3.1 Participation and cerebral palsy

Studies on people with cerebral palsy in more resourced communities have shown an increase in independence and integration in social arenas, as well as greater participation in activities than in previous years (Michelsen, Uldall, Hansen, & Madsen, 2006). This improvement has been associated with improved and advanced technology, better home support services as well as legal mandates in access in countries such as the UK, USA, and Nordic countries. Writing about their lives, people with cerebral palsy have described persistent, significant societal barriers to participation despite the improvements in access and participation in contemporary times (Fried-Oken & Bersani, 2000). Adults with cerebral palsy experience considerable loneliness (Balandin, Berg, & Waller, 2006a; Ballin & Balandin, 2007). They have difficulties establishing intimate relationships (Wiegerink, Stam, Gorter, Cohen-Kettenis, & Roebroeck, 2010). Few people with cerebral palsy lead their adult lives with a life partner (Michelsen et al., 2006). Many people with cerebral palsy  remain dependent on older parents (Hemsley, Balandin, & Togher, 2008a).

Most adults with cerebral palsy are denied fair opportunities for successful gainful employment, and may not be able to earn sufficiently so as to maintain financial independence (Barnes, 2012; Michelsen et al., 2006). There is a small body of research that has shown that adults with cerebral palsy benefit from leisure activities in that they provide opportunities for social interaction (Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2006) but experience barriers to participation in leisure such as access to leisure facilities, lack of opportunities for social interaction during non-working times in the working day at places of employment (such as socialising at lunch hour, or casual meetings over the Photostat machine) (Levin, 2010b). Few adults with cerebral palsy participate in sports (Siebers, 2012; Van Naarden Braun et al., 2006).

## 4. Communicative participation

Mirroring the move to the broader social disability models in the 1980s, those involved with the study of communication acknowledged that communication cannot be separated from societal participation (Worrall & Hickson, 2008). In their systematic literature search on the participation of people with aphasia, Dalemans et al. (2008) concluded that the studies reviewed had not defined participation, that the information was "scattered and fragmented" (p. 1071), and that there was insufficient evidence of theory to guide future research. Hence, the concept of the participation of communicatively disabled people is relatively new (Baylor, Burns, Eadie, Britton, & Yorkston, 2011; Yorkston et al., 2007), and the theoretical understanding of communicative participation is underdeveloped (Balandin, 2011; Baylor, Yorkston, Bamer, Britton, & Amtmann, 2010).

The understanding of communicative participation is influenced by foundational assumptions which I will now problematise.

### 4.1 Rhetoric, dominance and alignment with medical approaches to disability

The terminology used in the study of communication impairments reflects an individualised, normative ideology. There is a clear alignment with a medical approach in terms of the use of the term "disorder"[2]. This is not surprising because of the grounding of the study of communication disability, in many universities, within medical faculties. Importantly, many professionals in the health sciences, including speech-language therapists, are not schooled in the social sciences and in societal dynamics. As Threats (2010b, p. 90) stated, "Education using the medical model in the health professions emphasizes that our role is to narrow in on the disability, pinpoint the diagnosis, and provide an appropriate remediation for the deficits."

The term "pathologist" in the title of the profession of speech-language pathology in some countries speaks volumes about the status of the profession in its relationship to disability. Using this strong medical term, the profession – intentionally or not – aligns itself with the medical conceptualisation of the person presenting with a pathological condition. Many

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[2] The American Speech-Language and Hearing Association (ASHA) (2012a) defines a communication disorder as "an impairment in the ability to receive, send, process, and comprehend concepts or verbal, nonverbal and graphic symbol systems. A communication disorder may be evident in the processes of hearing, language, and/or speech. A communication disorder may range in severity from mild to profound. It may be developmental or acquired. Individuals may demonstrate one or any combination of communication disorders. A communication disorder may result in a primary disability or it may be secondary to other disabilities" (Web page Para. 3).

practitioners today have not interrogated the name by which they are called, calling into question the depth to which they have engaged with debate about disability matters.

### 4.2 Preoccupation with impairments, normalisation and intervention

Not only does the terminology indicate that there has been little engagement with disability matters, but it also indicates a lack of transformation from impairment-based perspectives to socially-based perspectives. A quick glance through the contents pages of the journals in the field of communication disability shows a persisting preoccupation with impairments and interventions.

There is no question that the interventions offered by rehabilitation professionals working within the medical framework have been of benefit to many disabled people, and there are numerous reports of improved quality of life and improved life satisfaction by consumers of these interventions. However, there have been calls for a move from looking at the impairments or communication limitations, to looking at assisting the communicatively disabled person to access and be included in everyday contexts (Balandin, 2011; Baylor et al., 2011; Duchan, 2001a; Threats, 2010a). These calls have resulted in some movement beyond the “disordered” towards a broader view that embraces the principles articulated by the social approaches to disability. This evolution in thinking is discussed in chapter 4 in which an overview of the study of communicative participation is presented. This socially-based construal is that communication is about how the person participates in everyday contexts, which demands a shift in research methodologies as well.

### 4.3 Research methodologies

A characteristic of the research on communication impairments has been a strong reliance on positivist research principles, and this emphasis remains. It seems to define the deficit frame within which communication disability is studied. As Kathard (2009, p. 20) wrote, “When our interventions demand engagement with personal, outside-of-a-deficit frame dimensions, it seems logical and important to create a different knowledge”. Although there are increasing numbers of editors of journals expressing their acceptance of qualitative methodologies (Balandin & Goldbart, 2011; Simmons-Mackie & Damico, 2001), as well as a journal launched in 2010 that specifically aims to publish qualitative research in communication (Journal of Interactional Research in Communication Disorders) [3], the majority of publications are still rooted in traditional scientific quantitative methodologies.

Many rehabilitation professions comply with the notion of evidence-based practice in which they are expected to definitively demonstrate that the interventions that they provide are effective. In order to do this, they have to select a specific behavior or set of behaviours, implement a procedure and measure the changes by using quantitative methods in which the behaviours that have been selected for remediation are specified. In many contexts, they have had to work within a managed-care environment in which this type of measurable change is demanded (Duchan, 2001a; Kovarsky, 2008). The epistemological underpinnings of evidence-based practice do not allow for the representation of the voice of the communicatively disabled person, and so little can be gleaned about the "intersubjective life world of clients" (Kovarsky, 2008, p. 47). Increasingly, qualitative methodologies have allowed for the personal story to be told, and for communication to be examined from a much broader perspective than the individualised structural and normative models (Dalemans, de Witte, Wade, & van den Heuvel, 2010; Hemsley, Balandin, & Worrall, 2011; Threats & Worrall, 2011).

### 4.4 Difficulties including people with communication disability in research

Despite the move to a less individualised, medicalised model by speech-language therapists and others involved in the study of communicative disability, the personal story remains mostly untold (Kathard, Norman, & Pillay, 2010). It is likely that one of the reasons for this is the preoccupation with impairment; another might be that it is exceptionally difficult to include people with significant communication difficulties in research in which the personal story is explored. Hence, most research with communicatively disabled people is conducted by speech-language therapists and/or linguists. Because of speech-language therapists' relative comfort with including people with communication impairments in research, research with communicatively disabled people, then, seems to have been confined to the field of speech-language therapy with little input from allied fields. This professional ownership, so to speak, of communication disability is inevitably restrictive.

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[3] http://www.equinoxpub.com/JIRCD : "*The Journal of Interactional Research in Communication Disorders* aims to provide a unique forum for qualitative research relating to speech and language disorders, therapeutic and educational interactions, and for research into the contextual issues involved in these interactions. Additionally, the journal will include quantitative studies in the area of social interaction."

Exclusion of communicatively disabled people from broader fields of research, results in the bias towards understanding the lives only of those who can contribute in articulate ways to the research process (Carlsson, Paterson, Scott-Findlay, Ehnfors, & Ehrenberg, 2007; Lloyd, Gatherer, & Kalsy, 2006). Underpinning the decision to exclude people with communication impairments in research is the assumption of researchers that meaningful data will not be obtained. The concerns surrounding the credibility of the data (Lloyd et al., 2006) obtained are genuine, warranting careful consideration.

Communication impairments can arise from difficulties at any or all of the cognitive, linguistic and sensorimotor levels of speech and language, resulting in restricted ability to express one’s ideas and thoughts. Communication impairments can arise from difficulties that people experience with sound production such as when experiencing spasticity or incoordination of the speech musculature. These impairments result in compromised intelligibility, and often these participants do not have alternative ways of expressing their ideas that compensate for their unintelligibility. Communication impairments can result in participants experiencing difficulties in the ability to construct their meaning due to cognitive-linguistic impairments such as attention deficits, orientation difficulties, memory difficulties, or difficulties coping with abstract information (Lloyd et al., 2006; Paterson & Scott-Findlay, 2002). Some people experience difficulties with expressive language such the inability to find the appropriate words, produce grammatically correct sentences, or describe what they would like to in-depth and in detail. These comprehensibility problems can also result in participants being restricted in their ability easily to provide rich data (Lloyd et al., 2006) in that their communication impairments may prevent them from being able to provide depth, detail, and specificity. Extremely difficult to manage within research are comprehension difficulties that participants can present with where they are not able to understand part or all that is said to them. Psycho-emotional issues play their part: some people are not able to share their meaning because they see little value in doing so, such as in Moyle’s (2002) work with severely depressed people in which the participants were found to have reduced linguistic complexity, paucity of thoughts, and a limited ability to interpret and describe their experiences. Other participants are influenced by the negative attitude of their listeners and in response try to cover up their disabilities, which Paterson and Scott-Findlay (2002) refer to as “image management” and which Lloyd et al. (2006) referred to as “secondary impairments”.

Hence, suspicion arises with regard to the credibility and value of the data obtained from people with communication impairments. The data cannot be understood by the researcher without some degree of manipulation such as in saying ,"I think what you said is…" which requires interpretation by the researcher, or "can you spell that?" which provides some cue but does not allow for the researcher to understand all the words and all the meaning. In cases where the data depend tremendously on the researcher's interpretation, the question is asked how much of the participants' reality is expressed (Lloyd et al., 2006). There are genuine concerns that the interpretation becomes an interpretation of an interpretation, leading one further and further away from the data itself (Csordas, Dole, Tran, Strickland, & Stork, 2010).

Therefore, in exploring communication disability, methodologies have not been explored to determine how best to represent what is being researched (Kathard, 2009). Although there is a growing body of research that has successfully included people with communication impairments, few published studies describe issues related to sampling, adjustments made to methods and strategies, transcription, and interpretation of unintelligible or incomprehensible data. In my reading of published journal articles in which people with a variety of communication impairments were included, most studies provide little or no discussion about methodological complications. Some authors provide broad, brief, and limited descriptions of the strategies used.

Gatekeeping[4] is a significant issue in sampling. For example, Paterson and Scott-Findlay (2002) used nurses as gatekeepers in their study on people who had communication difficulties following traumatic brain injury, who determined that the participants "did not have cognitive or speech deficits that constrained their ability to participate" (p. 400) . Even then, although their participants were screened, there were still cognitive communication, emotional and other difficulties that had not been detected on screening and which made their interviews challenging.

From an ethical perspective, it may be complex to rationalise the inclusion of communicatively disabled people in research because of challenges regarding obtaining informed consent, and the potential for harm. Obtaining informed consent from people with communication impairments is a thorny issue (Carlsson et al., 2007; Penn, Frankel, Watermeyer, & Müller, 2009). Penn et al. (2009) pointed out that many of the components of

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[4] In this context, I define a gatekeeper as any person who has the "authority to deny access to potential participants or who has the ability to facilitate such access" (King & Horrocks, 2010, p. 31).

the consent process require sophistication on the part of the research participant because of the linguistic and cognitive demands involved.

In sum, the inclusion of communicatively disabled people in research is fraught with difficulty, and has influenced to some degree the type of research conducted. The approaches and methods used have not always served to illuminate the issues that surround communication disability, particularly in relation to providing an opportunity for the personal story to be told, or for gaining a deep understanding of the full meaning of communication disability, including communicative participation.

### 4.5 Research on communication disability in South Africa

There have been two strands of research in communication disability in South Africa. The first strand is in line with the general international trends in which the focus is on discrete aspects of the communication process, specifically on the speech and language skills of communicatively disabled people. This research has been challenged by many factors. Firstly, the professions in South Africa, in line with Apartheid government policies as well as the way in which some universities aligned themselves with these policies, led to the training of predominantly White speech-language therapists and related professionals such as linguists, psychologists and social workers. This meant that few qualified professionals speak the languages of the majority of disabled people in the country (Levin, 2006). Consequently, there is extremely little research on the development of speech, language and communication in children who speak the vernacular languages spoken in the country (Jordaan, 2011). Allied to this lacuna, there is a paucity of research that elucidates the communication processes related to acquired communication disability (such as post-stroke aphasia) in adults in the country. A number of research projects have been undertaken but the limited ability of the researchers to engage with their research participants in their home languages is evident (Bham & Ross, 2005; De Andrade & Ross, 2005; Jordaan, 2011; Patel & Ross, 2003). Complicating the research, 11 official languages and sign language are used in South Africa.

The second strand, and much less prevalent, comprises studies that have looked at broader social aspects related to communication disability. Communication is fundamentally a social process, and requires a deep understanding of cultural practices and beliefs (Legg, 2010). This understanding is critical if we can avoid the interpretations of communication disability in various cultures being based on assumptions of the meaning of disability by professionals from their traditional Western models of communication, and their training.  For example, traditional healers play an important part in the lives of disabled people in South Africa. A significant body of research that looked into the beliefs and practices of African, Muslim Hindu, and Chinese traditional health practitioners in relation to communication disability has been conducted by Ross with various colleagues (Dagher & Ross, 2004; De Andrade & Ross, 2005; Patel & Ross, 2003; Ross, 2007). These studies, although extremely limited in number, have shown that Western notions of communicative health and disability are so very different from traditional notions.

The literature in communication disability is predominantly that of the global North, and the methods and interpretations of communication disability from the South African researchers' perspectives have in the main reflected Western models of communication. The bias from this cognitive authority is concerning in terms of the inequitable participation of disabled people in both the research and clinical processes.  There are two consequences here: the first is the positioning of the communicatively disabled person as "other"; and secondly, the meaning of being disabled for the disabled person is assumed by the professional. Of concern, too, is the fact that the rehabilitation professions such as speech-language therapy, social work, and psychology, are highly feminised in South Africa, and the interpretations of disability and approaches to the study of disability are influenced by this bias. To date, there is very little interrogation of these issues as they pertain to the understanding of communicative disability in South Africa (Kathard, 2009).

Regnant practices in the field of the study of communication disability may benefit from a critical disabilities perspective.

## 5. Critical disability studies

For many months, I sought a theoretical home for this study.  Communication has no disciplinary boundaries, and coming from a background of working as a speech-language therapist for more than 25 years, I was aware of a need to move beyond the confines of what my home discipline could offer. I started this study at a point in time where my own profession had become increasingly aware of the social meaning of communication. Much of the research on communicative participation had been embedded in the "biopsychosocial"[5] perspective of the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001) but I was concerned that the

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[5] This model acknowledges the interaction of the person, environment and health or disability condition.

ICF is a typology based on a model, not a theory (Hammer, 2011). In addition, the ICF has some serious limitations and is yet to be further developed – which I discuss in chapter 3. I looked to find a paradigm that would embody the multiple layers of meaning that my encounter with Gina and Mike represented to me.

Disability studies started as a field of study based on the disability activism that started in the 1960s. Various disability movements across the globe recognised the injustices encountered by disabled people including oppression, marginalisation, stigmatisation, and a host of other forms of violence. The social model of disability emanated from this early work and dominated discourse for a number of years. This model proposed that society was responsible for the construction of disability, and that were society to accommodate to the needs of disabled people, there would be no such thing as disability (Oliver, 1990). Despite its limitations, the social model of disability turned thinking around, and its political value was inestimable in changing thinking about disability and in providing disabled people with a voice which they had not had before (Morris, 2001). Over the years, a substantial field was developed which became known as disability studies, which offered a different perspective from the individualised one, in which to understand the meaning of disability.

Critical disability studies is a paradigm that has grown out of disability studies. Taking on some of the notions of critical social science, critical disability studies now examines more minutely the issues that are inherent in understanding the nuances and intricacies of disability as a social issue. Critical disability studies debates the issues that were identified in disability studies such as oppression; the role of the body; the role of power; politics and governments; human rights; medicalisation; and culture.  The intricacies of the explanatory paradigms are looked at from multiple perspectives – social, political, psychological, carnal, cultural and so on (Meekosha & Shuttleworth, 2009). Critical disability studies also invites analysis from multiple perspectives such as feminism, queer theory, crip theory, postmodern theory and as Meekosha and Shuttleworth  (2009) stated, from perspectives that would have, in the past, have been considered contrary to the social model of disability.

From the perspective of a speech-language therapist, trained in the science of rehabilitation, I needed a paradigm that would lead me away from the focus on the individual and on speech and language, to a broader perspective of the person. I needed a paradigm that offered a strong acknowledgment of the social meaning of communication, and one that would free me from thinking about normalisation.  I found myself being critical of work in my field that adopted a social perspective but only in as far as it continued to contribute to the idea of disability as a personal tragedy, and something that needed to be cured. Magasi (2008) called for rehabilitation sciences to be cognisant of the issues in disability studies in order to

> be more responsive, more relevant, and more empowering to people with disabilities by helping to challenge disabling social structures and the ongoing marginalization and devaluation of people with disabilities. Change cannot and will not occur without the hard work and concerted efforts of health and rehabilitation professionals. (p. 286)

There is evidence of critical disability studies contributing to breaking down barriers between disciples (Phelan, 2011). I embedded this study in the critical disabilities studies paradigm because of its potential to break down some of the dominant ideas of my professional training, and at the same time, build on a growing field of study of the social meaning of communication disability.

## 6. Description of the chapters

The study is organised into four parts.

## Part one: Conceptualising communicative participation

### Chapter 1: Introductory perspective and problem statement

This chapter provided a statement of the problem that provided the rationale for studying the communicative participation of communicatively disabled adults with cerebral palsy. It defined communicative participation very broadly as the access and inclusion of people in everyday contexts in which communication takes place. It showed that social participation of disabled adults is not a new idea and yet the definition of participation, as well as that of communicative participation, remains unclear. The introductory chapter proposed that the study of the communicative participation of people with lifelong communication disability is sparse, and is relevant given the increasing survivorhood of people with childhood disability. I explained how the study came to be immersed within a critical disability studies framework. In conclusion, I provide a description of the organisation of the study.

### Chapter 2: A critical disability studies framework

The main aim of this chapter is to provide the background against which the study should be viewed. It begins by providing a relatively brief overview of disability, including how disability is defined from various perspectives.  The chapter includes a review of disability in South Africa so as to contextualise this thesis.

### Chapter 3: Participation

In this chapter, I provide an overview of participation as a theoretical term.  So as to get a deeper theoretical understanding of communicative participation, the theoretical background to the more general term “participation” is provided, followed by an overview of ethical, political, psychological and medical orientations to the term. I end the chapter with a review of how participation is represented in models of disability.

### Chapter 4: Communicative participation

In this chapter, I provide a review of the research on communicative participation. I begin with a brief historical overview of the study of communication impairment to elucidate the development of the understanding of what communicative participation is. I then provide a review of the literature that has addressed communicative participation, and in so doing, identify the main themes that have been identified as well as the gaps in the understanding of this term.

## Part two: Methododology

### Chapter 5: Methodology

In this chapter, I provide a rationale for choosing the pragmatist grounded theory (GT) method promoted by Charmaz (Charmaz, 2006; Charmaz & Bryant, 2011),  for the study of communicative participation. The chapter includes the description of the participants.  I provide details of steps that were taken in the preparation of the study, the methods selected, and the transcriptions of the data.

The methods that were used to construct the data and the analytic processes through which the data were taken so as to develop a theory of communicative participation are described. I show how the inclusion of disabled people in oral interviews was possible and describe how, despite the oral limitations of the participants as well as some methodological challenges, the data were trustworthy.

## Part three: Results of the data analyses

### Chapter 6: Being recognised as a communicative partner

In this chapter, I present the results that highlighted the lack of recognition that the participants experienced in regard to being communicative partners. At times they experienced total exclusion from communicative opportunities. At other times they were included in communicative interactions but these interactions were characterised by vulnerability in that the status of the participants always was uncertain and ambiguous and likely to change without warning. It was rare for the participants to feel fully included as communicators in their interactions with others, and they described some of the conditions that were needed for this full communicative participation to occur**.**

### Chapter 7: Communicating in context

In this chapter, I present the data that showed that the participants experienced problems with communicative participation because of their communication difficulties. The difficulties arose from intrapersonal issues such as having to communicate in a second language as well as interpersonal issues such as being able to take on social roles, and being dependent on others for one's communication. Issues surrounding communicative contexts, such as noisy and group situations were identified as playing a large role. The analysis of the data showed that the participants had much difficulty with being able to communicate in a variety of acts such as in negotiating, arguing and joking.

### Chapter 8: An embedded communicative self

In order to participate in a social interaction in which one wishes or needs to communicate, one has to recognise oneself as a full and equal communicative partner. The participants showed themselves as living with a disabled identity to some extent, but that their communicative limitations played a role, but not a central role, in their identities. The discussion includes a description of some of the patterns of identity formation that were identified as well as the factors that contributed to the construction of the participant's selves as communicative partners**.**

### Chapter 9: Dynamic participation

Through the codes that captured changes through the lifetime, I discuss the development of the communicative participation of the participants through their lifetimes. I show that their experiences of being disabled, and having limited opportunities to participate as well as communicate in social activities, influenced their lives. Here I look at the participants' descriptions of their interactions with parents and friends; their communication in their school years including their experiences of speech-language therapy; and the transitions from childhood to adolescence and then to adulthood. I look at the context in which the participants have lived, with particular reference to living through the Apartheid years as children and young adults.

## Part four: The communicative participation of adults with cerebral palsy

### Chapter 10: Discussion

Using Honneth's theory of recognition (Honneth, 2003; van den Brink & Owen, 2007) and the work of Ikäheimo (Ikäheimo, 2010a, 2010b) that extended his theoretical presentation of recognition, I present a model of communicative participation based on the findings in this study that expresses it as a multi-layered expression of social participation. I propose that the word “silence” be used to symbolise the breakdown in the multiple levels of communicative participation.

### Chapter 11: Conclusions

In this chapter, I look to the limitations of the study as well as the strengths. I examine the relationship of this study to previous studies on communicative participation, and discuss how the immersion of this study in critical disability studies has helped to advance the understanding of communicative participation. In this chapter, I propose some theoretical as well as clinical implications of this study. I suggest directions in which this research can be extended.

## 7. Some notes on anonymity

The world of adults with cerebral palsy in Gauteng, the province in South Africa in which this study was conducted, is relatively small and many people with cerebral palsy know one another. So as to allow the participants to remain anonymous, they have been given fictitious names. In addition, in most cases where quotations are given, it is made clear which participant provided the information. However, there are instances in which the source of the information is made unclear deliberately because the information might have divulged the identity of the participant.

## 8. Some notes on terminology

Language is political. Language is the means through which disabled people have been hurt, disrespected, insulted, labelled and demeaned, as Wendell (2003, p. 77) stated, “languages so often betray us”. One of the main themes, I think, to have emerged from disability politics and its debates surrounding the language that is used, is that context is critical when evaluating what is acceptable and what the consequences are of one’s choices (Shakespeare, 2006; Wendell, 2003). This study uses the semantics of disability promoted by the British social model of disability. This model recommends the use of the term “disabled people” to communicate that it is society that disables people (Oliver, 1996). The preference in the USA is for the term “people with disabilities” so as to communicate that the disability should be seen as separate from the person and is part of the “People First” ethos of USA disability movements (Shakespeare, 2006). I have chosen to work with the British recommendations for the sake of consistency, but also because I have been inspired by the work of Simi Linton (2008), a prominent disability activist in the USA who has chosen to describe herself as a “disabled woman” rather than use People First terminology.

However, I agree with Shakespeare (2006) that the time has come to curb the objections over the terminology and work rather towards a universal understanding of society’s responsibility in embracing disability; and with Wendell (2003) who stated that demanding one form of language use and criticising anyone else’s language use detracts from the primary goals of disability activism. No matter the terminology used, society must acknowledge that disabled people remain oppressed and marginalised; and that disability must be owned by disabled people (Swartz, 2010). This is the philosophy embraced by this study.

## 9. Notation conventions used in this study

The transcription of the interviews uses the notations recommended by Von Tetzchner and Basil (2011, p. 145). These are shown in Table 1.

Table 1

*Notation conventions for different forms of communication*

| Utterance form | Notation | Example |
|---|---|---|
| Gloss of manual signs and gestures | Capital letters | MANUAL SIGN |
| Spelled written words | Underline and hyphen | S-p-e-l-l-e-d w-o-r-d-s |
| Written words spelled with prediction and Selection | Underline and hyphen of individual letters and letter clusters | c-a-cat, c-cat-cats |
| Selection consisting of multiple words or a ready-made sentence | Continuous underline | Sentence with several words |
| Naturally spoken utterances | Italicisation | *Naturally spoken words (note that I use quotation marks in the body of the text)* |
|  | Italicisation and quotation marks | *"Words and sentences spoken by a machine"* |
| Interpretation of other referring expressions | Quotation marks and explanation | 'No' (shakes head) |

# CHAPTER TWO: A CRITICAL DISABILITIES STUDIES FRAMEWORK

## 1. Introduction

This chapter is written from the position that in order to gain an understanding of what communicative participation means for people who have lived all their lives with communication disabilities, it may be useful to embed this study in a broader understanding of critical disability studies. Garland-Thomson (2012, p. 1) defined critical disability studies as an "extended conversation" in which new critical concepts are brought into "conversation with the existing conceptual canon of disability studies".

Critical disability studies can be applied in almost any scholarly field because, as Garland-Thomson (2002; 2011a) put it, if one looks, one can find disability anywhere. Consequently, disability has been interrogated within fields as diverse as sociology, anthropology, critical gender studies, the arts, building sciences – all of which have contributed to the deeper understanding of disability and the way we respond to it. Critical disability studies examines disability issues using a multiplicity of theories such as post-structuralist/postmodern theory, psychoanalysis, phenomenology, feminist studies, sociology of the body, social justice theory, and moral philosophy. Its aim is to explore the complexity of disabled people's experiences (Inahara, 2009) and to contribute to an emancipatory ideal (Meekosha & Shuttleworth, 2009).

So as to position this study within a critical disability studies framework, I present an overview of the approaches to disability, and speak to some of the current notions of disability that are particularly relevant to this study.

Most disability research has been conducted in Europe and North America (Meekosha, 2011), and my review of the field will reflect this bias despite the fact that most disabled people live in the global South. In order to understand the data considered in this study, it is necessary to develop a better understanding of disability within the South African context. Hence, the discussion of the current issues in disability studies that are relevant to this research is followed by a review of disability in South Africa. As such, the discussion contextualises this study.

## 2. Approaches to disability

The diverse and numerous approaches to disability reflect its complexity. The medical and social models of disability are presented here so as to illuminate core issues in disability studies. In addition, they are presented because they are models that typify approaches to the study of communication disability.

### 2.1 The medical model of disability

Many of the early approaches to disability were based on spiritual beliefs that viewed disability as the embodiment of evil spirits, witchcraft, the devil or G-d's anger (Clapton, 1997). The biomedical philosophy of disability that emerged around the 19th century changed conceptualisations of the locus of the problem. Disability came to be seen as a disorder of bodily function or bodily attributes, and was seen as caused by a range of material factors such as physical trauma, infection, the ingestion of toxic substances, and so on.

Within the medical approach, then, disability came to be viewed as a problem residing within the individual body. Because of the historical preeminence of biomedicine as a social institution, this individualised view of disability has come to dominate Western thinking, academic theorising, and institutional practice for centuries (Thomas, 2008). In addition, and more pervasively, the biomedical approach to disability has wielded tremendous power in broader philosophical thinking and socio-political locations (Thomas, 2007). This, then, is the source of the term 'medical model' which is used in reference to an individualised model of disability.

Because of the esteem in which medical personnel are held in many societies, the biomedical approach lends credibility (Mostert, 2002; Scully, 2008), cultural respectability (Lifton, 1986; Thomas, 2008), and economic advantages (Scully, 2008) to systems that adhere to its approach. Biomedical approaches are powerful, pervading societal structures on all levels (Barnes, 2012; Barnes & Mercer, 2003; Tremain, 2008). This pervasiveness and power was palpable, for example, in the abhorrent eugenic practices of the twentieth century. At the turn of the twentieth century, many of the world's scientists were influenced by Darwin's theories that posited that the health and endurance of a species is defined by the genetic strength of its progenitors. Groups of theories subsequently applied Darwin's theory to social evolution, espousing that competition drives social evolution and thus the genetic purity of a nation defines its fitness. In this inappropriate extension of Darwinism, natural selection is replaced by social policy which allows the most powerful, not the fittest, to survive. A mass of work, based primarily on pseudo-data, showed differences between groups of people on a range of measures such as race, behaviour, and wealth. According to Mostert (2002, p. 158), these studies “not only reinforced popular social prejudices, but enshrined them as irrefutable scientific fact”.

Eugenics, a social interpretation of Darwin’s theory first promoted by Francis Galton in the 1860s, posited that social morals had to adapt to prevent the less fit from breeding and the more fit from under-breeding. The eugenics movement took root with vigour in many countries including the United States Japan, Sweden, Canada, Finland, France and the United Kingdom (Emanuel, 1994). Indeed, it was the eugenics movement in Germany that laid the foundations for the central policy of Race Hygiene in Nazi ideology that provided the footing for the Holocaust. Bred within a climate of socio-political chaos, the perverse application of these philosophies culminated in the sterilisation of 400 000 disabled German men and women, and the deaths of more than 250 000 disabled German children and adults (Lifton, 1986). The Holocaust followed this eugenic programme. The Race Hygiene policy was predominantly conceptualised by, managed by, and supervised by medical personnel (Lifton, 1986). There can be no more powerful example of the power and pervasiveness of the biomedical model.

Apart from the extremism of radicalised eugenics, biomedical approaches fuelled, and continue to fuel, social policies that position disabled people as outcasts, as peripheral members of society (Tremain, 2008). Society has been fed by centuries of socialisation around the medicalisation of the body, the ostracism of disabled people from mainstream society, and the threat of disabled people to the health of society (Barnes, 2008). There is an enormous body of evidence that has shown that the preoccupation of the biomedical approach with the body, and in particular with the “disordered”, “abnormal”, or “defective” body, results in society marginalising disabled people on the basis of the body alone (Morris, 2001; Watermeyer & Swartz, 2008).

## 2.2 The social model of disability

The rejection of traditional models of disability coincided with the American Civil Rights Movement; post World War II liberation policies; the growing understanding of the horrors of the extreme eugenic policies of the Nazis; the rise of socialism and Marxist approaches within sociology; as well as the emerging feminist literature. The activism took different forms in different contexts.

In Britain, the challenging position was articulated very clearly: disability was seen not as an individual problem, but as one of social oppression. Rejecting the medical model, disability activism began to emerge in the early 1970s. The Union of the Physically Impaired Against Segregation (UPIAS), a British organisation whose membership was exclusive to disabled people, defined disability as “disadvantage or restriction of activity produced by contemporary social organizations which underestimate the worth of those with physical impairments and exclude them from the principal activities of social life” (Union of Physically Impaired Against Segregation, 1976, pp. 3-4). The development of the social model of disability followed this important work (Goodley, 2011).

Many early disability activists aligned with a Marxist materialist view of capitalism as a major contribution to notions of the human being as being valuable primarily in terms of his or her contribution to society (Finkelstein, 1980, 2004; Oliver, 1990, 2009). It has been suggested in the nomadic and/or agrarian societies of pre-industrialisation, disabled people lived in their communities within their families. According to historians, they were given tasks to do that they were capable of, and played their part in society. There were conditions under which disabled people were shunned, but as a rule, disability was viewed as a natural part of the cycle of life in rural communities (Finkelstein, 1980). Proponents of the Marxist material view claimed that it was the rise of industrialisation and capitalism that led to the repositioning of the lives of disabled people as reduced in value. In addition, capitalism was – and continues to be – viewed as a form of social control wherein disability is viewed as constructed by the beliefs and values of society which places tremendous value on individualism. In this way, disabled people have their societal roles removed, and their marginalisation is exacerbated by their relative lack of value (Barnes, 2012; Oliver, 1990).

Positioning disability within the organisation of society, calling on issues such as human rights and justice (Oliver, 1996), was a major shift, both theoretically and in practice. In the social model, exclusionary social systems defined disability (Oliver, 1999). Where many advocates of the medical model saw disability as a personal tragedy, advocates of the social model saw it as social oppression; the medical model focus was on individual treatment and the social model focus was on social action. The activists, then, initiated the struggle against social oppression and worked for the emancipation of disabled people from an oppressed and marginalised position towards inclusion in society (Hughes & Paterson, 1997). Oliver (1996), one of the early protagonists of this opposition and the person credited with naming the "social model" stated, it "turned the understanding of disability completely on its head" (p. 43). Its purpose was political.

The focus in the USA was on the economic implications of disability in a highly competitive capitalist society in which individualisation and financial success were highly valued. Aligning with American political thinking, disabled people were seen as a political minority group, which gave credibility to its opposition to discrimination and prejudice (Linton, 2008). American disability activism has focused to a large extent on ensuring that discrimination and oppression of disabled people is mitigated though legislation. The minority group approaches have been very clear about the need for society to adapt to accommodate the needs of disabled people rather than disabled people having to adapt to society (Linton, 2008). The Independent Living Movement that developed in North America in the 1970s stressed the de-institutionalisation, de-medicalisation and mainstreaming of disabled people (Barnes & Mercer, 2010).

Similarly, in Nordic countries, the medical approach to disability was rejected. Somewhat resonating with the North American human rights approach, but in line with broader Nordic socialist political philosophies, these countries have embedded their approaches to disability within a human rights perspective. The approach has been broad in that they have not aligned with one theory, but with a range of approaches. The Nordic approach has been called the "relational model". The main characteristics of this model are that disability is seen as a person-environment mismatch; that disability and context are interdependent; and that disability is not a fixed entity but is relative (Tøssebro, 2004). According to Goodley (2011), disability studies in the Nordic countries was immersed in the context of welfare. Furthermore, the relational model has been influenced by the idea of the normalisation of disabled people, particularly intellectually disabled people. This is one form of activism that reflected the needs of people with lifelong disabilities, in contrast to the British and North American approaches that were – and remain - championed mainly by people with acquired physical disabilities.

## 3. Core issues in critical disability studies

The "overtly partisan, emancipatory position" (Watermeyer, 2013, p. 7) that the social model has taken has been argued to have made it difficult to engage with scholarly argument and with developing critical concepts in disability studies (Watermeyer, 2013). In its determination to maintain a political focus, what has come to be called the "strong social model" (Hammer, 2011) has been argued to have effectively ignored two key experiential issues. First, the strong social model has been seen to defocus from (and even to some extent to disavow) personal accounts of disability (Morris, 1998) in speaking of them as "sentimental" (Barnes, 1998, cited by Thomas, 2007, p. 122) and as detracting from the core business of disability activism, which is to dismantle oppression (Watermeyer, 2013). Second, it has been argued to ignore the lived experience of embodiment, and of the body, including the realities of pain and difficulties in negotiating the physical world (Scully, 2008; Thomas, 2007).

### 3.1 The personal experience of disability

UPIAS (1976, pp. 3-4) defined impairment as "lacking part or all of a limb, or having a defective limb, organ or mechanism of the body;" and disability as "the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities". According to some, the distinction helped disabled people to separate their identities from their impairments, and in so doing, to become liberated. This sense of freedom and permission to be disabled gave people hope, improved self-esteem, and a political voice (Morris, 2001).

Consequently, in the face of critical debates on the impairment-disability dichotomy, many of the proponents of the strong social model have been determined to keep impairment and disability as distinct. In his later writing, Oliver continued to defend the strong social model's stance (Oliver, 2009). His standpoint has been that the strong social model is a fight for the recognition of the social forces that operate to disable people. He argued repeatedly that were the two to be conflated, it would devalue the opposition to the individualised models of disability (Oliver, 1996, 2008). He and colleagues stated,

> Disability and impairment are of course interconnected and the distinction between them less than clear, but in order to identify political strategies it makes sense to separate the two analytically, treating them not as concrete objects but as abstractions. (Sheldon, Traustadóttir, Beresford, Boxall, & Oliver, 2007, p. 209)

More contemporary materialist approaches continue to acknowledge in many ways the economic power that Oliver and the earlier disability writers within the Marxist perspective wrote of. There is abundant evidence that disabled people remain without the material resources in comparison with their able-bodied counterparts (Barnes, 2012). Moreover, contemporary materialists have proposed that the economic basis of disablement has possibly increased with societal changes over the years, commodification of the body, and globalisation (Barnes, 2012; Barnes & Sheldon, 2010).

Despite some of the proponents of the strong social model arguing to this day that the power of disability activism is reduced to nothing by those who conflate impairment and disability or those who allow for the personal tale to be told (Barnes, 2012), disability still exists even if the social barriers to disability are removed. Garland-Thomson (2011b), for example, wrote that the disabled body cannot "dematerialize if social and architectural barriers no longer disable it" (p. 592). Wendell (2003) argued that if indeed it is only society that disables people, then if society ideally provided everything that all its citizens required, disability would not exist at all.

Accordingly, there remains the quandary of how to recognise the disability-impairment binary in such a way that the political and the personal are both served. This blurring of the boundaries between impairment and disability is evident in the narrative of Beauchamp-Pryor (2011) who questioned the line between who is disabled and who is not in her personal reflections on no longer being blind following successful eye surgery. She continued to live with the identity of being a disabled person in her everyday life, although she was no longer sight-impaired. She recounted how she needed to learn to walk without stooping, and to look without staring because she was now expected to behave as a sighted person. Emotionally, she often felt like she returned to a safe place when she removed her glasses or closed her eyes. Her identity as a disabled person reflected who she was and continued to be, despite the fact that she was longer sight-impaired.

The arguments regarding the impairment-disability dichotomy are diverse (e.g. Paterson & Hughes, 1999; Shakespeare, 2006; Siebers, 2012; Thomas, 2007), led to much theoretical traffic, but they led in the same direction away from dualistic, polarised, politicised thinking towards a space in which there is a re-conceptualisation of the personal experience of disability.

It is absolutely clear from the stories of disabled people that there is no universality in the experience of disability; that there is variability within aspects including gender, types of disabilities, ages at which disabilities are experienced; that there are few shared perspectives on disability by disabled people themselves; and that not all disabled people identify with being classified as disabled or identify with other disabled people (Hammer, 2011; Wendell, 2003). Nevertheless, Wendell (2003) proposed that disabled people have a certain knowledge – a standpoint so to speak – that is different from able-bodied people's knowledge and that should not be repressed because of the value that understanding these standpoints can bring to the broader meaning of disability. Others refer to this as "patient knowledge" (Pols, 2010), which, when made explicit, is helpful in determining how the person who lives with the impairments fits into society, and how to live with the impairments. Without the personal story, this knowledge is made inaccessible. In effect, by preventing the personal experience of disability from occupying any discursive space, the strong social model of disability may have, in a paradoxical way, contributed to the silencing of disabled people.

In her autoethnography about being a person who has had a kidney transplant, in which she narrated her experiences of kidney failure, dialysis, transplantation and life afterwards, Richards (2012, p. viii) wrote,

> The pent-up feelings of nearly twenty years gushed out of my pen like the breaking of a dam or levee. I wrote about things I never knew I felt. It was as if I had found a secret self hidden inside me who had lived and experienced awful things without my knowledge as I went calmly about my day-to-day business for years. This being had escaped, had found a voice and was never going to be silenced again.

Telling her own story, her representation of herself rather than a representation by another, provided Richards with a voice, power, and ownership of her own story. Despite tremendous difficulties that she faced in writing her own story, she was able to articulate her experiences which gave those experiences meaning for herself and others. It provided her readers with knowledge that was previously inaccessible.

Hence, telling the personal story results in the exposure of subjugated knowledge (Kalfa, 2012). Richards' authoethnography showed how, in exposing this knowledge and in refining it, a strong disability identity can be formed, re-formed, changed, and negotiated, which is powerful in its use politically. Although there are many reasons for claiming identity, liberatory identity politics that result from the telling of the personal story enable the empowerment of disabled people to challenge exclusion, oppression, stigmatisation, marginalisation and exploitation. It seems that the feminists have been at the forefront of the work on disability identity, with a strong leaning towards acknowledging that identity is indispensable in relation to liberation from oppression. Many authors write about the solidarity and resistance that comes from this sharing of identity (Garland-Thomson, 2007; Kalfa, 2012; Linton, 2008). It would appear that this discourse has shown that there is little ground for the strong social model's argument that the focus on the self, or of inclusiveness, leads to or entrenches the categorisation of "otherness".

### ***3.1.1 Psycho-emotional disablism***

Underpinning the personal story are feelings. Swartz (2010) illuminated the powerful role that feelings play in how disabled people respond to their impairments and their disability. There is a lacuna in disability work on emotional responses, partly because the powerful anti-impairment models have sought to silence and suppress this dimension (Watermeyer, 2013).

The effects of social constructions of disability on the well-being and identity of disabled people are far-reaching and pervasive. Thomas (1999, cited by Thomas, 2007, p. 72) coined the term "psycho-emotional disablism" to denote the actions and words that able-bodied people use in interaction with people with impairments that denigrate and harm them. At the time of Thomas' work in the early 1990s, the focus had been on the material and structural barriers that created disablism, and so her addition to the definition of disablism was an important turn. Identifying the effects of disablism on the disabled person's psyche from a sociological perspective was considered significant because it gave ownership of this aspect of disability to disabled people. In so doing, this extended social relational model of disability prevented, to a large extent, the medicalisation of the psychological and affective aspects of disablism (Reeve, 2012). This addition to the definition of disability was important at the time because, historically, psychological theory had positioned disability as pathology and had paid little attention to social processes (Watermeyer, 2013).

Psycho-emotional disablism results from the interactions that disabled people have with people (familiar people as well as strangers) as well as the larger society (Thomas, 2007). It is created and reinforced through imagery, cultural representations and interactions with others

(Reeve, 2012). Psycho-emotional disablism, then, results from the manner in which people are treated by others as well as from disabled people's experiences in the world such as when faced with an inaccessible building. The manner in which disablism is conducted is often obscured, to the extent that disabled people are often not able to recognise oppression, and they become socialised and caught up in the way society operates. In this way, the oppression becomes internalised (Watermeyer & Swartz, 2008). Young (1990, p. 148) described the process as follows: "the cultural knowledge that dominant groups fear and loathe them, and to that extent end up assuming the position of the dominant subjectivity towards themselves and other members of the groups with which they identify."

Because of broader societal and cultural messages to hide the personal experience of disability, disabled people are often led to represent themselves as something which they are not when interacting in the world. They have to self-censor and so their shared experiences are not real. They are culturally programmed not to reveal their impairments and in so accommodating to the needs of the able-bodied world, they are not afforded the time and space to show themselves to others nor indeed to themselves (Watermeyer & Swartz, 2008). The literature is replete with tales of disabled people reporting that they cannot represent themselves, their true selves, in their interactions with others. The response is the "re-injuring of self through internalizing discriminatory values…lowering self-worth and lessening a sense of intrinsic value" (Goodley, 2011a, p. 90).

Among the crucial consequences of psycho-emotional disablism are that disabled people are made to feel different, unwelcome, and that they do not belong in society (Reeve, 2004). Psycho-emotional disablism can result in making disabled people feel as if they are not persons, or not valued as people. They are often left feeling as if their lives are not worth living (Reeve, 2012). Moreover, in having to deal with the assaults on their self, disabled people carry the burden of "emotional labour" (Williams, 2003, cited by Goodley, 2011a, p. 92) in which they have to put energy and focus into keeping their emotions safe and above board. Much of the time, however, emotions are eroded. Reflecting the embodiment of emotions, Williams used the term "corpsing" to describe the freezing of the ability to maintain this control over emotional reactions.

### *3.1.2 Disability identity*

Linton's (2008) autobiography of how she came to live with being disabled after having been injured in a car accident, described how her identity as a disabled person identity was forged primarily through her identification with other disabled people. Her self-identity evolved as she took direct and very active involvement in disability activism. Some authors have embraced group identity (Morris, 2001; Wendell, 2003), while others argue that group identity does not offer sufficient space for difference to be negotiated (Beresford, 2012; Shakespeare, 2006). Some have argued for feminist approaches to disability identity (Garland-Thomson, 2002) and others for queer and/or race identity (Kannen, 2008), all with the fundamental desire for difference to be appreciated. Kannen (2008, p. 153) stated,

> Identities, such as race/whiteness, gender, sexuality and disability are deemed representations of inner truths; signifiers that express something essential about each person and how they experience the world. These 'truths' are relied upon in order for us to become thinkable to one another.

Yet another argument is that group identity could further entrench separateness and re-emphasise normalisation (Tremain, 2008). In an attempt to find some middle ground in these debates, Thomas (2004; 2007) adopted an interpretation of disability as being an expression of a narratively constructed self, in which people come to see themselves as, and identify as disabled when they take on the public and cultural constructions around them. Linton's (2008) disabled identity developed from the ideas that she had about disability before she was injured which were molded as she developed her personal disabled identity. This was a slow process during which she heard and experienced public and cultural ascriptions of disability. Few disabled people, however, live with Linton's privilege of being exposed to disability politics and activism – or even other disabled people (Scully, 2008) – and so are limited to the constructions of disability presented to them in their daily lives by the people and institutions in their lives.

## 3.2 The body, impairment, and disability

Like personal experience, the body, and thus impairment, matters. Just why the body itself has to an extent been disregarded in disability studies seems to have been political, driven by the political stance of the strong social model theorists. Impairment is located in time and space but within the body, and so the ontological position of the body has therefore been reclaimed in many frameworks. Watermeyer (2009b) argued that individuals come to accept the notions of the exclusion of disabled people, their being marginalised, their feelings of humiliation and shame, their weakness and need for help, as "emanating from the fallibility and brokenness of the body; not from discrimination, social oppression and systematic exclusion" (p. 29).

Crow (1996), a disability activist and one time supporter of the social model of disability, lauded the social model as having given disabled people a very powerful change in their positioning. She wrote,

> For years now this social model of disability has enabled me to confront, survive and even surmount countless situations of exclusion and discrimination. It has been my mainstay, as it has been for the wider disabled people's movement. It has enabled a vision of ourselves free from the constraints of disability (oppression) and provided a direction for our commitment to social change. It has played a central role in promoting disabled people's individual self-worth, collective identity and political organisation. I don't think it is an exaggeration to say that the social model has saved lives. (Crow, 1996, p. 1)

Notwithstanding the powerful role that the strong social model played politically, Crow pointed out that disabled people had come to acknowledge that this stance was not enough. She wrote that in comparison with other groups searching for civil rights, such as Black people and women, the one big difference separating disabled people is the fact that impairments can be problematic and difficult. Since then, many writers have argued that the body is not just a social construction, but that the limitations imposed by impairments are real and that no amount of social adjusting can remove the corporeal experience in its entirety (Garland-Thomson, 2011b; Hammer, 2011; Shakespeare, 2006; Swartz, 2010).

Some have argued cogently that it is very possible to address the body in relation to disability without compromising the claim that disability is a social issue (Garland-Thomson, 2011b). Thomas (2007, p. 135) introduced her concept of "impairment effects" which "refer to those restrictions of bodily activity and behaviour, that are *directly attributable* to bodily variations designated 'impairments' rather than to those *imposed upon* people *because* they have designated impairments (disablism)" (italics in the original). The adoption of this concept implies that one acknowledges the body as biological, material and social. Garland-Thomson (2011b, p. 600) wrote that this has involved "coconstituting (the) relationship between flesh and environment". If indeed, "an embodied engagement with world is in fact life itself" (Garland-Thomson, 2011b, p. 600), then understanding what it is to be disabled requires engagement with the body.

Aside from the loss of the body by disabled people as emanating from the social model's fight against individualising the experience of disability, another source of delegitimisation of the power of impairments in the process of disablement is the result of the "social authority"

(Wendell, 2003, p. 119) that medicine has over people. In the powerful position that medicine occupies, the body is viewed as an entity unlike the entity of the body that experiences suffering, pain, difficulty. The medical view is of a body that is to be examined, measured, and compared to normality. It is to be diagnosed and treated. As Scully (2011) wrote, contemporary society turns easily to science to medicalise so that scientific knowledge can be applied to improve the quality of people's lives. She called this the "therapeutic imperative" (p. 4). Even though there has been an ever widening appreciation of the power of the voice of the patient, particularly in relation to medical choices (Siouta, Brostrom, & Hedberg, 2012), there is still an ever-persisting imbalance in the power of the "cognitive authority" (Wendell, 2003, p. 120) of the medical profession over the lived experience of the patient. The result of this is the alienation of the person from his or her body and a sense of lesser ownership and lesser control over the fate of that body.

It is also likely that the body had been "disavowed" (Shakespeare, 1994) because of the discomfort that disabled people and people writing about disabled people feel in relation to the private space. What is discussed in private or, in all likelihood kept from even the private space, is too exposing, too raw, and too personal, for the public space. So, matters are avoided because of people's reactions to corporeal topics such as sexual intercourse, management of menstrual periods, incontinence, drooling, and feeding difficulties. The reactions to these private visceral needs have been described as "disgust" (Nussbaum, 2009) at the "monstrous" (Shildrick, 2012).

Furthermore, disabled people have had to pretend that their bodies are not a source of pain, suffering, and effort. Morris (2001) wrote that disabled people have had to downplay their impairments so as to prevent people from confirming for themselves that disabled lives are not worth living. "Having to hide parts of one's self from others" (Hallberg, Klingberg, Setsaa, & Möller, 2010, p. 214) prevents disabled people from being stigmatised and from feeling different from others. Siebers (1998) wrote of his living with his "withered limb" that resulted from childhood polio,

> We have spent all of our lives trying to be normal, trying to pass the test, trying to run with the pack, to be liked and not pitied. To show self-pity is to add defect to defect, and more defect we do not want. (p. 6)

More recently, a participant in research on women living with VACTERL, a variable syndrome that results in a variety of medical issues, stated in relation to her noticeable incontinence as a child "...that's when I learned to lie. That's when I knew this was something I wanted to hide" (Kalfa, 2012, p. 74).

The limitations caused by, as well as the experiences associated with, impairments affect who disabled people are: the body plays a powerful role in the development of a disabled identity (Beauchamp-Pryor, 2011). Providing an interpretation of examples of how people's bodies come to influence their lives, Garland-Thomson (2007) wrote, "Our shapes, in all their uncontained variation, structure our stories" (p. 121). The literature in disability studies shows that there is an ever-widening acceptance that the body is central to the lived experience of disability. One such approach is the work has been based on the early ideas of Merleau-Ponty (cited by Paterson & Hughes, 1999) whose theory was in deep contrast to the disembodied medical approach. In his view, being is embodied. Meaning resides in the body and the body resides in the world, and so there is little of the dualism that is evident in the traditional social model or the medical approach to the body.

Taking this work further, disability scholars have identified an alternative way of looking at the body as fluid, vulnerable, changing, temporal and malleable. For example, Shildrick (2002, cited by Inahara, 2009, p. 54) configured the body, particularly the disabled body, not as a fixed body, but as "a moment of recognition in the process of being embodied" . Hence, the impairment is not fixed. Similarly, Garland-Thomson (2011b) acknowledged the dynamism of the body in relation to the environment and spoke of the critical term "misfit" in the following way:

> A fit occurs when a harmonious, proper interaction occurs between a particularly shaped and functioning body and an environment that sustains that body. A misfit occurs when the environment does not sustain the shape and function of the body that enters it. The dynamism between body and world that produces fits or misfits comes at the spatial and temporal points of encounter between dynamic but relatively stable bodies and environments. (p. 594)

For Garland-Thomson (2011b), looking at the goodness of fit of flesh and the environment is done with an appreciation of the fluidity of the body and the environment. At times, the body will fit and at times it will not. Both the environment and the body are dynamic, and articulate with one another differently in time and space. The size, shape and function of a person only become visible when there is a disjuncture, as she wrote, when round holes and square pegs meet. As Inahara stated (2009, p. 54), "embodied subjectivity is formed and reformed". This approach is very different from the traditional medical approach that suggests that bodies are fixed, singular entities (Pols, 2010).

## 4. Disability in South Africa

Social injustice characterises the experience of disability in South Africa. South Africa is a country with a history steeped in pervasive institutionalised social injustice. Despite living in an enormously resourced country, disabled people have rarely benefitted from any of its resources.

With a colonial history, the country was dominated and ruled by a minority White group. The 40-year reign of a tyrannical government ended with the first democratic elections in 1994. Apartheid policies, embedded in policies of White supremacy (Dubow, 1991), were the quintessential example of oppression. Not only were disabled people severely affected by policies of Apartheid and its related policies, but the discrimination that they experienced was exaggerated by the social responses to disability. The segregation policies of the Apartheid government were not restricted to people of colour, but the national social policies of the Apartheid regime encompassed eugenic beliefs.

The discriminatory politics were exemplified in the structure of education in the country, which is relevant particularly when examining the lives of people with lifelong disability. Disabled children were not welcome in regular schools, and specialised schools were built, having different syllabi from regular schools; different financial management; and different exit level opportunities. In addition, education for children who did not fit certain criteria was simply unavailable (Government of South Africa, 2001). However, education for children with cerebral palsy was somewhat elite. In 1939, the National Council for the Care of Cripples in South Africa was developed. It set up a committee to study the incidence and nature of cerebral palsy, and as a result, approached government to make provision for the education of children with cerebral palsy. In 1948, a group of parents of children with cerebral palsy formed the Transvaal Association for the Care of Cerebral Palsy, and established the first centre for educating their children (National Association for Persons with Cerebral Palsy South Africa, 2012). Thereafter, a number of schools were built around the country to serve children with cerebral palsy. The language of education in the schools was English and Afrikaans. The schools were in the major centres, and so children who travelled from afar were provided with boarding opportunities.

Schools for Black children with cerebral palsy were built in some of the major centres, but were less resourced than those built for White children, educated children in languages that were not their home languages, and did not have the residential facilities that the White schools did. Nevertheless, compared to schools for children with other types of impairments, schools for Black children with cerebral palsy were more available. Hence, children with cerebral palsy in urban areas who were Black – but far from the majority – had the opportunity to receive education. The children who were admitted to these schools, however, were however, generally high functioning individuals who were considered to be "educable". Other children with cerebral palsy were excluded, and for them, very few educational opportunities were available (Government of South Africa, 2001).

Hence, in the words of Watermeyer and Swartz (2006, p. 1), "In short, the story of disability – in our country as well as any other – is a story of social oppression". From a materialist perspective, disabled people were marginalised and excluded. The uneven distribution of resources, income, positions, reward and privileges (Young, 1990) within South African society defied any sense of justice. It was not only in economic terms of the material distribution of goods that disabled people were severely denied: they were denied opportunities. Society did not provide the conditions for people to realise their potential. Disabled people had little or no chance of developing their capacities or for expressing their experiences, and had little or no chance of having control over their own actions. They could not participate in determining what they wanted from life and had very little control over the conditions of their existence. These are the values that assume the equal moral worth of all persons (Young, 1990). The colonial and Apartheid past denied people these universal, fundamental values.

In response, many disabled individuals rejected the way in which their lives were directed, and forged a path towards liberation. Starting during the height of the Apartheid era, disabled activists formed national networks, which worked for recognition. Like the activism in the rest of the world, these activists saw disability as socially created. They aligned with the social model of disability particularly with the Marxist-type interpretation of a capitalistic oppression. However, their situation was compounded by the manner in which Black people were treated in the country. Denied basic human rights, often sent to live in parts of the country that were inaccessible particularly for disabled people, and subject to abject poverty, the activism inevitably had a strong political intention. The Nationalist government took on issues around disability but because they shunned any international initiatives (such as the United Nations and its many initiatives surrounding disability), and because their initiatives were aligned with their policies, local activists did not engage with local governmental initiatives. Instead, they used these as a forum for voicing their opposition (Howell, Chalklen, & Alberts, 2006). Hence, a double edged sword was sharpened: oppressed because of being disabled and oppressed because of their political alignment, their activism was made very difficult.

Nonetheless, many of the disability activist individuals and groups aligned themselves with the African National Congress, which was to become the political party that constituted the first democratic government in 1994. This political alignment allowed disabled people to become involved in the development of the country's Constitution as well as in the structuring of the post-1994 democratic government. This was an important contribution because the Constitution specifically addresses the discrimination of disabled people. And, because all formal policies in the country align with the Constitution, disabled people were given a strong political voice. As a consequence, many important policies in the country offer protection, as well as remedial steps for the transformation of societal structures to recognise disability and to better the lives of disabled people in the country. The involvement of disabled activists also resulted in representation in the highest forms of government, with an office in the Office of the State President representing disabled people (Howell et al., 2006). Today, disabled people are represented through the Ministry of Women, Children, and People with Disabilities. South Africa is a signatory to The Convention on the Right of Persons with Disabilities (United Nations, 2006) which recognises that "that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" and that "persons with disabilities continue to face barriers in their participation as equal members of society." The Convention makes specific mention of the participation of disabled people, emphasising full and effective participation and inclusion in society.

However, the extent of the oppression of the past and the legacies of Apartheid, as well as the societal attitudes to disability remain. Although there have been two decades of relatively peaceful political change, there have been tremendous challenges in transforming the health, educational and social opportunities for all people (Simkins, 2011). The citizens of South Africa have experienced poor service delivery; inadequate development of the education system; and rapid changes to the health system which is in an unstable state. Mortality has worsened in all age groups, and the country is ravaged by diseases such as HIV and AIDS, malaria, and tuberculosis (Kahn, 2011).

It seem that, as is the case internationally, there are increasing disparities despite overall economic changes (Petersen, Swartz, Bhana, & Flisher, 2010). In recent years, the world's economy has seen some disturbing downwards spiraling, sending the poor into even more desperate conditions. There have been important changes, but on the whole, disabled people remain oppressed. Transformation has come to the country but this change has been slow, and indeed, there is little change for millions who remain in poverty (Kahn, 2011; Simkins, 2011). There are many grants available to poor people, but there are many hindrances – transport to collect them; lack of official documents like birth certificates; and administrative mismanagement. These limitations render this financial support system unreliable (Kahn, 2011). The long-lasting effects of poverty are intergenerational and continue to impact on the economic status and socio-emotional well-being of families. Not surprisingly, disabled people and their kin who live in rural areas are among the poorest and under-served members of the population (Petersen & Lund, 2011). Education has been slow to transform – for example although inclusion is the policy of choice, there has been extremely little movement towards this in reality. Furthermore, a study showed that 22.1% of disabled children were found not to be in school system. In this study, of the 386,000 children that did not attend school in South Africa, 36,960 or 9.6% were reported as presenting with some type of disability (Fleisch, Shindler, & Perry, 2010).

South Africa remains a tremendously unequal country. Despite some important changes in service provision, in a country still operating on racialised terms in so many respects (Simkins, 2011), disabled people remain one of the most economically marginalised groups.

Cultural representations of disability are relatively unexplored, and in contemporary South African society, the notion of culture is opaque. The melting pot of South Africa defies the analysis of homogenous cultural constructions of disability to a large extent. Instead, research shows the diversity with regard to the beliefs and practices of people with regard to disability in the country (Ross, 2011). The understanding of the meaning of communication disability has been explored in a number of research projects. Researchers have examined cultural constructions of conditions associated with communication impairments such as hearing loss (De Andrade & Ross, 2005), cleft palate (Dagher & Ross, 2004), and aphasia (Bham & Ross, 2005). In these studies, themes that arise include beliefs about etiology. Within cultures and religious groups, there is much variability with regard to beliefs about magic, God's will, Karma, superstitious beliefs and so on. There are also beliefs that disability can be caused if a family member has done wrong, such as marry the wrong man (Ross, 2007). Allied to these belief systems, different people seek out different kinds of treatment – some seek spiritual guidance; others seek healing from traditional healers and/or religious leaders; and help is sought from, and in combination with, Western medical and allied personnel (Ross, 2011).

### 4.1 Researching disability in South Africa

Most of the academic work on disability has been conducted in the global North. This work does not always reflect the circumstances, conditions and state of affairs in the rest of the world. Most of the time, an agenda borrowed from Northern counterparts lacks reflection on local political, historical and social circumstances (Meekosha, 2011).  Broader issues need to be taken into account so as to provide culturally relevant, contextualised understandings of the meaning of disability.  Although many people in South Africa, both Black and White, identify with Western conceptualisations of living, and hence relate to aspects of international models of disability, Western conceptualisations of living are very different from African notions. For example, Western notions of independence as a goal of personhood are regarded as preposterous by many Black Africans (Mckenzie & Macleod, 2012; Metz & Gaie, 2010).

In her suggestions for the decolonisation of the practice of social work in South Africa, Ross (2011) highlighted some of the critical changes that needed to be brought in. She identified, for example, the need to take cognisance of how people seek help, and to whom they go for this help including traditional healers and elders; a need to engage with understandings of family and community so as to be able to shift to practice within families and communities instead of the Western focus on self realisation and autonomy; and a need to acknowledge African notions of spirituality that are in contrast to Western notions of visibility, rationality and individuality. There are moves within the country towards developing more relevant models that are more responsive to local circumstances, and that partner with local organisations. There is also a fairly strong networking with other countries in Africa (Mji, Gcaza, Swartz, MacLachlan, & Hutton, 2011).

Despite the networking and the visibility of disability activism, the understanding of disability in South Africa is limited by the paucity of research and much is assumed. There is a rich source of data about impairments, with professional bodies producing local journals.

However, these publications primarily address impairments; and they have not embraced disability in its broadest sense. Of great importance is that few disabled people themselves have been involved in this research. Swartz (2009) wrote that because of their reticence to become involved in scientific research which they associated with colonialism, as well as the lack of educational opportunity, disabled researchers, particularly those who are Black, have lacked skill to conduct research. A number of initiatives are on the go, but the research remains very limited. Recently, the African Journal of Disability[6] was launched, and offers promise for issues pertinent to disability in South Africa and developing countries to be promoted.

## 5. Chapter summary

I have identified some of the core issues that are evident in current disability studies that play a crucial role in how disability is constructed. There is the movement away from the strong social model's political focus on the role of society towards a greater acknowledgement of the power of the body and the personal story in the creation of disability. I have shown that disability is a function of context, and have shown that the experience of disability in South Africa is unique in many ways in terms of some of the critical social issues that have influenced the lives of people who have grown up in South Africa.

I now turn to an overview of what is meant by the term, "participation", in order to situate the study of communicative participation under the umbrella of this broader notion.

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[6] http://www.ajod.org/index.php/ajod: "The *African Journal of Disability* serves as a repository for cutting-edge, peer-reviewed research in all fields of disability studies and rehabilitation sciences in a uniquely African context. The journal encourages scholarly exchange between all disciplines and academics from both the developing and developed worlds, to work towards the betterment of human development and its practices across the continent."

# CHAPTER THREE: PARTICIPATION

## 1. Introduction

In this chapter, I review of the meaning of participation because it is the broader construct into which communicative participation is embedded. At first glance, the term "participation" is very easy to understand. It is a word used simply to mean "to take part" (Dijkers, 2010). What is clear from the literature is that participation is a whole lot more than performance, "the degree to which a person fulfils roles and has relationships, displays community presence; otherwise performs a portfolio of actions that can be witnessed by an observer" (Dijkers, 2010, p. S7).

The word participation is used in a variety of ways, depending on what is understood or implied by the word. Developing one theory of participation, or one way to measure it, therefore, is highly improbable. Nevertheless, there is a need to define it. For example, participation is a key goal of rehabilitation, but there are any number of issues surrounding the definition of participation which have led to difficulty with operationalising and measuring participation as a clinical concept (Dijkers, 2010; Mallinson & Hammel, 2010).

In this chapter, I provide a review of participation that seeks to determine the defining principles of participation which have been identified in a variety of approaches, for, as a participant in a symposium that debated the meaning of participation in rehabilitation stated, participation is "in the eye of the beholder" (Heinemann et al., 2010, p. S72). I end this chapter with an overview of the various the models of disability with a focus on their contribution to defining and understanding participation.

## 2. Participation

Whatever life's activities we take part in, we operate in relation to others. The well-known philosopher, Jürgen Habermas, was born with a cleft palate and as a result had indistinct speech almost all his life. Throughout his writing, he reflected on how his relationships with others influenced his being. He claimed that we come to be who we are through participation with others. Furthermore, he stated that, in essence, being able to participate in life's activities should result in one living a "good life" (Habermas, 2004). Undergirding participation, then, are the principles of social justice that speak to fairness and dignity of all people, particularly those who are marginalised in society.

## 2.1 The capabilities approach

The capabilities approach is a theoretical approach to the assessment of basic social justice, which emerged as an alternative to theories that focus on economic growth as the main indicator of a nation or region's quality of life (Dixon & Nussbaum, 2011). The capabilities approach has a very wide audience and has been used for multiple purposes (Bozalek, 2011; Nussbaum, 2009). It has been used to interrogate aspects surrounding disability (Mitra, 2006; Morris, 2009; Trani, Bakhshi, Bellanca, Biggeri, & Marchetta, 2011), so it would be useful to look at its potential to contribute to understanding the meaning of participation. According to Sen (1998), an economist and philosopher who originally conceptualised this approach, the good life means that a person is able to live the way he or she has reason to value, and so the aim of the capabilities approach is the development of the public space so that people can live the lives they value (de Tienda Palop, 2011). The principle tenet of the capabilities approach is that the indicator of social justice is what people can do and be, rather than an average measurement of what a nation provides its citizens. In the capabilities approach one looks to the social resources that a person is accorded, but it is not only the resources that count: it is what the person is able to do and be with those resources that matters (Dixon & Nussbaum, 2011).

The approach differentiates between two constructs: functionings and capabilities. 'Functionings' are the states and activities that make up a person's being. Life is considered to be made up of interrelated functionings, such as participating in political life; living to an old age; being able to move freely from place to place; being happy; and being free of disease (Mitra, 2006). In the case of communication, functionings would include participating in a conversation; expressing an opinion, telling a joke; communicating with others in a group situation; communicating on the telephone; being free to express an opinion; and being listened to. Functionings are influenced by the commodities that the person has available, his or her personal characteristics, as well as the environment in which he or she lives. 'Capabilities', on the other hand, refer to a person's real freedoms to achieve such functionings irrespective of whether they choose to exercise these or not (Sen, 2005).

An example would be of two people with severe communication disability, both of whom experience severe unintelligibility, who need to inform someone that they are in pain. Person A comes from a supportive background with access to rehabilitation personnel well versed in assisting people to use AAC; person B lives in poverty and has no access to AAC. They are both, however, able to inform someone that they are in pain – but person A has AAC available and the task is made relatively easy by this form of communication whereas person B is only able to use rudimentary gestures, making the expression of his thoughts very effortful and at times very difficult to understand by his communicative partners. The goal can be achieved by both, but the capability sets of the two people differ. Hence, looking at the end product alone masks the injustices that are evident throughout the processes in getting to the end (Wilson-Strydom, 2011).

Achieving social justice depends on fundamental entitlements. Sen was rather vague about precisely what the fundamental entitlements are and in response to this, Nussbaum (2003) took the capabilities approach a step further. Extending Sen's conceptualisation, basing her work on his and thus on a fundamental acknowledgement that capabilities are about human dignity (Nussbaum, 2003), she developed a list of these fundamental capabilities. Her ten central capabilities are the claims to minimal social justice, which she equated with providing a life worthy of human dignity. Her list includes life; health; bodily integrity; development of senses, imagination and thought; practical reason; affiliation; access to recreation and play; control over the material and social environment; access to a good relationship with nature and the environment, and emotional health.  A society that fails to honour these central capabilities is one that fails to serve justice for its citizens. Simply being a person born to another person is, in this view, enough to warrant being accorded dignity like that of every other person. Nussbaum's approach to human dignity, unlike many others, does not have rationality as a condition.

In sum, the capabilities approach views participation as something that is both activity and state; that has value for the person; and that must be looked at not only as the achievement of a task but as a process in which opportunity is evaluated. It is undergirded by the idea of human dignity.

### 2.2 Fraser's "participation parity"

Fraser (2003) offered the idea of parity of participation as a principle of a theory of justice that speaks to the conditions of the freedoms that underpin capabilities. This principle holds that in order to respect both the equal autonomy and moral worth of people, each must be given the status of full partners in social interactions, as equal peers. Hence, every partner must be accorded the prerequisites that assure participatory parity. In Fraser's (2003; 2010) view, this involves providing the partners with equal opportunities and access to material resources, as well as equal social standing. Anything short of this full provision of economic resources and social standing is a failure of equal respect. In order for all partners to interact as peers, three conditions need to be met (Fraser, 2010). Firstly, all partners should have access to equally distributed resources. This redistribution entails removing everything that prevents people from being exploited, deprived, or being treated unfairly in any way. Harms of lack of redistribution include exploitation, economic marginalisation, and deprivation (Fraser, 2003, p. 13).

The second dimension of Fraser’s theory of justice is recognition. Recognition occurs when the social markers or the attributes that people have – such as age, race, gender, impairments, position in a social hierarchy and so on – are fully respected. It is only in this way that people can “pursue self-esteem under fair conditions of equal opportunity” (Fraser, 2003, p. 32). Misrecognition occurs when one is not afforded respect on the basis of one’s social markers, and injustice then is expressed as “status subordination” which has its roots in “institutionalized patterns of cultural value”(Fraser, 2003, p. 29). In other words, the recognition paradigm looks at harms such as cultural domination in which one is obliged to live in ways that are socially-defined but not like one’s own; non-recognition through which one is made invisible; and disrespect which entails being depreciated or belittled in everyday life interactions or in stereotypic cultural representations.

When the social and cultural patterns allow for people to be peers, to participate equally with others in social life, then they are recognised reciprocally and are accorded status equally. Hence, status subordination is the primary marker of the injustices of recognition. The “quintessential harms of misrecognition” (Fraser, 2003, p. 23) include being harassed, being assaulted, having one’s experiences trivialised, being marginalised in public spaces, being socially excluded, being stigmatised, being disparaged in everyday life and so on. The remedy for misrecognition is cultural or symbolic change that recalibrates the status recognition of people (Fraser, 2003; Fraser, 2010).

In her later work, Fraser (2010) introduced a third level, a political recognition. This is what she called representivity. On this level, representivity refers to who is regarded as included or excluded, who is given a voice or not.  For Fraser, society as a whole, including the political constitution of society, must ensure parity on every level. Hence, Fraser’s tri-variate theory of social justice includes redistribution, recognition, and representivity, which are all interdependent

## 2.3 The normalisation principle

The recognition of the full and equal moral status of all people was a core example of the classic work of Nirje (1969), who described the "normalisation principle" as the principle of promoting intellectually disabled people to live as normally as possible. Responding to the human rights infringements of World War II, people in Scandinavian countries started to question the exclusion of disabled individuals, which resulted in the establishment of movements that promoted the inclusion of individuals, their deinstitutionalisation, and their integration in the community (Fougeyrollas, 2010). The goal was to integrate disabled people into society, in social roles that were valued in society. Nirje (1969, p. 19) wrote, "The normalization principle means making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society".

For proponents of the normalisation principle (Nirje, 1969; O'Brien & Sullivan, 2005; Wolfensberger, 1983), people with disabilities are excluded from communities because there is a mismatch between their biological needs, the expectations that they and others have of them, as well as the inadequate supply of the resources in the environment to support their needs (Goodley, 2011). For Nirje, normalisation required a number of conditions, including having a normal routine of life; experiencing typical annual functions including holidays and family days of personal significance; consideration of and respect for personal choice; living life as a sexual being; having as close to normal as possible economic standards; having the same physical standards as those available for all citizens; and undergoing the normal developmental experiences of the life cycle (Nirje 1969). Similarly, Wolfensberger (1983) developed the notion of "social role valorization" which proposed that the roles that people take should be socially valued so that people are more likely to be treated with respect and dignity. Later, those who promoted the normalisation principle acknowledged that there had to be more active involvement of disabled people. In tandem with these developments, the Independent Living Movement, which was started by disabled people themselves, promoted the active contribution and self-management of disabled people, which demanded full recognition. For this movement, misrecognition resulted in the disempowerment of disabled people where they did not have control over their own lives, their decision-making, and the development of opportunity. Hence, participation came to be understood as the actions of people, not what is done with them (Fougeyrollas, 2010). However, in the normalisation model, which was developed mainly with intellectually disabled people in mind, recognition does not require full independence.

## 2.4 Interpersonal dependency

Dependency on others seems to be an inescapable reality. There is a fundamental dependency that people have on one another, some more than others (Swartz, 2010, 2012). Moreover, in some cultures, dependency is more valued than in others. In society in general, a large part of disablism entails disabled people being designated as dependent, and, as Fraser (2003) said, the problem lies with the designation of dependence as inferiority because when people are designated as dependent, they are designated as being of a lower status to others.

At the centre of Nussbaum's work (2009; 2011) is her notion that equal and just participation of people in life depends fundamentally on their being accorded equal moral standing. How one is accorded status and whether one is accorded equal moral standing depends on one's interrelationships with others. To be able to live a dignified life, people need to live in the social space, and to participate in life in relation to others. In terms of this study, that means to be in a world in which one can communicate with others. This brings me back to Habermas (2004) again, who related his experiences growing up with a cleft palate. He stated,

> Needless to say, I can no longer remember that first operation on my cleft palate. But when I was forced to repeat the same experience at the age of five – in other words at a point when I had a clear memory – my awareness of how one person always depends on others undoubtedly became more acute." (2004, p. 3)

In relation to participation, an African understanding of the interdependence of people on one another has normative connotations. This interpretation of interdependence is that it is only through interdependence that one can be self-realised (Mji et al., 2011). Any behaviour that takes away from cooperation with others, be it selfishness or ignoring a person, results in the diminishing of one's personhood. One is considered less of a person – sometimes even considered to be an animal – if one does not interact in positive ways with others, but also if one does not act in ways that are for the communal good (Metz & Gaie, 2010).

There is a contrast here with Western ideals of the treatment of the individual in society. In many African cultures, the belief is that one is bound to the community, so that harmony is the combination of "solidarity and identity" (Metz & Gaie, 2010). This principle suggests that people derive their identity from their interconnectedness to others (Mji et al., 2011). It would seem, then, that although interpretations of the type and nature of the interrelationship differ across cultural groups in the world's societies, participation is reliant on the interrelationship of people with one another.

However, despite the centrality of dependency on human development and being, Kittay (2011) pointed out that most Western theories of justice assume independence and autonomy to be fundamental tenets of dignity. Challenging these theories, she wrote,

> People do not spring up from the soil like mushrooms. People produce people. People need to be cared for and nurtured throughout their lives by other people, at some times more urgently and more completely than at other times. (Kittay, 2005, p. 443)

As a result, when disabled people are misrepresented by most theories of justice, it brings into question whether these theories of justice are, in fact, just. Kittay (2011) rejected

> an ethics that puts the autonomous individual at the forefront, that eclipses the importance of our dependence on one another, and that makes reciprocal exchanges between equals, rather than the attention to other's needs. (p. 51)

Tronto (2010) suggested that the role of values of caring including attentiveness, responsibility, nurturance, compassion and meeting others' needs, be recognised as intrinsic to moral behaviour. Society has a role in embracing care – and hence the acceptance of human vulnerability – as part of the fabric of its moral existence. Care, then, is a precondition for social justice, and the right to give or to receive care is an issue of social justice. For example, Kittay's work on the ethics of care is based on her belief that "the ability of a being to give and receive care is a source of dignity for humans no less than the capacity for reason".

Within the capabilities approach, the aim of functionings and capabilities is the achievement of a dignified life. One of the weaknesses of this approach is that it does not explicitly take note of individuals, such as people with severe communication impairments, for whom making choices to take advantage of that which is available to them is not always possible. Nevertheless, it could be implied that having a person to help, who acts in their interests, is inherent in the capabilities aspect.

African morality considers all people to be part of a family that deserves care. A fundamental notion of Ubuntu is the strong identification with others; strong togetherness, such that how one is cannot be separated from how others are. How one treats others is reliant on how one treats oneself and how one treats all others (Metz & Gaie, 2010). Furthermore, the idea is that personhood is acquired as one develops, hence the respect accorded to the elders who are considered to have come closer to full development of full personhood (Metz & Gaie, 2010). If no one is a full person, and all life's activities are carried out in such a way that the person works towards achieving full personhood, then no person can be considered to be of less worth or dignity than oneself because no one is complete (Metz, 2010a). In Sub-Saharan African ways of caring, it is considered one's duty to care for all, and not only care for those who are able to reciprocate this care. What the notion of Ubuntu does is embody the idea that who one is, and who one becomes, is in relation to one's belonging to a community (Metz, 2010b).

### 2.5 Performance skills

There is no clear cut argument as to whether people need to have performance skills in order to participate as equal peers. In fact, this is a particularly taxing topic. Taking the stance of feminist philosophers such as Kittay (2005), that the person exists is sufficient for him or her to be accorded a part in a moral community. So, for philosophers like Kittay, participation does not necessarily require any performance criteria. Being human, a capability, means to participate in any way that humans participate – in being loved, being cared for, being acknowledged, enjoying music, smiling at people, and so forth. As a philosopher and father of an adult son with Down Syndrome, Bérubé (2009) pointed out that any performance criterion, such as the ability to be independent, leaves some people out of the definition of being human, which for him is deplorable.

There are, however, many philosophers who do not share in this belief system. These writers place certain attributes as markers as to whether a person is of equal personhood, equal moral status, as others. These opinions are extremely difficult for some parents of disabled children, like Kittay and Bérubé, to live with. At the risk of being extremely reductionist here, but to ward off a lengthy discussion on the theories of moral personhood, I will provide an extremely brief overview of their arguments, exemplified in the work of Singer (2009) and McMahan (2005).

For the likes of Singer (2009) and McMahan (2005) attributes including rationality and autonomy are what make people human.  McMahan argued that people that he labelled as being at the "margins" of moral personhood have fewer claims to moral personhood. It would seem that McMahan's opinions are based on his fundamental belief people who are "normal" live "richer and better" lives (McMahan, 2009, p. 593). Singer (2005), on the other hand, differed in that he did not consider any form of disability to be a disadvantage – although he stated that it is "common sense that it is better not to be disabled" (Singer, 2005, p. 133) – but his argument, like many others (Kittay, 2005) about who has entitlements to full moral personhood are based on the definition of what a person is. For him, being a person means that one has the rationality to know that one has a life. He only affords equal moral status to people that he labels as '"self-aware people with disabilities" (2005, p. 133). This begs the question as to the moral grounds of participation: are people who are self-aware able to participate or can all humans participate? And what other performance criteria afford one full moral status? These questions are the basis of centuries of philosophical debate.

### 2.6 Cooperation and reciprocity

The degree to which one accords others equal moral status determines their degree of participation, seen in how people cooperate with others to facilitate participation. People cooperate not only for their own well-being, but for the well-being of others. They cooperate to "uphold social norms, and behave ethically for its own sake" (Bowles & Gintis, 2011, p. 3). Bowles and Gintis (2011) showed that there is evidence that there are evolutionary and biological explanations for this behaviour. Cooperation is of great benefit to those who practise it. However, it is not about only self-motivation to cooperate. Social institutions are designed in many ways to reward cooperation and so people who may wish not to cooperate do so because of the rewards and the penalties that society offers (Bowles & Gintis, 2011).

Cooperation takes different forms, and there are degrees of cooperation. As Becker (2005, p. 19) wrote, most situations in which one participates are with a "tough crowd" in which bargaining is a necessity. In pliant and well balanced societies or social situations, where there is little tension, the common good and the individuals' needs are well balanced (Becker, 2005). People are more likely to cooperate if they know that their partners in social interactions have cooperated; and they are more likely to cooperate if their will to cooperate is communicated through to their interaction partners (Bowles & Gintis, 2011; Lister, 2011).

Hence, the principle of cooperation becomes a defining principle of participation. People participate in the presence of others, and in order for participation to occur, there has to be a degree of reciprocity, of mutual action, and inevitably, of mutual influence. Most humans have an intrinsic understanding of what it is to be just and fair, and share with others an understanding of what constitutes the common good (Becker, 2005). This is the fundamental philosophy underlying the concept of the "norm of reciprocity" first identified by Gouldner (1960) who proposed that the norm of reciprocity means that people are responsive to others in terms of reciprocating what they are given, in all cultures and societies. Reciprocity is viewed as a glue that binds society (Zhang & Epley, 2009, cited by Pound, 2011, p. 198). The fact that reciprocity is a norm, that it is universal, does not imply that it is fixed; on the contrary, Gouldner (1960) argued, reciprocity can be enacted in any number of ways. For example, he cited the example of a society in which, when a person pays for a doctor's bill on behalf of a friend, it may be expected that that person repays the debt by securing the friend's son employment in the local government. Hence, what is considered moral and right in one society might not apply in another, as stated by Becker (2005, p. 18),

> Every society of record has an elaborate set of social practices that amounts to a pretheoretical conception of reciprocity, that such pretheoretical conceptions differ significantly from each other, and that they are everywhere regarded as defining something fundamental to human life.

## 2.7 Recognition

Cooperation and reciprocity depend on the recognition of others. Recognition as a theoretical term has taken on many forms. Honneth (2007) showed that no matter how it is used, it usually designates "a form of interaction with which persons respond to valuable characteristics of persons or groups" (van den Brink & Owen, 2007, p. 30). Fraser's (2003) status model of recognition proposed that to be misrecognised does not result in lack of the development of self-realisation and so for her, impaired subjectivity is not a result of being depreciated by others. Rather, in her model, misrecognition arises when institutions are structured to according to norms that prevent participatory parity. Hence the aim of reclaiming social justice is to remove cultural, institutional barriers to recognition and to create opportunities for participatory parity, and not to "repair psychical damage" (Fraser, 2003, p. 30). She wrote that if we do focus on identity, then we reify that difference, and that this also leads to the displacement of redistribution politics.

In contrast to Fraser, Honneth (2003) suggested that social recognition is, at its core, an issue of personal identity. Honneth based his work on the theories of Hegel who had proposed that the way in which people function in the world is in relation to others. This interpretation of human agency is in contrast to the work of some who have as the basis the idea that conflict is the natural effect of the natural characteristic of people to be self-interested. Honneth wrote that one’s development and formation as a subject and as an agent depends on one’s responsiveness to others. His basic ideas were that one needs to care for needs and emotions; respect moral and legal dignity; and have esteem for one’s social achievements (van den Brink & Owen, 2007). This mutuality is the starting point of Honneth’s theory of reciprocity. An important point is that recognition, as per Honneth’s theory, is a moral issue in that members of society have a moral claim to be protected as subjects under social conditions under which they can create, form and maintain their identities as moral subjects and agents (van den Brink & Owen, 2007)

Honneth based his work on the acknowledgement of three forms of social behaviour that constitute recognition. They are love, respect and esteem. In his theory, when an individual loves another, he or she shows care for the well-being and happiness of that person. The result of this love is that the person develops self-confidence. When an individual respects another, he or she respects that that person has authority over oneself, which means then that that person signifies something important. This leads to the development of self-respect. Thirdly, when an individual holds another in esteem, it means that he or she sees the other person as having value, which results in a person living with self-esteem. Hence, recognition is central to the development of these three characteristics of identity.

An individual’s identity as a moral agent and subject develops as a result of being dependent upon the responsivity of others (Honneth, 2007). A person can develop his or her identity if others respond to the need for care in terms of one’s needs and emotions, respect for one’s dignity, and esteem for one’s inclusion in society. Participation in interactions with others provides the opportunities for identity development, and so any form of social interaction that does not offer these forms of recognition results in damage to identity. Honneth (2003) stated, “for only by participating in interactions whose normative preconditions include reciprocal orientation to specific principles of recognition can individuals experience the enduring value of their specific capacities for others” (p. 143).

Honneth’s work has been tested out in its relation disability issues in a few publications (Danermark & Gellerstedt, 2004; Danermark & Möller, 2008; Yilmaz, Josephsson, Danermark, & Ivarsson, 2009), which have demonstrated that there is indeed a significant role to be played by these normative defining principles. One example is in Danermark and Möller’s (2008) descriptions of the applicability of this approach to deafblind individuals in which they showed how being deafblind limits participation because of the three levels of misrecognition. Honneth's work was expanded by Ikäheimo (2010b, 2012; Ikäheimo & Laitinen, 2007) who developed a model of social inclusion based on principles of recognition. He used the model to explain the lack of inclusion of disabled people in society (Ikäheimo, 2010b).

Ikäheimo suggested that social inclusion can be viewed as a case of **"*A including B in C in manner D with the status E*"** (2010a, pp. 85, italics his). A and B are always assumed to be individuals or groups of people. C is always considered social life. D is categorised as three ways of inclusion in social life. The technical (D1) includes the material facilities that help people to participate such as AAC equipment, wheelchairs, ramps, and cell phones. The institutional dimension (D2) includes the rights that society accords people such as one's right to life or right to communicate. The third dimension is the interpersonal (D3), which means social inclusion in "concrete events and contexts of interaction through the attitudes or attention of concrete others who are also partakers in them" (2010b, p. 85).

E refers to the status that one is accorded by others. Ikäheimo's (2010) premise is that the lack of status accorded to disabled people is the key problematic in the social exclusion, segregation, isolation and marginalisation that they experience. For him, the lack of recognition of disabled people as persons (as opposed to humans) is the reason why disabled people are socially excluded and hence restricted in their participation in life's activities. Therefore, according to his theory of recognition, the key issue is whether an individual is accorded the status of personhood by the people with whom he or she interacts.

In more specific terms, Ikäheimo referred to the concept of "interpersonal personhood", referring to the definition of personhood within social interactions. He differentiated between two ways in which people are seen as persons (as opposed to non-persons). The first way is by means of attributing psychological attributes to the person. These attributes are then "person-making attributes". An individual may see a human as a person, for example, if that human is able to think; can converse; or can negotiate the world.

The second way that humans are given personhood by others is in terms of their status. Here, B awards A a moral status of personhood that non-persons do not have. Status is awarded on two levels. On the first level, the institutional level, persons are awarded deontic status, such as the right to live, the right to food, or the right to communicate. The second level, the interpersonal level, is being seen by others in terms of "person-making significances" that distinguish A as a person as opposed to a non-person.

Hence, Ikäheimo's position is that recognition is taking someone on as a person, and there are three specific terms of this "personifying attitude" or "recognitive attitudes". These are respect, love and contributive valuing.

(i) Respect: When an individual respects a person, he or she sees that individual as a person. However, respect is more than simply seeing a human as a person – it implies that an individual sees the partner in his or her interaction as having authority over him/herself. This is a critical issue because when an interactive partner has authority over oneself, then one is engaging with a person who has significance for one, and not simply a person. When A and B have authority over one another, there is "co-authorisation" and mutual respect. This is the basis of the dialogic nature of recognition proposed by Honneth in which there is no such thing as one-sided recognition (van den Brink & Owen, 2007). Building on Buber, Honneth and others, Ikäheimo (2010) proposed that not only does B award A moral status, but A awards B moral status as well, so that together they build the "we", or a moral community. Interaction is thus dialogic. The premise, then, is that a person becomes a person in interaction with another.

(ii) Love: Love is a term that is used to denote the care that an interactive partner has for the partner's happiness or good life. Happiness is defined by Ikäheimo (2010a, p. 13) as "nothing else than valuing something and thereby wishing what one values to flourish. When one experiences what one values flourishing, one is happy or leads a subjectively good or flourishing life". However, mutuality is very important in Honneth's theory. Love works to establish the moral community which is made stronger if love is mutual. Having a standing in the shared world comes from others seeing one's happiness as important. But not only are persons, as persons, concerned about their own lives. They can be, and usually are, concerned about the lives of at least some other persons as well. In caring about the happiness of another person one values and wishes those things that he or she values to flourish. Valuing things, and thereby wishing that they flourish, simply because they are constitutive of another person's happiness, or in other words for his or her sake, is one of the basic senses of what is meant by loving someone (Ikäheimo, 2010a).

(iii) Contributive valuing: Contributive valuing is the term of recognition that is used to denote the perception of others that one has a contribution to make that is valued. "Arguably, you feel gra titude towards someone if you believe that she/he contributes positively to something you value *and if* you value her/him contributively (or as a contributor)" (Ikäheimo, 2010b, p. 81). Honneth's original description of contributively valuing was stated in slightly different terms. Honneth spoke of the experience of being socially esteemed as leading to a feeling of self-confidence that "one's achievements or abilities will be recognised as 'valuable' by other members of society. . . . To the extent to which every member of society is in a position to esteem himself or herself, one can speak of a state of societal solidarity" (Honneth, cited by van den Brink & Owen, 2007, p. 14). One of the important notions associated with contributive valuing is that people in interaction with one another do not passively accept one another as of value, but in order to do so, they show concern for individual traits and abilities of one another (van den Brink & Owen, 2007).

The unifying characteristic of the three recognitive attitudes is that they are appropriate responses to claims of psychological personhood.

## 3. Participation in the field of disability

Thus far, I have provided an overview of some of the core ideas that contribute to the understanding of the theoretical underpinnings of participation. I now turn to an analysis of how the various disability models contribute to our understanding of the meaning of participation. The politics of disability management have been overshadowed by the potent medical fraternity, and for many years there was a professional-knows-best ideology that governed rehabilitation. However, this has not been the case for many years: in most professional fields, to some extent at least, cognisance has been given to the needs, choices, and involvement in decision-making of the clients who are served (Baum, 2011). In Baum's (2011) words, rehabilitation is now see as a "continuum" along which it now bridges the gap between biomedical and sociocultural systems. These changes are reflected in the various models of disability.

## 3.1 Models of disability

The models of disability aim to define disability and in so doing, determine what it is that should be assessed and managed. In addition, through the use of these models, it has been hoped that disabled people could be assisted through activism and legislation (Institute of Medicine, 2007; Verbrugge & Jette, 1994). The many disability models available speak to the complexity of the issues that they address, and each model contributes in its own way to the conceptualisation of participation. Most disability models have incorporated societal outcomes (Whiteneck, Bogner, & Heinemann, 2011a). However, there remains very little agreement on how to conceptualise and measure participation (Whiteneck et al., 2011a). What follows is a review of some of the prominent disability models, with specific focus on their conceptualisations of participation.

### ***3.1.1 Saad Nagi models***

The Nagi models (cited by Verbrugge & Jette, 1994) of the 1960s and 1970s differentiated among concepts of pathology, impairment, functional limitations, and disability. Nagi included in his model consideration of the person's personal characteristics. In this model, disability is considered to be a product of the interaction of a person with a health condition with his or her environment. In the 1991 update, Nagi acknowledged that people could present with stigmatising conditions (e.g. mild facial scarring from burns) that might not cause functional limitations but that could be disabling. The 1991 model also included items that could affect well-being – biological, environmental and lifestyle. At this stage, the model also included an element of quality of life. In addition, the 1991 model looked to elements in the person's social and physical world that could be included in intervention so as to change the well-being and quality of life of a person (Institute of Medicine, 1991). Hence, as early as 1991, participation in life was recognised as the marker of the well-being of a person. In this model, well-being is seen as the antithesis to disability.

### ***3.1.2 Verbrugge and Jette's "Pathways to Disability"***

In the mid-1990s, Verbrugge and Jette developed a model that specifically looked at how people functioned in society. Their definition of disablement was "impacts that chronic and acute conditions have on the functioning of specific body systems and on people's abilities to act in necessary, usual, expected and personally desired ways in their society" (Verbrugge & Jette, 1994, p. 3). This model was novel at the time because Verbrugge and Jette emphasised that all domains in life were to be included, and that no domain was to be considered more important than any other domain. They used Nagi's terminology (pathology, impairment, functional limitations and disability) but placed an emphasis on the social aspects. They envisioned a "pathway to disability" from pathology through to disability, influenced by three main categories of factors. The first is risk factor, defined as "certain longstanding behaviors or attributes elevate the chances of functional limitation and disability, when chronic conditions occur and progress" (Verbrugge & Jette, 1994, p. 8). The second and third groups of influencing factors are intra-individual factors that include aspects such as lifestyle and behavioural changes, psychosocial attributes and coping skills; and extra-individual factors that are social, as well as physical environmental factors including medical and rehabilitation services, external supports available in the person's social network, and the physical environment.

### ***3.1.3 Person-environment-occupation model***

Law and her colleagues (1996) presented the Person-environment-occupation model (POE) model in response to developments in occupational therapy at that time. Influenced by a number of theoretical fields, models of clinical practice in rehabilitation, as well as American and Canadian legal requirements, this model was intended for use by occupational therapists. The POE model describes the reciprocal interactions, the transactions, between the person, the environment and the person's occupation. The person is seen in a number of ways, including being involved in a variety of roles at any given time. The person is also seen as holistic in terms of consideration being taken of mind, body and spirit.

Activity, task and occupation fall under the rubric "occupation" and although they are discrete, they are seen as being "nested". Activity is considered to be the basic unit of a task. It is the single pursuit that an individual does in an occupation. An example would be the act of speaking. A task is a set of purposeful activities that a person does. An example would be verbally providing a narrative. Occupations are groups of self-directed, functional activities in which a person engages over a lifespan, that achieve a purpose. An example would be "teach" which requires the person to provide narratives on a regular basis when teaching. Occupational performance is the outcome of the transaction of the person with the environment and the occupation. The aim in rehabilitation is to work for a harmonious fit between the three components.

The POE model has been used to a fair degree, particularly in Canada (Gibbs, Boshoff, & Lane, 2010; Vrkljan, 2010) and has contributed to seeing participation as a dynamic process that comes about as a result of the interdependence and transactional interchange of the three components. One of the on-going criticisms of more recently developed models (such as the ICF described later) is that they do not capture this transactional interdependence (Penn, 2005).

### ***3.1.4 Disability Creation Process Model***

In Quebec, Canada, the Disability Creation Process (DCP) model was developed with participation of individuals in society as the chosen, explicit marker of well-being (Fougeyrollas et al., 1998; Noreau, Fougeyrollas, & Vincent, 2002). In this model, participation is viewed as the result of the person with his or her personal characteristics and "organic" capabilities, in interaction with various factors in the environment. The DCP views the person as living out his or her "life habits" which are the daily roles and activities that a person recognises in his or her cultural context. In specific wording, life habits are defined as "daily activities and social roles that ensure the survival and development of a person in society throughout his or her life" (Noreau et al., 2004, p. 347). Capabilities are defined as the "potential of a person to accomplish physical or mental activities". The DCP determines the quality of performance on a continuum from full participation to fully disabling participation.

Social participation involves all the activities that are socially constructed, and therefore includes all activities including those of daily living, as well as social roles. The DCP envisions all activities, including for example nutrition and dressing, as situational, defined by the social environment, and therefore socially constructed. However, it does not distinguish between activities that can be performed independently from those that are performed in relation to others. The DCP is structured into domains, which include nutrition, fitness, personal care, communication, residence, mobility, responsibility, interpersonal relations, community, education, employment, and recreation.

### ***3.1.5 International Classification of Functioning, Disability and Health***[7]

In 1980, the World Health Organisation (WHO) published the International Classification of Impairment, Disability, and Handicap (ICIDH: World Health Organization, 1980). The aim of this classification system was to classify function in relation to disability that was associated with various health conditions. In this model, the ICIDH also made conceptual

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[7] The reader will notice that I have provided an in-depth evaluation of this model. The reason for this is the central role that this model has taken in research on communicative participation. (See for example, Fried-Oken & Granlund, 2012; Simeonsson, Björck-Åkessön, & Lollar, 2012; Threats, 2010b; Worrall et al., 2011).

distinctions, like in the Nagi model. However, in the ICIDH, the terms impairment, disability (replacing Nagi's functional limitations), and handicap (replacing Nagi's disability) were used. The WHO justified the use of the term handicap as reflecting that the problems lay not just within the individual but in society as well. This model was criticised for many reasons (De Kleijn-De Vrankrijker, 2003), but relevant here is that the model did not recognise sufficiently the role of the environment. It was a heavily medically-based model which saw the person as not able to fulfil social roles because of the health condition that he or she experienced.

In 2001, the WHO presented its International Classification of Functioning, Disability and Health (ICF: World Health Organization, 2001). The 1980 ICIDH was revised substantially, taking into consideration the Nagi model, the DCP, as well as the host of work that was done that had highlighted the limitations of the ICIDH (Badley, 2008). The ICF is a two-part item. The first part is a model or a conceptualisation on which the second part, the classification of an individual's functioning, is based. The ICF conceptualises living with a "health condition" as an interaction of one's Functioning[8] (and the negative of Functioning, Disability) with Contextual Factors. Figure 1 illustrates this model.

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[8] Functioning here is used differently from the Capabilities Approach. In the ICF (World Health Organization, 2001, p. 12), Functioning is described as follows:

"Body functions are the physiological functions of body systems (including psychological functions)."

"Body structures are anatomical parts of the body such as organs, limbs and their components."

"Impairments are problems in body function or structure such as a significant deviation or loss."

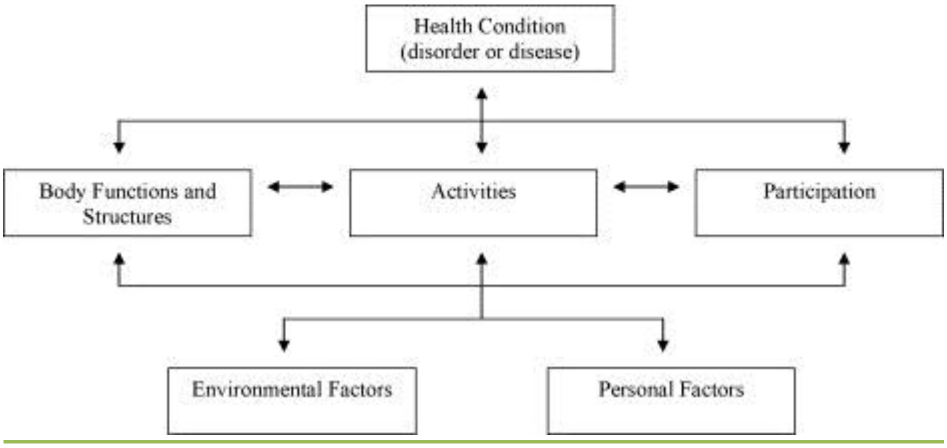

*Figure 1*. Components of the conceptual model of the ICF (From WHO, 2001, p. 18)

The Functioning and Disability part consists of the two components of Body Function and Body Structure, and Activities/Participation. Contextual Factors consist of Environmental Factors and Personal Factors. The Activity/Participation component consists of eight chapters including Learning and Applying Knowledge; General tasks and demands; Communication; Mobility; Self-care; Domestic Life; Interpersonal interactions and relationships; Major life areas; and Community, social, and civic life. The negative terms for these components are Activity Limitations and Participation Restrictions.

Participation, using the ICF, is looked at as a function of health and well-being. The defining construct of the ICF is the biological health condition. The ICF claims to be positioned from a bio-psychosocial model (Badley, 2008, p. 2335) which is a broad model that considers biological, psychological and social factors as playing significant roles in how people function in the context of health and disease. However, all constructs that are presented in the ICF rest on the fact that this model is a medical model; it is all about health and health-related domains. Hence, disability is viewed in this model as the antithesis of health as seen in the ICF's statement that "A person's functioning and disability is conceived as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors" (p. 8). Nevertheless, the ICF serves to demonstrate that social participation is a vital component of human life that is linked to health conditions.

In contrast to the DCP, the ICF differentiates between "Activities" which are defined as "the execution of a task or action by an individual", and "Participation" which is defined as "involvement in a life situation". The negative terms for these are "Activity limitations" which are difficulties an individual may have in executing Activities and “Participation restrictions” which “are problems an individual may experience in involvement in life situations” (World Health Organization, 2010, p. 3). For the description of activity and participation, two qualifiers are used: capacity and performance. The capacity qualifier describes an individual’s ability to execute a task in a standard environment, and the performance qualifier describes what an individual does in his or her current environment.

The ICF as it stands requires further development, particularly if it is to be used to clarify the meaning of participation for a number of reasons. Probably the most significant issue lies in the definition of participation itself. The precise definition of participation by the ICF is “involvement in a life situation”, which is an extremely broad description. Quite which life situations, and to what extent that involvement is, are undefined. The term “involvement” is open to interpretation.

The contextual factors included in the ICF are “Personal factors” and “Environmental factors”. “Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives” (World Health Organization, 2001, p. 3). Environmental factors are described in much detail, in five chapters and 258 categories. In their evaluation of the lack of specificity in the components of the Environmental Factors of the ICF in relation to research, Whiteneck and Dijkers (2009, p. S28) wrote, “with the thousands of environment aspects and the hundreds of groups with different but significant impairments, this is not an efficient method of studying behaviors”.

Environmental factors are coded in much detail, but although the ICF model acknowledges the role of personal factors in the well-being and participation of people in life’s activities, personal factors are not coded at all because of the cultural variation. Personal factors, according to the ICF, include age, race, gender, educational background, profession, coping styles, past experience, upbringing, social background, other health conditions, and lifestyle. Personal factors form a central part of the concept, though, and users are encouraged to document the personal factors that contribute to the person’s function.

The ICF does not make a clear distinction between Activities and Participation. It only provides one list of life areas for both; and it does not provide the user with one way in which to manage them. Instead, four options are offered (Whiteneck & Dijkers, 2009) so that the user can make an individual decision about whether to combine them or not. Despite ongoing debate, there is no consensus as to how to manage this distinction, a problem recognised as one of the most important problems for users of the ICF (Dijkers, 2010; Threats & Worrall, 2004; Whiteneck & Dijkers, 2009). Among others, Whiteneck and his colleagues (Whiteneck, 2005; Whiteneck et al., 2011b) have interrogated how best to disentangle the issues surrounding the difficulties with the distinction between activities and participation. They looked to the older disability models (Whiteneck & Dijkers, 2009) and determined that both the Nagi models and the ICIDH had originally made clear distinctions between the two concepts, that could be used to modify the ICF. These models identified activity as the things that people do on their own. These activities can be assessed independently of the person's function in society. Participation, on the other hand, denotes the things that people do in social roles. In order to fulfil social roles, they need to be able to do a variety of activities, and select which activities best suit their purposes in those roles. Participation then cannot be measured in isolation; a person's participation has to be regarded within the social milieu. Hence, for example, a person may participate in a conversation by accessing different activities. He or she may not be able to do the activity "speak intelligibly" but might be able to "use AAC devices" and so the choice of activity provides opportunity for participation. On the basis of this interpretation, Whiteneck and his colleagues recommend that activities and participation be seen as distinct processes in the ICF (Whiteneck et al., 2011a; Whiteneck & Dijkers, 2009).

#### *3.1.5.1 The ICF and communication disability*

The ICF has been widely accepted as a gold standard by speech-language therapy associations internationally (Threats, 2008). There are a growing number of studies on communication disability that are based on the ICF conceptualisation of well-being; there are growing numbers of researchers involved in developing code sets for various types of communication impairments. However, the ICF is not without complication for the conceptualisation as well as the coding of communication impairments, including those that are lifelong. Despite the amount of research, there are many limitations to the ICF at this juncture.

One of the limitations is the conceptualisation of communication as a matter of well-being. The ICF codes the individual and the focus then, of classification of a person's communication functioning, is as an individual. The problem is seen as the individualised problem, and goes against modern discourse in disability as I have shown in chapter 2.

Communication in the ICF is awarded its own chapter. In addition, the lack of an accepted conceptual model of communication does not make it easy for all professionals to engage equally with the way in which communication is analysed in the ICF classification system. The underlying theory of communication that clearly was used in the conceptualisation of this chapter is the outdated, transmission model that has been severely criticized for at least two decades in the field of communication theory. In this model, communication is viewed as the sending or receiving of messages or transferring information (Craig, 1999). The transmission model is in essence a model in which only certain aspects of the communication process are addressed. More contemporary models of communication, such as the constitutive model that conceptualises communication as a process that produces and reproduces shared meaning, or the dialogic model which sees the construction of meaning as co-constituted by people cooperating with one another, are metamodels. These models consider various models of communication as each contributing uniquely, differently, and with variability, to the communication process (Littlejohn & Foss, 2008).

The focus of the Communication chapter is on skills, coding what people do, in the form of verbal and nonverbal messages in order to communicate. Most, if not all, of the items in this chapter are activities (such as receiving and producing communication, and using communication devices) and do not incorporate the social functions of communication. Whiteneck and Dijkers (2009) pointed out that conversations and discussions are activities and not social roles, and hence do not reflect social functioning per se. The interactive aspects of communication, the relational functions of communication (Davidson, Worrall, & Hickson, 2008), have to be coded within other chapters. Difficulties with coding have been identified by many researchers, particularly with regard to communication 'disorders'– some codes are vague, others excessively broad (Threats, 2008; Worrall et al., 2011) and thus interpretation is difficult. In addition to the vagueness and obscurity in coding, many of the so-called functions of communication, such as the phatic function in which an affective or social message rather than a referential one is conveyed, are not captured at all.

Can communication be captured within the ICF chapters? In relation to communicative impairments, there is evidence that there is some congruence between the ICF categories and the views of communicatively disabled people. In a study that garnered the goals by aphasic people and coded them according to the ICF, researchers found that the nine categories of goals that were identified could be linked to all the ICF components (Worrall et al., 2011). The logic then, is that the ICF is a useful model in which to organise the goals of disabled people. When using any checklist or grid to code human behaviour, it is highly likely that one will seek and find that which is universal but miss that which does not fit into the grid (Kleinman, 1977). Behaviours that do not fit the grid will not be coded, or will be interpreted in such a way that they are coded according to the parameters of the grid even if they do not really fit the descriptions in the grid in their entirety. Thus, by seeking the 'universal', data are forced to fit categories, leading to a falsification of the categories, a phenomenon labeled by Kleinman, in his classic work, as a 'category fallacy'(Kleinman, 1977). The authors of the article in which the goals of aphasic people were coded on the ICF (Worrall et al., 2011) acknowledged the marked difficulties that they experienced with coding – their inter-coder reliability did not reach an acceptable level. Moreover, the authors suggested that the researchers coded goals in different ways, and many of the goals had to be coded at least twice in order for their meaning to be captured. The extent of category fallacy (Kleinman, 1977) evident here confirms that it is difficult to falsify the grid thus rendering its validity questionable, particularly in relation to its use for the understanding of communicative processes such as communicative participation.

The ICF is a system that codes a person's functioning at one point in time. This is somewhat problematic for people who live with communication impairments that are lifelong, or indeed that change over time. The ICF does not consider the factor of time (Wade & Halligan, 2003). The importance of including time in a definition of participation is underscored by the fact that many developmental theories suggest that participation changes over time, and there is a growing body of evidence that demonstrates this (Anaby et al., 2009). This is particularly pertinent to children, but applies to adults as well. McDougall, Wright and Rosenbaum (2010) suggested that the ICF be expanded to view disability as a developing process, stating, "Disability is not a fixed condition or state. Rather, there is a continuum of ability and disability that is fluid and changeable" (p. 208). Their primary motivation for this suggestion is that it would resonate with systems theory that recognises that change in one system will influence another system. Nevertheless, the ICF is used for people over the age of 18-years of age. The ICF-CY which is used for children up to the age of 18 years complements the adult version. There are gaps between the two, and there is on-going work to close those gaps so as to ensure a smooth transition from the one system to the other (World Health Organization, 2007).

## 4. Chapter summary

In this chapter, I have shown that there are a number of theoretical approaches to the meaning of participation. There are conditions under which participation is possible, which have their roots in social justice. Participation occurs in the social space, and most human function happens in cooperation with others, and so an understanding of the meaning of participation must regard issues around the interdependency of humans on one another as well as those around reciprocity and cooperation.  I have identified that participation influences, and is influenced by one's identity, and that there are various theoretical positions in regard to this notion, which need to be recognised in understanding participation.

Participation is socially constructed, and dependent on opportunity and environmental and contextual variables. However, it is the extent of the involvement with others that is debatable. Attempting to find the common denominators in the definitions of social participation, Levasseur, Lucie, Gauvin and Raymond (2010) analysed the content of 43 definitions of social participation. They came up with a taxonomy that describes it as comprising levels of involvement with others, ranging from proximal to distal involvement. Reflecting the multidimensionality of social participation, their taxonomy comprises 6 hierarchical levels which are useful in differentiating "participation" from "social participation".

The first level involves the activities that a person does alone, or with assistance, in preparation for contact with others. This level includes activities such as eating, dressing, watching TV, and preparing meals. Like the DCP, this taxonomy recognises the social construction of such activities but places them at the bottom of the hierarchy demonstrating limited, minimal, or even no direct interaction with others. The second level involves activities where there is no interaction with others although they are around. An example would be buying tickets on the internet or going to movies alone. The third level involves contact with another person but not to achieve a common goal. An example might be being with others at a cocktail party but not interacting with them. The fourth level involves an individual collaborating with others for a common goal. Having a conversation or playing tennis, are examples of this level of interaction. Levels three and four include some social roles such as being a parent. The fifth level includes activities in which a person helps another (such as volunteering), and the sixth level involves contributing to society, such as involvement on committees.

A number of authors have differentiated between participation and social participation but there is little consensus (e.g. Badley, 2008 cited by Levasseur et al., 2010, p. 2147). The taxonomy is a useful way of differentiating participation and social participation. According to the taxonomy, participation includes all levels, and social participation excludes levels 1 and 2. Levasseur et al. also then distinguish social engagement from social participation, by seeing social engagement as part of social participation but excluding levels 1 to 4. Hence these definitions are based on the relative proximity of involvement with others.

Communicative participation is by definition interactional, and hence is an integral part of both social participation as well as social engagement. This is the topic of the next chapter.

# CHAPTER FOUR: COMMUNICATIVE PARTICIPATION

## 1. Introduction

In this chapter, I present an overview of communicative participation. I begin with a brief history of how communicative participation has come to be conceptualised, and follow this with an overview of current definitions of communicative participation. I then provide a literature review of studies of communicative participation, with emphasis on lifelong communication disability.

## 2. From “defective speech” to “communicative participation”

The understanding of communication disability has been relatively confined to the field of speech-language therapy, with input from clinical linguistics, social work, and psychology. Duchan’s (2011) review of the history of speech-language therapy demonstrates that the profession was grounded in the medicalised models of disability. Her review shows that the aim of the early work on communication impairments in the early part of the 20th Century was to determine what constituted “defective” speech and to devise techniques to normalise the individual. Towards the middle of the 20th Century, deeper knowledge of acquired language impairments developed alongside developments in linguistics and psychology, which led to the conceptualisation of language and speech as distinct although inter-related processes (Duchan, 2011).

The mid-century years were characterised by a focus on the incidence and nature of communication impairments in children and adults, with a specific focus on the structural components of speech and language. During this time, a plethora of diagnostic categories, groups and sub-groups was established (e.g. ‘specific language impairment’; ‘apraxia’; ‘developmental apraxia of speech’; and ‘childhood aphasia’), with researchers seeking new categories and characteristics of the structural components of the speech and/or language of categorised groupings. The focus was on the individual; the central signifier of disability was the body. As Watermeyer (2009b, p. 27) wrote, “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.”

It was toward the last quarter of the last century that researchers began to look beyond the structural components of language towards the use of language, which led to the development of a new field of scientific and clinical work which became known as “pragmatics”. In the most basic terms, pragmatics means the functional use of language in context. This working towards the broader focus of a functional contextual model from the micro focus on linguistic form, structure and content was considered so remarkable that it was described as a “revolution” (Lund & Duchan, 1983). During the next 25 years, the pragmatic revolution was characterised by a marked shift from the analysis of communication impairments with the focus on the individual and on linguistic structure towards more transactional and social approaches that gave attention to communication partners and to contextual variables (Holland, 2008). The focus of clinical pragmatics, however, was on the transmission and reception of a linguistic message (Worrall, 2000).

Emerging alongside the pragmatics paradigm, research from the clinical perspective described whether the individual’s communication was “functional” (Duchan, 2001a) such that the individual could communicate his or her basic needs. Consequently, the functional approach was a step forward from the impairment-based, individualised model toward the consideration of the individual as well as the conversational partners in context (Worrall, 2000). Functional communication was defined by different people in a variety of ways. For example, the American Speech Language and Hearing Association (ASHA) (1990, cited by Worrall, 2000, p. 4) defined it as “the ability to receive or convey a message, regardless of the mode, to communicate effectively and independently in a given environment”, while Holland (1982, cited by Worrall, 2000, p. 4) defined it as “getting the message across in a variety of ways ranging from fully formed grammatical sentences to appropriate gestures rather than being limited to the use of grammatically correct utterances”. Hence, the study of functional communication was situated in a linguistic framework. In a seminal article that proposed a model of “communicative competence” for people who use AAC, Light (1989) suggested that

> functional skills involve the skills which are required to initiate and maintain daily interactions within the natural environment, be it asking for directions from a stranger, telling a joke to a friend, ordering a pizza for lunch, or explaining the new data base to a fellow employee.” (p. 138)

An example of a measure that was developed to measure functional communication was the Communicative Effectiveness Index (CETI) (Lomas et al., 1989), a popular measure used in a wide variety of studies, that is still used today, and that has been adapted by researchers (e.g. Joubert, Bornman, & Alant, 2011). The developers were intent on devising a tool that would take into account personal values, verbal and non-verbal behaviours, and that would measure performance. In addition, the tool was devised to measure change over time. They asked people with aphasia to describe situations in which they were required to communicate, and then gave that list to a panel of experts to veto. The result was a 16-item tool which requires significant others in the person’s life to rate performance on a 10-point scale from not able to fully able. To illustrate, the CETI comprises items such as “Giving yes and no answers appropriately”; “Communicating his/her emotions”; and “Indicating that he/she understands what is being said to him/her”.

This test is an example that shows that despite the enormous contribution that the shift in emphasis made to the understanding of the social aspects of communication, there were a number of limitations to this approach. Firstly, many clinicians did not conceptualise functional communication as a part of the social process and continued to see functional limitations as what people with communication impairments could not do (Duchan, 2001a). The term was often considered only as the person’s ability to independently get a message across, with little, if any, consideration of the role of communication in establishing and maintaining social links (LPAA Project Group et al., 2001). Worrall (2000) identified a number of limitations of the functional approach, including the fact that the functional communication approach did not consider sufficiently the individuality of experience.

Later, the pragmatic-functional movement expanded to take a very much broader, panoramic view of communicative competence (Holland, 2008). The communicative partner was seen as critical to communicative success (Pound, Duchan, Penman, Hewitt, & Parr, 2007). Working from this basis, Kagan and her colleagues (Kagan, 1998; Kagan, Black, Duchan, & Simmons-Mackie, 2001; Simmons-Mackie & Kagan, 1999) showed that people with aphasia communicate better with some partners than with others. This led Kagan and colleagues to develop guidelines for use in talking to people with aphasia. In so doing, they demonstrated the power of the communicative partner in helping to promote the potential for the individual with aphasia to communicate more successfully. Their ‘Supported Conversation for Adults with Aphasia’ ™ (Kagan et al., 2001) is an exemplary intervention method that moved the research focus from the individual onto the individual in interaction with others.

The close of the last century saw many programmes that advocated working with communication partners of people with a variety of communication impairments (e.g. Brinton, Fujiki, Spencer, & Robinson, 1997; Girolametto & Weitzman, 2006; McConkey, Morris, & Purcell, 2001) and the eyes of researchers were drawn to issues around quality of life (Worrall & Holland, 2003). Thus, with this broader view of communication in context, the advent of the social model of disability (Threats, 2008), and a growing recognition of the chronic nature of some conditions (Holland, 2008), the participation of communicatively disabled people in society became to be looked upon as a natural extension of the clinical pragmatics movement.

## 3. Definitions of communicative participation

As I have discussed, understandings of communication disability have been medicalised and steeped in the individual-tragedy model of disability, and there has been little engagement of this research with the issues that have been foregrounded by disability studies. It is also likely that the study of communicative participation has been somewhat limited by the reliance on the ICF (World Health Organization, 2001), which is aligned with health and disease-related conceptualisations of communication disability. Many of the authors of studies on communicative participation mention the ICF, and indeed justify the study of communicative participation on the basis of the framework suggested by biopsychosocial model of the ICF, but without deep exploration of the issues encompassed by the participation aspects of the ICF (see for example Ashton et al., 2008; Baylor et al., 2011; Baylor et al., 2010; Bricker-Katz et al., 2009; Doyle, McNeil, Le, Hula, & Ventura, 2008; Eadie et al., 2006; Hartelius, Elmberg, Holm, Lövberg, & Nikolaidis, 2008).

Nevertheless, the ICF (World Health Organization, 2001) has been most influential in providing researchers with a framework in which to visualise the participation of communicatively disabled people in life’s activities (Hammel et al., 2008; Ma, Threats, & Worrall, 2008; Threats, 2006, 2008), and is the reason why I gave it as much attention as I did in the previous chapter. There has been, of course, important work by authors who have worked with the concept of communicative participation independently of the ICF (e.g. LPAA Project Group et al., 2001; Simmons-Mackie & Damico, 2001; Worrall, 2000).

Biopsychosocial models have played a significant role in boosting the changing philosophies of communication disability. Aligning themselves with the ICF conceptualisation of participation as involvement in life situations, Eadie et al. (2006, p. 309) described communicative participation as "taking part in life situations where knowledge, information, ideas, or feelings are exchanged". Their definition includes various communicative forms including speaking, listening, reading, writing, or nonverbal means of communication. Central to their definition is the core notion that "life situation" implies that communicative participation occurs in a social context of "what is being communicated, where, when, why, and with whom" (Yorkston et al., 2007, p. 435). Hence, the definition views communication as a reciprocal process, involving more than one person, and as involving a communicative exchange (Yorkston et al., 2008). A communicative exchange involves a message being delivered and an opportunity for a communicative partner to respond. Communicative participation may take place for a defined social goal, for a function /role, and/or in a particular context, and may occur in multiple life situations or domains.

A similar definition was offered by Doyle et al. (2008), who considered communicative participation as embedded within the construct of communicative functioning. They defined communicative functioning as "the ability to engage in common, everyday behaviours, tasks, activities, and life situations that involve understanding and/or producing spoken, written, and/or non-verbal messages, signs, and symbols" (Doyle et al., 2008, p. 720). Aligning with the ICF model, this definition

> conceptualises functioning as an umbrella term that encompasses body/mental functions, activities and participation. Thus communicative functioning encompasses body/mental functions of voice, speech, language, communication, and communication related tasks and activities, and life situations involving spoken, written, and nonverbal communication. (Doyle et al., 2008, p. 721)

Kovarsky, Culatta, Franklin and Theadore (2001) presented a model of communicative participation that was based on the understanding of communication needing to extend to "specific facets of human interaction and the broader, inclusionary, communicative context" (p. 1). The philosophy behind their model is as follows:

> Humans do not simply exist in a physical, material world the way an apple is housed in its skin (Buber 1965b); rather, they construct a life-world (Habermas 1987) by imbuing it with meaning through inter-subjective experiences and interactions with others that are constituted primarily through language (Stewart 1995). Without communicative participation through language where understandings, values, expectations, and identities can be negotiated between

> individuals, there would be no life-world (Habermas 1987). (Kovarsky, 2008, p. 50)

Kovarsky et al. defined communicative participation as "how individuals participate in talk and interaction" (p. 2). Their model comprises five overlapping levels:

1. The first level is "life-world participation", which Kovarsky et al. see as the broadest level. Life-world is expressed in various ways. Communicative participation at the life-world level is the expression of people's identities, their agendas as well as their values. In addition, watershed events provide information about the life-world of people. The barriers and facilitators that affect inclusion and exclusion are included in the life-world level of their model.
2. The second level of the model is "participant structure". This involves the acceptance of ways that communication happens; the ways in which knowledge or information is exchanged; and the way in people are afforded opportunities to participate.
3. The third level is "participant stance", meaning the roles that the person takes in the communicative exchange. At times a person might be a listener; at other times a speaker. At times a person might be dominant and at other times might be less controlling of an exchange. There is tremendous variability here, and the expectation is that there will be shift and negotiation.
4. The next level is "participant accommodation", which refers to the way in which the communicative partners accommodate to one another.
5. "Participant resources" are the strategies that the communicative partners bring to communicate with one another. These include verbal and nonverbal resources.

The Participation Model (Beukelman & Mirenda, 2005) was developed to guide the assessment and intervention of persons who use AAC. (A figure of this model is included in the appendix.) This model has been endorsed by the American Speech-Language and Hearing Association (2012b) as well as by Speech Pathology Australia (2004) for the assessment and management of AAC. The model is based on the ICF conceptualisation of participation, in that the goal of the provision of AAC is viewed as the participation of the individual in society. In this model, the assessment is based upon a comparison with a non-impaired age-matched peer's performance. The AAC user's performance is matched to that of the peer. The systematic steps that are recommended include the assessment of the AAC user's abilities, potential to use AAC, as well as the barriers, in terms of access and opportunity, to communication and participation. Intervention is provided in natural contexts with the aim of enhancing the individual's specific skills, as well as those of the communicative partner. Interventions are then directed at facilitating opportunities and natural ability, environmental support and adaptations, as well as the required interventions with regard to the AAC system selected. Of significance is that this model encourages clinicians to assess the current communication potential, skills and needs of the AAC user, as well as consider future needs.

There are definitions of communicative participation that are not grounded in the ICF model, and/or which do not necessarily use the term "communicative participation". For example, building on the work of Lomas et al. (1989), Donovan, Kendall, Young and Rosenbek (2008) defined "communicative effectiveness" as a person's ability to actively and efficiently get his or her message across successfully in his or her home and community settings to fulfil life roles. Authors have also referred to "social communication" (e.g. Davidson et al., 2008). Researchers have examined concepts that are similar to communicative participation, such as quality of life (e.g. Klompas & Ross, 2004), or lived experiences in which aspects of the research point to communicative participation (e.g. Cruice, Worrall, Hickson, & Murison, 2005). Not all of the terms used when referring to social communication/ communicative participation/ communicative competence are synonymous, and some are used interchangeably. This lack of consistency points to the relative lack of understanding of what communicative participation is, and the impact of this lack of consistency is significant for researchers, clinicians, and for policy makers.

## 4. A review of research on communicative participation

In this section, I provide a review of studies on communicative participation. I did not do a systematic review because the definition of communicative participation is a multidimensional concept and is poorly defined. Because the definition is so broad, so vague, and used differently by different people, the question was what definition to use of communicative participation so as to select the studies for inclusion in this chapter. I have based the review on a very broad definition of taking part in and constructing the life-world in which communication occurs. Using a very broad definition meant that doing a systematic database literature review was out of the question. Instead, the review was based on a very broad and wide literature search. I looked to literature that addresses participation, but have focussed on the literature that addresses communication as a core feature of participation. The studies that I accessed were entered into my Endnote® library, and in filing them, I coded them according to keywords that I chose that included “lifelong communication disability”, “communicative participation” and “participation”. In this way, I created a database and called up articles by keyword. What resulted was a very broad thematic analysis of the literature.

I have included studies that address both lifelong communication impairments as well as adult acquired impairments. Although there are very important differences in the experience of communicative participation by these two groups of communicatively impaired people, the primary aim of this review – aside from providing a critical review of the study of communicative participation in the lives of people with lifelong communication disability – is to identify core issues that affect people’s communicative participation, and that contribute to the theoretical understanding of communicative participation. The literature on the communicative participation of adults with acquired communication impairments is very rich in comparison to that on lifelong conditions, and offers important insights that may well apply to issues surrounding lifelong impairments. One of the limitations of the research on lifelong disability is the failure to address issues that refer specifically to communication. There is a significant body of research that has addressed the social participation of people with lifelong disabilities, but very little of this work makes direct reference to the role of communication in social processes.

Communicative participation has been studied from a variety of perspectives. In the literature review that follows, I present the general themes in the research, shown in *Figure 2*. Studies show that communicative participation is a multifactorial concept. Intrapersonal factors include those that are intrinsic to the type of condition with which the person lives; and values that the individual places on communicative participation. Interpersonal factors include the communicative partner or group, as well as networks and relationships with others in which communication plays a core role.  Factors that contribute to the person’s communicative participation in the external physical environment include such things as access to technological support, financial support, and life’s activities. Although some models – such as the ICF (WHO, 2001) – place attitudes in the environment category, I have chosen to make it a stand-alone category because of its centrality in the disablement process, and because it is the basis of inclusion. Inclusion, in the context of communicative participation, can be defined as the process in which the communicator is provided a place in the communicative world by another person, group, or society. Attitudes undergird inclusion.

Factors that are situated within the communicative exchange contribute to how the person participates in the communicative world, and although I do not review functional communication, I have shown how the development of the notion of communicative participation grew out of clinical pragmatics.

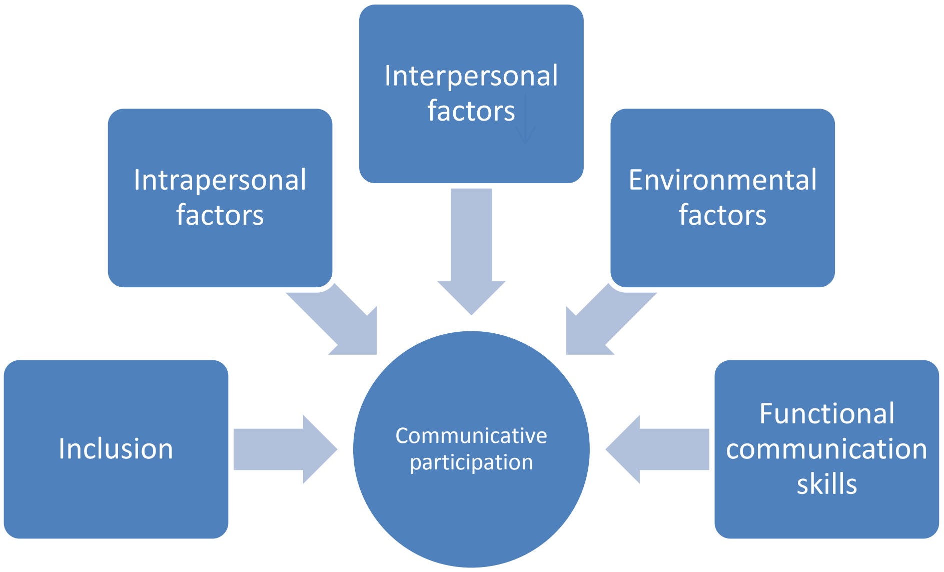

*Figure 2.* Communicative participation literature review themes

## 4.1 Condition-specific issues

Individuals experience barriers as well as facilitators to communicative participation that are specific to their particular impairments. The type of speech and/or language difficulty has different effects on the participation of communicatively disabled people. Condition-specific impairments associated with the communication impairments influence participation.

### *4.1.1 Acquired conditions*

Using a short form of the Communicative Participation Item Bank[9], Baylor et al. (2010) examined variables associated with communicative participation of people with Multiple Sclerosis, revealing that communicative participation was strongly significantly associated with fatigue, slurred speech, and depression. It had a weaker association with increased

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[9] The CPIB is an instrument currently under development (Baylor, Yorkston, Eadie, Miller, & Amtmann, 2009; Yorkston et al., 2008) to provide measurement of communicative participation in everyday speaking situations. It is a self-report outcome measurement tool for adults with a wide range of communication disorders. The items ask about the extent to which a participant's 'condition' (i.e., health condition or communication disorder) interferes with participation in a variety of everyday speech communication situations (Baylor et al., 2011).

problems in thinking, employment, and perceived social support. Bringfeldt, Hartelius and Runmarker (2006) investigated the variables affecting communicative participation in a group of participants with Multiple Sclerosis through qualitative interviews. Their participants spoke of problems other than their communication problems as being significant. Most of them were affected by aging, physical problems and memory difficulties. Problems such as pain, bladder problems, vertigo and emotional problems were identified as being important. Using a diary as well as interviews with people with aphasia, Dalemans et al. (2010) found that the factors that influenced their participants' communicative participation included personal factors such as motivation, physical condition and communication skills.

Hartelius, Jonsson, Rickeberg and Laakso (2010) researched the communicative participation of people with Huntington's Disease through content analysis of semi-structured interviews and focus groups. They specifically focussed their questions on communication. They reported that the factors that were found to influence communication negatively included the fact that they had fewer people to speak to; that others communicated too fast for them to be able to keep up; that they experienced stress and depression; that the personality changes associated with the progression of Huntington's Disease affected their relationships and communicative interactions with their family members; and the lack of eye contact blocked communicative access. The participants reported on some positive influencing factors. For example, they reported that they felt safe with familiar communicative partners; that they had greater communicative access if the communicative partner was skilled; and that if they felt that were part of a trusting community, they could communicate more. This study therefore showed that people with Huntington's Disease experience a number of issues that affect their communicative participation that are specific to the nature of the speech, language, cognitive and behavioural characteristics associated with the progression of the disease.

#### ***4.1.2 Stuttering***

In a study of older people who stutter, who had experienced stuttering all their lives, Bricker-Katz identified that social anxiety remains a significant issue. Using a variety of measures, she demonstrated that social anxiety with regard to speaking in social situations is a lifelong trait, and has the potential to limit, sometimes severely, older adults' participation. They can fear being evaluated in a negative way by others and will avoid speaking; this may in turn lead to social isolation; and restrict participation in life's activities around health and financial management, issues pertinent to those who are aging. Bricker-Katz's work was original in that it was the first study to show that stuttering persists long into adulthood and has lifelong implications.

Content analysis of interviews with people who stutter (Klompas & Ross, 2004) showed that, despite much variability, stuttering affected participants' education including their relationships with teachers and classmates. Furthermore, the participants experienced difficulties with making and establishing friendships. Their opportunities and choices in employment were limited by their speech, including their relationships with their superiors and co-workers, and their opportunities for promotion. Their stuttering also affected their relationships with their family members. Although this study looked at quality of life, it is clear from the results that the participation of people who stutter was affected markedly by their stuttering.

Butler's (2013) study of the educational experiences of people who stutter, looked at over six decades, showed that in general, children who stutter experience very little social interaction in educational settings. The participants described a sense of being physically separated throughout their educational experiences and described a distinct lack of encouragement from peers, mentors, teachers and others in educational settings. Crichton-Smith (2002) used in-depth interviews to explore the communicative experiences of people who stutter, and found that their participants reported that their stuttering had had significant effects on their lives, particularly with regard to limiting their employment, education and self-esteem.  Well into adulthood, the participants described that the avoidance behaviours that they developed in childhood persisted.

### *4.1.3 Language impairments*

Specific language impairments (SLI) are defined as language impairments that are expressive, receptive, or both and that are generally not associated with any other diagnosable set of impairments. Many children with SLI present with mild impairments in other areas of development, such as fine motor coordination. There is a small body of research that has examined the participation of children and later, adolescents and adults, who live with specific language impairments (Dempsey & Skarakis-Doyle, 2010). Children with language impairments have been found to experience difficulties throughout the lifetime with social skills (Beitchman et al., 2001). There is an association between language skills and social cognition, and social skills such as making and maintaining friendships. In addition, there is an association between SLI and behavioural problems (Beitchman et al., 2001; Myers, Davies-Jones, Chiat, Joffe, & Botting, 2011).

Carroll and Dockrell (2010) followed up a group of children with SLI after the age of 16 years, to examine their participation and other outcomes in young adulthood, and found that the communication impairments played a significant role in blocking the young adults' participation in many of life's activities. They experienced educational failure, difficulty accessing post-school education, difficulty finding employment, and difficulties with establishing friendships and relationships. The quality of the participation was influenced by the severity of the language impairment. In a study that looked at aspects of the quality of e mails sent by adolescents with and without a history of SLI, it was found that those who had a history of SLI made more spelling errors and their e mails were rated of being of a lower quality than those e mails sent by typically developing adolescents (Conti-Ramsden, Durkin, & Walker, 2012).

The problems associated with SLI have been found to persist into adulthood, and have implications for people to be able to participate in social life as adults. A longitudinal study followed up on children who had mild to moderate phonological and/or language impairments, into their adult years (Felsenfeld, Broen, & McGue, 1994). In interviews, the participants reported that they had performed less well at school than their peers, and had required additional educational support throughout their school careers. They had completed fewer years of education. As adults, they were employed in semiskilled or unskilled jobs with greater frequency than their matched peers and gender-matched siblings. In a study that involved 35 adults with a history of SLI (Arkkila, Räsänen, Roine, & Vilkman, 2008), participants were found to live more often with their parents, and were unemployed more than members of the general population. The participants continued to experience language impairments such as word-finding difficulties and difficulties remembering instructions. Although this study measured health- related quality of life and not participation, it is clear that the participants experienced difficulties in life because of their problems in expressing themselves and in understanding information.

#### ***4.1.4 Hearing loss***

Naturally, the communication impairments associated with hearing loss are bound to affect people's participation. The implications of the particular problems associated with hearing loss on the participation of individuals with lifelong hearing loss have been documented for many years. The population of hearing-impaired people is heterogeneous and few generalisations can be made. Factors that impinge on an individual's participation include the severity of the hearing loss, the type of hearing loss, as well as symptoms associated with auditory problems such as tinnitus, visual impairment (e.g. Usher's Syndrome), physical impairments (e.g. cerebral palsy) and intellectual impairment. The age of onset of the hearing loss plays a large part, and probably the most significant factor is the language development of the individual which is heavily influenced by the age of diagnosis (Korver et al., 2010; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). Studies have shown that people experience difficulties in accessing a range of life's opportunities because of issues of stigma associated with hearing loss (Downs, 2011). Hence, the participation of people with lifelong hearing loss is very variable and depends on any number of factors. Nevertheless, there is evidence that people with hearing loss have reduced opportunities for full integration in education throughout the education continuum (Fuller , Healey, Bradley, & Hall, 2004); fewer hearing-impaired people are able to gain meaningful employment – including those who have acquired college level education (Schley et al., 2011); hearing-impaired people tend to earn less than hearing people; and hearing-impaired individuals have been found to experience depression and feelings of isolation as  a result of the lack of inclusion (Most, Ingber, & Heled-Ariam, 2012).

#### ***4.1.5 AAC users***

People who have severe communication impairments and who use AAC experience communicative participation differently from people who use oral speech. Higginbotham, Shane, Russell and Caves (2007) wrote that communicative access for AAC involves the broad range of communication tasks, the partners involved as well as the context in which the interaction occurs. They defined access as:

> the right, means, or opportunity to use or benefit from something (e.g., operate a communication device); approach or see someone (e.g., converse with a person); obtain or retrieve information from a person, the environment or an artifact (e.g., read from a communication device) and provide use or benefit from something or someone (e.g., assist someone to communicate using AAC technology.  (p. 244)

A number of barriers to communicative participation are experienced by AAC users. One of the issues is the difficulty that naive communicative partners experience with AAC. For example, Balandin et al. (2001) found that AAC users experienced communication difficulties while in hospital for reasons related to a lack of AAC resources as well as the difficulties that the nurses had in not knowing about AAC or how to communicate with AAC users. Looking at the under-usage of AAC devices in England, Hodge (2007) found that many of the reasons for the lack of usage impinged on communicative participation. One of the problems with communicative access experienced by AAC users was related to the portability of devices. Furthermore, AAC users had difficulties communicating when their devices had to be repaired or serviced. Some users required the assistance of others to prepare their communication devices for use, and this assistance was sometimes not available. Some users found the speed of communication slow and others had difficulty typing. Hence, the types and nature of problems experienced by AAC users in relation to the devices themselves can have a marked influence on how they participate. Another problem that their participants faced was the vocabulary used. Not all AAC users are able to use typed messages and many rely on pre-programmed vocabulary and other representational systems. Bryen (2008) described the research that is necessary to develop vocabulary symbol sets that are relevant for adult AAC users in terms of the various adult roles that they assume. For example, vocabulary is necessary for the expression of meaning relating to work and occupations, sexuality, income, and so forth.

Raghavendra, Olsson, Sampson, Mcinerney, and Connell (2012) described and compared the school participation and social networks of children with physical disabilities and complex communication needs, children with physical disabilities only and children with typical development. They observed 39 children at school. Their findings showed that the children with complex communication impairments rarely used their AAC, and were not provided with sufficient communicative opportunities at school. In addition, they had fewer acquaintances and friends. AAC users are among the group of disabled people who are more likely not to acquire post-school education. The reasons for this are numerous. Studies have shown that AAC users are not prepared in high school for higher education. For example, they have been found not to have academic coping strategies to manage their workloads; they do not have adequate literacy skills to be able to cope with the academic demands; and they do not experience sufficient peer interactions to prepare them for establishing and maintaining relationships in educational settings after high school (McNaughton & Bryen, 2007).

Nevertheless, AAC has opened the doors to communicative participation for many people. One of the participants in Hodge's (2007) study reported that obtaining an AAC device at 31-

years of age was transformative. He felt that he no longer felt discriminated against and had a voice; that he was able to gain independence; and through it was afforded opportunities to start his own business. In a series of personal essays written by AAC users (Fried-Oken & Bersani, 2000), one of the themes that is evident is that despite the difficulties in communicating, having access to the communicative world through the use of AAC made a significant difference to all the users. One of the contributors wrote of how grateful he was to have been literate, because it was through his being literate that he could use an AAC device which gave him the opportunities for "making sense out of the world and having the reciprocal ability of letting the world make sense out of you and come to respect you for all that you have to offer and contribute" (Williams, 2000, p. 247).

Although AAC has provided people with little or no functional speech with improved access, challenges remain. McNaughton and Bryen (2007) reviewed the AAC needs of people with developmental disabilities across the lifespan. They looked at participation in three major domains: post-secondary education and training, the workplace, and community living and social interaction opportunities. As a result of their review, they made recommendations for the development of AAC to better support its users, including improving AAC for face-to-face communication, such as improving opportunities for ensuring privacy, being less obtrusive, and being more accessible and reliable under adverse condition such as noisy environments. Williams, Krezman and McNaughton (2008) wrote a paper about what can be expected of AAC development in the next 25 years. Their recommendations resonate with calls for improved communicative participation. They wrote of the urgency in providing AAC to those who need it, and of the fact that the AAC user requires tremendous flexibility in terms of the availability of devices, partners, strategies and communicative environments. In addition, AAC users "require support for full participation in a variety of interactions across all ages and interests" (p. 195), and need to be involved in all aspects of AAC research, development, and intervention.

### 4.1.6 Autism spectrum disorders

Most, if not all, people with autism spectrum disorders (ASD) experience throughout their lifetimes the classic diagnostic signs of communication impairment, impaired reciprocal social interactions, and repetitive behaviours. There is some evidence that a very small proportion of children with ASD outgrow these signs (Perkins & Berkman, 2012). The behaviours associated with ASD are, by definition, those which impair social function. As a result, children with ASD have been found to experience social isolation, and their participation in the full range of childhood activities is affected.

Children with ASD have difficulty making contact with others. Research on the use of cell phones as a means of communication with children with Asperger Syndrome has shown that their ability to participate in reciprocal communication is impoverished, and they also demonstrate less motivation to engage with others socially through the use of cell phones. They tended to use the phones for playing games rather than communicating (Durkin, Whitehouse, Jaquet, Ziatas, & Walker, 2010). The core problems of ASD make it difficult for children with ASD to be included by their peers. For example, they have difficulties with imagination and social play, and children do not easily play with them, leading to isolation as well as limiting the learning opportunities that children benefit from play (Wolfberg, Bottema-Beutel, & DeWitt, 2012).

Adolescents with ASD experience isolation in schooling, in peer relationships, in their families, as well as in the broader social setting. Social isolation is particularly evident for adolescents with autism who use AAC (Chung, Carter, & Sisco, 2012). Few adolescents with ASD make a successful transition from school to higher education. In a study that looked at what factors contribute to the success of those who do make successful transitions to higher education (Chiang, Cheung, Hickson, Xiang, & Tsai, 2012), it was found that the high school's attitudes to the child's future, the parents' economic status, the parental expectations, type of high school, and the child's academic performance were the main influencing factors that made higher education possible.  A British study determined aspects regarding social participation of three groups of children from a group of children who were enrolled in special education (Shattuck, Orsmond, Wagner, & Cooper, 2011). The three groups included adolescents with learning disabilities, with SLI, and with ASD. The adolescents with SD were more socially isolated than those in the comparison groups. Almost half of the adolescents with ASD rarely saw friends out of school, never received phone calls from friends, or were invited to social activities. The researchers found that the main factors that contributed to this reduced social participation were parent's income, the inability to participate in conversations, and poor functional cognitive skills.

There is a very small body of research that looks into the trajectory of the three signs associated with ASD, but there is evidence that they remain problematic into adulthood, and are compounded by issues such as depression which are thought to be associated with isolation and loneliness (Happé & Charlton, 2012). Hines, Balandin, and Togher (2011) pointed out that today for those adults with severe communication impairments associated with ASD, AAC was not readily available when they were children, and hence there is little use of AAC by adults with ASD. In a systematic review of the literature pertaining to the employment of adults with ASD, Holwerda, Klink, Groothoff, and Brouwe (2012) found that although a number of factors were found to contribute to employment, the data were inconsistent. They wrote that further studies are needed. Nevertheless, some of the studies that they reviewed identified that better speech and language skills may lead to better outcomes. Language skills and IQ are highly correlated, and studies found that higher IQ was related to better outcomes. In addition, better early language abilities correlated with better language abilities later, which were associated with better outcomes.

### ***4.1.7 Intellectual disability***

One of the difficulties in evaluating the literature in relation to the communicative participation of people with intellectual disabilities is the lack of focus on the communicative aspects of participation. There is a wealth of literature that addresses the participation of people with intellectual disability, and in fact, it is this body of research that has led to the development of many of the philosophical approaches to and models of participation, such as Nirje’s (1969) work on normalisation and models such as the integration model proposed by van de Ven, Post, de Witte, and van den Heuvel (2005). However, very little literature in the speech-language therapy literature refers to the components of communication that contribute to participation, and very little literature in the broader intellectual disability literature refers *directly* to communication impairment. Isolating the communication factors from the other factors in a multi-dimensional condition such as intellectual disability is fraught with difficulty.

An issue that arises in the research is that intellectually disabled people with severe communication impairments tend not to be included in research. Furthermore, research tends to examine the participation of people with mild intellectual impairment in the main (Verdonschot, De Witte, Reichrath, Buntinx, & Curfs, 2009). Also, it is difficult to evaluate the research because often than not, the communication skills of the research participants are not described in the studies on the participation of people with intellectual disability.

There are many challenges in researching the communicative participation of people with intellectual disabilities. Intellectual disability is a heterotypical condition, and it is difficult to make generalisations. Furthermore, the living arrangements of people with intellectual disabilities differ. When determining the participation of people with intellectual disabilities, there is much variation in the way in which participation is visualised. Nevertheless, there is evidence that people with intellectual disabilities experience participation differently, and experience isolation and marginalisation more than others. In addition, social exclusion persists through the lifetime.

Children with intellectual disability have been found to participate in different ways. King. Shields, Imms, Black, and Ardern (2013) assessed the participation of intellectually disabled children, matched with typically developing children using the Children’s Assessment of Participation and Enjoyment and Preferences for Activities of Children questionnaires. They found that children with intellectual disability participate in fewer Active-Physical activities; participate in fewer Skill-Based activities; participate in more Recreational activities; participate in more Social activities at home; and  participate in more activities alone.

The factors that influence the communicative participation of people who are intellectually disabled are numerous, among which is the ability to utilise alternative symbols. For example a study looked at the effectiveness of the use of symbol to supplement or replace text for people with intellectual disability who are illiterate (Poncelas & Murphy, 2007). It has been assumed that symbols used in lieu of text would enhance the understanding of various concepts. These researchers demonstrated that symbols may not be as effective as assumed. In contrast, there has been a body of research conducted on the use of Talking Mats®, which is an AAC system using pictures, that has been found to improve the communicative participation of people with intellectual disability (Bornman & Murphy, 2006; Murphy & Cameron, 2008).

One of the major shifts in the field of intellectual disability, and which should have the potential to change how the research is conducted and/or interpreted, is the move away from the individual, towards a philosophy that “the judicious application of appropriate supports can improve functional capabilities of individuals with intellectual disability, thereby enhancing a person’s independence⁄interdependence, productivity, community integration and satisfaction (Luckasson et al. 1992, 2002)” (Riches, Parmenter, Llewellyn, Hindmarsh, & Chan, 2009, p. 327). Riches et al. (2009) describe the development of this changed perspective. Starting in 1992, the American Association on Intellectual and Developmental

Disabilities (AAIDD) adopted a major change to their existing definition of intellectual disability, and that was the change in how severity is measured. No longer is severity judged on the basis of scores on an intelligence test; the AAIDD acknowledged that severity depends on the intensity of support required by the individual to participate in life's activities. Future research might be enhanced by the use of scales such as I-CAN (Riches et al., 2009) which, among many other domains, specifically looks at issues surrounding communicative support in its evaluation of an individual's support needs.

### ***4.1.8 Commonalities among communication impairments***

Despite very limited research, it seems that there are a number of variables that affect the communicative participation of people across different types of communication impairments and etiological groups. Baylor et al. (2011) conducted interviews with adults who lived with a variety of medical conditions, including spasmodic dysphonia, multiple sclerosis, stroke, stuttering, Parkinson's disease, amyotrophic lateral sclerosis, and laryngectomy. They conducted a secondary analysis of qualitative data collected in cognitive interviews during development of the Communicative Participation Item Bank, to look for common themes that affected their participation. They found that their participants generally experienced limitations in accomplishing their tasks. They also experienced similar emotional consequences.

Baylor et al. commented that the fact that these similarities beg the question as to whether the study of condition-specific issues is not misleading, and contributing to the lack of theoretical development about communicative participation. There is probably some value in this argument, but the fact is that they studied people who had different underlying reasons for their communication problems but all had dysarthria and not language, cognitive, behavioural communicative problems. In addition, there are too few studies that have looked at similarities across different types of communicative disabilities to provide substantial evidence. All the same, it would be valuable to have more research of this kind so as to be able to determine how the similarities (and differences) could contribute more to the theoretical understanding of communicative participation.

Certainly, this limitation applies to the research on lifelong communication disability. The nature and type of communication impairment, in combination with associated impairments, play different roles in providing people with the ability as well as the opportunity for participation, and this is particularly so throughout the lifetime of those who live with lifelong communication impairments. Many, if not most, communication impairments that occur in childhood, persist into adulthood, but are not unchanging. The features of the communication impairments may change over time; so too do the ways in which they impact the lives of people.

## 4.2 Communicative participation in different contexts

A number of studies have examined the factors affecting communicative participation in selected settings. One of the pathways to inclusion in society and to participation is the access that one has to a range of opportunities. Kagan and le Blanc (2002) suggested that just as people who use wheelchairs are provided with ramps to make the environment accessible, so too should communicatively disabled people be provided with environmental support. Communicative access has been understood in the literature as the barriers and the facilitators that people experience in relation to participation.

### *4.2.1 Health care settings*

The knowledge and attitudes of health care providers, the physical hospital environment and healthcare services, systems and policies affect the communicative participation of communicatively disabled people in the healthcare system. Using narrative analyses, Devault, Garden and Schwartz (2011) described some of these problems, and also contributed to the understanding of how access for Deaf[10] people in the health care system is affected by the medical fraternity being ignorant of the nuances of Deaf culture, communication choices, and communication difficulties experienced by Deaf and hard of hearing people. A number of studies have looked at the access that deaf and hard of hearing people have to healthcare. One group of studies interrogates the acquisition, prevention, and treatment of HIV/AIDS. Mall and Swartz (2012) reported on the lack of information and services available to hard of hearing and deaf individuals in South Africa due to issues including language and communication barriers, and insufficient information being available in South African Sign Language. The kinds of issues that differ among people with acquired versus lifelong impairments is evident in the absence of sexuality training in schools, and the inaccessibility of lifelong healthcare information such as this for communication impaired people, including the Deaf. For example, Mall and Swartz (2012) reported on a lack of information provided to

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[10] Deaf culture describes the social beliefs, behaviours, and values as well as societal traditions such as art, to be influenced by deafness. People in deaf communities usually use sign language to communicate. When used as a cultural label, ‘deaf’ is written with a capital D. When used as a label for the audiological condition, it is written with a lower case d.

learners in schools playing a large role in the broader picture of HIV/AIDS in South African Deaf communities.

O'Halloran, Grohn and Worrall (2012) conducted a meta-analysis of three qualitative studies to identify themes in the healthcare environment that acted as barriers to successful communication of people with aphasia. Their themes included the knowledge, attitude, characteristics and experience of the health care providers. However, they also identified that the structure of the healthcare unit played a significant role in terms of things like patient opportunities to communicate, inclusion of the families, the use of communication aids and equipment, opportunities for staff to learn communication skills, policies and procedures and the physical environment.

There is evidence that people with intellectual disabilities face challenges in the healthcare system, and there have been calls for changes to be made at policy, organisation, and personal levels (While & Clark, 2010). Very little research has examined the factors related to communication impairments in relation to healthcare. Hemsley and her colleagues looked at a range of issues in health care settings with regard to the communicative participation of people with severe communication impairments. Seeing communicative participation from a very broad perspective in acknowledging the roles of multiple communicative partners of an individual, they examined communicative participation from the perspective of older carers who are parents of people with communication disability (Hemsley, Balandin, & Sheard, 2004; Hemsley, Balandin, & Togher, 2007); nursing staff who took care of them in hospital (Hemsley, Balandin, & Togher, 2008c); and people with severe communication impairments themselves (Hemsley, Balandin, & Togher, 2008d). Recently, Hemsley et al.(2011) looked at communicative participation in hospital settings for people with intellectual disabilities. The findings of these studies reveal that not being able to communicate with healthcare providers places the patients in an isolated and marginalised position; and the burden of care then falls on their parents. Furthermore, in the case of aging people with significant communication impairments, it is an exhausting and overwhelming responsibility for elderly parents to cope with having to be the insurer that their children are able to communicate and be communicated with in healthcare settings.

### ***4.2.2 Public service***

Universally, concerns have been expressed about transport disadvantage experienced by disabled people. It is not just using transport that is the issue, but not being able to use transport successfully has implications for accessing life's activities which require one to travel such as healthcare, education, and entertainment (Davies, Stock, Holloway, & Wehmeyer, 2010). There is little research that has addressed the role of communication impairments in this regard. Ashton (2008) determined the barriers and facilitators that people with aphasia encounter in using public transport. Her qualitative study used in-depth, semi-structured interviews and observations with seven participants who lived with mild-moderate aphasia. Interviews were conducted before and after the journey. Observations were conducted throughout the journey, from planning the trip to arrival at destination. The participants identified that the barriers that they encountered on their journeys emanated mostly from transactions which required verbal expression, such as booking a taxi from a phone, asking about schedules when these changed, and when their communication skills were taxed by the fact that the booking system was complicated. They had difficulty with complex signage and unclear maps. They were also impeded by time constraints such in having to hail a bus. They found it very difficult when they were expected to be able to talk, and when they encountered uncooperative and unhelpful transport workers. They identified a number of factors that facilitated their communicative participation including written materials, and support from other people.

### ***4.2.3 Rehabilitation organisations***

Examining communicative participation in organisations, Pound et al. (2007) wrote that healthcare organisations have had a rather paternalistic attitude to its users, and people with communication disability are often dealt with according to the decisions made by professionals within these organisations rather than having a say. One of the crucial barriers to access is therefore their subjugated position in organisations, even those that are particularly developed to serve them.

Hughes (2009) argued that what we have done in the rehabilitation professions is make the mistake of confusing the social model with the biosocial association model. The biosocial model is based on the ideas of Rabinow (1997, cited by Hughes, 2009, p 678) who suggested that when people have something in common on a biological level, that this allows for them to create a community. Hence, rehabilitation organisations have been formed to provide support to people who share some biological identity, usually based on deficit. Hughes argued that the epistemologies of rehabilitation are based on expert knowledge and the needs of the clients. He claimed that although rehabilitation efforts have been altruistic rather than oppressive, they have subjugated the people that they claim to have served. This may be so to some extent, but there has been an acknowledgement that the social approach to communication disability requires a reframing of the positions of the professional and the client (Pound et al., 2007). For example, researchers associated with Connect – The Communication Disability Network, the British-based voluntary sector organisation that works with people with aphasia, have described the changes that have come about in the participation of their members by including them as central, decision-making autonomous members of their association (Byng & Duchan, 2005; Parr, Pound, & Hewitt, 2006; Pound et al., 2007). People with aphasia are involved in all aspects of the association, from being decision-makers, to training service providers, and delivering conversational groups. These changes have been challenging for the organisation, but the results appear to have brought about more access for people with aphasia, and certainly, as Pound et al. (2007) put it, more consideration by the professionals about the meaning of access and participation.

One of the fundamental problems facing people with communication impairments is the reduced power that they have in their roles in life. In many of the studies that have been reviewed so far, participants spoke of the need to be able to make choices, express their ideas, have a voice, and be listened to. Autonomy, authority, and power are issues that have driven disability activism. Within therapeutic relationships, the power imbalances that arise lead to a kind of oppression by the therapist. Pound (2011) demonstrated the transformative effects of including people with aphasia in activities associated with Connect – The Communication Disability Network in more active roles. In these active roles, the participants assumed greater degrees of authority, leadership, choice-making, and thus were accorded more “active citizenship” within the organisation. The repositioning of the participants resulted from reflection on how better to apply a more socially relevant perspective. Taking a social perspective requires a major philosophical shift on the part of the clinicians, and as Duchan (2001a) and Pound (2011) have suggested, clinicians working with communicatively impaired people need to engage in some deep reflection on the role that they play, and that they encourage their clients to play, in engaging with the communicative world.

There is, on the other hand, very deep involvement by disabled people in the disability movements. The international disability network, Disabled People International, is almost entirely run by disabled people, but as with most other organisations, it is rare for people with severe communication impairments to participate, particularly in management and senior representation level positions.

### ***4.2.4 The arts***

Drawing upon the increasing involvement of disabled people in the arts, Duchan, Jennings, Barrett and Butler (2006) embarked on a programme people to improve access to museums and art courses. The people with aphasia involved in their project were encouraged to be involved at every level of this initiative, from making contact with the arts organisations in their community, to setting up welcome and information stations at the sites. They also organised accessible workshops in the community arts settings and took part in evaluating the outcomes. They based this project on the goal of Connect – the Communication Disability Network, to provide contexts in which people with aphasia plan, run and participate in contexts that encourage their communicative participation. Another example of working towards greater inclusion in the arts is the aphasia theatre (Côté, Getty, & Gaulin, 2011), facilitated by speech-language therapists and professional theatre professionals, which provides a forum in which people with aphasia participate in theatrical productions as a means of rehabilitation of impairments, but with a view to using communication in a social activity.

In more developed countries, there are multiple opportunities for disabled people to access the visual arts, as is evident in a Google search in which hundreds of hits emerge in response to the search term "intellectual disability" or 'autism" or "deaf" with "and the arts". The arts have proven to be a highly visible, sometimes controversial, but powerful means of expression for disabled people in terms of visual arts as well as literature (Garland-Thomson, 2009; Siebers, 2012). In relatively extensive reviews of the representation of disability in the arts, there is little, if any, mention of communication disability (e.g. Garland-Thomson, 1997; 2009; Siebers, 2012). There are few exceptions that make communication disability visible and heard in the arts, such as the comedian Josh Blue who has cerebral palsy and associated dysarthria, and whose humour is based on his impairments and his life experiences as a disabled person. (See, for example, http://www.youtube.com/watch?v=qMSrpZi_6WM). In contrast, there are almost no points of access for the artistic expression of disability, as well as for participation independent of disability, for people in less resourced countries. There are, of course, exceptions, such as FTH:K[11] , a visual theatre company in South Africa that is for both deaf as well as hearing actors.

### ***4.2.5 Social protection***

Communicatively disabled people are vulnerable members of society and measures have been taken to improve their communicative access to social safety. One example is the work of Bornman et al. (2011) with people with severe and profound communication impairments in South Africa. Communicatively disabled people are vulnerable to abuse, neglect, as well as being the victims of crime. This is particularly so in South Africa which unfortunately has a high crime rate. Furthermore, many South African people, particularly those who are disabled, are illiterate. In recognition of the need for greater protection of this vulnerable population of people, Bornman and her colleagues developed communication boards in four of the 11 official South African languages (Afrikaans, English, Sepedi, and isiZulu). The aim of the boards is to allow for people with communication impairments to inform a first responder[12] that they have been a victim of crime, abuse, or neglect.

Togher and her colleagues (2006) have worked on a programme in Australia to provide better access to legal resources for people who have sustained a TBI. They cited a fairly large body of research that had effectively demonstrated that people with severe communication impairments are at great risk for abuse but do not have the resources available to support them in obtaining justice. The main problems that people had been shown to experience were the lack of physical access to legal resources as well as a lack of training of personnel in the legal system to communicate effectively with people with severe communication impairments. Over time, Togher and colleagues have developed the "Improving access to the justice system for people with communication difficulties: a training program for people working in the justice system". They described the key learning objectives of their programme to include having their participants develop an understanding of AAC; to be able to discuss and be familiar with AAC systems; to be aware of the communication difficulties that AAC users face; to recognise behaviours that indicate to them that the person with severe

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[11] http://www.fthk.co.za/ : " FTH:K is a young, independent theatre company whose with the mantra of: *Listen with your Eyes*. Its non-verbal, visual theatre integrates the Deaf and hearing communities, and has won multiple awards in its 7 years of existence. Its aim of bringing together Deaf and hearing artists, audiences and educators is best illustrated through its unique Tell-Tale Signs programme which is currently training South Africa's first generation of Deaf people for inclusion in the professional performing arts industry."

[12] A first responder is a professional person to whom the situation is disclosed in an attempt to obtain help, such as a religious leader, paramedic, teacher, therapist, police or security officer, or social worker (Bornman et al., 2011).

communication impairments is having difficulty communicating; and to learn strategies to successfully communicate with people with severe communication impairments. These are indeed challenging goals, and the program is time consuming, expensive, and relies on buy-in from the relevant stakeholders. This programme demonstrated that attaining communicative participation for communicatively disabled people is demanding, and so not only does it require time and resources, but also a good theoretical basis on which to develop programmes.

### ***4.2.6 The retail world***

The demands of developing programmes to enhance the communicative participation for people who have sustained a TBI were shown by Goldblum in her doctoral work (Goldblum & Alant, 2009). Grounded in the socio-political context in South Africa in which the transformation of corporate and other employment situations is a key political agenda following the 1994 transition to a democratic government, Goldblum's work involved setting up a training programme with employees of a large national retail supermarket chain. Focus groups helped to identify the barriers that customers with cognitive-communication problems associated with TBI experienced. Thereafter, professionally-made videos were used to train personnel, ranging from managers to shop floor assistants. Using a randomised controlled trial design, stores in one region of the supermarket chain were randomly assigned to the experimental and control groups. Statistical analyses of the performance of the participants showed that the training made a significant impact on their ability and their confidence in identifying barriers to, and facilitators of, communication with customers with cognitive-communication problems associated with TBI.

Many people in developing countries engage in purchasing food from local markets. An example described by Crowley et al. (2013) in their work in a poor community in Ghana. Mothers of disabled children expressed their desire for their children to participate in an activity that is regarded as germane to child participation in their community, which is to go to the market to purchase food for the family. The speech-language therapists developed an AAC programme to facilitate this which has proven to be most effective. The programme involved teaching the disabled people and their parents how to use AAC to complete the task, and then involved working with the sellers in the market to accept the alternate way of communicating. The therapists had to work on changing the belief systems of the sellers so that they would believe that the disabled children were capable of carrying out the required tasks; and the sellers needed to adapt their interactional styles with the children.

## 4.3 Sociological, political, and economic contexts

In the following section on contextual effects on communicative participation, I focus on challenging aspects including poverty, and the economic implications of communication impairment.

### *4.3.1 Poverty*

It is well-documented that disabled people are among the poorest and most economically marginalised groups internationally. This is particularly so in developing countries. A number of research projects speak to the challenges to participation faced by people in such contexts. Legg's (2010) anthropological analysis of the lived experience of people with aphasia in an urban township in the Cape in South Africa revealed the pervasive effects of poverty on living with significant communication impairment. Legg argued that in this context, the history of South Africa as well as current socio-political arrangements have had a devastating effect on social cohesion, and that life in such contexts is difficult for all. For Legg's participants, issues that arose were related to care, support, and security. Her participants were targets of prejudice towards the elderly, towards women, and towards disabled people. Her participants experienced very marked isolation and vulnerability.

The lack of professional services in poor communities contributes to reduced participation. Crowley et al. (2013) described some of the work that they have been doing as speech-language therapists in Ghana, a country in which speech therapy services are extremely limited, and which has a very high rate of poverty. There is no training of speech-language therapists at this juncture in that country and services are provided by a handful of therapists, often by those who visit the country for short periods at a time. Nevertheless, the development of programmes has been possible, and has depended on external resources, as well as education of communities regarding communication disability. Naturally, the limited number of therapists who are available in this country limits the extent to which these changes can be realised.

In developing contexts, the lack of policy development hinders participation. For example, despite some international bodies, such as the United Nations, recommending that nations make sign language available, many countries have not done this, and hence at a policy level, people who use sign language face barriers to social participation (Bjarnason, Stefánsdóttir, & Beukes, 2012; Geraci, 2012). Even when policy is developed, they can be restricted in some contexts. For example, looking at the participation of a woman in Cape Town in South Africa who was deaf, and who had no oral language, Haricharan, Heap, Coomans, and London (2012) showed how she could not adequately access healthcare because she did not have access to an interpreter. They argued that people in the healthcare context in South Africa have a right to available interpreters. Using the Convention on the Rights of Persons with Disabilities (CRPD) and the limits of General Comment 14 of the International Covenant on Economic, Social and Cultural Rights, they argued that General Comment 14, which addresses informational accessibility, is insufficient because it does not address language as a pre-requisite.

### ***4.3.2 Economic implications for communicative participation***

A number of programmes that have been developed to assist children and adults with communication impairments to participate have been described in the literature. These programmes are not always available and accessible. People who have communication impairments cannot access support because of the inaccessibility of the programmes as well as the high cost involved in many programmes. An example of programmes that were developed to ensure better participation for children who use AAC in Canada was described by Batorowicz, McDougall, and Shepherd (2006). They developed two community partnership programmes, “Story Time” and “Dress Up and Drama” which provided opportunities for children who use AAC to participate in community programmes. The authors stressed that their criteria for participation included active participation and not just attendance at these programmes. They describe the success of these programmes in that the children communicated, interacted socially, and controlled the environment. However, the programmes required time, effort, financial resources, accessibility, personnel and many other resources.

An example of the contrast between resourced and less resourced communities comes from studies on the use of the internet in enhancing participation. The internet in contemporary times in many contexts has proven to be a rich resource for people with communication impairments. For example, Light et al. (2007) motivated for the employment of adult AAC users to act as mentors to younger people who use AAC, and instituted a successful programme using the internet to achieve this goal. In contrast, in Ghana, Crowley et al.

(2013) were unable to use many of the resources that were available to them in their work in developed contexts because of the unavailability of the internet.

### 4.4 Personal values of the communicator

Training communicative partners has proven to be an effective means of improving the communicative participation of people. However, it has also been shown that the opinions of those who require the communicative support need to be expressed. For example, Hemsley, Balandin and Togher (2008b) explored the perceptions of adults with cerebral palsy and significant communication impairments with regard to the roles and needs of their family carers in hospital. They found that their participants reported that they needed much communicative support, but not to the extent that their decision-making would be affected, and they wished to be treated as autonomous adults on all levels.

In academic literature, it would seem there is a lacuna with regard to what people with lifelong communication impairments value and choose with regard to participation. There are published books, mostly for the layman, that speak to these issues (e.g. Creech, 2003; Fried-Oken & Bersani, 2000; Rush, 2003). According to Hammel et al. (2008), disabled people have expressed their view that their own experiences and perceptions of participation are more meaningful, relevant and valid than the perspective that outsiders have of their experiences, and of the way in which participation is measured by outsiders. In their study of 63 people who took part in focus groups, they wrote, “Participation was defined as both a means and an end to the expression of personal and collective societal values. People viewed participation as an expression of their values rather than as a defined, preset or normative set of activities” (p. 1449). The values that the individuals identified as being central to their participation, were choice and control; meaningful engagement; personal and social responsibilities; having an impact and supporting others; social connection, inclusion and membership; and access and responsibility. All of these values were underscored by the participants’ needs for being treated with respect and dignity.

Hammel et al’s (2008) research included people with a range of disabilities, and they did not specify how many, if any at all, had communication impairments. The significance of Hammel et al’s findings is that their participants revealed that participation has, at its core, personal and individual meaning. The meaning of communicative participation at a personal level is unexplored in the literature, a point raised by Kathard et al. (2010) in their research on the personal meaning and identity development of people who stutter. Few studies refer to what *communicative* participation means to the individuals themselves.

## 4.5 Communicative participation and the communicative partner

The communication partner is a key contributor to the measure of communicative participation.

### ***4.5.1. The characteristics and roles of communication partners***

Research has looked at the contributions that communication partners make to the talk in interaction of people, such as that of Ferguson and Harper (2010). Their research entailed involving a person with aphasia with a friend and a family member in an interview with the researcher. In their analysis of different types of discourse, they found that the communication partners provided communicative support often, in terms of speaking for the person, providing communicative assistance to the person, and speaking instead of the person. They also determined that the type of discourse played an important role in communicative participation in these encounters.

Within the body of work on communicative participation, a number of studies have analysed the linguistic demands of participation in communicative contexts. The work of Davidson et al. (2008) showed that communication comprises two levels. The first is the level at which information is exchanged. The second, and the one truly relevant to relationships, is the interactional level, defined as the relational component of communication. Davidson et al. looked at how older people identified interactional communication. Using a weekly diary, interviews and simulated recall through the use of replaying a video of interaction with the participants, their qualitative analyses showed that one of the main themes to emerge was connectedness. Their participants felt it important to “be on the same wavelength”, to share the topic and have shared interests. They also needed to share time, to be given time to communicate. In addition, participants stressed the importance of humour. Humour was found to be something that helped to establish and maintain communicative relationships for their participants. Like humour, phatic communication plays significant roles in establishing social ties. With phatic communication, the exchange of words is the interaction. “Have a nice day” and “let’s meet soon” are classic examples, as is small talk. Being able to use phatic functions was found to be critical by the participants for successful communicative participation. Revelation of self was a third theme. Participants spoke of how important it was to share of themselves and reveal themselves through their communication.

The importance of the role of the communicative partners as well as the social context in communicative participation was demonstrated by Kilov, Togher and Grant (2009) in their work with people who had sustained a traumatic brain injury (TBI). People with TBI often experience cognitive communication problems. They are often not able to have conversations or take part in social communicative interactions successfully due to problems with topic maintenance, being able to organise their thoughts, maintain their attention, and self-regulate. As a result, their social interaction is markedly impaired. Basing their work on the central role of friendship in social life and on the roles that friends could play in mediation, Kilov et al. investigated the participation and performance of individuals with and without TBI in discourse while they were involved in a shared problem-solving task with their friends. The participants were given an unusual object a (tap turner or a belliclamp), and were asked to work out the name and function of the object. The analysis of the transcriptions of the discourse revealed that the participants with TBI did not differ from their matched control group in terms of the shared contributions that each communicative partner made to the problem-solving task. This finding suggested to the authors that this kind of social communicative context could be used for peer mediation in rehabilitation.

The preceding paragraphs referred to the communication partners of adults with acquired communication impairments, which identify patterns of communication that adults find to be relevant to their communicative participation. These adults have experienced communication patterns that are very different until the time of the acquisition of their impairments. Although this information is important for identifying key issues in adult communicative interaction, the problem with comparing this data to the communication patterns of people who have long-term communication impairments is that those who have grown up all their lives with atypical communication have entrenched, sometimes persistent, manners of communicative interactions with others.

There is research that unpacks the ways in which communicatively disabled children interact with children and with adults. This research has shown that communicatively impaired people interact differently on multiple levels. There are differences on a linguistic level. For example, adults tend to use simple sentences, limited vocabulary, ask more yes-no questions and use restricted variety in their narratives when speaking to language-impaired children or children who have difficulty with communication such as those with cerebral palsy (Girolametto & Weitzman, 2006; Pennington, Goldbart, & Marshall, 2004). Parents of children who are unintelligible have been shown to be the dominant communicative partners, taking more conversational turns, introducing most of the topics, using more questions and commands rather than other speech functions, and controlling the conversation (Pennington & McConachie, 1999). Notwithstanding the heterogeneity of the groups of children with cerebral palsy, it has been shown that conversations are used as goal-directed interactions, rather than being used for general communicative purposes (Ferm, Ahlsen & Bjorck-Akesson, 2005, cited by Pennington, Thomson, James, Martin, & McNally, 2009, p. 1121). Research on the interaction patterns of children with cerebral palsy has shown that the children tend to be passive communicators. They tend to be responsive, and have been shown to initiate very little within communicative exchanges (Pennington et al., 2009).

In many cases, parents assume the role of translator for others and are not always true translators in that they add in their own contributions that may or may not be relevant to what the child says (Brewster, 2012). Interaction partners of communicatively impaired children do not use the same language teaching strategies as parents of typically communicating children (Girolometto & Weitzman, 2002 ). Kent-Walsh and McNaughton (2005) summarised some of the communicative behaviours that AAC partners have been encouraged to change. They have been found to dominate communicative interactions, use mainly yes/no questions, and take the majority of the conversational turns. In addition, conversational partners do not offer AAC users the opportunity to initiate communication or to respond to communication. They often interrupt AAC users in the middle of their attempts to communicate. Partners have a tendency to focus on the technique or the technology instead of on the message. Kent-Walsh and McNaughton described the consequences of these behaviours of the communication of the AAC user. They tend to be passive, and are able to produce a very small range of communicative functions. Furthermore, they have a very restricted repertoire of linguistic forms.

### *4.5.2 Training communication partners*

A large number of programmes have worked to train communicative partners to provide increased communicative support. For example, Kagan and her colleagues have demonstrated the value in providing training to the communicative partners of people with aphasia. Their “Supported Conversation” programme has been shown to be of benefit for training people in a wide variety of roles (Kagan et al., 2001; Kagan & Simmons-Mackie, 2007; Kagan et al., 2008; Simmons-Mackie et al., 2007). For example, the principles of supported conversation have been used to train medical students to obtain case histories (Legg, Young, & Bryer, 2005), and nurses to communicate more effectively with patients (McGilton et al., 2011).

Communicating with people who use AAC has been enhanced by partner training. Training communicative partners of people who use AAC is challenging because of the type of training that is required. Training is required in terms of attitudes, where a variety of factors such as age, the type of technology used, and the user's skill play a part in effectiveness of use. In addition, training is required with regard to the technical management of the devices, and in some cases, the programming and inputting of communication. Training involves facilitating the understanding of how to best communicate on an inter-personal and on a symbol level. Hence, successful partnering with a person who uses AAC takes sophistication and flexibility on the part of the communicative partner. Pennington et al. (2004) published a review of studies that looked at interaction training with parents of children with cerebral palsy. At that time, there were few studies, but the evidence had started to show that there was indeed potential for change. Since then, a number of studies have been conducted. It is difficult to compare the studies because they use a variety of research methods; they involve participants of various ages and skill levels; they train various aspects of communicative partnering; and they use a variety of approaches.

An example of one of the types of approaches followed is that of Starble, Hutchins, Favro, Prelock, and Bitner (2005). Their aims were to develop and carry out a training programme based on the principles of family-centred intervention. To this end, they worked with the primary caregiver who was to be the main communicative partner, carried out a needs assessment, and identified the contexts in which communication was a priority within the family and its functioning. They targeted training how to use the device, and training the communicative partner. The results of the study showed that those involved were satisfied with most dimensions of the training. However, like many other studies, this study did not look to the long-term effects of the training.

The way in which the effectiveness of training is evaluated varies in studies. In a study in South Africa conducted by Lilienfeld and Alant (2005), in which the researchers developed a peer-training program with the Grade 8 peers of an adolescent who had severe physical disabilities and who used AAC, measures included the frequency of interactions as indicated by the number of messages per hour. They also measured extent of the interactions by determining an increase in the number of messages per interchange. Finally, they examined their outcomes by determining discourse structures and communication functions achieved the modes of communication used by the adolescent who used AAC, and the responses of his peer partners.

Hence, there is variability in the types of training provide for communicative partners. There is variation in the goals, the methods, and the measures. It would seem that training is one of the hallmarks of successful communicative participation for people with communication impairments. However, there remain questions with regard to what behaviours to target; how to implement the training; how to measure the outcomes; and whether the changes that are facilitated are long-term.

### ***4.5.3 Communicative participation and relationships***

Communicative partners are partners in relationships. Not only has it been important to look at how people communicate, and what they communicate about, but at the barriers and at the factors that help people to connect to others. The work on communicative participation has thus been extended further into examining the effects of communication disability on relationships, taking communication beyond the level of the transactional model in which communication is defined restrictively as the transmission of a message. In an account of intimate relationships that people with TBI experience with their spouses (Gill, Sander, Robins, Mazzei, & Struchen, 2011), many factors were found to interfere, and communication impairments played a significant role. A common finding was that the topics of conversation lacked what Gill et al. (2011, p. 61) called “intellectual and emotional depth”. In addition, the partners with TBI were reported to avoid discussions about issues regarding intimacy. The impact of these communication problems on intimacy between the couples was most striking in that some questioned whether it was ethical to continue to have intimate relationships with partners whose communication interfered with the relationship so deeply.

Research has examined marital communication of people with amyotrophic lateral sclerosis (ALS) (Joubert et al., 2011). ALS is a rapid progressive neuromuscular disease that usually results increasingly deteriorating speech intelligibility. Although not common, ALS can be associated with linguistic and cognitive involvement as well. Using a battery of standard measures, Joubert et al. monitored marital communication through the progression of ALS, and found that it deteriorated significantly as the participants' illness progressed, and was related to the degree of speech unintelligibility.

The relationships of people with aphasia with their family members have received attention. A recent study (Hallé, Duhamel, & Le Dorze, 2011) examined the changes in perceptions that daughters of women with aphasia reported in their relationships with their mothers. The aims of the study were to identify the factors that affected their relationships, and to see if the aphasia itself influenced the relationships between the mothers and their daughters. Data were collected over a 12-month period. The daughters all referred to their mothers as being fragile not only in terms of health, but in terms of their communication difficulties. For example, they were afraid to leave their mothers alone in case of an emergency in which the mother was perceived as not being able to express her needs. The daughters felt a need to protect their mothers in communicative situations. They would accompany their mothers, for example, to the doctors' rooms to ensure that communication was supported. In terms of trust, the daughters felt that they could trust their mothers if they had abilities, and they would work hard to provide their mothers with support so as to have those abilities demonstrated to them. One example was in providing communicative support. An issue that emerged was that it was difficult to understand what their mothers wanted, which led them to having to take on decision-making positions without including their mothers' opinions.

The relationships between siblings and AAC users were examined by Dew, Balandin and Llewellyn (2011) using a life course approach. Adults with cerebral palsy and significant communication impairments as well as their siblings were interviewed twice. A grounded theory approach was taken to analyse the transcriptions. The interviews tapped the importance of AAC in the relationships of the siblings from childhood through adulthood. The life course approach highlighted the influence of sociocultural and geographical history on the siblings. For example, two of the participants were born during a time when rhesus incompatibility was common and thus they had cerebral palsy as well as a hearing loss. Another participant's life was significantly influenced by having been born in the 1960s which meant that he benefitted from moving out of home as the Australian system supported independent living for disabled people at the time when he was a young adult. These broad life course changes brought their own influences into the relationships that their siblings had with them. Taking these life course changes into account, the study showed that AAC played a most central role in the relationship between the siblings. Some siblings did not live together in childhood because the siblings with cerebral palsy lived in boarding schools due to the distance of the educational facilities from their homes. The siblings who lived together throughout childhood had close relationships attributed to being familiar with the AAC used. This need for on-going sibling contact and proximity so that AAC would be familiar to the siblings was also evident in adulthood. The life course approach also gave insight into future needs of the siblings. As parents age and are likely to be less able to look after their aging disabled children, or pass away, siblings often come to take on a more involved role, and it is here too that familiarity and comfort with the communication mode of the disabled sibling becomes important.

A number of studies have demonstrated that children with language impairments experience difficulties with friendships (McCabe & Meller, 2004), and there is evidence that early language impairments have long-lasting effects. For example, Durkin and Conti-Ramsden (2007) found in their study of 120 adolescents who had significant language impairments as children, that they experienced difficulties with the quality of friendship. In a review of the social difficulties that adolescents who are language-impaired have, Durkin and Conti-Ramsden (2010) found that the main problems that impacted on their socialisation were difficulties with peer relationships, difficulties making and maintaining friendships, and their emotional and psychiatric issues. They found that the adolescents with language impairments were more vulnerable than typical adolescents with regard to these problems.

Clegg, Hollis, Mawhood, and Rutter (2005) followed up on 17 men who had been diagnosed in early childhood with severe receptive language impairments. They were assessed in their mid-thirties. The researchers found that these individuals had normal intelligence with higher performance IQ than verbal IQ, a severe and persisting language disorder, severe literacy impairments and significant deficits in theory of mind and phonological processing. They found that there was a strong correlation between higher intelligence scores and better language skills in childhood with higher cognitive functioning and better language skills in adulthood. In terms of social participation, the group experienced significantly worse social adaptation. They had difficulties with prolonged employment, a paucity of friendships, and very few had been able to establish or maintain close love relationships.

These social adaptation difficulties as well as the difficulties with friendships are closely related to the idea of loneliness, which has been looked at in a number of studies by Balandin and her colleagues. Their research has shown that people with cerebral palsy and significant communication impairments experienced exceptional loneliness (e.g. Balandin et al., 2006a). Ballin and Balandin (2007) interviewed older adults with cerebral palsy and significant communication impairments and Cooper, Balandin and Tremblath (2009) interviewed younger people with cerebral palsy and significant communication impairments to determine what they thought contributed to their loneliness. The findings in the two groups were very similar, except for a few things such as the fact that the older group had lost friends. The communication impairments and the use of AAC played important roles in the connectedness of the participants. They had reduced opportunities to communicate; they reported that their communicative partners were often insufficiently trained to be able to support successful interactions; and they were not given sufficient time to communicate. Technology such as the phone and the internet had helped the participants, but they had their limitations as well. Having the use of AAC had contributed to mitigating against loneliness, but participants experienced the limitations that AAC imposes such as when literacy levels are poor.

The social networks of the participants were generally fairly limited, some more than others, and the relationships that the participants differed from conventional ones. For example, many people with cerebral palsy require assistance with daily living, developing close relationships with their caregivers. The relationship with the carergivers mitigated against loneliness for the participants in these two studies to some extent, but some of the participants did comment on the unusual nature of this relationship due to the fact that they were paid workers. Participation in social activities was useful for some participants but access to these activities, negative attitudes of people, and the difficulties of communication in terms of things like being given time to communicate did not help the participants to feel connected to people. Relationships were described that also pointed to the particular needs of the participants. For example, the participants expressed that family connection was very important in warding off feeling lonely, but family was often not available. This type of relationship that is necessary for people for whom opportunities to forge other social relationships might be limited has to be considered not only in clinical work, but also in the development of understanding of communicative participation.

### 4.6 The contribution of stigma and attitudes to communicative participation

Stigmatisation, by definition, leads to the exclusion of disabled people from social activity. In the research project in which Hammel et al. (2008) asked disabled participants what the meaning of participation was for them, it was found that the values that they placed on participation were undergirded by their need for respect and dignity. They wanted to be treated like everyone else and have their differences respected, not just accepted. Stigmatisation erodes dignity. "For many people with disabilities, psychosocial effects of stigmatization have been more handicapping than biophysical limitations imposed by the disability itself" (Downs, 2011, p. 106) and stigma invades families and society as a whole.

The story of the Deaf people of Adamorobe in Ghana, recounted by Kusters (2012), is an example of the effects of stigma on communicative participation and social participation in general. In this village, there were historically a very high number of deaf people. They used a sign language developed in the village, were accepted members of society, and most people in the village learned sign language. The Deaf people of the village were fully integrated members of society. In 1975, it was decided by a village "Gongbeater" that deafness was unacceptable, and a decision was made that deaf people were to be prohibited from marrying deaf people because that would limit the number of deaf children being born. The stigmatisation that resulted was marked, in that Deaf people were now assigned a lower status than others. Critically, their participation in society was markedly affected: they experienced marital problems especially if they were married to hearing people; the incidence of abortion increased and, according to Kusters, is probably the main reason why the prevalence of deafness has decreased over the years as it has; there is a sense that deaf people have less of a right to choose who to marry; and the economic marginalisation of the Deaf has increased. Kusters wrote that the survival of the deaf culture and sign language in Adamorobe is at risk.

The Adamorobe story is an extreme example of stigmatisation. Nevertheless, the causes and effects of stigmatisation are multifaceted. Smart (2001, cited by Downs, 2011, p. 107) listed the degree of stigmatisation for disabilities according to the type, onset and visibility of the disability. People with communication disability are stigmatised in various ways and to various degrees in complex ways. For example, a person who acquired a communication impairment through aging may be more stigmatised than a person who acquired a communication impairment as a result of being injured as a soldier in war; a person with an invisible impairment such as hearing impairment in a person who does not wear hearing aids may be less stigmatised than a person who has a highly visible communication impairment such as the hearing impaired person who uses sign language.

Emerson and Enderby (2000) investigated the perception and experiences of people with speech impairments and of the general public when communicating with speech-impaired people. They collected data in a number of ways: they held discussion groups with members of the public, carried out in-depth interviews with speech-impaired people and conducted an experimental study examined encounters between speech-impaired people and shop workers. They determined a rage of responses from the public as well as from the speech-impaired people themselves. Emerson and Enderby (2000) demonstrated that stigmatisation is effected and perceived in many complex and sometimes subtle ways. It is beyond the scope of this chapter to discuss these, but what is relevant is the manner in which people with communication impairments are stigmatised within communication itself. There is very little literature that speaks to this issue. How people are spoken to; what linguistic tactics are used for purposeful, and sometimes unintentional, stigmatisation; and how people are permitted entry into communicative situations by communicative partners, are concerns that have not been documented to a great degree. Nevertheless, there is a small body of literature that has addressed these issues such for people who stutter, have hearing loss, use AAC, and have voice disorders (Emerson & Enderby, 2000).

### 4.7 The trajectory of communicative participation

There exists a significant divide between paediatric and adult services and research. As a result, little is known about the long term trajectory of childhood conditions. There has been an increase in the studies that document ageing with lifelong impairments (Balandin, 2011; Balandin, Llewellyn, Dew, Ballin, & Schneider, 2006b; Fesko, Hall, Quinlan, & Jockell, 2012; Ingvaldsen & Balandin, 2011; Stendal, Balandin, & Molka-Danielsen, 2011). I have included some of these studies in the reviews in preceding sections. However, there are gaps in the literature on the participation of adults with lifelong communication impairments. Levin (2008) stated,

> “despite the gains that have been made to paediatric neuroscience from the parting of the adult and paediatric perspectives, we should be cognizant of the lack of a common language and theoretical focus in the paediatric and adult perspectives. In our research and clinical work, we must work towards continuity and connectivity in order to overcome the effects of the divide.” (p. 2)

Little is known, for example, about the participation of communicatively impaired adults in the developing world, in minority communities in the developed world, and in rural communities. There are significant gaps with regard to adult communicative participation in populations such as long-term survivors of brain cancer, childhood acquired TBI, and childhood aphasia acquired through childhood neuroencephaly. The disproportionate information from the research, such as on AAC users and adults with acquired communication impairments, calls for further research of a broader range of conditions, in a wider range of contexts.

Tracking social participation – and communicative participation – through the lifetime is immensely challenging exemplified in the complexity of adolescent life with its associated transitions. The complexity of adolescence is reflected the United Nations report on adolescence (United Nations, 2011). Issues that adolescents face include developmental issues such as puberty and making the transition from child to adult roles. They have to deal with the challenges of development in their morality, sexuality, emotions, cognitive and psychological growth. They are faced with an increase in their social networks beyond the family and school and interact with more people. They also enter more life situations as their networks expand and their independence increases.  There is a paucity of information on the role of communication in these contexts and developmental areas for disabled people. A report was published in Australia in 2013 that mapped social inclusion or exclusion of young disabled Australians, aged between15 and 29, between years 2001 and 2011 (Llewellyn, Emerson, & Honey, 2013). The researchers found that social inclusion had changed over the decade under study. However, the disabled adolescents were found to be significantly less likely to experience social inclusion. The summary of the findings is presented in Table 2.

Table 2

*Social inclusion of disabled adolescents in Australia 2001-2011*

| Compared to their non-disabled peers, young disabled Australians in 2011 were significantly | |
|---|---|
| less likely to: | more likely to: |
| Be employed<br>Be fully engaged in education or work<br>Attain Year 12 or equivalent educational qualification<br>Obtain non-school qualifications<br>Feel they have someone to turn to in time of crisis<br>Have a voice in the community<br>Have social contact with family or friends | Live in a jobless household<br>Experience long-term unemployment<br>Have lower economic resources and to experience financial stress and material deprivation<br>Have mental illness<br>Have fair or poor health<br>Have a lower satisfaction with their life<br>Feel unsafe in their local community<br>Report being a victim of personal crime |

*Note.* Adapted from “Llewellyn, G., Emerson, E., & Honey, A. (2013). *Left behind: 2013. Monitoring the social inclusion of young Australians with self reported long term health conditions, impairments or disabilities 2001-2011*. Sydney, Australia: Centre for disability research and policy, University of Sydney.

### 4.8 Measurement of communicative participation

Because of the complexity of communicative participation, difficulties arise in relation to developing valid and reliable measures. Furthermore, there are questions surrounding how communicative participation is to be measured, and whether communicative participation should be measured by disabled people themselves who provide an “insider” perspective, or whether people associated with communicatively disabled people should measure it. In addition, questions arise as to what to include in the measures.

Eadie  et al.(2006) conducted a review of the self-report tools available that would possibly have evaluated communicative participation as per their definition. Hence, all items that were considered to meet the criteria for measuring communicative participation had to include a communicative exchange between communicative partners, in the context of a life situation. So, excluded were items such as “reading” where there is no partner, but included were items such as “reading to a friend”. Excluded was “using a computer”, but included was “sending an e mail”, where there is opportunity for a response.  Items such as “write your name” were excluded because such items measure constructs that are similar to, but not the same as, communicative participation.  The items were then classified into the domains of the ICF – personal care, household management, work/education, leisure/recreation, relationships, and community. As in the ICF, where items were general and could appear in more than one domain, they were classified as general communication.  The researchers then looked at the psychometric properties in terms of the target population studied, the actual sample and the sample size. They assessed the reliability of the measures including test-re-test reliability and internal consistency. Validity was examined in terms of the tool’s content validity, face validity, concurrent/convergent validity, divergent validity, predictive validity, and construct validity. Finally, they evaluated the number of times the instrument had been used in peer-reviewed literature.  None of the six instruments that they identified came up to expectation in terms of their three criteria: the match between their definition and the items, the relevance of the individual items to communicative participation, as well as the psychometric properties of the tools.

In response to this review, Eadie and her colleagues (Baylor et al., 2009; Yorkston et al., 2008) have worked towards developing the “Communicative Participation Item Bank”.  This tool is designed to be a self-report tool for use by community-living adults. The items determine whether the person faces barriers to communication in everyday speaking situations. The wording is “Does your condition interfere with…?” The participants rate their responses as “not at all; a little; quite a bit; and very much”. Examples include “communicating in a small group of people”; “keeping in touch with family and friends by phone”; “confiding in someone you know well”; “ordering a meal in a restaurant”; “getting your turn in a fast-moving conversation”; “having a friendly debate with someone you know”; “asking a stranger for direction”; “making a phone call for household business”; and “talking to a store clerk who is in a hurry” (Baylor et al., 2011).

The CPIB has been used in studies that have examined the communicative participation of people with spasmodic dysphonia (Yorkston et al., 2008), multiple sclerosis (Yorkston et al., 2007), and people with dysarthria as a result of a range of underlying etiologies (Baylor et al., 2011). According to Baylor et al., (2011) on-going, but as yet unpublished, work is being done with regard to the psychometric properties of this scale.

A similar scale is that developed by Hustad (1999). Her Communication Effectiveness Survey (CES) is a measure of treatment outcomes for motor speech disorders. Her vision was that outcomes would be measured that reflected the person’s functioning in real life situations. The participants were asked to rate their performance on a 4-point scale from not effective to very effective. Examples include: “having a conversation with a family member or friends at home”; participating in conversation with strangers in a quiet place”; “conversing with a familiar person over the telephone”; and “having a conversation with someone at a distance (across a room)”. There has been some work on establishing the psychometric properties of the CES (Donovan et al., 2008), but a search through citation indexes (including Google Scholar, Pubmed, CINAHL, Psychinfo, and Cochrane) revealed no further publications on it. This search was done using the name of the test and/or the names of the authors.

The CES is also similar to the CETI (Lomas et al., 1989) which was described in a previous section. The CETI has been used in a number of studies. It has also been modified (Ball, Beukelman, & Pattee, 2004) and this version has also been used in studies that have looked at communication effectiveness in speaking situations (Joubert et al., 2011).

The limitations of these measures are apparent if one takes a broad view of communicative participation as being more than the barriers to what people are able to do communicatively in speaking situations. A somewhat extended scale has been developed by Hartelius and colleagues (2008). Called “Living with Neurologically Based Speech Difficulties”, the aim is, as with the aforementioned scales, to determine how communicatively disabled people perceive their speech difficulties, but also how they adapt to them. The scale was developed on the basis of a literature review, as well as a qualitative study in which people with multiple sclerosis were interviewed, where they described their communication difficulties in real life situations.

The scale is divided into ten sections, and each item in each section is rated on a 6-point scale from “definitely false” to “definitely true”. The first three parts determine the problems that people experience in relation to their speech, language and fatigue. Examples include “I run out of air when I speak”; “My speech is slow”; “I have difficulty finding words” and “I don’t always understand what people say to me”. The following three sections present statements to the participants regarding emotions, people and situations. For example they are asked to rate how the following affect them: “My speech difficulties get worse when I’m angry or sad”; I worry about my speech difficulties”; It’s difficult to communicate with members of my family”; It’s difficult to talk when we have friends visiting”; and “It’s difficult to talk with one or two people at home”. In the subsequent section, participants are asked about the restrictions to their roles. For example, “take part in social gatherings with relatives and friends in the way I would want to”; and “actively take part in work and studies in the way I would want to”.

The next section determines what the participants perceive to contribute to change. For example, participants rate the statements, “difficulties in thinking, remembering and concentrating”; “physical difficulties”; and “fatigue”. The next section examines how the participants perceive the level of their difficulty. For example, they are presented with statements such as “I communicate like I want to, but not as much or as often as I would like”; “I communicate like I want to, but it’s difficult”; “I communicate like I want to, but listeners often fill in words or try to help out”; and “I have to rely on others to be able to communicate like I want to”. The final section looks at the strategies that the participants use. For example, “I believe that my speech can be changed”; “I explain my communication difficulties to other people”; “I take a break and rest a little when I notice that I’m not being understood”. Unfortunately this scale has not been used very much, and publications are very limited as a search through citation indexes (including Pubmed, CINAHL, Psychinfo, and Cochrane) revealed no further publications on it.

## 5. Some critical comments on the literature review

Writing this chapter proved to be challenging because of the paucity of research on lifelong communicative participation. There are many studies that have looked at the participation of people with lifelong disabilities in general social activities, but they have failed to address the notion of *communicative* participation.

There was debate as to whether to include studies that had addressed the communicative participation of adults with acquired communication impairments. I made the call to include these studies because they offer the opportunity to examine issues that are common to all people with communication impairments. I have not assumed that the experiences of people with acquired communication impairment equate with these with lifelong communication impairments. The question arises in a review that combines the two groups of people as to what the knowledge gap is relevant to this study. I think that the answer to this question is partly answered by the choice to include both groups: the gaps in the information about lifelong communication impairments are evident. The studies on lifelong communication impairment show that the participation of people with communication impairments begins in early childhood. What the literature had failed to yield is sufficient analysis of the build-up to adult life.

This review of the studies on communicative participation has shown that communicative participation is indeed a difficult term to define, measure, and operationalise. The topic has been approached from many perspectives, but the dominant one has been from the disabled perspective, in that most of the work has focused on people who have communication impairments. The studies emanated from the rehabilitation literature in the main. There is a distinct lack of attention to communication disability in the literature on disability and critical disability. The lack of engagement of disability studies with communication disability was evident throughout my literature search and was confirmed by Paterson (2011) who stated,

> Although many disabled people are excluded from … opportunities to communicate, and find it difficult to have their voices heard and understood, disability studies has little to say about this exclusion and issues of communication remain theoretically undeveloped from a social model perspective. (p. 165)

The studies have looked at communicative participation from the perspective of the person living with communication impairments, although there is a somewhat limited body of work on the personal story. This is not that surprising given the difficulty with the expression of ideas that communicatively disabled people experience. However, this is a lacuna in the body of research on communicative participation which might, if filled, contribute to a deeper understanding of the personal experience of communicative participation. Nevertheless, there is some research that has looked at the value that people assign to participation. The research has identified some of the consequences, on a personal level, for people with communication impairments, such as the work on identity.

The studies have examined what the barriers and facilitators to communicative participation are in a variety of contexts. These studies are influenced by the broader context in which people live although few studies reflect on the broader context in which they were conducted. For example, in societies in which legislation protects disabled people, access to opportunities for communication might be expected to be richer than for people in less developed contexts. The studies are also limited to people in developed countries, with very little evidence from under-resourced communities, or communities in which communicatively disabled people might not be protected by philosophies of fair and equitable recognition and redistribution. The growth in the past decade or so in the number of studies that have looked at communicative participation in a variety of contexts is evident.

The studies reflect a number of different methodologies used to determine the different aspects of communicative participation that have been probed. The number of qualitative studies is noticeable. Related to this increase in the number of, and range of, qualitative studies, is the search for tools that can capture the essence of communicative participation. This has proven to be a tough exercise influenced by the context in which people live, as well as the type and severity of communicative impairments with which they live.

The ideas around dependency, dignity, and human value, have not been addressed explicitly in these studies despite these philosophies underlying much of what has been done, and which have been identified in the few philosophical papers on the topic (e.g. Brown, Worrall, Davidson, & Howe, 2012; Byng & Duchan, 2005; Duchan, 2001a; Kagan et al., 2008; LPAA Project Group et al., 2001; Worrall et al., 2011).

## 6. Chapter summary

In this chapter, I presented an overview of some of the core features in the study of the communicative participation of people with lifelong communication impairments. I grouped the studies according to the six main themes that were evident. I examined interpersonal factors that contribute to communicative participation, and included aspects related to the specific communicative issues associated with various conditions. I showed that communicative participation is influenced by these issues. However, I also showed that there is some commonality of the experience of the interpersonal barriers to communicative participation. The review then presented an analysis of the personal factors that contribute to communicative participation and shows a dearth in the literature that examines values and ideals. Although not without exception, studies on communicative participation have neglected to look at personal issues.

The second part of the review summarised some of the core issues that have been found in terms of interpersonal features, including the communicative partner, and relationships between people, as well as attitudinal influences. The review highlighted the difficulties that communicatively impaired people experience throughout their lifetimes with regard to the use of communication interpersonally. Although there is literature on disability and relationships, there is a paucity of information with reference to the direct influence of communication in this regard for people with lifelong disabilities.

Similarly, the paucity of focus on communication in specific terms is evident in the literature that reviewed the environmental contributions to communicative participation. There are hundreds of environmental factors that affect participation(Whiteneck & Dijkers, 2009), and so in this review, I looked to the broader socio-political context, and issues around economic opportunity.

The review also illuminated the role that the communicative act plays in facilitating communicative participation. Although I showed that the analysis of functional communication from a linguistic perspective was a part of the trajectory of the study of communication disorders that has led to the study of communicative participation, I have shown that functional communication is an intrinsic part of communicative participation.

In the opening chapters to this study, I have sought to provide an overview of the state of the understanding of communicative participation. I have shown that disability studies has not examined issues surrounding communication disability, and those who have studied communication disability from a communication sciences perspective have engaged relatively distantly with issues that the social models of disability have championed. I have shown that despite the breadth and variety of studies, there remain gaps in the understanding of communicative participation, particularly with regard to people who have lived with communication impairments all their lives.

There is also a paucity of information regarding the communicative participation of people in developing countries. Hence, I now turn to presenting the study in which I looked at the experience of communicative participation of adults with cerebral palsy in South Africa. In the next chapter. I present the pragmatist grounded theory approach and methodology that was employed to explore the topic.

# PART TWO:  METHODOLOGY

# CHAPTER FIVE:  METHODOLOGY

## 1. Introduction

In this chapter, I specify the aims of the study, and motivate for the use of a pragmatic, constructivist approach to grounded theory. The selection criteria for the inclusion of participants are presented followed by a description the sampling method and the recruitment of the participants. This is followed by a description of the nine people who agreed to be part of this study. Thereafter, I provide an account of how I went about setting up a series of interviews and observations with the participants, and provide information on how these data collection methods were implemented. I discuss the ethical issues that were relevant to this study and how they were managed. I then provide a detailed overview of the data analysis methods, and discuss the trustworthiness of the study.

## 2. Aims of the study

The broad aim of the study was to explore how adults with cerebral palsy and significant communication impairments experience communicative participation. The following research questions were used as introductory questions to guide the study:

1. What does it mean for you to participate in the world as a person with communication difficulties?
2. In what activities and life situations do you participate in which you want to or need to communicate?
3. What are the barriers and facilitators to your communicative participation?
4. What were the issues growing up as a person with cerebral palsy and communication difficulties that have influenced your participation in life?

These questions were based, in part, on those used by Hammel et al. (2008) in their exploration of the meaning of participation for disabled people. These questions served as sensitising concepts (Blumer, 1969, cited by Charmaz, p 16). These were general concepts that provided a “point of departure” (Charmaz, 2006, p. 17), and also provided an overall frame for the study. To paraphrase Charmaz (2006, p. 17), the research was not “locked into” these original questions, but later followed the leads that I constructed from the data.

## 3. Theoretical influences on the methodology

I elected to base this study on a pragmatist-constructivist grounded theory approach as advocated by Charmaz (2006). It is relevant to specify from which ontological and epistemological positions one situates oneself as a researcher as well as the approach taken and the interpretations that one makes (Charmaz, 2009). I will provide a description of the ontological basis of this study because this perspective on the nature of social reality will indicate what is counted as relevant knowledge in the study (King & Horrocks, 2010).

### 3.1 A pragmatic constructive-interpretive paradigm

A paradigm is a basic set of beliefs that guides action (Denzin & Lincoln, 2005) and comprises epistemological, ontological and methodological premises. I present this study within a constructivist-interpretive paradigm (Denzin & Lincoln, 2005). I therefore assume a relativist ontology in which I assume that there are multiple realities, a subjectivist epistemology in which I understand that the researcher and the participants co-create meanings, and prefer a naturalistic set (i.e. in the natural world) of methodological procedures (Denzin & Lincoln, 2005).

### 3.2 Grounded Theory: Charmaz's pragmatic constructivist approach

This study was about a broad and relatively unexplored topic, which lent itself to qualitative methods. Furthermore, I sought a method that would resonate with my pragmatism and that would be open in permitting interpretation. Having had close professional contact with people with severe and profound communication impairments, I predicted that it would be very difficult to adopt a method that would be tight, have narrowly defined measurement specifications, and that would expect definitive answers. In addition, given the difficulty that the participants would bring with regard to expressing their ideas in intelligible, comprehensible forms, I could not adopt an approach that was not sufficiently flexible with regard to the treatment of the participants' narrative, and elected instead to employ grounded theory.

Grounded theory is a mass of approaches that has developed from the work of two collaborating sociologists, Glaser and Strauss in the middle of the last century. Following their landmark publication, "*The discovery of grounded theory"* (1967), they produced a series of publications that described their approach. In essence, they opposed what was, at the time, a strictly positivist, deductive approach to the study of social life. Opposing this positivism, they offered instead a method that proposed a different approach. In their vision, researchers enter a field of study as blank slates, starting with the specific meaning of data – whether qualitative or qualitative – and move the data through a series of interpretive, inductive processes to come to a general understanding, a mid-level theory grounded in the data. In time, Glaser and Strauss took very different paths and diverged in their interpretations of grounded theory: Strauss remained pragmatist and less positivistic, collaborating with others (in particular with Corbin) and Glaser remained true to the original classic grounded theory logic (Charmaz, 2009). Over the past 40 years, a number of clusters of types of grounded theory have developed. Today, grounded theory is the most popular form of qualitative research although it takes many different forms (Bryant & Charmaz, 2007b).

I was drawn to the constructivist approach that was developed by Charmaz (2006, 2008, 2009). I was motivated by her particular allegiance to symbolic interactionism, which resonated with my pragmatist background. In fact, symbolic interactionism is rooted in the pragmatic tradition (Corbin & Strauss, 2008).

### ***3.2.1 Pragmatism***

Pragmatism is a philosophical tradition that originated in the United States around 1870. Charles Sanders Peirce, William James, and John Dewey are generally regarded as the founders of this approach (Corbin & Strauss, 2008). Pragmatism is really a middle ground philosophical stance, in which most dualisms (e.g. body-mind; realism-anti-realism, determinism-anti-determinism) are rejected in favour of a more moderate approach which speaks to finding a solution to working out problems (Charmaz, 2009). Pragmatism resonated with the study of communicative participation because this approach sees reality as constructed by both the physical and natural world well as the world that emerges from social and cultural, linguistic, psychological and subjective ideas. Hence, the pragmatic notion that places high regard on the reality of the inner world and human experience(Corbin & Strauss, 2008). Pragmatists see life as process-oriented, comprising continuous and changing transactions between the person and the environment (King & Horrocks, 2010).

Pragmatists regard beliefs and research conclusions as tentative, always. For example, I have watched theories change and grow over time, and have had to remain flexible as a clinician to adapt my thinking and my work as theories have changed over time. Accepting the fallibility of theory is a core feature of pragmatism (Charmaz, 2009). Theory, then, is evaluated on the basis of how well it works.

### ***3.2.2 Symbolic interactionism***

Social interactionism can be defined as a set of theories that explain how human behaviour is formed and expressed through social interaction. The proponents of symbolic interactionism have developed many forms of interpretation of this theoretical approach, but the core ideas remain. The three core ideas that were originally articulated by Blumer (1969) were that individuals live in a symbolic world in which meaning is learned; that we act toward things on the basis of meanings that things have for us; and that meaning is developed through our interactions with others.

The self is defined as a process that involves a continuous communication between the "I" and the "Me". Based on Mead (1934, cited by Aldiabat & Navenec, 2011), symbolic interactionism views the "I" as a spontaneous, uncontrolled part of the self that reacts to the attitudes of others. The "I" is therefore the human subject. The "Me" is the organised set of attitudes, understandings and expectations of others. The "Me" then defends and interprets the self as reflected in the behaviour of others. Hence, the "Me" is social self. The self then comprises the "I" that takes in and interprets how the person is seen by others. The "Me" may be a brother, sister, employee, friend, communicative partner. The "I" will be influenced by how the "Me" interacts in the world with others (Aldiabat & Navenec, 2011).

Blumer identified three forms of objects:  physical objects, such as apples; social objects, such as communicative partners; and abstract objects, such as moral principles. Objects have no meaning in and of themselves, but are accorded meaning in interaction with others. Meanings are not permanent but change and are redefined through interaction. The social world, then, consists of objects, as well as of people who have their own social meanings of these objects. People interact socially with one another based on the social meanings of these objects. Charon (1979, cited by Aldiabat & Navenec, 2011, p. 1066) proposed that the self is a social object like other objects shared in interaction. The process of interaction in which a human becomes an object himself or herself is called "role-taking." which involves imagining oneself as one is seen by others.

The underlying premise, then, of symbolic interactionism is that society is created through interaction, in which people attach symbolic meaning to objects. The symbolism is expressed through language and non-verbal symbols. Blumer proposed that social behaviour results from how people interpret objects, and how they deal with those interpretations. Hence, in interaction with others, people consider one another as symbolic objects, and adjust their behaviours in relation to one another and one another's actions. Social actions, therefore, are an expression of social structures or "hidden" forces that reflect these meanings (Roe, Joseph, & Middleton, 2010, p. 31). Social interactionism is not essentialist, and does not ignore the role of societal structures or brute facts (Roe et al., 2010). In the case of the present study, social interactionism invites the idea that cerebral palsy and its associated impairments exist, but how the individuals function depends on how they develop their selves in relation to others. It also acknowledges the broader social world in which people live. This approach is particularly relevant in the study of the role of communication impairments in social life, where communication is inevitably a human function indivisible from social interaction.

### 3.2.3 Symbolic interactionism and grounded theory

There are many opinions regarding the relationship between symbolic interactionism and grounded theory. Glaser (2005, cited by Stern, 2008) wrote that symbolic interactionism is simply a theoretical code. Stern (2008) suggested that symbolic interactionism is "a kind of a backdrop for grounded theory" (p. 121) but not as a theoretical basis of grounded theory. Conversely, Corbin and Strauss (2008) based many of their axioms on social interactionism. Similarly, Bryant and Charmaz (2007a) claimed that the fit between symbolic interactionism and grounded theory is very strong. For example, both assume the agency of the actor and the importance of studying processes.

### 3.2.4 Constructivism

As well as her identification with symbolic interactionism as a theoretical basis that matches tightly with her approach, Charmaz's approach to grounded theory is a constructivist approach. Proponents of constructivism propose that knowledge is always invented because we can never really know reality. Hence, our ideas determine what we know. Hence, the ontology of constructivism is not based on what exists but on what people perceive to exist. It denies the existence of an objective reality, claiming that reality is a construction of the mind. Therefore, there are so many realities as there are individuals, although many aspects of reality will be shared. The epistemology of constructivism then assumes that the researcher presents his or her reality of what is being studied. Constructivism invites interpretation. Charmaz (2006) suggested that constructivist grounded theory is based on the idea that the data and analyses are socially constructed. Data are constructed as an interaction between the researcher and the participants, and the data and the analyses reflect the interpreted understanding of the participants' meanings.

This acknowledgement of the role of the researcher is a very important one in relation to disability research, as well as to conducting research in South Africa. Allowing the researcher to take a place in the research alongside the participants and to see co-construction and cooperation between the researcher and the participants diminishes the skewed power relations of the researcher-as-visitor and researcher-as-expert, notions that have permeated research with disabled people. In addition, the idea of giving oppressed people their own voice as opposed to so-called objective researcher perspectives is something that is called for in South African society where top-down and powerful forces have oppressed disabled people.

### ***3.2.5 Use of grounded theory in disability studies***

Charmaz's approach is a contemporary approach to grounded theory, and the motivation to use it was reinforced by the fact that it has been used extensively and has been used to look at various aspects in disability research (Dew et al., 2011; Power, McManus, & Fourie, 2009; Wee & Paterson, 2009). This approach was appropriate approach because of the flexibility that it promised (Charmaz, 2009). This approach seemed to offer a capacity to interpret complex phenomena (Charmaz, 2006). Grounded theory has played a large role in looking at social issues (Aldiabat & Navenec, 2011) and has contributed to examining socially constructed experiences (Charmaz, 2009; Hallberg et al., 2010; Stern, 2007).

## 4. Ethical considerations

The proposal to conduct this study was approved by two university ethics committees, one being the university at which I am registered as a PhD candidate and the other being the university at which I was employed at the time. The certificates of approval are included in the appendix (University of the Witwatersrand: NM101015; Stellenbosch University: N10/08/247).

### 4.1 Ethical concerns

The study was conducted on a group of people who are considered by ethical boards to be "vulnerable" (Penn et al., 2009). The concerns included the following:

**4.1.1** Coercion: I was cautious not to convince the participants to take part in the study. Fortunately I had a fairly large sample that I could approach and was not under pressure to find participants.

**4.1.2** False hope and expectations: I was concerned that the participants should understand that taking part in the study was limited to a 6-month period, and that I would have no contact with them thereafter. Participating in research can be therapeutic and meaningful for participants, but these experiences too can be problematic. People with communication impairments, particularly if the impairments are significant, are often lonely (Ballin & Balandin, 2007). Many also live with significant physical impairments and cannot get out and mix socially (Orlin et al., 2010). For such participants, the social contact with the researcher may be rewarding, and may be regarded as personally meaningful. It can be difficult to set boundaries as the researcher, and to terminate the connection upon completion of the research. I was aware that I might run the risk of participants misconstruing the interviews and the relationship with me as friendship. On the other hand, there is danger that data can be restricted and narrow when the researcher insists on maintaining a distance, while not allowing reciprocity in the research relationship to develop and become intrinsic to the research process, as articulated by Peterson (2011) in her reflections of her research as a White able-bodied women conducting research with Black disabled women. Throughout the research process, I remained cognisant of these potential problems and was able to manage them by discussing the issues with the participants. In addition, I treated the research relationship as a therapeutic one and worked towards termination by gently reminding the participants that the research was working to a close.

**4.1.3** Benefit: It was important that the participants were made aware that that they were not necessarily going to derive any immediate benefit from their participation in the study. They were made aware of this issue in the information letter.

**4.1.4** Anonymity: I assured the participants that I would not inform anyone of their participation in the study. I also assured them that I would not reveal their identity through my study to any person, and would not describe their experiences in a way in the study that would reveal their identities. I selected pseudonyms for the participants.

**4.1.5** Privacy and confidentiality: The participants took part as adults, and so I refrained from discussing what they had told me with their caregivers, parents or any other people associated with them. I also insisted on interviewing them in a private place, and alone.

**4.1.6** Video-recording: Recording is recommended for research. However, for some of the participants, video-recording was invasive and problematic. All participants were given the option of no recording but I explained that I required an audio recording, if possible, so that I would be able to analyse the data. I assured the participants that the only people who would have access to the recordings other than myself would be my research assistant, my supervisor, and only if the need arose, members of the University Ethics Committees. All participants agreed to be audio-recorded. Three participants agreed to be video-recorded.

**4.1.7** Emotional vulnerability: Sharing personal information with strangers is unusual. Asking participants about their private lives, to talk about topics that may be difficult in nature and content, might be viewed as being therapeutic (Moyle, 2002) but being therapeutic requires a lot more than simply providing an opportunity to talk. Whether or not the divulging of private, deep and meaningful information is treated as therapeutic or not is of ethical concern (McKeown, Clarke, Ingleton, & Repper, 2010). The topic of the study was personal, and I anticipated that it might have evoked some anxiety or sadness. I mentioned this to the participants at the beginning of the study as throughout the study, I reminded the participants that they were not obliged to talk to me about anything that made them uncomfortable. I also made the participants aware that they would have the choice about reading the final study, to comment on its reflection of their experiences. I informed them that this might be upsetting and that they were prepared for this. All of the participants were offered, before the start of the study as well as at times through the study the opportunity for professional counselling by a social worker, but no participant felt that this was required.

**4.1.8** Interviews can be difficult contexts for people with communication impairments. Interviews are oral contexts, demanding that participants communicate, most of the time orally, and often using AAC (e.g. Brewster, 2004), sign language (e.g. Arndt, 2010) or assistive devices (e.g. Ferm, Sahlin, Sundin, & Hartelius, 2010). By definition, people with communication impairments have difficulties communicating, so the researcher is placing the participant in an inevitably stressful, demanding context. Researchers have identified distress that participants can experience from becoming tired in interviews, being upset by the topic, becoming anxious if they think that the interview is an assessment of their ability to communicate, and from fatigue leading them to misinterpret questions (Carlsson et al., 2007; Paterson & Scott-Findlay, 2002). I discussed these issues with the participants, and remained cognisant of the pressure that they were under to communicate.

**4.1.9** Desire to leave the research process: All participants were informed by me as well as in the information sheet that they were free to decide to leave the research project at any time. No participant left the study.

### 4.2 Obtaining informed consent

In the first meeting with each participant, I described the study in full. I had drawn up an information sheet which had been approved by the University Ethics Committees (A copy is in the appendix). I went through the form with the participants and answered any questions that they had. I then informed them that I was not in a hurry for their answer and would leave the information with them for a week or so. If they wished to decline participation, they could let me know by text message to my cellphone, by e mail, or by asking a second party to phone for them. Five participants agreed in the first meeting to participate, and four participants agreed after a week when I contacted them by e mail, or by texting messages on cell phones. Two potential participants declined the invitation to participate.

I went through the written informed consent form with the participants. Those who could sign did so. I signed on behalf of those who could not sign, in the presence of a witness.

#### ***4.2.1 Informed consent from communicative partners***

I obtained informed consent from communicative partners for the observations, where appropriate and possible. These participants were given an information sheet and provided written consent to participate (A copy of this form is in the appendix). For example, in a restaurant, I did not get consent from waiters; however, in family interactions, I obtained written consent from participating family members.

## 5. Feasibility study

The feasibility study was conducted for two reasons:

(i) To determine the viability of including people who did not speak English

(ii) To determine whether it was possible to include people who had intellectual impairments.

When drawing up the proposal for the study, I intended to include people with a wide range of intellectual impairments, as well as people who did not speak English.

I visited with people with cerebral palsy who spoke little English, and determined that including interpreters was problematic for a number of reasons. Firstly, trained interpreters are very expensive to employ, and this was beyond the finances that were available for this study. Not only would the interpreters be expected to accompany me to the interviews, but would be expected to transcribe and translate the transcriptions. I also determined that I would need to train the interpreters to communicate with communicatively impaired adults and then to act as interpreters of their interpretations of what was said. I was concerned that this would take the meaning of the data too far from the actual data. Very soon into the research recruitment process, I became aware that Black people with cerebral palsy are often able to speak and understand English fairly well because of their educational backgrounds. I located Black African participants who spoke English which, although not ideal, presented a partial solution. I had opportunity given the organic nature of grounded theory, to call on Black Africans who did not speak English, but this did not become necessary because the conceptual categories that were developed were informed sufficiently by the participants.

Including people with significant communication impairments as well as cognitive issues brought significant challenges to the research. I had intended, at the proposal stage, to include people who had intellectual impairments, seeing as many people with cerebral palsy are intellectually impaired. However, in the feasibility study in which I interacted with a number of people with cerebral palsy who had associated intellectual and cognitive impairments, I realised that their experiences may have been very different, and that I depended on their communication as data, and therefore included only those people who were able to understand the research questions. (Please refer to the section entitled “Recruitment” for a description of how this was determined).

## 6. The participants

Nine adults with cerebral palsy and significant communication impairments participated in this study.

### 6.1 Selection criteria

6.1.1 The participants were expected to be in middle adulthood, between 30 and 55 years of age. I wanted to include participants in adulthood, but did not want developmental issues to cloud the data.

6.1.2 The participants were required to have been given a diagnosis of cerebral palsy in their early childhood, by a medical practitioner.

6.1.3 I wished to include participants who presented with significant communication impairments that were associated with their cerebral palsy. However, given the nature of the research, the participants were required to have a form of communication that would allow them to communicate with me, such as AAC, gestures, written language, or speech that was intelligible to me as a stranger at least some of the time. I determined this in the first meeting with the potential participants.

6.1.4 I expected that the participants would not experience communication impairments that were not related to cerebral palsy, such as acquired communication impairments following stroke.

6.1.5 I required the participants to be able to speak and understand sufficient English so as to participate in the study, including being able to give their consent to participate. I evaluated this in the first meeting with the participants.

6.1.6 I required the participants to be able to understand the research questions, and engage in communication with me such that they could provide argument, information, and could do so spontaneously. Please refer to the “Recruitment” section for more detail on how this criterion was established.

6.1.7 I did not wish to include people with cerebral palsy whom I had seen for speech-language assessment or therapy as children because of the preconceived ideas that I might have brought to the interpretation of the study.

### 6.2 Recruitment

Many people with cerebral palsy know one another in South Africa, and so I used snowball sampling (King & Horrocks, 2010) where the participants suggested the names of others they thought would be a appropriate participants in the study. To protect anonymity, no participants were told who had elected to participate in the study. In addition, I recruited the names of potential participants from residential homes for people with disabilities, from speech-language, occupational and physical therapists that I knew were involved with adults with cerebral palsy by virtue of their membership with professional associations, and from people that I knew having been involved with people with cerebral palsy professionally for many years.

The recruitment of Black participants with cerebral palsy proved to be difficult because of the difficulty in determining whether their impairments were indeed due to cerebral palsy. Many disabled adults did not know if they had cerebral palsy, and some labelled themselves as living with cerebral palsy even if this were not accurate – for example, if the person lived in an institution for “cerebral palsied adults”, he or she assumed that they had cerebral palsy. A number of potential participants that I met with turned out to have childhood acquired lifelong conditions, such as post motor vehicle accident TBI; acquired encephalopathy such as that due to childhood meningitis; as well as genetic syndromes. I only accepted participants who had been given a definite diagnosis in childhood of cerebral palsy.

I contacted the potential participants telephonically or by e mail, and set up appointments to go to see them. In many instances, I had to set up the initial meeting by speaking to a second party because there was no other way to communicate with the potential participant. I wanted to prevent gatekeeping, so indicated to the relevant contacts that I was seeking to include people who had cerebral palsy and significant communication impairments but who had some form of communication.

My initial interview with every potential participant was an informal meeting at the person’s home. The meeting was private and no other people were present in the room. In some cases, I had to persuade the significant others, including parents and caregivers, that I was willing to talk to the person and that I would be able to make myself understood and that I would call on them if need be. At this meeting, I posed one broad question: “I am interested in doing research with adults with cerebral palsy. From your experience, what do you think I should be looking at?”, and if that question was not understood, it was re-worded as “We don’t know much about what it is to be an adult with cerebral palsy. What should we know?” I was interested in two aspects pertaining to the replies:

(i) Could the participants understand that question and subsequent questions so that they would be able to participate in the research? I did not want to include people who could not understand the concepts involved. Although a large percentage of people with cerebral palsy are intellectually disabled, there is a vast range in intellectual ability. In order to better the chances of saturation, it was necessary to limit the group of participants to those who could engage with the concepts that I was intent on researching. This was of course, linked to how they were able to respond.

(ii) Could I use strategies to help the participants to express themselves sufficiently for me to interpret their meaning? I did not exclude anyone on the basis of limited communication expression. My training and experience as a speech-language therapist allowed me to engage with the participants from the start. I took with me

> a spelling chart that would allow the participant to spell out a word; I also used a basic set of pictures from PCS[13]; and I used yes/no questions. I did much interpreting of signs and/or verbalisations and asked "is this what you are telling me?" The decision as to whether to include the participant or not was based on how they responded to my interpretations of what was said: I looked for affirmation but also for argument, as well as if the participant could add any further information without prompting.

At this stage, I rejected four potential participants from the study**.**

I was concerned about mailing an invitation to participate and information sheet because I was not certain about how much agency and choice the participants would have given their communication impairments. I was more confident that having personal contact with the potential participants was likely to be more effective. At the meeting, I introduced myself, and explained the study, staying as close as possible to the information sheet that had been prepared so that I would not come across as too convincing or as coercive. At the end of the meeting, I left the participants with a copy of the information sheet. The participants were invited to contact me if they wished to participate or if they wished to decline the invitation to participate. They were given my e mail address and cell phone telephone number so that they could message me without having to talk to me if so desired. This lack of personal contact with me would possibly make it easier for them to decline participation. I informed them that I would contact them within a week if I did not hear from them. Five participants agreed at the first meeting to participate. I made contact again with the additional participants about a week later. If they agreed to participate, I made a follow-up appointment with them. The participants were not all recruited at the start of the study but as the study evolved.

## 6.3 Description of the participants

Nine participants agreed to participate in the study, and I did not seek to include more because the data that were obtained were sufficient to create a theory of communicative participation (Charmaz, 2006). I had a larger group of available participants but I was confident that I had sufficient data to develop the conceptual framework (Stern, 2007) and that no further interviews were required. The relevant demographic factors are provided in Table 3 and in Table 4.

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[13] PCS: Picture Communication Symbols are predesigned, commercially available picture symbol systems that are printed from a software programme. I created a set of pictures depicting communication, group activities and general pictures. The pictures are transparent, and depict action as well as nouns.

Table 3

*Description of participants*

| Participant (pseudonym) | Sex | Possible diagnosis[a] | Type of mobility | Age at interview | Race | Home language |
|---|---|---|---|---|---|---|
| Parks | Male | Athetosis with spasticity | Power wheelchair and walking | 49 | White | English |
| Ellie | Female | Spastic quadriplegia | Wheelchair | 59 | White | English |
| Mary | Female | Hemiplegia | Walking | 33 | White | English |
| Lebo | Male | Athetosis with spasticity | Domestic walking[b] and wheelchair | 32 | Black | Setswana |
| Nic | Male | Hemiplegia | Walking | 37 | Black | isiZulu |
| Seamus | Male | Spastic quadriplegia | Wheelchair and domestic walking | 43 | Black | French/isiXhosa |
| Tiny | Female | Spastic quadriplegia | Power wheelchair | 40 | White | English |
| Serena | Female | Spastic quadriplegia | Power wheelchair | 48 | White | English/Afrikaans |
| Beauty | Female | Spastic quadriplegia | Power wheelchair | 34 | White | English |

Note. Race is entered because of its significance with regard to Apartheid and the significant role that race played in the lives of South Africans.

[a] I assigned these diagnoses on the basis of my observations because none of the participants knew what type of cerebral palsy they had been diagnosed with.

[b] Domestic walking refers to short distance walking such as around a bedroom.

Table 4

*Residential, education and employment information*

| Participant (pseudonym) | Type of residence | Description of residence where applicable | Education | Profession |
|---|---|---|---|---|
| Parks | Own home | - | Matric | Clerical assistant |
| Ellie | Own home | - | Standard Eight school leavers' certificate | Administrative work |
| Mary | Parents' home | - | Standard Eight school leavers' certificate | Sheltered employment workshop |
| Lebo | Parents' home | - | Matric | Sheltered employment workshop |
| Nic | Residential institution | 150 residents; all have physical impairments; some have associated intellectual and/or cognitive impairments; All residents have private bedrooms and share bathrooms. Trained and untrained caregivers. Private funding and government subsidy | Standard Eight school leavers' certificate | Sheltered employment workshop |
| Seamus | Residential institution | 25 residents; all have physical impairments and some have associated intellectual and/or cognitive impairments. All residents share bedrooms with one other; communal dining room; shared ablution facilities. Untrained caregivers. Government-subsidised | Standard Eight school leavers' certificate | Sheltered employment workshop |
| Tiny | Parents' home | | Matric; post graduate diploma | Part time employment in a social agency |
| Serena | Residential | Same as Nic. | Matric | Sheltered employment workshop |
| Beauty | Residential institution | 120 residents. All residents have their own bedrooms; communal dining room; trained and untrained caregivers; Church-subsidised | Matric; undergraduate university degree; post graduate university degree | Part time employment in a corporate |

A broad description of the intelligibility of the participants is given in **Error! Not a valid bookmark self-reference.**.

The participants presented with varying communicative impairments. These impairments are described in more detail throughout the study. All of the participants had significant speech impairments. Mary and Serena had not been able to develop oral speech.

Table 5

*Communication of the participants*

| Participant (pseudonym) | Intelligibility of oral speech | AAC |
|---|---|---|
| Parks | Most of the time to familiar people, some of the time to strangers | none |
| Ellie | Most of the time to everyone | non |
| Mary | No oral speech | Alphabet board[a], written language, gestures, Makaton |
| Lebo | Some of the time to familiar people, rarely to strangers | Alphabet board, some pictures, Makaton[b] |
| Nic | Some of the time to familiar people, rarely to strangers | Digital photos, typed words on computer or cell phone, gestures |
| Seamus | Some of the time to familiar people, rarely to strangers | Gestures, alphabet board, Makaton |
| Tiny | Most of the time, except when emotional | none |
| Serena | No oral speech | VOCA[c], alphabet board, gestures |
| Beauty | Most of the time to familiar people, some of the time to strangers | none |

[a] Alphabet boards are a type of AAC. The alphabet board is generally a square board with a grid of letters and numbers to which an individual points to communicate. The individual may point to the appropriate letter by gazing at it or through the use of a head pointer if available. Alternatively, the communication partner may point to letters on the board and the individual may somehow indicate that this is the desired letter. The process continues as words and phrases are spelled out. "Yes" and "No" options are also available on the grid. The alphabet boards used by the participants in this study were homemade and were laminated.

[b] Makaton is an AAC system that uses gestures (signs) and symbols (pictures). It is based on British Sign Language but was modified to make the signs much simpler to learn for young children as well as people with intellectual disabilities. Today, Makaton incorporates symbols as well, but in the years in which the participants were children, Makaton included signs only. (Adapted from http://www.makaton.org/). Makaton was used widely in specialised schools in South Africa.

[c] VOCAs (Voice output communication aid) are electronic devices that are able to generate printed and/or spoken text.

## 7. Method

Charmaz (2009) wrote that "our data collection methods flow *from* the research question" (p. 134, italics in original). I wished to hear from the participants themselves about how they experienced communicative participation, and so I decided to interview them. Interviews are oral situations, and I was aware of the difficulty that this would pose given the participants' communication impairments. However, I was confident, given my background as a speech-language therapist, as well as the results of studies that have included successfully people with communication impairments in research (such as Dew et al., 2011; Legg, 2010; Wickenden, 2011), that this would be possible. I also wished to spend some time with the participants to see their communication in action in their lives, and so I spent time with them, observing their interactions in their everyday lives.

### 7.1 The interviews

#### *7.1.1 Timing*

I interviewed the participants in their homes, at their places of work where it was convenient for them, and in social settings such as restaurants. The participants were interviewed over a 6-month period. I did not extend the period of contact longer than 6-months per participant because that is the time frame that was specified to the participants at the start of the study. Each participant was interviewed on multiple occasions. The decision as to who to interview and when was guided by the grounded theory method in which data and analysis are intertwined. The data were collected between January 2011 and May 2012.

Each interview lasted about 60 to 90 minutes. However, in some instances, the participants became fatigued. Most of them did not want to end the session at that point, but requested instead a short break.

#### *7.1.2 Recording*

Because video recording was unacceptable to some of the participants, I kept copious field notes so that I would be able to match my notes to the transcriptions of the voice recordings. Field notes of the interviews were notes taken on the responses that the participants gave to my questions. I wrote verbatim when I could (which was relatively easy for slow-speaking participants); and key words where I could not write detailed information. I also included information on the non-verbal cues, as well as gestures and vocalisations. The notes were sequential and so followed the sequence of the interview. The notes did not contain any interpretations or analyses at all. They were taken only as a way of complementing the transcriptions.

I used an Olympus DM-550 digital voice recorder to record the interviews, and a Canon 1000X video recorder to capture the audio-visual data in interviews in which the participants agreed to be videoed.

### 7.2 The observations of communication in context

I spent a few hours with the participants in their natural settings at least once. I observed the participants at work, at home, and in interaction with others. The aims of the observations were as follows:

7.2.1 Having a context to talk about helped me to understand more of the participants' communication. Intelligibility is dependent on context and having a topic that was familiar to both of us helped in this regard.

7.2.2 The observations provided me with the opportunity to observe the communication of the participants in their everyday lives. The observations provided opportunities for joint reference. In this way, I was better prepared to talk to them about their communicative experiences. I could relate what they told me to what I observed and in this way, was able to discuss general as well as more specific issues. Having being together in life situations in which they communicated gave us shared situations to discuss.

7.2.3 Spending more time with the participants allowed me to become more familiar with the participants' communication styles which enabled me to better understand them in the interviews over time, and thus generate more accurate data.

7.2.4 Getting to know the participants in their everyday lives, in more congenial and relaxed settings as opposed to the interview setting, and showing an interest in them helped to develop trust and a more open relationship with me. This enhanced relationship would encourage the participants to communicate more freely with me so that they could see themselves as partners in the research.

The observations were scheduled at the convenience of the participants. They also chose the setting in which they were comfortable to have me accompany them. With regard to how they chose to introduce me to the people with whom we interacted, I suggested that the participants introduce me in any way that they felt comfortable. Most of them introduced me as their friend, and some chose to introduce me as a person doing research with them.

I chose to make field notes in most of the observations. I did not take notes in some situations such as when walking around a residence with a participant because it was impractical. The field notes focused on communication only. I noted with whom the participant interacted, what the context was, and what the topic of conversation was. I commented on the participant's communication tactics e.g. repetition; ignoring the partner; asking for clarification. I made notes on any difficulties that I noticed e. g. participant cannot express idea; listener does not understand; topic is not followed.

Because of the ethical issues in getting consent to record people in a public space, I did not audio or video record any of the observations. Within 24 hours of the observations, I wrote up a detailed description of the observation, including information such as the content and topics of the communication, the setting, the problems that I observed and the relationship between what I observed and what I had discussed or planned to discuss with the participants. The information obtained in the observations did not act as data unless it was incorporated into an interview as a topic of conversation, and in this way, the participants acted to determine and confirm the accuracy of my interpretations of the observations.

## 7.3 Summary of each interview and observation

Within 24 hours of each interview or observation, I wrote a summary of my impressions of what was communicated with me, and included my interpretations of the research session.

The schedule of interviews and observations is shown in

Table 6.

Table 6

*Schedule of interviews and observations*

| Participant (pseudonym) | Number of interviews | Audio/video -recorded | Number of observations and context |
|---|---|---|---|
| Parks | 5 | Video | 1 Work |
| | | | 2 Shopping |
| | | | 3 In conversation with mother |
| | | | 4 In conversation with a group |
| Ellie | 1 | Video | 1 Work |
| | 3 | Audio | 2 In conversation with a caregiver |
| | | | 3 In conversation with a friend |
| Mary | 5 | Audio | 1 Work |
| | | | 2 At home with the family |
| | | | 3 Shops |
| Lebo | 5 | Audio | 1 Work |
| | | | 2 In conversation with caregiver |
| Nic | 5 | Audio | 1 Work |
| | | | 2 At home |
| Seamus | 4 | Audio | 1 At home |
| Tiny | 6 | Audio | 1 In conversation with mother at home |
| Serena | 5 | Audio | 1 Work |
| | | | 2 In interaction with a friend at home |
| Beauty | 5 | Video | 1 At home |
| | | | 2 In a restaurant |
| | | | 3 In conversation with boyfriend |

## 7.4 Transcription

Almost every interview was transcribed. I did not transcribe the interviews that were conducted in noisy environments such as at a restaurant. In one interview I had understood very little of what the participant was attempting to communicate. The participant had a cold and her speech was more unintelligible than usual for me. I recorded the interview but was unable to transcribe her speech. I used my field notes and the memo that I wrote about the session instead.

Given the enormous amount of time that it took to transcribe the interviews, I transcribed only the talk that was related to the study. The introductory sentences and usually the last few sentences of an interview were not transcribed.

I was able to secure funding for a research assistant who transcribed some of the interviews with verbal participants. This was very helpful. I checked the transcriptions by listening to the recordings and reading what the assistant had transcribed. She is a speech-language therapist who was familiar with speech impairments. She was registered with the Health Professions Council of South Africa and was therefore accountable with regard to respecting the anonymity of the participants. I transcribed most of the interviews. We transcribed the recordings onto a pre-prepared transcription form which comprised a two-column table with rows that were numbered. Each turn was given its own row. Hence, in the presentation of the data in the results chapters of this study, I present the data as the participant's name, interview number, and line number. For example, (Ellie, 4, 21), refers to line 21 in the 4th interview with Ellie.

Transcriptions were orthographic and followed the conventions suggested by Von Tetzchner and Basil (2011) (as presented in Table 1 in chapter 1).

I transcribed the interviews as soon after the interviews as possible. This was sometimes delayed because of the enormous amount of time that each interview took. I calculated that for every 30 minutes of interview I required 90 minutes to transcribe. I found that I sometimes conducted a second interview before having transcribed the first because I wished to follow up with the participants without delay, and could not wait for the transcription to be done. The summaries that followed the interviews were therefore very useful. I printed out the transcriptions on A4 paper and kept a file of the transcriptions.

### 7.5 Data books

I did not have qualitative computerised programmes available at the start of this study, and so I worked with hard copies of all paperwork. I found that it was easier to work on hard copy than on the computer. I created an A4 exercise book for every participant. This book contained the field notes taken in each interview, and the hand written summary of each interview. I also made notes in these books at various times. Having all the data in one book for each participant helped to keep the copious amounts of data cohesive.

## 8. Grounded theory methods used to analyse the data

Grounded theory is described both as an approach as well as a method. Grounded theory methods vary depending on which approach the researcehr follows, although all share a number of strategies (Charmaz & Bryant, 2011).

The methodological strategies that characterise grounded theory are as follows:

- Data collection and analysis are done simultaneously.
- The process in iterative and the researcher uses constant comparative methods that compare data with data, data with codes, codes with codes, codes with tentative categories, and categories with categories.
- The goal is to examine the role of the processes and actions in the lives of the people that are studied.
- Theoretical sampling is a key strategy which entails sampling for the properties of a tentative category. The researcher collects data and then more data to substantiate the codes or the categories that are constructed.
- When the data no longer provide new information, or when the properties of the categories are saturated with data, the researcher brings the research to a close.

## 8.1 Coding

Charmaz (2006) suggested in her grounded theory approach that the researcher takes the data through three main coding processes. The first is initial coding in which the researcher codes the raw data; the second is focused coding in which the researcher narrows the field of codes to tighter groupings of codes that are repeatedly evident; and theoretical coding in which the researcher looks for the relationships between the codes so as to integrate the data.

### ***8.1.1 Initial coding***

The first process is initial coding, where the researcher codes the participants’ actions and statements. Charmaz (2002, 2011) encouraged the use of gerunds (noun versions of verbs) to code the data. In this way, the researcher remains close to the data, and the coding allows for processes to be studied as well. The gerunds also assist the researcher to stick to the data and in so doing, prevent to a large extent, the imposition of preconceptions on the data.

The transcriptions were entered on to the transcription template. On the template, each utterance was numbered. In many grounded theory studies, researchers code line-by-line, word-by-word, or incident to incident (Charmaz, 2006). I used line-by-line coding for the participants who were able to produce verbal utterances that could be analysed line-by-line. For those participants who could not produce verbal utterances, I coded their verbalisations, gestures or statements that I made to them. Examples of the initial codes are shown in Table 9 in the appendix.

### ***8.1.2 Focused coding***

Focused coding is the second process through which the initial codes are grouped. The codes are synthesised so as to reduce the large amount of data. Focused coding allows the researcher to determine the adequacy of the codes. Moving between the initial codes, re-reading the transcriptions and writing memos helped to create a smaller set of codes that were more appropriate, and that were evident repeatedly. Comparing codes with codes and groups of codes with groups of codes provided the opportunity to see similarities, question relevance, and indicate gaps that required further sampling.

Resulting from the constant comparisons of codes, I also used a form of axial coding as promoted by Charmaz (2006). In this stage, I coded sub-codes of focused codes. Over time, the focused codes were revisited, refined, re-grouped, and sorted. Examples of focused codes are included in Table 10 in the appendix.

### ***8.1.3 Theoretical coding***

Theoretical coding follows focused coding. This is the stage in which the codes are taken to a higher, more abstract level, in which the researcher looks for relationships between the codes and is able to categorise the data. It is a stage in which the data start to cohere because the theoretical codes provide some indications of how the data can be integrated. Charmaz (2006, p. 187) wrote that the categories are developed to “count for relationships defined in the empirical data and each concept rests on empirical indications” so that the concepts are “grounded in the data”. Understanding what categories are has expanded as grounded theory has developed over the years. Whereas researchers used to conceptualise categories as comprising codes that matched, that had similar meanings, and that had defining features, it is now recognised that categories are created not by comparing features alone, but by being informed theoretically. Categorical judgements depend on the researcher’s understanding of the world (Dey, 2007).

In their early work, Glaser and Strauss (1968) recommended that researchers avoid preconceptions and allow, instead, the categories to emerge from the data. They did not altogether shun engagement with existing literature but recommended instead a very broad engagement with fields other than one’s own, and not necessarily academic fields (Dey, 2007). Dey (2007, p. 176) made the point at “we should not confuse and open mind with an empty head", suggesting that the researcher engages with existing theory because of its importance in creating categories, but that the researcher remains reflexive. He stated, "The point is not to avoid preconceptions, but to ensure that they are well-grounded in arguments and evidence, and always subject to further investigation, revision, and refutation". This is where memo-writing, theoretical sampling, sorting, and reflexive writing play critical roles, as I will describe in the next section. Examples of the theoretical codes are presented in Table 11 in the appendix

#### ***8.1.4 Collaborative coding***

The nature of this research, that is, interviewing people with severe communication impairments about a deeply personal issue, required that I was the only person to gather the data. In addition, I coded all the data. Given the opinion of many proponents of grounded theory that the method itself – which requires that the researcher revisit the data repeatedly so as to check on the analytical accuracy of the data until saturation is reached – provides trustworthiness, I elected to discuss the codes with two people: the research assistant and my research supervisor. I discussed the codes with my supervisor who read and re-read submissions in which I analysed the data using codes, with examples to support the codes. The research assistant had a Master's degree in the field, and was familiar with qualitative research. We met twice to collaboratively code the interviews that she had transcribed because she was familiar with them. We analysed the initial codes and then the tentative focussed codes that I brought to the meeting and we worked through these codes together. I held regular conversations with her telephonically about the progress of the coding, and we met again when I had reached the stage of theoretically coding to discuss these codes. Finally, she read the final draft and agreed that the theoretical categories represented the meaning of the data. Hence, both the research assistant and my supervisor acted as collaborators in the coding of the data.

### 8.2 Memo writing

"By writing memos continuously throughout the research process, the researcher explores, explicates, and theorizes these emergent patterns" (Lempert, 2007, p. 245). The memos conceptualise the data in the form of narratives (Lempert, 2007). Memos are written throughout the grounded theory process. In this study, I wrote a memo after every observation and every interview. The memos are a textual form of data organisation in which the writer refers to the data. Memos are sometimes reflective, but the aim is to consolidate the meaning of the data, search for meaning, construct categories, compare the data to previous memos and code structures, and later, as more abstract and theoretical understandings of the data are constructed, to incorporate previous literature and in so doing, place the research in the context of what has been done before. The early memos were speculative, lacked coherence, and took the form of free written narratives. Later, I included relevant information from the literature as I got more of a hold on the emergent patterns. I have included excerpts from memos in the results sections of the study.

### 8.3 Sorting

Researchers use various means to sort the data. Diagrams are often used by grounded theory researchers to provide a visual representation of the data. I tend to avoid any form of visual representation when sorting the data because I find them difficult to interpret. I elected instead to use alternative ways of conceptualising the data that are described by Badenhorst (2007) in her work on scientific writing and qualitative research. Badenhorst recommended the use of a variety of creative writing tactics to organise the researcher's thoughts and ideas, as well as to unify data. I used, for example metaphors, poems, and analogies. An example of the use of metaphor was one that I wrote after having watched a television documentary about the social lives of wasps:

> Wasps. You have to be a wasp (a communicator) to enter the nest. Other wasps must see you as a wasp or they will fight you off (recognition as a communicator). You have to be a wasp to do a wasp's job (being a communicator and knowing how to do it). You have to know you are a wasp (bees don't fly into wasps' nests. You have to know you can do this). The wasps go to particular parts of the nest to do particular jobs (enter communicative situations; do certain communicative acts in those situations). As you grow you do different things (like people grow and develop and change).

### 8.4 Theoretical sampling

Once I had established tentative theoretical categories, I continued to sample, not to look for generalisations (Charmaz, 2006) but to ensure that I gathered data that substantiated (or, alternatively, challenged) the categories. One of the goals of theoretical sampling is to look at the properties of the categories that are established. Theoretical sampling is emergent, and so I sampled as I worked my way through the analyses.

## 9. Saturation

Grounded theory differs from generic inductive qualitative methods in terms of the definition of saturation. In general, data collection is brought to an end when collecting more data would be a “waste of time” (Hood, 2007, p. 161). Grounded theory, however, uses a different definition than substantive saturation of the generic qualitative methods. In grounded theory, the researcher stops collecting data when a category that the researcher has determined cannot be further expanded upon (Stern, 2007, p. 117), or when the key theoretical categories cannot be developed further (Hood, 2007). I chose to stop sampling once I had developed the key theoretical categories, and a degree of abstraction of the data that allowed me to explain the data theoretically. I remained somewhat uncertain that saturation had been reached, particularly in light of the fact that I had interviewed three Black male participants and no Black female participants. I understood why Hood (2007) called the idea of saturation “troublesome” (p. 163) but I took heed of Dey (1999, cited by Charmaz, 2006, p. 114) that saturation is best viewed as “theoretical sufficiency”, and in this way, together with my research supervisor and research assistant, determined that the data had reached saturation.

## 10. Reflections

The premise of constructed grounded theory is that the researcher constructs the data with the participants, and it is the researcher’s constructions that are presented as the findings. I kept a research diary in which I reflected various aspects of the research. I wanted my involvement with the interpretation of the data to be made transparent (Ortlipp, 2008; Silverman, 2011), and in so doing, kept this self-reflective journal. I was the only person involved in the data collection and was very aware of the tremendous influence of my personal involvement with people with cerebral palsy for a quarter of a century. This was particularly important given the communicative impairments of the participants.

I felt uncertain about the meaning of the data at times, and my self-reflections helped me to work through this uncertainty. I was encouraged by my reflections to sample further or to analyse my codes more closely.

The diary also acted as a trail of my research which is an important consideration for the trustworthiness of the study (Ortlipp, 2008).

I include some of these reflections in the results sections of this study.

## 11. Research rigour

In this section, I have referred to Silverman’s (2011) methods of the evaluation of the credibility of qualitative research, and have looked at rigour in light of the question that Guba and Lincoln (2005) posed, “Are these findings sufficiently authentic … that I may trust myself in acting on their implications?” (p. 205).

### 11.1 Credibility

Credibility refers to the faithfulness of the description of the phenomena under study (Charmaz & Bryant, 2011). In Charmaz and Bryant’s (2011) terms, I strove for methodological, analytic, and theoretical credibility.

In the data analyses, the use of gerunds that remained close to the data (Charmaz, 2006) prevented me from making assumptions and kept my personal and professional bias at bay. The use of gerunds also helps to avoid the common error of anecdotalism (Silverman, 2011, p 357) because almost all interpretations are based on exemplary instances of the behaviour. The constant comparative methods in which the researcher revisits and compares and contrasts codes and categories, as well as the theoretical sampling which helps to ensure that rich data are obtained, help to build the persuasiveness (Silverman, 2011) of the interpretations. In this way, the selection of which instances to include and which to exclude is more explicit, and enhances the representativeness of the instances that are included. The constant comparative method is not only a way to look for trends and commonalities, but is also a way to look at how the data falsify previous assumptions about the data. This is, according to Kirk and Miller (1986, cited by Silverman, 2011, p. 358), a way in which qualitative research can be made credible.

I kept records of the data by audio and/or video-recording the interviews; I kept a data book for each participant; kept a self-reflective research diary; and held regular discussions with my research supervisor. This audit trail (Silverman, 2011) contributed to the credibility of the data.

### 11.2 Reliability

Silverman (2011) argues that qualitative research is subject to questions of reliability, that is, the degree of consistency with which researchers would project and come up with the same results. He argued that reliable research is associated with “low-inference descriptors” (p. 361). In order to ensure that the research avoids high-inference descriptors, he recommended that the researcher tape records each interview; transcribes the tapes meticulously; and presents examples of verbatim instances in the report. These recommendations were followed.

## 11.3 Validity

Silverman (2011) describes validity as the extent to which the interpretation of the data represents the phenomenon under study. In contrast to classical versions of grounded theory, constructivist grounded theory is epistemologically subjective and ontologically relativist. Meaning is constructed through the researcher's interpretive understandings (Charmaz, 2009). This does not mean that the research is not bound to validity (Guba & Lincoln, 2005). I used a number of strategies to enhance the validity of the research, as recommended by Silverman (2011). He recommended that credibility is achieved in five ways: analytic induction; the constant comparative method; deviant-case analysis, comprehensive data treatment; and using appropriate tabulations. These are classic grounded theory methods that were included in this study.

I did not engage in participant checking of codes or theoretical categories. Silverman (2011) wrote that it is unlikely that participants have a privileged understanding of their positioning in theoretical terms. However, I engaged in member checking of the actual data throughout the research process. For example, I summarised some of what had been discussed previously if I wished to pursue a topic as in in this excerpt in which I summarised the content of the previous interview which had addressed Parks' communication before undergoing surgery, so that I could ask about his experiences post-surgery (Parks, 2, 19):

Karen *Ok, Parks, given that you can almost adjust your competency with a machine, in the last interview you brought up some really interesting points, and one of the points that you brought up was that you were unintelligible, chose a lot of the time to just not communicate because it was easier, but a lot of the time you were excluded from communication because you were unintelligible. Does this still happen today?*

## 11.4 Generalisability

According to Silverman (2011), the generalisability of qualitative research can be enhanced by "purposive sampling guided by time and resources and theoretical sampling" (p. 394). The grounded theory methods employed in this study, and which have been described in the preceding sections, are consistent with this recommendation.

## 11.5 Concerns about accuracy

Through the process of the research period, I became aware that the accuracy of the transcriptions, although very useful and at times essential, was not critical. I had field notes and memos, a research diary as well as regular conversations with my research assistant. In this way, I came to see why Glaser (2002, cited by Charmaz, 2006, p. 16) wrote that “all is data”:  the analyses were not dependent upon a line-by-line or incident to incident basis alone. Glaser (1998, cited by Stern, 2007, p. 118) wrote about “worrisome accuracy”, referring to what he regarded as unnecessary and invasive attention to the accuracy of the interview data. He and Strauss suggested that the researcher should not see accurate data as the only and complete evidence. They suggested instead, that the essential information would become apparent and obvious, and would be remembered by the researcher. Covan (2007), once a student of Strauss, commented that he taught her that she should not be too concerned about transcribing or recording because he stressed that “if something were important, we would see or hear it again” (p. 68).

Stern (2007) recommended that instead of concerning oneself with every word of every transcription, that the researcher should take on a “search and seizure operation” (p. 118), looking at but beyond the actual transcriptions. This was a very useful recommendation given the difficulties that the participants had with communication. It was a particularly reassuring approach when there were sections of the recordings that were unintelligible and could not be transcribed. This search and seizure approach allowed me to chunk sections of whole interviews and to comment on them, when very little was communicated over time. It was also useful when analysing sections in which the participants grappled with ways in which to express themselves. Despite being assured by Glaser and Strauss that the accuracy of the transcriptions was not always critical, I was concerned that taking on this search and seize approach, as well as depending more on my notes and memos than on transcriptions might have led me away from the data. Charmaz (2006) warned that this could happen if researchers do not work with transcriptions, because the assumption is the participants’ views and actions have been captured.  As Charmaz (2006, p. 70) wrote, “An emphasis on plausibility rather than thoroughness and systematic study risks constructing superficial analyses” (p.70). The constant comparative method, however, allowed me to keep going back to the transcriptions, and to determine what the gaps were that could be followed up.

The length of time over which the study was conducted, and the fact that I met with the participants on multiple occasions, mitigated the effects of unintelligibility and/or incomprehensibility. I had the opportunity to go over topics, to probe deeper, to ask for clarification, and to hear of different experiences that confirmed my previous interpretations. I got to know each participant over a period of no less than 6-months, and so became familiar with their communication patterns over time, which made communication more authentic.

Not only was I more familiar with their communication patterns, but we became more familiar on a personal level, and this trust and collaboration allowed me to probe, as well as to indicate more comfortably when I had not understood what the participant meant.

### 11.6 Voice

This is a study based on conversations with communicatively disabled adults. Paradoxically, communicatively disabled people participated in a study that required that they be included in the communicative world of the oral research interview, so that their conversations could be supported and heard: a feat for both the participants as well as the researcher. The partnership between the participants and the researcher led to a shared construction of the data.

On repeated occasions, I reminded the participants that I wanted to hear their voices, and asked them to tell me if I was not hearing what they were saying. I stressed to them the importance of their honesty with me. My standard line was "This research is about you. It's not about what I think, so if I am saying things that you did not say, please tell me. Don't feel bad…I need to represent you, not me".

The participants were eager to participate in the research, were willing to share with me personal, and sometimes painful, experiences. They kept in touch with me, sometimes e mailing me to request an interview. In my research diary, quite early in the research process, I wrote about my sense that the participants were appreciative of the opportunity to engage personally with someone who was not daunted by their communication difficulties. In time, I came to appreciate the value that the participants put on participating in the research. Their enthusiasm and willingness to share their stories with me helped to ensure that their voices were heard.

I reflected on the representation of the voices of the participants throughout the research process, and have included some of these reflections in the results sections of the study.

## 12. The constructed categories

Four theoretical categories were constructed. They were as follows:

1. Being misrecognised as a communicative partner
2. Contexts for communicating
3. Living with an embedded communicative self
4. Dynamic participation

I present the results of the study in four chapters, corresponding to the titles of the four categories. In each chapter, I provide a table which depicts the construction of the categories.

# PART THREE: RESULTS OF THE STUDY

The analyses of the data led to the construction of four theoretical categories, each of which is presented in a separate chapter. The first category was “being misrecognised as a communicator”, which showed that the participants were not acknowledged as having equal moral participatory status in communicative exchanges. The second category, “contexts for communicating”, indicated that the participants lived with significant communication impairments which resulted in their experiencing limitations in a broad spectrum of life’s activities. The third category, “an embedded communicative self”, illuminated that the participants saw their communicative disabilities as embedded within a broader picture of being disabled, and that their communication impairments had a marked effect on their identity development. Through an analysis of lifetime contributions to communicative participation, the final category, “dynamic participation” revealed how communicative participation is a fluid, ever-changing process.

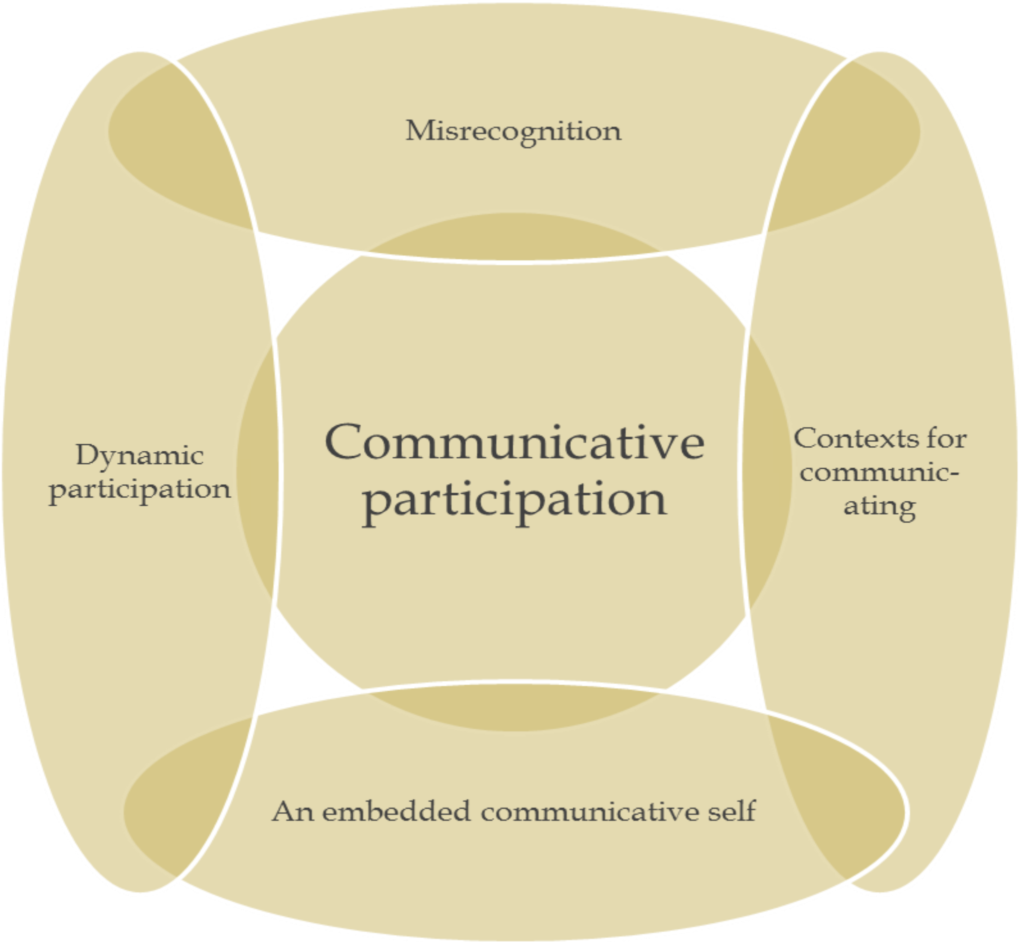

*Figure 3.* Theoretical categories constructed in this study

# CHAPTER SIX: BEING MISRECOGNISED AS A COMMUNICATOR

## 1. Introduction

‘Being misrecognised as a communicator’ was the first of the major categories to emerge from the data analyses. In the initial coding of the data, I became aware of having used the gerund “being” in almost all the codes. (Examples are shown in Table 14 the appendix). I became concerned at first about my overuse of this gerund, but it struck me that this was precisely the word that was needed to define the way in which the participants saw themselves in relation to participating with others (Charmaz, 2006). In the earliest interviews, every participant spoke about the reactions and attitudes of their communicative partners. My coding showed that the participants saw themselves as subjects, as opposed to agents, in the communicative process. Hence, they spoke of how they were communicated to, how they were treated by others in communicative interactions, rather than of how they communicated with others.

Through the distillation process of the codes, it became apparent that what was happening was that the participants identified that being recognised as equal, competent, and worthy communicative partners underpinned their communicative participation. The participants described different degrees of participation in different contexts, and with different people. All of them experienced being totally shut out of the communicative world at some points in their lives, a phenomenon I have called “inclusion denied”. They also described having access to the communicative world in which they wanted to or needed to communicate, but that this access was restricted. I have called this type of inclusion “come on in but not too far”. Finally, and very rarely, the participants experienced full recognition as communicative partners, but their communicative participation was always vulnerable and fragile. These three positions are explained further and form the basis of the analyses that follow.

The inductive route to the theoretical code “misrecognition as a communicator” is illustrated in Table 7.

Table 7

*Inductive route to being recognised as a communicator*

| Focused codes and sub-codes | Categories | Theoretical category |
|---|---|---|
| Being physically isolated | Having inclusion denied | Being misrecognised as a communicator |
| Being excluded | | |
| Seen as incapable | | |
| Stigmatised | | |
| Dismissed | | |
| Silenced | | |
| Being invisible | Having inclusion restricted | |
| Not being listened to | | |
| Being misled | | |
| Being dominated | | |
| Experiencing gate keeping | | |
| Abused | | |
| Being rule bound | | |
| Being unequal in the communicative act | | |
| Communicative burden | | |
| Being feminised and infantilised | | |
| Being accepted as disabled | Being given full inclusion | |
| Being cared for | | |
| Having choice | | |
| Being understood | | |
| Being given time | | |
| Being respected | | |
| Experiencing vulnerability | | |

## 2. Inclusion denied: Experiencing total exclusion from communicative life

The participants described scenarios in which they were totally excluded from communication in the social space. They were excluded from communicative situations or, if they were in a social situation in which communication occurred, they were prevented from communicating.

### 2.1 Being isolated

Most of the participants described being excluded from communication at various times in their lives. Every participant described situations in which they were physically isolated from other people in a communicative situation. Ellie described a number of work-related scenarios that confirmed for her the deliberate exclusion from social interaction on the part of her colleagues. She worked in an administrative position in an organisation in which she was the only disabled person. The other administrative staff shared a communal office, but Ellie was situated in a tiny office across the corridor from the main administrative office. The reason that was given was that she needed space and quiet in order to concentrate. Another example that she cited was the deliberate keeping her away from any communal situation such as staff tea parties and meetings in the organisation. The justification that she had been given by her employers as well as her co-workers was that these meetings were inevitably held at the time when she needed to be taken to the bathroom by her caregiver. However, Ellie believed that she was isolated because her speech irritated her colleagues, and they avoided interaction with her.

Physical isolation was reported by Tiny, whose family would leave the dining room after a meal and leave her alone until her caregiver came to take her to her room. Beauty spoke about how her caregivers would not respond to her pressing her call button in the institution in which she lived, taking advantage of her being isolated so as to avoid conversation with her.

Physical isolation was sometimes caused by the caregivers not having the resources to accommodate the participants’ impairments. In the institution where Serena lived, the residents would be put to bed by the caregivers by 8pm. Serena described this as fair for the caregivers who had to go off duty, but that this created a situation in which she felt isolated from others. She was alone in her room at night unless people with whom she lived were sufficiently independent to come to her room. The caregivers tended, however, to discourage night visits. Serena was helped to get out of bed between 6 and 7 am. She said that getting used to this physical isolation was the hardest part of her adjustment to institutional living. When I asked her if communication had anything to do with this feeling, she typed everything. For Serena, the physical isolation did not make her anxious because she had a button to press to call for help, but she described the isolation as cutting her off from people.

This feeling of being cut off from communication due to physical isolation was mentioned by Lebo, whose family often left him at home when they went out of the house on weekends. They had their daily activities to deal with such as doing the shopping and he could not accompany them. He said, *"They do their shopping and the post office and that but I can't go with them because I must stay and look after the house, and they, I am too difficult for them to take on the roads, you know they are not good, and also it cost too much to take the wheelchair in the taxi, so I must stay by the house"* (Lebo, 1, 15). When asked if being left at home concerned him, he said *"Ja, but I am used to this"* (Lebo, 1, 18).

### 2.2 Being excluded

The participants were excluded from communicative participation by their being perceived as being incapable of communicating, by being stigmatised, and by being silenced. As Tiny described of a situation (Tiny, 3, 58-70):

| | |
|---|---|
| Tiny | *No, like I was invited to join a bookclub and um they said it was at a venue that would be hard for me 'cos the wheelchair wouldn't go through and I asked them to go check* |
| Karen | *And did they?* |
| Tiny | *I don't know* |
| Karen | *You don't know?* |
| Tiny | *Ja, they never told me I am still waiting* |
| Karen | *Ok,so they invited you but you have not heard from them again* |
| Tiny | *Ja* |
| Karen | *How awful* |
| Tiny | *Yes but you see they are ignorant* |
| Karen | *So um are you are telling me that they could not find another venue or maybe didn't look?* |
| Tiny | *Ja, they just never did it* |
| Karen | *Ok Tiny, so I think, um do you think that perhaps they didn't bother?* |
| Tiny | *Ja, and then you see they get your hopes up and you are so disappointed* |

### 2.3 Perceived as incapable

Most of the participants reported that at some stage they had experienced being ignored. They perceived that their communicative partners assumed that they were incapable of communicating, or incapable of thought. As Ellie stated, *"They look at me and think I've got half a brain"* (Ellie, 1, 14). Tiny described how she was not included in conversations at all in her immediate family circle when they met in group settings. She was considered by them, in her words, as *"too dumb and too brain damaged"* (Tiny, 3, 49).

## 2.4 Stigmatised

This feeling of being considered “dumb and brain damaged” led to Tiny having poor relationships with her siblings for reasons that were separate from her cerebral palsy (including a large age gap), but she felt strongly that her having cerebral palsy was the main issue. For her family, the stigma attached to cerebral palsy was so profound, particularly for her mother, that it caused her to be excluded from communication. Tiny’s response in the first interview to the question, “Tell me what communication means” was *“it means for me that I am able to communicate with my family”* (Tiny 1, 18). Throughout the interviews, as she came to reveal more about her family reactions, it was clear that communication meant inclusion in the family. She lived with her mother, and had a number of opportunities for engaging with people outside of her home. She had part-time work which involved direct contact with people; she was a member of a few social groups (religious and community); she had much contact with her extended family; and she had a close personal friend. She was also an avid Facebook[14] user and had made many contacts all over the world with whom she was in contact. However, the main importance of communication for her was communication with her immediate family. By not communicating with her, they effectively shut her out. And for Tiny, shutting her out by not communicating with her was their way of shutting out the cerebral palsy from their lives. Tiny’s mother had never ever referred to Tiny as having cerebral palsy. She said, *“Oh I think so. She talks about me as her disabled child. Not once, ever in my 39 years, have I ever heard her use the word cp. Never”* (Tiny, 3, 125).

Ellie described an encounter at a bank where an elderly woman objected to disabled people appearing in public: *“One woman said to me, ‘why are you here?’ I said, ‘the same reason that you here, to get money’. She said, ‘people like you’, now this is public but it... was an old lady, so I had to gather patience with her and she said, ‘if I was you I wouldn’t come out’, and I said,’ why, then we don’t get anything to eat, no money, nothing to eat.’ She said ,’my husband’s outside, my husband’s also disabled’, so I said, ‘ shame poor man’ ”* (Ellie, 1, 45).

## 2.5 Evoking reactions of others

The participants also perceived that they were ignored because their unintelligibility instilled a degree of discomfort in people because they did not have the necessary skills to communicate with people with communication impairments. Typical examples of this were

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[14] Facebook is a popular free social networking website that allows registered users to create profiles, upload photos and video, send messages and keep in touch with friends, family and colleagues. (From http://whatis.techtarget.com/definition/Facebook)

people excluding them from the communicative interaction such as their description of waiters asking, “*Does she want some tea*?”, and doctors asking, “*How’s your daughter doing*?” This “does she take sugar” phenomenon has been described repeatedly by disabled people, as behaviour that dismisses them and overlooks their very existence (Scully, 2008).

In some cases, the participants reported that they depended on someone advocating for them because they were not able to do it for themselves, such as Tiny, whose mother had developed the standard line, “Please talk to my daughter” when anyone spoke to her instead of directly to her daughter. In other cases, they were able to state their own needs, and as Beauty stated, often she became so irritated with the dismissive attitude communicated to her by the assumption of her inadequacy by the speaker, that she would respond with irritation or anger.

Lebo spoke from the perspective of an adult who lives in two worlds. He lived with his family in an area which is known today as Soweto, a township southwest of Johannesburg that was established during the Apartheid regime in South Africa. Soweto remains a segregated township. Lebo had had contact with his immediate family as well as neighbours. He spoke only his home language there. On a daily basis, Lebo was transported to an organisation outside of Soweto in which he interacted with mostly White disabled people, and where he spoke English. He spoke of being feared: in his home environment, he believed that *“people run away from me. They scared. You see, disability is not a good thing and maybe they see me as something that they must be scared of”* (Lebo 1, 31). He did not see people as fearing his speech, or fearing interacting with him, but fearing what he might represent to them in terms of their African beliefs about disability and of physical disability. In his words, *“They’s frightened of disability in my culture. It’s better these days but it’s still here. Those people, I think they … I don’t know what they believe. My grandmother she tell me that she think, she thought, I’m a something from the past, but really, the people believe all things, all kinds of things(laughing)” (*Lebo, 1,47).

The intersection of race and disability was apparent in this analysis. In the organisation that he attended daily, Lebo reflected on a different fear. He spoke of the fear that he instilled in others in relation to his race. Despite fact that the organisation has been open to all races for at least 18 years, and Lebo had known it only as an organisation where people of all races have met, he spoke of being treated with reservation by some of his peers. When I asked him if being Black made any difference, he said that it did, saying *“they racist here so many of* *them. I'm not blaming them…it is how they were brought up. And we didn't go to school together and get big together. They lived there and we lived there. Now we must be used to each other…huh…this is very very hard for some of these people, but it's not like that anymore here. Now we are all the same"* (Lebo, 1, 54).

Lebo was markedly unintelligible. His speech was less intelligible when he spoke to strangers, and he spoke of how uncomfortable he felt *"when I see them so scared of me. They look so scared. Why must they be like that, hey? Jesus, they must just listen and they must just stand there not so (Laugh accompanied by gesturing with his hands over his face). Jesus, this is terrible you know"* (Lebo, 1, 60). Hence, Lebo perceived that his interaction partners feared him in respect of being a disabled person in his community, as a relatively unintelligible person in some of his communication interactions, and as a Black man in a predominantly White organisation.

He said that throughout his childhood, and well into his adulthood, people in his immediate community would prefer not to have him around. When I asked him if his speech had anything to do with this fear, he said that he did not think his speech was any more of a factor than the disability as a whole. He saw his speech as indivisible from the whole picture.

In contrast, Parks had been very aware of his speech from early childhood. He saw his speech as an important contributing feature of his disability, and that his unintelligibility had been a major influence on his life. He did not mention the word 'fear' in relation to others, but spoke of their discomfort. Tiny put people's sense of discomfort down to people not knowing about disability. She said, *"Yes and because they haven't been educated about disability. There is so much ignorance and people don't know how to be with people with disability"* (Tiny 4, 19). In relation to people other than her family members, Tiny spoke of how both her speech and her physical impairments made people uncomfortable. Throughout the interviews, she made a definite distinction between her speech and her other impairments, and identified that there were times when one aspect was more dominant in creating discomfort in others.

### 2.6 Silenced

The participants described their experiences of being silenced upon entry into a potential communicative situation. In other words, they were given an indication by people around them that they were not to speak. This would occur even if they did not intend to speak. Tiny spoke about how her mother would look at her in a way that Tiny took to understand as a silent message that she was expected to keep quiet. Or, the indication to be silent was given if they showed the intention to speak. Beauty said that it was very clear to others that she wished to speak because the physical effort that was required by her to speak resulted in her having to take a breath, and she often extended her arms when initiating speech. The spasticity in her trunk increased with the anticipation of speaking and so she arched her back. This very obvious set of movements meant that people could see that she was preparing to speak. At times like this, she had experienced others turning away from her, or purposefully starting to speak before she could start.

At other times, the participants were silenced when they spoke. Ellie spoke of how people would interrupt her, mid-sentence, and how this would effectively silence her. She would feel *"so bad"* that she would *"just keep quiet. I mean, why carry on? They don't care about you so you just shut up. Like what you have to say is rubbish"* (Ellie, 2, 8). The participants were also silenced by their communicative partners indicating to them that what they had said was indeed unimportant. Tiny told a story about how she was involved in telling a person at a group that she met with about a particular occurrence. She said that this person rolled her eyes and that she felt *"so small"* that she would not continue. Tiny said that this kind of humiliation happened to her *"quite often"* and that *"you just feel so unimportant"* (Tiny, 3, 212).

In contrast to Tiny describing how her family members in particular would *"make me feel so stupid that I would never dream of saying anything"* (Tiny, 3, 78), being silenced was not always perceived as being purposeful. Serena said that she often wished to enter a conversation, but did not because she had learned that people did not have the patience for her, and would not give her the time, so she often sat in silence. She felt that people would know that she had a contribution to make, but would deliberately ignore her. Sometimes, they would say something to her but before she could respond, they would be off onto the next sentence or topic. She felt that by doing this, her communicative partners completely disregarded her need to share.

### 3. Being allowed in but not too far

The participants perceived that they were often permitted to enter a communicative exchange, whether initiated by them or initiated by another, but that the depth of their involvement in the interaction was limited. In the words of Devine and Parr (2008) in relation to their analysis of the participation of disabled people in leisure opportunities, the participants in this study were invited, in relation to communicative interactions, to "come on in but not too far".

### 3.1 Being made invisible

In many cases, the participants would be invited to join a social group, such as a church meeting, or a dinner party. However, they described how once their presence was acknowledged, that the extent of involvement in communicative exchanges was really quite limited in many cases. Almost total exclusion was described by Tiny in scenarios in which she was invited to a family member's home but, once there, was ignored by those present. Similarly, Parks was invited to church meetings but when he got there, no one would initiate conversations with him, and if he initiated conversations, people would make excuses to walk away. Both of these participants described themselves as being made invisible.

Parks said he was able to enter social settings because of the opportunities that he had established for himself. Parks was very active. He attended a gym at least once a week, went horse-riding, and went walking in his local park. He also had contact with his physiotherapist weekly. He was also deeply religious and was a very active member of his church. He also held down a full time job and had multiple opportunities to interact with people at work. He said that in many social situations, but because he could not make himself understood, he would keep quiet and *"let the conversation soar around me"* (Parks, 1, 158). Very few people ever asked for his contributions. He stated, *"They never ask me what I think, maybe because I sit there quiet and I (*laugh*) let them get used to me like that but I often want to say that this is what I think and I want to say something like no that is wrong like… "* (Parks, 2, 40).

The participants described scenarios in which they would be in the middle of communicating something (oral and/or non-verbal) when their communicative partners would be distracted by someone else, and would move towards another conversation. At times, their listeners would excuse themselves, but at other times, they would simply move on with no acknowledgement of the presence of the participant, or of the content of the participant's discourse. Lebo spoke of being made invisible: *"you know, they act like they can't see me even, like I am talking and then even if they can still hear me, I am not there"* (Lebo, 1, 67).

### 3.2 Not being listened to

A code that cropped up repeatedly was not being listened to. All the participants described scenarios in which people would not give them the full attention that was required for conversation. They found that they would be talking or expressing themselves through their AAC or non-verbal communication, and their communicative partners would look away as if uninterested. Sometimes they would smile or make inappropriate comments, or interrupt them. They often walked away while the participant was still communicating, changed the topic, or made excuses to get away.

Not being listened to had some serious implications. Beauty had a number of caregivers who rotated their shifts. She said that she dreaded shifts when one of the caregivers was on duty because she *"just does not listen. She is unbelievable. She thinks I'm dumb and stupid and I really actually hate her. I tell her something and then she asks me a question some time and I know I spoke to her about it. She does not listen and it is really so irritating"* (Beauty, 4, 9). For Beauty, not being listened to was deeply insulting, hurtful, and cast her as different. *"They don't listen and it's very rude. They would never treat a person who is not disabled like that. They have no idea how hurt this makes me feel. Ooh, ooh it makes me mad"* (Beauty, 4, 11).

For the AAC dependent participants, listening took on a different form. Serena used a device that spoke the words as she typed them. Serena had very limited use of her arms, and was able to type with her index finger, very slowly. It took effort for her to press the buttons. She always tried to communicate with gestures and facial expressions first, and if not successful, she used her device. She typed d-o-n-t w-a-i-t f-n-s-h t-a-l-k and g-u-e-s (Serena, 3, 91). When I asked her to confirm that people do not wait for her to finish typing before they take their turn to speak, she nodded and typed r-u-d-e (Serena, 3, 95). She expressed that people guessed what she was saying as she typed, so that she had to stop, inform them in some way that what they had said was not what she was wishing to say, and go back to start again. This interruption interrupted the flow, irritated Serena, and made her feel that people were rude when not listening to her.

Mary used paper and pen as well as gestures. She was unable to verbalise at all. She could not initiate voicing and was silent at all times. Mary also had very limited use of facial expression. Her lips were retracted due to spasticity in the oral and facial musculature, and it appeared as if she were smiling most of the time. She also attempted to communicate with gestures and only used her pen and paper if she had to. Often she shrugged if people did not understand her and abandoned communicating. If she was asked to write, she would do so. She said that people often did not wait until she had expressed herself, but said what they thought she was saying. Like Serena, she became irritated, but unlike Serena who persisted with communication and would not stop until she had achieved her communicative goal, Mary stopped communicating. She smiled, nodded her head and made out that she agreed with the person talking to her, even if she did not. If the person asked a yes/no question, Mary would select one of the answers. When I asked her why she abandoned communication, she wrote t-o-o h-a-r-d (Mary, 4, 61) w-h-y b-o-t-h-e-r? (Mary, 4, 63) d-o-n-t w-a-i-t f-o-r m-e (Mary, 4, 77).

### 3.3 Being misled: Pretending to understand

The participants described situations in which they would be saying something and they would see the partner nodding or pretending to understand, and then surprise them by answering with an irrelevant comment or something totally unrelated to what they had been saying. I asked Beauty if she was always aware of her listeners' degree of understanding and she said that she the thought that she was but had never really thought about it. Parks said that he could not read the signals that the listeners gave him because they were mixed. He said that *"sometimes people tell me that they cannot understand me but sometimes they don't"* (Parks, 2, 274), and that *"I can't always tell by myself if they have understood me"* (Parks, 2, 276).

Beauty found it hard for her to concentrate on what she was saying as well as on the listener's reactions. Her opinion was that she just had to talk and leave the responsibility of understanding to the listener. Serena typed that people pretending to know what she was talking about was one of the things about communicating with people that b-u-g-s her most (Serena, 3, 116). This excerpt shows how strongly she felt about being interrupted (Serena, 3, 106-120)

| | |
|---|---|
| Karen | *Are you saying if they interrupt you that you then have to stop?* |
| Serena | [Gestures](? she is angry) |
| Karen | *Stop?* |
| Serena | [Gestures] (? that she types and then is interrupted and she has to stop typing) |
| Karen | *And?* |
| Serena | [Gestures](? Start again or type more) |
| Karen | *And um, okay that you have to start all over again?* |
| Serena | [Nod and gestures] |
| Karen | *Uh huh. Mm, oh, ok* |
| Serena | [Gestures] (Getting very animated, lots of vocalising, getting excited, many arm movements, ?angry) |
| Karen | *Ah, so you have to stop, start again, and that makes you cross?* |
| Serena | b-u-g-s |
| Karen | *It bugs you a lot?* |
| Serena | [Gestures](?big) |

| | |
|---|---|
| Karen | *The most?* |
| Serena | [Laugh] (both) |

In one of my memos, I commented on the inauthenticity of communication that occurs when communicative partners pretend to have understood a person whose speech is unintelligible (See memo 1 in appendix). When this pretence happens, there is a sense that the partnership is inauthentic. It becomes unfair in that the speaker is not given any indication that his or her message is being lost, and the end result is that they are under the impression that what they have said has been understood, when in fact, the opposite is true.

## 3.4 Being dominated

The participants described many scenarios in which the communicative partner dominated the interaction.

### ***3.4.1 Having topics controlled***

Limitations were imposed within the exchange itself. For example, Tiny spoke of people deciding on the topic of conversation, and if she initiated a topic which her partners did not want to discuss, they would change the topic, or would say to her directly, *"we're not talking about that right now"* (Tiny, 1, 199). Parks described how communicative partners would change the topic if they did not understand him, which made him feel like he was *"not really part of things"* (Parks, 1, 107).

Topic control occurred when the participants wished to talk about sensitive topics. Tiny said of her mother, *"She likes to pretend these things don't exist and then we don't talk about them"* (Tiny, 3, 156). Tiny wanted to talk about moving out of home, about her loneliness, about her desire to have an intimate sexual partner, and about her dreams for getting married one day, but her mother had told her that there was no need to discuss things that were unlikely to happen.

Similarly, Beauty spoke of how her caregivers would shut her out by avoiding communication with her. If they did not talk to her at all, they could pretend that they knew what she wanted. For example, in the institution where Beauty lived, residents were permitted a bath every second day due to there being insufficient personnel to bathe the residents every day. Beauty found this appalling and an infringement of her human rights "*And on the days we don't bath we get a body(?) bath, you know how undignified that is, not being allowed to bath*" (Beauty, 4, 125). She was unable to voice her objection to her caregivers because they avoided the topic of conversation. They pretended that they had not understood her, or they did not respond. Parks reported on how the avoidance of talk was used by his caregiver-driver. Parks described a few scenarios in which he wished to confront his employee about some serious issues including those of salary as well as the theft of his possessions. When Parks tried to negotiate with him, his employee would walk away, or pretend not to have understood him.

### ***3.4.2 Experiencing gatekeeping***

During the course of the research, Nic's mother telephoned me. She asked me to please avoid any talk about relationships. Nic had developed a close relationship with a disabled woman at the institution where he lived. The woman was intellectually disabled and a good few years older than Nic. His mother was concerned that I might tread on toes because she was working with Nic and others on how to manage the intimate and sexual side of their relationship. It was difficult to keep his relationship with his girlfriend out of our discussions, although I did try to steer clear of discussing anything to do with his relationship with her. It was only later, in reflecting on the results, that I realised that Nic's mother was a gatekeeper in this scenario.

Gatekeeping as an issue in communicative participation was certainly evident in the experiences of other participants. Tiny described being taken to the doctor by her mother. Her mother insisted on accompanying her and she always tolerated this because she said that this how it had always been and her mother would get upset if she were asked to sit in the waiting room. Tiny said, however, that she only spoke to the doctor about the reason for coming to the doctor. If it was about the pain in her hips, that is what was discussed, but if Tiny wanted to ask the doctor about something else, her mother would interrupt and say something like *"not now, darling"* (Tiny, 4,78).

### ***3.4.3 Being abused***

(Note: in this section I have purposefully left out the names of the participants). A number of discussions with the participants brought to the fore blatant abuse by caregivers. This abuse was influenced not only by the participants' communication impairments, but by other factors as well. However, the communication impairments were the cause of the abuse to some extent, and were also part of, if not the reason why the abuse could not be managed.

One of the participant's caregivers, who had been employed by the participant for many years, would threaten that she was not going to take her to the bathroom if she was in any way questioned. This abuse occurred, for example, when she questioned her employee's behaviour in relation to house management or the use of her possessions without her permission, or if she did not comply with her employee's wishes. The employee would also use verbal abuse such as by saying *"What do you know?"* Hence, the employee used the power that she had to avoid topics. She also used the participant's communication impairments as a means to humiliate her employee which had significant consequences. Aside from the psychological effects of this on-going verbal humiliation, the participant became very emotional which made her speech more unintelligible.

Another participant experienced a similar response from his caregiver, who resisted any form of authority from his employer. He reported that if the participant questioned him, the employee shouted at him, ignored him, walked away from him, or refused to fulfil the requirements of his job. For example, he might refuse to drive his employee somewhere, or would handle him roughly when bathing. There were many other examples of this man's behaviour that were clearly abusive, and that related to the participant's inability to use communication skills necessary for managing this situation, such as to argue or to negotiate.

There is no doubt that disabled people are at risk of abuse (Goodley, 2011a; Roulstone, Thomas, & Balderston, 2011), and that the abuse is expressed in different ways. Hence, hearing the tales of the experiences of the participants was disturbing but not all that surprising. However, the fact that the abuse was primarily caused by the participants' communication difficulties, and that their difficulties expressing themselves prevented them from being able to stop the abuse or modify their life situations in such a way that the abuse could be avoided, gave some insight into the meaning of communicative participation from a different perspective. Communication then plays a very powerful role in the preservation of the self in life's activities, and is not confined to getting a message across or of socially interacting, as per definitions such as that of Eadie et al. (Baylor et al., 2011; Eadie et al., 2006), but plays a role in personhood. Quite what the effects of this lifelong experience of abuse meant for the development of the psyches of the participants in unknown. But, given the evidence from the literature of the gravity of the consequences of abuse (Sinason, 2010), the relationship of abuse to communication impairment was most concerning.

(Note: these revelations by the participants were managed in discussion with the participants. They were offered assistance, were given the details of appropriate referral sources, and the participants were assured of anonymity. At the time of writing, one of these employees had been replaced. In the second situation, the participant had agreed that the situation could not be managed without assistance, and family members had intervened).

#### ***3.4.4 Having to obey the rules***

The communicative situations and opportunities were controlled by others in the institutions where the participants lived as well as by their dependency on others for mobility. Seamus had lived in an apartment in a different city. Unfortunately, his finances were depleting and he had no choice but to take up residence in a government-funded institution. In this institution, he was not permitted to be outside after 7pm. Hence, one of the activities that he most enjoyed which was to sit outside of an evening, drink a beer and chat to his friends, was not permitted.

Nic was not permitted to be alone with his girlfriend because the managers of the residential facility as well as his mother were very concerned about Nic's choice of girlfriend and were concerned about the sexual side of this relationship. Similarly, Seamus spoke of the restrictions placed on the residents in his residential home, saying that private company (for example, when a couple wished to have personal time together) was permitted on Saturday afternoons only. Beauty spoke of the managers of the institution in which she lived not permitting the residents to lock their doors – the justification that was given was that it was for the safety of the residents – and so intimate and private time was problematic unless she disobeyed the rules, which usually led to altercations between the caregivers and herself.

These restrictions placed limits on the participants' opportunities for social engagement, and in so doing, limited their opportunities for communicative participation.

### 3.5 Being made unequal communicators

Communication was dominated by the communicative partners. This was evident in the expression by the participants of their relatively passive roles in communication. For most of the participants, communication was initiated by them unless they were in the company of familiar communication partners. Most of the participants spoke of how people did not initiate communication with them. None of the participants spoke of not wanting to initiate communication.

The participants described scenarios in which their communicative partners used tactics to control the exchange. For example, Tiny described how her mother would talk about something very quickly, and purposefully talk so fast that Tiny would not be able to participate with her in that situation at all. The participants spoke of being interrupted, of having the topic changed, and of people talking too much. I found that I was doing this in my interviews in the early stages of the research. When reading the transcriptions, I became aware of how long much I spoke in comparison to the participants. Even in later transcriptions, this imbalance was very obvious, particularly in relation to participants who used AAC, or those who were markedly unintelligible.

For any number of reasons, the participants experienced having their communicative partners leave the communicative situation physically. Parks stated, *"Karen, it is amazing how many meetings people have. They will interrupt me in the middle of a sentence and say, "gotta go, got a meeting' "* (Parks, 3, 301). When asked why this happened, Parks said he was not sure but thought it had something to do with either not having the time to listen to him, or because people could not cope with having to deal with his speech.

Tiny said that people would simply walk away when they had had enough. Her mother avoided sensitive topics, and would state *"you are being ridiculous*" (Tiny, 3, 155) and walk away, taking Tiny's opportunity to continue to say what she thought was important with her.

### ***3.5.1 Carrying the burden of communication***

The participants described how they felt the burden of communication. They did not feel that they took an equal role in the communicative exchange. They described their communicative burden as the burden of dealing with the attitudes of their partners and how they treated them (e.g. the not listening, the interrupting, and the topic control), as well as having to deal with being the passive partner in the communication. Being passive meant that they could not start a conversation or get someone's attention, or interrupt. They were burdened because they had not learned certain communicative skills that would have enabled them to more easily enter, maintain or terminate communication. They also had the burden of having to work hard to become, and to remain, a communicative partner.

Tiny said that she concentrated so much on making herself understood, that she often could not focus on the topic. She felt that people were so intolerant and impatient, as well as ignorant about how to talk to a person with a communication problem, that she had to take on the responsibility for making sure that she was as intelligible a possible and that she put effort into entering and maintaining her place in communicative interactions.

### 3.6 Being feminised, infantilised, and spoken down to

The participants were spoken to in demeaning ways. The male participants described scenarios in which they were feminised. They did not think that men spoke to them in the tone of the voice, the use of words, as well as the attitude that they expected to be spoken to as men. Nic said that many people spoke to him with a smile on their face as if trying to appease him, saying *"the way you look at a cute child…but I'm a guy"* (Nic, 1, 76). Nic said that he wanted to talk about girls, beer and rugby but no one ever spoke to him about those topics. He wanted to be included in dirty jokes and to tell them, but he could not. He also said that no one would punch him on the shoulder or tackle him, and so he felt that in communicative exchanges that he was treated as if he was *"soft"* (Nic, 1, 66-89). The intersection of gender and disability is a topic of exploration and it has been suggested that masculinity and disability conflict because disability is associated with being dependent and helpless "whereas masculinity is associated with being powerful and autonomous" (Shuttleworth, Wedgwood, & Wilson, 2012, p. 174). The attitudes of communicative partners showed this tension, which was clearly described by Nic in his interpretations of how he thought people viewed him.

Other participants spoke of being spoken to as if they were children. The patronising attitude of some communication partners was interpreted by the participants as infantilising. Beauty acknowledged that, at times, being spoken to like a child was an over-accommodation on the part of the communicative partner, but Ellie saw it as demeaning. She thought that people equated her disability with her being weak, incapable and dependent, like a child. Infantilising as a form of equating disability with child-like being is well described by disabled people (Dovidio, Pagotto, & Hebl, 2011). Seamus was particularly aware of this as a recent resident in an institution. He claimed that the caregivers spoke to him as if he were a child, using simplification of their vocabulary, and that this infuriated him. *"I mean, I'm not like (name of a resident); I'm not five years old but when (name of caregiver) talks to me she says things like "do you have 'jamas', "here's your 'brekkies'* [15]*– and says it with a squeak – shit that pisses me off"* (Seamus, 3, 145).

Ellie described her interactions with her caregiver being confrontational because of her caregiver's attitude to her as being incapable. Her caregiver regularly reminded Ellie that she had *"half a brain*" (Ellie, 1, 4), and Ellie felt that her caregiver "*won't let me forget that I'm*

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[15] In South Africa, these are terms that are used by some in child directed speech to refer to pyjamas and breakfast.

*disabled"* (Ellie, 1, 4). The manner in which she was spoken to vacillated from patronising and infantilised to *"downright hostile"* (Ellie, 1, 6) if Ellie chastised her for treating her in an unacceptable manner. This made Ellie angry, as she said, *"when we get home I give her blazes!"(*Ellie, 1, 4).

Beauty's experience of an incident in which she was shouted at by a caregiver describes the humiliation, anger and despair that she felt, as well as the injustice that she perceived. She reported, *"The one time, I had alcohol in the room or whatever ---(unintelligible)--- and then that night the one nurse went off her rocker at me, and one of the other residents heard it and he went to (manager's name) and he complained how dare a nurse shout at me. I ended up crying from being shouted at. I feel that we are here 'cos we have to. We don't want to be here. I've actually said several times, I was born this way, I don't want to be this way but I am and they are here to help us"* (Beauty, 2, 152).

### 3.7 Being governed by being disabled

One of Ellie's stories provides some insight into how being disabled influenced people's attitudes towards the participants, which had implications for how they were spoken to. Ellie invited a work colleague with whom she had had previous social contact to her home for tea. Without informing her, the colleague was accompanied by another of Ellie's colleagues whom she had not invited. These colleagues left the room where they were having tea to ostensibly go to the bathroom. However, it became apparent to Ellie that they were walking through her home. Ellie was furious because she felt that her colleagues had no right to tread on her personal space. She confronted the friend that she had invited: *"but I said, 'don't do this again unless you, don't bring anybody else to tour of my house', and she sort of looked at me and said, 'oh, ok', and you know that kind of, those kind of people I don't like, because what do they want to do? They first want to come visit me as a friend, and then it turns out, you know, that they want to see what the house looks like, and that I don't like, 'cos even if there was a dustbin in front of the the in their garden, I wouldn't say, 'I wouldn't put it there', because that's their business. Honestly, and then (name) got me here at (work) , and she wanted to social worker to come, I don't want that kind of thing, what for, you know, I mean if I'm not pleased with something I go to my church and say 'look, this is going on, how would you handle it?'" (*Ellie, 1 , 80).

## 4. Full communicative inclusion

For the participants, full inclusion to communication in social interaction was undergirded by their being in social interactions under conditions in which they were recognised as communicative partners. For the participants, recognition as a communicative partner was determined by a number of conditions, but all of these conditions related to how the individual was treated by others as a person.

### 4.1 Accepted as being disabled

Beauty and Ellie said that they felt like they could participate in the company of people who did not judge them at all. Again, their speech or language impairments were not seen as central to their restricted communicative participation, but acceptance of them as disabled people was. The literature is replete with descriptions and analyses of the shunning of disabled people but what is relevant here is that the rejection of the participants as disabled people impacted on their communication. The lack of regard for them as disabled people was inextricably tied in with their communicative experiences. Ellie described going on holiday with a friend: *"you know, I went to their holiday, and there was 14 of us, but it was so much fun because you know we all, now there was norm (unintelligible 4 s). I was the only disabled person, and I got on so well with everybody, um, it was very, very nice"* (Ellie, 1,114). Ellie spoke about the fact that she was accepted as being disabled, and throughout the holiday she felt free to be herself, which included being free to communicate. She felt invited, and no different from anyone else.

### 4.2 Being cared for

With regard to her caregivers, Tiny said *"Yes, but most of the caregivers should not be employed and should go and do other jobs because their heart is not in it. It is just a job. And so I have to, to educate them but they still don't care. It's not stupidity, they just don't care at all"* (Tiny, 2, 108). Beauty also spoke about the importance of the care provided in terms of communication, speaking of her caregivers in the same light as Tiny did. Kittay et al. (2005) wrote that how care is given and received is not only based on human need, but also upon cultural, ethical and socio-economic issues. In the South African context, care is enmeshed with politics and history in which women, particularly Black women, have been in caregiving roles (Swartz, 2012). Often, the caregiver is a person who requires care herself. Nevertheless, the participants in this study perceived that the lack of care from their caregivers had a significant impact on their feeling recognised as communicative partners. It was rare for the participants to experience satisfactory care. Beauty said of one of her caregivers, *"She is fantastic, and we have such a nice relationship. She comes and does things for me, and of course I pay her, but it's not about that (unintelligible), you see she is one who cares and so we can talk to one another as girl to girl and that is how it should be"* (Beauty, 5, 47).

### 4.3 Having choice

Serena said that that living among disabled people who accepted one another was the advantage of living in a residential facility for disabled people. She said that on a day-to-day basis, she was accepted and could communicate easily. Serena had trained her caregiver to communicate with her. She had befriended a man who had significant communication difficulties himself but who understood her communication. She had adapted to being a listener rather than a speaker. Hence, under conditions of being able to control selecting her communicative partners, Serena had communicative access.

### 4.4 Being given time

Most of the participants spoke about how much they valued being given time to communicate. Serena found this a particularly challenging issue. Lebo said that he often would not start speaking because he could see that his communicative partner would be in a hurry and he did not want to delay the person. He said that he found this upsetting.

### 4.5 Being understood

Another of the conditions of access was that the communicative partners understood the participants' communication. Parks said that he had better access to communication once his speech was more intelligible.

### 4.6 Being given respect

| | |
|---|---|
| Seamus | *And my family (? because) And so they respect us* |
| Karen | *Ok, so it's part of the respect for your family* |
| Seamus | *Yes* |
| Karen | *Got it, and others?* |
| Seamus | *Who?* |
| Karen | *Other people, like strangers?* |
| Seamus | *Nah, they the worst* |
| Karen | *At, I mean what are they um the worst at?* |
| Seamus | *Hey, they like you know they dis (? dis) me and I am a man and disabled and there's just no like you know no respect like* |
| Karen | *So you want respect as a man and as a disabled person?* |
| Seamus | *Ja, but you see, respect, it's how you treat (?see) me and then you talk to me with respect* |
| | (Seamus, 3, 18-28) |

The participants expressed that because they were not respected as people, they were not communicated with in ways that they considered to be decent. Seamus spoke of his expectations of being respected as a consequence of his being a man, and adult, a disabled man, and a member of his family. Importantly, how he saw himself respected as a person was reflected in how he perceived people spoke to him.

### 4.7 Vulnerability

Full communication inclusion was rare, and was very vulnerable. The participants described very few scenarios in which all the conditions for communicative participation were met. There were, however, times when they felt that they were full and equal communication partners and could therefore participate fully.

Beauty spoke of her relationship with her able-bodied boyfriend. In most contexts their communication was successful for both parties. However, there were times when this success was damaged. One example that she gave was when they engaged in romantic talk, and her ability to keep her voice quiet and gentle was extremely hard for her. She also had to work hard to ensure that they did not enter situations in which she would not cope communicatively. Beauty's story spoke to the vulnerability of their communicative participation.

## 5. Conclusion

The participants had identified that being recognised as a communicator was crucial to their communicative participation. On a continuum from total exclusion to inclusion in communicative interchanges, the participants experienced tremendous vulnerability in being recognised. Participatory parity (Fraser, 2003) was challenged by this lack of recognition. The status of the participants as communicators was lowered, rendering them in a state of invisibility or a state of liminality (Murphy, Scheer, Murphy, & Mack, 1988).

In order to participate in society as a communicator, the communicative partner has to recognise one's communicative status, and for communication to be successful and effective for all partners, status as communicators has to be equal. It was clear that in most of life's situations in which they communicated, they were treated as if they were of a lower status. They were not recognised as communicators.

The capacity for autonomy, to communicate as a communicative partner of equal status, does not only depend on the cultural values, or on the values and moral behaviours of the communicative partners. It also depends on the communicator having certain resources available to act freely. A potent resource that was unavailable to the participants was the power of intelligible speech. How does one participate in social interactions successfully when one’s ability to communicate is severely restricted? This was the second theme that emerged from the data, which forms the topic of the next chapter.

# CHAPTER SEVEN: CONTEXTS FOR COMMUNICATING

## 1. Introduction

In this chapter, I present the analyses of the data that revealed that the communicative skills of the participants had a marked effect on their communicative participation. Developmentally, when the representation of meaning through symbolic language develops, as well as an intelligible means of expressing that meaning, one is able to communicate one's meaning with more specificity and clarity (Charmaz, 2009). Furthermore, one is able to attract and maintain the participation of communicative partners with increasing sophistication. This renders the communicative interchange more fluid, and less effort is required for the partners to share and construct meaning together. Hence, although communicative participation is not defined as depending on linguistic sophistication and speech intelligibility, it does make sense that these factors would contribute to the degree of sophistication of communicative interactions, and their effects.

The participants lived with severe communication impairments. They experienced difficulties with intelligibility as well as comprehensibility. These problems were exacerbated by contextual factors. In this chapter, I describe the categories that were identified that resulted in the construction of the theoretical category, "Contexts for communicating".

A number of factors related to the associated difficulties that the participants experienced as a result of cerebral palsy were identified, as well as issues related to communicating in a second language. The influence of communicative partners was significant. The technical and institutional support that they participants experienced played an enormous role on participation. In all communicative encounters, the interactants are dependent on one another to some extent, but the results speak to just how this is different when one of the communicative partners has communication impairments. The experiences of AAC users was unique. Technology played a role in the lives of the participants. Contexts influenced participation. The participants were not able to take part in situations in which a range of pragmatic communicative acts were demanded.

The induction route that led to the development of the theoretical category of this chapter, contexts for communicating, is illustrated in Table 8.

Table 8

*Inductive route to contexts for communicating*

| Focused codes | Categories | Theoretical category |
|---|---|---|
| Second language | Intra-personal communication | Contexts for communicating |
| Cerebral palsy<br>Effort<br>Pain<br>Illness<br>Drooling<br>Moro reflex | | |
| Partners<br>Familiarity<br>Acceptance<br>Burden | Inter-personal communication | |
| Roles | | |
| Opportunity<br>Leisure<br>Arts<br>Employment<br>Socio economics | | |
| Communicative dependency<br>Proxies<br>Translators<br>Physical dependency<br>Training | | |
| AAC | | |
| Technology | | |
| Groups and noise<br>Physical accessibility<br>Institutional living | Communication in context | |
| Acts<br>Communicating differently | Linguistic pragmatics | |

## 2. Intrapersonal contributions to communicative participation

### 2.1 Second language issues

The participants in this study spoke a variety of home languages, and all spoke English. Seamus, Lebo and Nic had been educated in specialised schools for Black children with cerebral palsy during the Apartheid years; Lebo's and Nic's education was completed after 1994. Their schools taught only in English and so they had become bilingual through their school years. In relation to questions around intelligibility, they reported that they could not tell if their listeners who were English-speaking could not understand them because of their accents which were distinctive of their home languages, or whether their speech impairments were the cause of the communicative breakdowns. They were definite in their thinking that they were more intelligible in their home languages, which rendered communication in their home language preferable. However, throughout their lives, they had been immersed in English-speaking contexts, first through education and later through employment opportunities.

As an adult, Nic also lived in an institution in which English was the dominant language spoken. He thought that he was fully bilingual and that he had become comfortable with communicating in English.

Seamus' home language was French, but he did not speak English with a French accent. He reported that he was comfortable speaking either French or English. He said that once the family moved from Cape Town to Johannesburg where his father had secured employment, he started to attend a specialised school. His parents had spoken English and French to him and so he had no difficult with the language of instruction. However, he felt excluded by the children who spoke vernacular languages. Over time, he learned to speak Xhosa but not very well. It enabled him to understand some of what the children spoke, and to interact a little more easily with people. The family lived in a Black township, but mostly associated with families from their home country, and so Seamus was comfortable with them as his French was well-developed. However, when interacting with other Black children at school or in his neighbourhood, he experienced difficulties, limiting his participation in social communication interactions.

### 2.2 Communication and impairments associated with cerebral palsy

A number of condition-specific factors that are experienced by people with cerebral palsy were found to influence communicative participation. Consider this excerpt (Tiny, 1, 73-82):

| | |
|---|---|
| Tiny | *And I used to drool a lot but now I don’t drool at all* |
| Karen | *Did it interfere with your speech?* |
| Tiny | *I can’t remember, but I think so. Now I have the opposite – I have a dry mouth from all the medication* |
| Karen | *Are you on lots?* |
| Tiny | *Ja. I had 21 operations you know and I resent those operations ‘cos they were failures and did not do me any good* |
| Karen | *Are you feeling lots of effects as you get older?* |
| Tiny | *My CP is much worse. I am wheelchair bound and really can’t move.I have a catheter – it was a good decision ‘cos now I can go to the meetings and not have to worry. And I have a lot of difficulty in transferring. And my mobility is severe, it is really bad, Karen. I am not able to move around very much at all.* |
| Karen | *mm* |
| Tiny | *I had a rhizotomy when I was 16 and it was bad. I was too old to have it and I have had a shoulder op and 5 hips ops and leg operations and oh so many, too many, and it was all bad and I also have Moros, bad ones, you know, I get frights easily so that interferes with things.* |

### 2.2.1 Effort

Communication required effort. For example, all the participants in this study experienced some degree of functional limitation while eating. Eating is a social activity during which much communication takes place. However, for all participants, eating was an effortful activity which prevented them from being able to communicate at the same time. Mary and Serena were able to eat independently but while eating they were unable to communicate in any way other than by using gestures. Tiny and Ellie were independent feeders but eating was slow and they were not able to eat at the same pace as others and so they often chose to eat alone. Beauty was an independent feeder although her food had to be cut into very small bits in order for her to manage. Beauty was able to speak within mealtimes, and she was able to keep up in terms of the pace of a meal, but communication took tremendous effort on her part.

Communication was also curtailed when the participants were walking or pushing themselves in their wheelchairs. Although communication did occur during these activities, it was slower, interrupted more often, and in some instances intelligibility was compromised.

Hence, the effort involved in carrying out one activity led to compromise in communication functionality. In addition, the participants reported that they fatigued easily when communicating – and of course, this fatigue was exacerbated by illness or stress. Beauty and

Parks felt some degree of responsibility in ensuring that their listeners understood them, which compounded the effort that they had to expend when communicating.

### ***2.2.2 Pain***

Tiny's experience of pain exemplified the difficulties faced by the participants. Through the course of this research, Tiny experienced an exacerbation of the pain in her hips that she had experienced for many years. She had undergone almost 30 orthopaedic operations in her lifetime, many of them related to her pelvis, hips and legs. In a period of about 6 weeks that Tiny had a rapid deterioration in hip function with accompanied pain, she was not able to leave the house except to see the doctor. She was heavily medicated which made her feel distanced and disoriented. She was unable to sit and had to lie in bed most of the time and so she could not access the computer. Her interactions were limited to her caregivers and her family members. Despite the extreme nature of Tiny's experience, pain and its effects on social isolation were reported by all participants. They all reported that pain interfered with their making contact with people, and exacerbated their communication impairments. Communication when in pain required extra effort.

### ***2.2.3 Illness***

All participants reported that illness took a heavy toll on them, and subsequently on their communication. The common cold was experienced very significantly and often resulted in upper respiratory complications, sometimes requiring hospitalisation. For Serena, illness usually resulted in her not being able to eat, and she became weak. The periods of isolation due to illness, as well as the effort to communicate meant that for certain periods of their lives, the participants' ability and opportunity to interact with others was limited. Furthermore, they described significant communication issues related to their illnesses, such as the difficulties communicating with healthcare practitioners. Serena said that when she was ill, she was not able to use her VOCA and Lebo said that doctors assumed that he was unable to express himself.

Both Serena and Lebo expressed their dissatisfaction with doctors assuming to know what to treat and their inability to satisfactorily protest. Beauty spoke of the importance of having a family practitioner who had known her all her life and who was aware of how to communicate with her, but also the importance of communicating with her directly.

### *2.2.4 Moro reflex*[16]

Tiny and Beauty described their Moro reflexes as interfering with their communication. Both of them described that their Moro reflexes drew attention to their bodies, and interrupted the flow of communication.

### *2.2.5 Drooling*[17]

Although none of the participants mentioned drooling as interfering with their communication, I became aware of the effect that their drooling had on their communication, and when I asked the participants about it, they agreed that it did interfere with their communicative participation. Serena and Mary experienced difficulties controlling saliva. Mary’s drooling increased with physical effort, and when she used her pen and paper to communicate, saliva would often spill onto the page. Serena drooled as she fatigued in her attempts to communicate for long periods, which did not interfere with her ability to get her message across, but which did draw attention to itself.

## 3. Interpersonal communication and communicative participation

### 3.1 Partners

Unsurprisingly, the participants felt more comfortable communicating with familiar people, as well as people who were more accepting of them. Parks said the following (Parks, 2, 133-139):

Parks *She understands me more than her father does.*
Karen *She understands you more than her father does?*
Pars *Ja*
Karen *Understands your speech more than her father does?*
Parks *Yes*
Karen *Not understands you as a person?*
Parks *(Unintelligible 3s) tell her how I feel (unintelligible 3 s) and she says she’s not doing well and for her I tend to be able to keep my voice intelligible because she doesn’t really come back at me, she accepts what I’m saying.*

However, Nic and Seamus said that familiar people often spoke for them and assumed that they knew what they wished to communicate. Beauty and Tiny also felt that familiar partners

---

[16] In response to a noise or unexpected visual stimulation (such as one opening the door unexpectedly), people with cerebral palsy have a startle reaction, or Moro reflex. The legs and head extend while the arms jerk up and out with the palms up and thumbs flexed. Shortly afterward the arms are brought together and the hands clench into fists. This is a reflex that is present in young babies and is mostly inhibited, but is retained in many people with cerebral palsy.

[17] Drooling refers to the spillage of saliva towards the front of the mouth or over the lips due to a reduced ability to swallow, and may be hampered by a reduced ability to sense the presence of saliva (Workinger, 2005).

took ownership of them and spoke as if they were them. Tiny described how her mother would accompany her to the doctor's rooms and would tell the doctor what was wrong, and also how bad the pain was without actually having discussed this with her daughter first.

### 3.2 Roles

Symbolic interaction theory proposes that the roles that people construct for themselves and that are constructed for them are always interactional. In other words, a social role is not a role unless it is defined in relation to interaction with others. The role then, is not only the role for the person enacting the role, but is enacted in cooperation – or possibly in competition with – another person or persons. Furthermore, roles lack purity in that they are tentative, dynamic, exploratory, constantly being negotiated.  Because of this tentativeness, a person constantly constructs roles and uses means to ensure that others see their role – at a time and within a context – as fitting or as advantageous (Denzin, 2001). One of the ways in which roles are defined and negotiated is through communication. Communication impairments impinged on the participants' construction of the roles that they played in life. The typical expectation of autonomous adults is that they will have the ability and the opportunity to play a number of roles – as William Shakespeare wrote, to have exits and entrances and to play many parts. The inability to communicate with effortless fluidity made an impact on whether the participants could take on a social role and/or enact it as they desired.

The limitations imposed by speech were exemplified by Tiny's experiences. Tiny described her communication as an 'adult daughter' to an aging mother. She felt that her ability to assert herself as an 'adult', who wanted to make her own choices, was constrained on many occasions by her communication impairments. She was not always able to put herself forward as an autonomous and independent thinker because of her speech impairments. As an 'employer' of two caregivers, Tiny could assert herself verbally and felt that she had established herself as the employer, but had to work very hard at maintaining boundaries, and at keeping her status as a person who could instruct others. She felt that her reduced and inconsistent ability to communicate clearly with her employees, particularly if she was stressed, ill, or fatigued, played an important role in the maintenance of her role. When she could not communicate easily, her caregivers acted out their roles as if Tiny were to be instructed instead of the other way around. As a 'friend', Tiny felt that her communication impinged on her ability to maintain relationships; however, she felt that it was her dependency on them that was the main issue and not her communication. For example, she might ask a friend for help with personal needs such as assistance to go to the bathroom. Tiny had experienced this type of personal dependence – which she claimed was an intrinsic part or a condition of friendship with her – pushed people away. Her work situation involved much talking to people, and she felt that her speech did not impair her abilities at all because she was competent at her work, and was rarely in a group situation. As a ‘participant in a group situation’ in on-going work-related training, her communication impairments interfered significantly as she found that she often had to work at avoiding speaking because she did not want to call attention to her disability which she felt might make people de-value what she had to say because of their stigmatising attitudes. She also felt that she had to work very hard at her speech intelligibility so that she lost focus on the topic, or was not able to state what she wanted to comfortably.

In contrast to Tiny, Beauty described herself as an autonomous adult, whose drive and perseverance should have allowed her to take on any role that she chose, but she acknowledged that her communication impairments interfered with her role taking and limited the roles that she could take. For example, her role as ‘girlfriend’ was constrained by the type of communication that she could engage with in her relationship with her boyfriend. She could not speak to her boyfriend on the phone and so their daily communication was limited to short message service (SMS) messages on the cell phone. She could not make herself understood to the people who were employed by the institution to care for her and so she could not easily assert her role as an ‘autonomous adult’ despite her dependency on them. At the time the research was conducted she was finding tremendous difficulty in securing employment despite having the necessary qualifications and expertise required and claimed that it was not only the communication impairments that caused this but the overall difficulty that any employer had employing a person who is physically disabled.

Lebo worked in an environment in which he was treated very much like a person without choice. He could not assert himself as a ‘worker’ because he could not protest about work that he did not want to do. He could not take part in staff meetings because the discussions were fast: “*Hey, they talk like you know, whew, it is so fast, I mean I can understand them but I can’t talk like them, so fast, so you know, I just can’t say these things when they talking*” (Lebo, 4, 66). Moreover, he could not participate at all in group discussions because he did not know how to inform anyone that he wished to make a point, and because he did not think that his colleagues or his employer would allow him the time to communicate his thoughts. Lebo was comfortable with his roles within his family as ‘brother’ to a younger sibling, as ‘son’ to his mother and father, and as a ‘cousin’ to his extended family members because he said that they respected him and his needs. However, as a ‘friend’, he felt that he generally complied with the needs of others, and that they included him but within limits. In my observations I saw that Lebo was very integrated into his group of friends, and that they allowed him time to speak, but interrupted him and often did not let him make his point or allow him to continue to speak. He did not persevere with his talking, but allowed the conversations to drift in another direction.

## 3.3 Opportunities

### ***3.3.1 Socio-economics***

Disabled people are among the most financially marginalised groups of people in South Africa. The participants in this study were all dependent on government disability grants except for Parks who had an independent income. Despite having skills, the participants were not employed in positions that provided sufficient income for independent living. Some of the participants were still dependent on their parents for financial support.

Those that might have benefited from AAC did not have the finances to purchase technical devices that would have aided in their communication. Serena’s VOCA was very old. They could not all afford supplementary technical devices that may have augmented their communicative participation such as cell phones and computers. During the course of this research Beauty’s cell phone was stolen and it took over a month to replace. The costs of running a cell phone were of on-going concern to her. Nic, Serena and Beauty had very old wheelchairs. These were giving problems but they could not afford to replace them.

Speech-language therapy services are not easily available, nor accessible, for adults with significant communication impairments in this country, and even then, the participants did not have the finances to pay for assistance by a speech-language therapist.

### ***3.3.2 Involvement in arts, leisure and intellectual activities***

The participants’ involvement in the arts was very limited. They watched TV but rarely communicated while doing so; they went to movies, but for all participants, this was a rare activity due to accessibility as well as expense. Beauty had recently taken up a form of creative art and was most successful. She could not afford to continue with lessons.

The participants engaged to a limited extent in intellectual activities that could offer communicative opportunities. Nic used his computer to engage in social activities by inviting others to play games. Few of the participants attended seminars or meetings. Although most of the participants desired more social interactions in formalised intellectual activities such as attending seminars, casual lectures at church, and other meetings, their opportunities for doing so were relatively limited by cost, accessibility as well as transport. Nic wanted to take up photography as a hobby but was unable to get transport to take him to the local photography interest group. Transport to activities was experienced as a significant limitation, as Tiny stated, *"Like I have a friend, an able-bodied friend who asked me to come to things at the local Anglican church but it is impossible for me to get there at night because my mom does not drive at night"* (Tiny 3,72).

Sports offered some of the participants a range of opportunities for social interaction and communication. Communicative opportunities were enhanced by both participating in sports and in watching it. Parks participated in gym and Lebo went to soccer matches with family members and occasionally with friends in his community. Lebo was only able to participate with the young men in his community if one of them came to fetch him to push his wheelchair to the local informal soccer ground. Seamus and Serena both adored cricket, and watched cricket on TV at every opportunity. Both of them described how they found the matches to be opportunities to watch with other people and to talk throughout the matches about the proceedings, and then to converse about the matches once they had finished as described by Serena (Serena, 5, 46-51):

| | |
|---|---|
| Karen | *So they come to your room?* |
| Serena | Nod |
| Karen | *And you watch together* |
| Serena | Nod. Spend a lot of time here. Watch c-r-k-t. [Gesture talking] |
| Karen | *So they come here, you watch together and it's time, I mean an opportunity for you to talk?* |
| Serena | [ head movement ?nod] Talk a lot |

### ***3.3.3 Employment***

There is no doubt that the choice of profession was determined by both the physical impairments as well as the participants' communication impairments. Tiny was the only participant whose job required interpersonal communication as a core part of the day-to-day tasks. Despite the fact that her speech was not fully intelligible, she was able to carry out her responsibilities. However, she worked for two to three hours per week, which did not put a heavy demand on her speech and communication.

Beauty's profession did not carry a heavy communicative load. Beauty had a university education as well as a post graduate degree. Her profession required that she work for a year as an apprentice. She had experienced difficulties securing an apprenticeship because of issues such as physical accessibility to and within the building, as well as the firm's owners being reticent to employ her. Beauty's physical disabilities meant that her work speed was compromised. As a result of this, the employer did not provide her with the opportunities that he gave to the other apprentices. Beauty stated, *"But I need to be stimulated; I feel I need to be trained. And everybody isn't more normal than me. And I don't get the training that all the other interns (?are)"* (Beauty 3, 246). Ellie also experienced all kinds of barriers to promotion and accessibility to equal opportunities in the workplace. The type of work that she did was determined by what she was able to do physically; her opportunities for socialisation at work were limited by the deliberate exclusion to an isolated office and exclusion from the social activities in the work context.

Although somewhat less extreme, Parks also experienced limitations in terms of the choice of career as well as the opportunities for social communication in the work context where he chose to remain isolated and not to join in social activities. He reported that it was very difficult to work as a member of the team in his office because he could not participate in meetings easily because of the speed of his speech. His employer and colleagues rarely asked him for his opinion.

Mary, Nic, Serena and Lebo had permanent jobs but in part time positions. The type of work that they did was dictated by their physical and communication abilities, their lack of post-school education, as well as the lack of promotion and growth opportunities in their work environments. Their day-to-day tasks had few small communication demands, and most of these demands could be fulfilled by gestures, facial expressions and by yes-no questions directed to them. The opportunities for social communication in their work contexts were broad. They worked in group settings in which communication was encouraged by their employers. They worked with able-bodied as well as disabled people and they faced were few, if any, attitudinal barriers in the work context. Nic, Serena and Lebo communicated comfortably with their colleagues, many of whom were familiar to them and understood their communication. They used oral speech, gestures, and their alphabet boards and Nic used the digital photographs on his camera to supplement his speech. Despite being in a communicatively rich environment in which Mary faced few attitudinal barriers and was offered opportunities for social communication, she chose to keep to herself and to initiate communication very rarely.

### 3.4 Communication in relationships

Communication is central to initiating and maintaining social relationships (Cooper et al., 2009). The difficulties that the participants experienced with their communication impacted on their relationships with family members, colleagues, friends, strangers and also played a major role in the construction of the participants' roles within relationships.

#### ***3.4.1 The burden of communication***

The participants described difficulties that they experienced in relation to initiating relationships. They found that people immediately judged them when they first met as being disabled, and all of the participants felt that they had to prove themselves worthy of being communicated with right from the start. This portion of an interview with Tiny illuminates this conditionality (Tiny, 2, 75-81):

Tiny *Yes, and then if they think (unintelligible portion 3s) you tell them …um… that it is well, that you tell them it is CP they think you are brain damaged*
Karen *Yes*
Tiny *And then I have to tell them if they know that I am CP that it is remember that it is only a part of the brain that is damaged*
Karen *So you have to define your CP*
Tiny *Ja, you see I also don't look CP really if you see me sitting in an armchair you won't think I am CP because I am not so um dis… um… deformed and twisted*
Karen *So you don't look CP*
Tiny *No and then they think I am ok and they talk to me*

For Parks, the willingness of a person to communicate with him was how he defined friendliness, and this perception of how friendly people were towards him determined his relationships with others. All of the participants, except for Mary, said that they had no reservations about initiating communication with others. They did not hesitate to greet people, and to start up conversations. However, they all described some sense of trepidation and expectation of failure right from the start. As described by Lebo (Lebo, 3, 17-25):

Lebo *So so so they , well, I don't start the conversations, the talking I mean, I think*
Karen *Are you saying that you don't like to start talking?*
Lebo *Ja, and I wait for people to start talking to me*
Karen *Do you know why you do this?*
Lebo *Um, no not really*
Karen *Are you -*
Lebo *M, um, maybe, like maybe it's a confidence thing. I'm like, well you see, it's not easy*
Karen *mmm*
Lebo *I'm not used to talking so much. I think I like others to start and then I can join in. You see, well, um, it's like this. I know they's not going to listen; it's what I'm used (to), and also you see, it's too hard, they don't understand like you do. You understand me (laugh), many many people, they don't know what I's saying*

Maintaining the conversation was effortful for all the participants. They felt that they carried the burden of the interchange. Throughout the interviews, Parks informed me how he had been told by his father that the world is a tough one for disabled people, and that he had to ensure that he worked hard to integrate into society. Parks saw the responsibility for maintaining conversations as dependent on his making sure that people understood him. Similarly, Tiny said that she sometimes concentrated so hard on her speech production that she would not be able to focus on the topic. Mary worked hard to provide her listeners with cues. Like Mary, Serena and Lebo used cues to provide the listener with their topic. This excerpt from an interview with Mary demonstrated this (Mary, 2, 100-118):

Karen *Ok, so you can use few words with people who know you and know how to communicate with you*
Mary [Nod, smile]
Karen *Hm*
Mary [Point at Karen]
Karen *Like me*
Mary [nod]
Karen *Ok, so doing like I'm doing now?*
Mary [Nod]
Karen *Doing the talking*
Mary [Nod]
Karen *And when you write you give like a sort of cue?*
Mary [Gesture ? do not understand]
Karen *A cue, like I say a word and that cues you so you know what I am saying and you can like pick up on my cue and then we can carry on talking about the topic that is my cue. Like if I want to*
Mary [Nod a lot]
Karen Ok, so you know what I mean!
Mary [Nod and smile]
Karen *So you are a master at giving clues and then the person you are talking to you can do the talking*
Mary [Nod]

And yet some of the participants felt that the burden of the responsibility for maintaining conversations – and thus relationships – fell to the communicative partner. Beauty felt that people shared the responsibility for communicating. She said that people had to accept that she was disabled, that her speech was difficult to understand, but if they respected disabled people, they would understand the demands that were placed on them. Serena expressed similar sentiments. She said that people who wanted to maintain a relationship with her did so despite her communication impairments. She said that people could work around the communication impairments if they wanted to.

Mary said that she had experienced repeated communicative failure, and that the effort of communicating was so huge that it was easier to let others carry the burden. She felt that if people really wanted to communicate with her, that they had the skills to do so (Mary 5, 1-22):

Karen *So Mary, how do you start conversations with people?*
Mary [shrug]
Karen *Do you ever?*
Mary [Shrug and hand gesture from side to side]
Karen *Sort of?*
Mary [Nod]
Karen *Ok, so you sort of start conversations. Do you mean that you generally wait for people to start talking to you?*
Mary [Nod]
Karen *So do you think they are responsible for communicating with you?*
Mary [Nod]
Karen *And what role do you play?*
Mary l-i-s-t-e-n s-t-a-r-t w-i-t-h m-e t-h-e-n I k-n-o-w w-a-n-t- t-o
Karen *Ok, so if they start a conversation with you, you feel they want to, and you will contribute.*
Mary [Nod]
Karen *Uh huh. And do you think they are responsible for making sure the conversation continues?*
Mary t-h-e-y c-a-n
Karen *They can? Do you mean they should take responsibility for the communication 'cos it's easy for them?*
Mary [Nod]
Karen *And you? What is your role?*
Mary t-a-l-k
Karen *So you do think you should be part?*
Mary [Nod and gesture talk]

### ***3.4.2 Friendships and intimacy***

It was apparent that the participants experienced significant loneliness, small social networks, a lack of intimacy, as well as distanced friendships. Many of these problems were related directly to the participants' communication difficulties. Nic and Seamus had girlfriends, both of whom were disabled. Seamus' girlfriend experienced very significant communication difficulties, but Seamus said that they were able to understand one another. Beauty had recently terminated an intimate relationship with an able-bodied boyfriend. The other participants had never had intimate relationships.

Parks described his dreams of having a girlfriend as being dreams only that could never in his opinion become reality because of his speech. He had a very close relationship with a colleague at work and he wished to pursue the relationship and approach her with a view to becoming romantically involved, but he did not have the courage to do so. Similarly, he had another opportunity to become involved romantically but was unable to take the relationship further because he felt that his unintelligibility, among other things, made him appear incapable of maintaining a relationship. He stated, *"I should have pursued it"* and *"I should have taken God's opportunity",* but *"it has something to do with my personality and my cerebral palsy"* and *"yes, I suppose my speech has something to do with it too"* (Parks, 3, 100-125).

The participants described a variety of types of friendships as well as degrees of closeness and intimacy. Tiny was isolated in terms of living in a new place which was a far distance from her friends. She interacted mostly with family members as well as with her mother's friends. She also used Facebook to keep in touch with people, but most of the people on her list of Facebook friends were family friends. She described feeling intensely lonely (Tiny, 3, 128): *"You can't imagine how lonely I get. I am alone most of the time and I can't get out and about. I miss my friends, especially my best friend who lives in Johannesburg, and I have not got anyone my age to be with. Yes, yes, I would say that I am extremely lonely most of the time".*

Many of the friendships that were described by the participants were distanced friendships. Parks spoke of people at his church as being his friends, as well as a woman who worked in a shop in his local shopping centre. He did not socialise with these people, such as having them over to his house or going to movies with them. It seemed as if Parks described people who expressed acceptance of him and friendliness towards him as friends. He had one friend with whom he socialised and went to gym. Mary, Tiny and Lebo lived with their families, and described their friends as being friends of the family. None of them described having friends who were their own. They had friends at work, but never interacted with them outside of the work context.

Lebo's interactions with the young men in his community were distant. They included him in social activities but rarely initiated this – it was often his father who would call one of them to come and collect him to go out. He considered these people to be his friends because he had interacted with them since early childhood. They rarely spoke to him, and if they did, they addressed him but did not wait for his response. He was very comfortable in their company and looked forward to being with them. He said that there was no need for him to talk – just being among people was socially satisfying for him. He said, "*Well, that's how it is. I must be ok, yes, even if I am not talking a lot, I am there and they know I am not talking but we are friends"* (Lebo, 4, 12).

In contrast, Beauty had a wide circle of friends and her communication with them was considered by her to be a very important part of her relationships.  She was the only participant who had a broad network of people with whom to interact. She had retained contact with her school friends, and had made new friends through her university, church, family, and more recently in the institution in which she was living. Beauty was confident and determined to maintain relationships. She was an avid user of Facebook and e mail and used this electronic communication to keep in touch with people. She invited people to visit regularly. She went to her parents' home regularly and invited people to her parents' home as well.

There was evidence of communicative imbalance in the relationships that the participants had with their friends. On the whole, they seemed to prefer to interact with people who were accepting of them, but even then, they questioned on whose terms the relationship was defined. The participants all appreciated relationships in which they were given sufficient time to express themselves. Serena typed, "I like her so much. She really listens, and never feel rushed. She gives time. No rush no run very important." (Serena, 4, 82). They felt that in these relationships they had more of a voice. The interrelationship of their communication difficulties with their being physically disabled was evident here: although the participants related their communication difficulties to their difficulties with maintaining an equal status in the relationships they had with others, it seemed that they did not see their communication impairments as separate from the whole picture. However, time was the crucial factor here. Being given time meant being listened to, and having sufficient time meant that the participants felt free to try to put across their meaning fully and freely, and to construct it together with their communicative partners. Being given time was very unusual for the participants, even in close and intimate relationships. Nic said*, "But my girlfriend, even she says I must hurry up, and it's okay because she is my girlfriend"* (Nic, 4, 32).

### ***3.4.3 Communicative dependency***

All the participants were dependent on others for their communication to be fulfilled. They required their communicative partners to be knowledgeable about how to communicate with communicatively disabled people. Additionally, they wished to have their chance to speak respected by being accorded sufficient time. None of the participants expressed a desire to be dependent on others. Tiny said that it was unpleasant as dependency took away her voice, emphasised her being disabled, and made her feel inadequate. She said that she thought that people who saw her as dependent on others to speak for her had a lower opinion of her. *"It is really not nice…they hate it…and I hate it more. I do not want to be like this, but that is how it is, and I have to depend on them for everything, yes also my speech. They have to understand that this is how it is. They don't like it and they make me feel so humiliated and stupid and hate being disabled and I don't like it, but that is how it is"* (Tiny, 5, 93-101).

### ***3.4.4 Proxies***

At some stage, all the participants had proxies – someone who would talk for them. They needed these proxies in different contexts such as making a call on the telephone, or in informing a third party about something when the third party had difficulty understanding their participant's communication. The participants seemed to accept that they required proxies at some points, but also resented it when the proxies spoke for them when they felt that they could have made the attempt themselves. Seamus said, *"I hate it when people think they know what's in my head. They say, Seamus said 'lalalala', but that's not what I wanted to say, like my mother, my mother does that all (emphasised) the time"* (Seamus 2,75). They also resented the proxies for speaking in terms that did not express exactly what they wanted to say, again pointing to a lack of voice in some situations.

### ***3.4.5 Translators***

Mary and Serena depended on translators in some situations. Mary's mother acted as her translator. She was very careful to put across what Mary was communicating. She waited for

Mary to gesture or express herself, and would then translate her gestures. The same applied to Serena's caregiver who translated Serena's signs and gestures. This caregiver had been trained by Serena to translate. She made it very clear that she had taught the caregiver not to put any of her own thoughts into the situation, but to stay as close as possible to Serena's signs. Serena depended on her caregiver in most situations involving strangers. She preferred to use the translating services of her caregiver to her VOCA in some situations. However, the caregiver was a worker in the institution in which Serena lived and was often unavailable to translate.

### *3.4.6 Physical assistance*

The participants depended on the physical assistance of others to communicate in some contexts. They needed the help of others to position them physically in such ways that were comfortable and that helped them to ensure the best speech production possible. They needed people to make telephone calls for them, or to dial telephone numbers. They depended on others to ensure that their alphabet boards were attached to their wheelchairs. They depended on people to wheel them to social situations in which they could communicate, and depended on being transported to social situations as well.

### *3.4.7 Training*

All the participants felt that the people on whom they depended for successful communication required training. They did not have access to professional services and felt that this was an important lacuna in their lives.

## 3.5 AAC and communicative participation

The lack of access to AAC was a particularly striking feature in this research. AAC has been available in South Africa for decades. The Centre for AAC at the University of Pretoria has been in existence for over twenty years, offering AAC as an academic interdisciplinary training facility[18], and other facilities such as university departments and schools have offered AAC services.  In addition, an association for AAC users has been active on a national basis[19]. AAC devices have only recently begun to be subsidised by government, and private

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[18] The reader is referred to the CAAC website: http://web.up.ac.za/default.asp?ipkCategoryID=9742&subid=9742&ipklookid=9&parentid=

[19] Interface South Africa is a Non Profit, non-governmental organisation for children and adults with severe and profound communication impairments. It provides support to people who require or use AAC, and promotes public awareness. (Adapted from  http://www.interface-sa.org.za/index.html)

medical insurance companies today pay significant portions towards the costs although with significant limitations. Only Mary and Parks had private medical insurance. In the past, and certainly when the participants in this study were children, AAC was not subsidised, and has been very expensive to purchase and maintain.

Mary had attended a school for children with cerebral palsy for 12 years. She had used a VOCA that employed a picture based system (Minspeak®)[20] from the age of 10 until she was 17 years old. At that stage, she chose to stop using the device. She found it very difficult to express the reasons why she had stopped using it. She did indicate that she had given up communication because it was too much effort, and that she felt that people did not listen to her so w-h-y b-o-t-h-e-r (Mary, 4, 77). Although Mary had never used oral speech at all (she could not vocalise voluntarily), she elected to use pen and paper if she could not make herself understood using facial expressions and gestures. Mary had chosen to communicate as little as possible. She rarely initiated communication with anyone but her mother and father. She always responded when spoken to, but in the briefest way. She would nod her head in response to a yes-no question if her answer was the affirmative; she would rarely shake her head if the answer was 'no' if it meant that further clarification was needed, and so instead she would shrug her shoulders and smile. This rendered the communicative partner uncertain – and often uncomfortable – resulting in the communicative partner re-orienting the discussion to another yes-no question. Mary would write her answer only if asked. She rarely kept pen and paper on her and would have to look for some if it was required.

Parks had never been offered AAC as a child although his speech was markedly unintelligible prior to his surgery at 17 years of age. Post-surgery, he was unintelligible to strangers and could not speak on the telephone. As an adult, his speech was unintelligible to most people unless the context was quiet, the topic known to the listener, and if he was able to put effort into speaking. He had never considered any augmentation to his speech. He used e mails to communicate but did not see this as augmentative. Nic's speech was unintelligible to most people most of the time. He had never been offered any form of AAC and knew nothing about it. Similarly, Lebo's speech was unintelligible to strangers, and it worsened under stress. He had never been offered any form of high-tech AAC. At school he had used an

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[20] Minspeak® is a programme used with various AAC devices. It comprises a series of pictures that represent language. The pictures are icons and can represent various meanings.

alphabet board as well as picture books constructed using Boardmaker[21]. As an adult, he had discarded the pictures and relied on his laminated alphabet board if he could not make himself understood.

Beauty's speech was markedly unintelligible as a child. She had used a Canon communicator®[22] and various similar devices as a child, but for the past 5 years had relied on her speech which she felt had improved sufficiently for to her to be independent of any communicative assistance.

Serena used an old VOCA. She was terrified of anything happening to it, and so used it in select circumstances only. She lived in an institution and said that everyone understood her without her using the VOCA. Only if she had one-on-one discussions, or if she really wanted to make a strong point, did she use the VOCA. She did not like to take it everywhere she went because she was scared that it would slip off the stand on her wheelchair. She was concerned that the battery did not charge properly any longer. Serena lived on a government disability grant and did not have funding available to replace the device.

### 3.6 Technological support

As adults, most of the participants used modern technology to aid their communication. They made use of social networking, cell phones, e mails, as well as digital photography. Two of the participants were active users of Facebook, finding that social networking was a useful way to keep in contact with people. They also reported that they engaged with people easily on Facebook, and that they were able to be in contact with people that they would not have been able to keep in contact with any other way. For example, Beauty was in touch with old school friends as well as people who had immigrated to other countries, and she enjoyed keeping in touch with them. Tiny enjoyed using Facebook although it required tremendous effort on her part because her use of the computer was very limited by her physical impairments. Her typing on the keyboard was very slow and she found it frustrating, nevertheless, she reported that she went onto Facebook at least once a day.

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[21] Boardmaker ® is software that allows the user to print communication boards using Picture Communication Symbols ™. (From http://www.mayer-johnson.com/boardmaker-software/)

[22] A Canon Communicator® is portable augmentative communication device, about the size of a postcard. Text is typed in by the user on a QWERTY-style keyboard that responds to very light touch. The unit comes with a built-in memory to store frequently needed words and/or phrases. It can record and playback voice. It can generate printed output on a thin paper tape. (Adapted from http://www.wtec.org/loyola/hci/ac_canon.htm)

Parks made extensive use of e mails. He had access to e mail at work, and communicated regularly with his friends, his pastor as well as family thought this medium. Beauty found the use of e mails to be particularly useful as a means of being in regular contact with her family. Tiny used e mails as the primary means of communication with her friends. Having moved to a town that is a fair distance from where she grew up, she had found that e mail allowed her to be in touch with people that she would otherwise have lost contact with. For Tiny, this electronic contact was especially important. Her social group was very small and she felt isolated in a small community. Although she had contact with people, her group of friends in this community was very small, and so maintaining contact with her friends through electronic communication was very important.

Tiny, Beauty, Parks and Nic used cell phones. Tiny found it extremely useful to have a cell phone to make calls, and she spoke on the phone to familiar people. She was aware that her speech was sometimes unintelligible on the cell phone so she used it to call familiar people only. If she used it to call people who were not familiar with her, she tended to have to put a lot of effort in to speaking, and so she avoided using it. The regular telephone was easier for her to use. Similarly, Parks used his cell phone to call people but made use of the phone only rarely. He blamed poor technology for contributing to his unintelligibility of the cell phone.

Beauty used the short message service (SMS) on her cell phone regularly. She had a cell phone pouch which she kept next to her at all times except when she bathed. She felt that the cell phone had made the most significant difference to her life. Beauty felt that she no longer had to rely on anyone to make a call for her. Her cell phone gave her independence, connection to people, as well as a sense of safety. She lived in an institution but in a room on her own. She felt that she was always able to get in touch with someone if she needed to and that gave her a sense of safety. She also enjoyed the privacy that SMS had given her. Prior to having a cell phone, she would have to tell someone what she wanted to communicate, and so there was always a third party involved. With her independent use of SMS, she was able to communicate privately which she felt was very important, particularly in relation to her relationship with her boyfriend.

Nic was adept at using his cell phone as well as his computer. He used his cell phone in innovative ways. He was an avid photographer, and took photographs throughout the day. He had developed a complicated but most effective system of filing folders on his cell phone. In this way, as he spoke to a person, he was able to pull up photographs to supplement and augment his speech. In this way, the listener was provided with a context, and on-going visual clues as to what Nic was saying. He used his photographs in every conversation that I had with him, as well as in most interactions with others. Although his involuntary movements interfered with his use of the equipment, he had developed some innovative ways of using the equipment that provided him physical stability which made his use of the equipment more effective. Nic also used his computer as a means of communication. He had a computer in his room in the institution in which he lived and had many computer games. Nic used his computer to attract people to interact with him and he spent many hours playing games with them.

Mary, Ellie, Seamus, and Lebo did not have access to a cell phone or a computer. Ellie had a regular telephone at home which she used when necessary. She was able to make herself understood to familiar people over the telephone. Serena had a computer which she used to access the internet, but she did not use it for communicative purposes at all. She used the internet sparingly as the institution in which she lived limited her access due to costs involved.

## 4. Communicative participation in context

### 4.1 Groups and noise

Beauty said , *"Oh, I definitely prefer to be in small groups. I don't even like the dining room. I find big groups so hard to cope with. I can't talk loudly and the effort that I have to put in to speak in (?noise) is just terrible*" (Beauty, 3, 55). The access that the participants had to communication was affected by the environment. They found it very difficult to interact with others in noisy environments, and all of the participants described how this affected their communication. They found it very difficult to compete with the noise, and to concentrate on their speech. They found that they felt stressed and avoided noisy situations as much as possible. The same applied to group situations. All of the participants described how they would choose to avoid group situations, or choose to avoid communication if they were in group situations. The context, however, made a difference here. Although the participants who worked in environments in which other disabled people worked had to communicate in noise as well as in a group setting, they found their communication was less difficult in this context as compared to unsupportive contexts. Seamus said*, "Here, you see, here where it is a big noise, it's okay. You are very good with talking…ha...maybe you are have much* *experience. I am okay with you, but with another (somebody?), I am not sure I can talk like this here, no I think it is too hard place, too much noise and that here"* (Seamus, 4, 103).

### 4.2 Physical access

The effects on communication differed in most contexts, such as when accessing public transport, when going to vote in an election, when going to public places such as shopping malls and restaurants, and when participating in social events such as church meetings or dinner parties. In all of these contexts, the participants described structural barriers to their communication such as the lack of accessibility. All of the participants spoke of the problem of physical dependency in that they all had to have someone take them to where they wanted to go as none of them drove or could access public transport independently. The effort of assisted mobility is reflected in this memo:

> I took (name of participant) to (name of venue) for coffee today. I was sure that I would see and hear a different person if I could get her out of her room. I am astounded at how exhausted I am! Is this what mobility does to communication?? I arrived at …'s home. I helped her to get ready – handbag etc. then I locked her door. Then we got to the mobile wheelchair and I transferred her to it. Then I pushed her to the car. I transferred her from the wheelchair into the car. Then I put the wheelchair in the boot. Then off we drove, and I found it so hard to understand her at all while driving. I did not know the route well, the car is noisy, and she spoke non-stop. We arrived at the venue. I took the wheelchair out of the boot. I transferred her out of the car. I wheeled her into the restaurant. Whew. Then she ordered food which I had to help her to eat. I also could not understand most of what she was saying because she tired, and the effort of eating made her less intelligible. Then I wheeled her to the car, transferred her to the seat, put the wheelchair in the boot, drove to the home, took the wheelchair out of the boot, transferred her to the wheelchair, pushed her inside, transferred her to the power wheelchair, walked with her to her room, unlocked her door and assisted her inside.
>
> I am totally finished. Would I do it again in a hurry?

Transport was not always available and was also expensive. The participants had difficulty with physical accessibility in various places – absence of elevators, uneven paths, and often there was nowhere to put a wheelchair. All of the participants described how they were excluded from social functions if the function was held at a place that was physically inaccessible as not all of their hosts prioritised their needs when arranging these social functions. They spoke about the day-to-day difficulties that blocked their communication such as their inability to go to the door to greet a visitor, or to answer a ring on an intercom.

### 4.3 Formal systems

The participants reported that some formal systems such as banks and cellular phone companies had relatively good policies in place to support them as disabled users, but that this did not necessarily apply to their communication impairments. It was rare for the participants to go to a place unassisted and unaccompanied. Hence, they generally did not experience situations in which they could not communicate because they were accompanied by a familiar communicative partner.

### 4.4 Communicative participation in institutional living

Institutional living influenced the participants' communication on a number of levels. Despite their objections to the segregation of disabled people into institutionalised living, institutional living provided important benefits to the participants in terms of their communicative participation. The lack of judgement and acceptance by their co-residents allowed the participants to feel comfortable about their speech. Serena was able to describe her experiences of this freedom in some detail. She described the people with whom she resided as having a very close bond with one another because of their being disabled and because of their enforced community. She said that this bond existed despite the fact that they d-o-n-t a-l-l l-i-k-e e-a-c-h o-t-h-e-r (Serena, 3, 29) This bond allowed for acceptance of one another's limitations, and Serena felt that this gave her freedom to communicate in whichever way she felt the need. Similarly, Nic stated that no one judged him and he felt free to communicate.

In institutional living, the residents had become very familiar with one another and with the communication patterns and styles of people with communication impairments. As a result, they reported that they had many communicative partners who were not only comfortable communicating with them, but who had learned skills and tactics to communicate with them effectively. Serena also felt that more intelligible people would talk for her in group interactions if she could not make herself understood. Only if she disagreed did she let them know and they then said something else, together creating a process of elimination of ideas until Serena's ideas had been communicated. She also said that within this communication process, her communicative partners would often use humour to lighten the discomfort.

Institutional living offered residents opportunities for communication. In one institution, the residents lived together and spent every day with one another. Opportunities were provided by the institution for social interaction such as communal lounges, arranged outings, and careful planning of small groups in the dining rooms.

The benefits afforded to these participants by institutional living – comfort in communicating, a sense of freedom, the lack of stigma, as well as having multiple effective communicative partners and many opportunities to communicate – were not valued by all participants. Beauty, for example, detested living in an institution, and spoke about her attempts to raise sufficient funds to enable her to leave. She had avoided all kinds of interaction with others. She objected to being "forced" into living among disabled people. She felt that this categorised her and limited her opportunities for communicating with able-bodied people. *"I normally am a very patient person but in the last few months (unintelligible 35 s) why am I being punished. 'Cos that's how I feel, I feel like I'm being punished because I can't get out of here" (Beauty, 2, 184).*

### 4.5 Privacy

(Tiny, 3, 169-187):

| | |
|---|---|
| Tiny | *Ja, I am concerned as it is a bit but I never have privacy* |
| Karen | *Really?* |
| Tiny | *No one respects that at 39 I want privacy* |
| Karen | *Not at all?* |
| Tiny | *They will like if my door is closed they will just walk in and never knock* |
| Karen | *Wow, so you have no privacy at all* |
| Tiny | *Nothing, never, they don't respect that* |
| Karen | *Tiny, do they treat you like you are 39?* |
| Tiny | *No, they treat me like 20 years ago, more , like an adolescent* |
| Karen | *And they do you think mmm, that they talk to you as if you are an adolescent?* |
| Tiny | *Yes* |
| Karen | *So the people you are closest to, are the people you are most dependent on, and they treat you as an adolescent?* |
| Tiny | *For sure that is really a problem to me* |
| Karen | *And can you say anything?* |
| Tiny | *I do but there is, I have a hard time trying to learn to be assertive and...(unintelligible 2s)...aggressive. I get emotional and then I really can't say to them what I want to say. My mom will listen in on a conversation, but I can't say anything.* |
| Karen | *So do you become aggressive?* |
| Tiny | *Yes, but not always but I have to work so hard to manage in the world and I have to work so hard at being assertive* |

All of the participants spoke of a lack of privacy for communication. Some needed communication partners to make phone calls for them. Others said that they needed to ask someone to dial a number for them so they always had to reveal to whom they were intending to speak. Ellie said that she had to speak on a speaker phone so that all conversations could be heard by people around her. Tiny was concerned that everyone could hear her because of her loud speech, and her inability to whisper meant that she could not tell secrets. Tiny was unable to manage her privacy issues, partly because of her impaired communication.

### 5. Linguistic aspects of communicative participation: "linguistic pragmatics"

A vignette described by Beauty led to an exploration of communicative participation from a functional perspective. She described the marked effect that her inability to engage in "pillow talk" had on her relationship with her partner. She had described her excitement and joy at having this relationship, but was extremely disappointed with the effects that her various impairments had on the relationship, including the sexual side. She felt that her inability to whisper, to talk softly, and to make herself understood affected their sexual relationship. From having this story told to me very early on in the research process, I explored the effects of the limitations of the participant's communicative abilities on the performance of communicative acts.

The participants described a range of communicative limitations, such as difficulties with having an argument, negotiating, debating, chattering, and gossiping. Other communicative acts which were difficult to achieve included having a conversation, telling a joke, deliberately obfuscating and engaging in banter. It was difficult to complain, to request, to pass an opinion, and to be abstruse.

The limitations in communicative acts also extended to modern technological communication. Beauty and Tiny, who were regular users of Facebook to socially interact with others, could not engage with the "online chat"[23] because of their slow speed in typing.

### 6. Communicating differently

In an interview with Tiny who had described many communicative limitations, her reply to my question, "so what do you do?" was unexpected and led to exploring how the participants reconfigured the ecology, so to speak, of their communicative participation. The following excerpt (Tiny, 5, 99-117) provided an example of communicating differently in such a way that the act of arguing is lost but in which Tiny held onto some of the ownership of her portion of the argument:

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[23] Online chat may refer to any kind of communication over the Internet, that offers a real-time direct transmission of text-based messages from sender to receiver (From https://www.facebook.com/pages/Online-chat/109129945773516)

Tiny *You see, my speech goes so bad when I can't, when I am emotional, and so, what happens is my mom walks away from me*
Karen *And then you've lost*
Tiny *Yes, I can't argue*
Karen *So what do you do?*
Tiny *I flail my arms and make a big noise and my voice goes all loud and squeaky*
Karen *On purpose?*
Tiny *For sure and also I can't control it*
Karen *So do you get angry?*
Tiny *Yes and that why 'cos she walks away from me*
Karen *So do you think she notices?*
Tiny *Not always but she can't walk away, it looks like I'm an epileptic* [laugh]
Karen *And so you keep her attention?*
Tiny *Ja*
Karen *And what about the argument?*
Tiny *No , she still won't talk about it*
Karen *So did you gain anything?*
Tiny [Laugh] *her attention , she's looking at me and my caregiver looks and I'm making a noise…*
Karen *…So you still have some power?*
Tiny *I suppose so, I never thought about it like that*

People who have difficulty speaking do not have access to a full range of verbal and non-verbal resources, and as a result do not have the privilege of redundancy and flexibility that makes communication flow. However, the participants used a plethora of behaviours, both verbal and non-verbal, to communicate content and social meaning. Nevertheless, these accommodations often lacked specificity in many cases, and did not augment the communication successfully. As Wickenden (2011) described of her participants, the participants in this study used eye movements, gaze and facial expressions; they used a variety of gestures, some formal and others esoteric and self-designed; they used vocalisations, laughs, and different intonations. They used head movements, leg kicks, wide arm movements, and small hand gestures. This multiplicity of attempts at augmentation was quite remarkable and there is indeed almost no research that has looked at "atypical" communication patterns in terms of their structure and effectiveness. It was clear to me that as I became more familiar with the participants, I was able to understand them more as their unusual patterns of communication became familiar to me.

It was also clear that the participants could not describe or analyse what they did to augment their communicative attempts. Over time, the participants became more analytic with regard to their communication, and were able to describe in more detail and with greater specificity, the effects of their communication impairments on their interactions.

The following excerpt from an interview with Serena exemplifies the difficulties with interpreting the participants' communication (Serena, 3, 12-24). Note the hesitancy in my final turn in this excerpt:

Serena [Shake head]
Karen *So you are lucky*
Serena [Gestures (not sure what it means)]
Karen *Yes, and so you have your own space, and you have privacy*
Serena [Nod and gesture (not sure what it means)]
Karen *Can you type that for me please?*
Serena Peace
Karen *And peace. Yes, I am sure you need to be alone sometimes*
Serena [Nod]
Serena too much
Karen *Too much? Do you mean being with people can get too much?*
Serena [Gesturing (not sure what it means. Possibly something about her room)]
Karen *Uh huh, I think that it is really nice that you can come to your own room, close the door, and live as if you are living by yourself. So it seems that you have the best of both worlds. You have the place which gives you, um, everything like the dining room and friends, but then you, um, also can come here*

When I asked the participants, "So what do you do?" in relation to their stories of communicative failure, most of them described waiting for a more appropriate time. "More appropriate" was described as a time when they had more time to talk, when they had had time to think about how to say what they wished to say with less effort, or when they were less emotional.

The participants saw themselves as good listeners. Although they were not aware of the power of being good listeners on the communicative participation, it became apparent from their stories. When I asked Serena what helped her to communicate, she indicated that she was a good listener which she felt made her a good communicator. When asked to give an example, she explained that because she listened, many of her co-residents came to her for counselling. She had never thought about the fact that it was easier for her to listen than it was to speak, although she had typed I l-i-s-t-e-n y-o-u t-a-l-k (Serena, 2 , 95) and that she adopted a strong listener role which enabled her to be a powerful member of a communicative interchange.

Mary used silence to avoid difficult situations, but she also used her silence to communicate. Mary's silence made her communicative partner responsible for the communicative interchange, and so she could take the role of the silent, yet controlling, communicative partner, as shown in this excerpt (Mary, 2, 1-14):

Karen *But you remain silent?*
Mary [nod]
Karen *And it works?*
Mary [nod and gesture]
Karen *Ok, so are you telling me that when you want to make a point, you keep, um, you don't do anything? Do you nod or shake your head?*
Mary [Nod]
Karen *Ok, do you write?*
Mary [gesture]
Karen *Too slow* (3 s pause). *I'm scared of putting words in your mouth but are you saying to me that by keeping so silent, you get attention*
Mary [shrug]
Karen *You suppose so?*
Mary [nod]

## 7. Conclusion

Communicative participation is facilitated by successful communication that requires as little effort as is necessary. One's ability to fulfil all the requirements of communication will affect one's communicative participation. What was apparent was that although the participants all lived with very marked communication difficulties, they expressed that they were expected to be communicative. The participants spoke of their interactions with others as demanding them to engage in discourse; to use signs; and to enter into dialogue with others. They needed to provide information, and to connect to individuals. Their communication was intrinsic to the structure of social order in their lives, and was important for their critical thinking and intellectual being (Craig, 1999).

The analyses showed that the participants had problems on so many levels of communication. The sheer effort of communication was evident for all participants, some more than others, and in some contexts more than others. What was apparent from these discussions was that the participants needed to take a very active role to be able to participate in communicative interactions. They needed to be highly motivated because of the tremendous demand that communication put on them. They needed to be able to deal communicatively and psychologically with having to rework their communication in different modes and in different words so as to get their meaning across. They needed to be able to persevere and manage regular communicative failure. The extent of communicative demand on the participants to be able to participate stood out for me, and led to the notion that the participants had to have developed a “communicative self”. The understanding that the participants had of themselves as communicators emerged from the data as will be discussed in the next chapter.

# CHAPTER EIGHT: LIVING WITH AN EMBEDDED COMMUNICATIVE SELF

## 1. Introduction

Identity is a very powerful construct, but it is also a very broad one (Vignoles, Schwartz, & Luyckx, 2011). My construction of “a communicative self” is based on the analysis of how the participants saw themselves as communicators, based on the question, “who am I?” that forms the basis of the definition of identity (Vignoles et al., 2011). I identified three constructions of a communicative self. I have called them “an able self”, in which the participants appear as successful and able communicators; “a trapped self” in which their communicative identities are placed in a vulnerable, at risk position; and “a submerged self”, in which their communicative identities are submerged beneath contextual influences, and are consequently hidden.

## 2. An embedded communicative self

Despite my attempting to go into the research with a blank slate with regard to what communicative participation meant for the participants, once the theoretical category “a communicative self” was constructed, I realised that what they had told me was not what I would have expected them to bring to the research as people who experienced lifelong significant difficulties with speaking. I would have expected them to see themselves as communicatively disabled and to have developed an identity as disabled communicators. I have assumed in my clinical practice that people who have communication impairments see themselves as impaired, and I have been informed by literature that proposes that speech impairments play a considerable role in the way in which people construct their identities (Bricker-Katz et al., 2009; Kathard et al., 2010). Given the central importance that communication has been accorded in theories of human life (Littlejohn & Foss, 2008; Threats, 2006), I have also always assumed that being able to communicate is the most important attribute for a person to live a meaningful life. I have been heavily influenced by statements like “ the conscious affirmation of *being in communication* or *having communicated* is tied to a feeling of connectedness to a world outside of one’s skin, a world of potentiality and hope” (Macke, 2008, pp. 126-127) so that attachment through communication to others provides the path to a meaningful world.

Contrary to my long-held assumptions that the participants would see themselves as belonging to a group of disabled people whose significant communication impairments would be the *core* of their identity, the participants saw themselves as disabled but their identity was not dominated by their communication difficulties. What I did not expect, then, was the participants' lack of focus on the distinctive, peculiar and specific contributions of their communication difficulties on their experiences of being disabled, but their perceptions instead, of their communicative impairments as an integral part of their whole picture. Communication was no more important than any other skill or attribute in their identity formation. In the discussions with the participants, I became aware that they had a sense of self that unified their bodies, their communication and their selves. This chapter provides the evidence of the construction of the participants' self-identity as communicators, which I came to understand as there being "an embedded communicative self" that defined, guided, and sometimes misled them in their communicative participation.

Why the participants saw their communicative disabilities as embedded within the whole picture of being disabled is perhaps because few of the participants had ever analysed their disability and their impairments before taking part in this research. They experienced their communication impairments as a generic, "it's hard to speak" idea, but had not broken the difficulty down into its component parts – not unexpected in a population of lay people. In reply to many of my questions related to the component parts (e.g. communicative acts, intelligibility, speed, and so on), many of the participants replied, "I have not thought of that before". In contrast, they were more easily able to analyse their physical actions like walking or getting dressed.

Not only were the participants unaware of the components of communication, but there is possibly also a psycho-developmental explanation for why they did not see communication as separate from all their other abilities and as a distinct part of their selves. Unlike people who have acquired physical and speech impairments or those who acquire problems such as those related to chronic illness, the participants had lived with their impairments all their lives. They did not experience loss; they did not experience having to reunify their bodies with their self which people who have lost skills have to do (Charmaz, 1995; Inahara, 2009). They had not experienced a disruption between their bodies, their communication and their selves. They had constructed their selves as integrated and whole and their communication – be it successful or impaired – was part of their wholeness. Hence, to break down their component abilities into parts, was, in a way, to break up their sense of their whole selves which, for them, was artificial and unreasonable. This excerpt from an interview with Seamus illustrates this point (Seamus, 1, 45-65):

Karen *Do you think your speech affects how you get it achieved?*
Seamus *I don't know. It is hard to speak sometimes*
Karen *Speaking. Like walking?*
Seamus [Nod]
Karen *Speed?*
Seamus *Um, I think so* [giggle and smile]. [Vocalisation] *(unintelligible 2s)*
Karen *Making the sounds, um, saying all the speech sounds like sh, z, th clear?*
Seamus *For sure*
Karen *And what else?*
Seamus *I don't know about that*
Karen *Is it your voice? You told me you tend to talk loudly*
Seamus *Oh, ja , of course, I always have to talk loudly and everyone can hear and it's how it is* [laugh]
Karen [Laugh], *yes, your voice can be loud. Does this worry you? Does it worry others?*
Seamus *I used to worry about my speech but I don't know if it was loudness, maybe it was, and also the sounds*
Karen *Have you ever thought about all these parts that speech is made up of?*
Seamus *It is just talking you know…I talk and it is sometimes hard and you just carry on, and talking is talking just like that. You have to try hard. Sometimes you must listen more; sometimes you talk and try harder to talk nicely.*

Although I have found very little literature on the development of the self in people who have lived with lifelong physical and communication impairments, it would seem reasonable to assume that all aspects of one's development are intersected and interdependent. It would seem that it is only through disruption that the component parts take on more differentiated importance. Denzin (1992, cited by Galvin, 2005, p. 394) wrote about "epiphanic experiences" as those which have a large impact on people's lives and that can change identity formations. It seems that disruption to communication made the participants renegotiate their constructions of their identities as communicators. What was shown in the last chapter, however, is that many times, the participants did not recognise breakdown in communication, and so disrupted communication was sometimes an opaque and ambiguous experience.

Another perspective to consider is that of the multiplicity of the impairments that contributed to the participants' limited participation in society. Some research has unpacked the contributions of communicative impairments to the constructed identities of people who have lived with lifelong communication impairments such as that which has included people who stutter (Bricker-Katz et al., 2009; Kathard et al., 2010). It seems that these people were more easily able to identify and articulate the contributions of their communication to their personal identities than the participants in my research. Unlike people with lifelong communication impairments such as people who stutter, all the participants in this research lived with severe restrictions in their abilities physically, and over the course of their lifetimes had experienced varying degrees of impairment and change. Their lives were governed to a large extent by not being able to do a lot of activities with freedom and with choice, with effortlessness and with success. Communication was not the dominant contributor to their identities as communicators.

For example, Seamus' lack of choice in his daily activities was a significant part of his disabled identity. He said that although his communication was a problem for him, he had lived with it all his life and had coped with it. He said that his identity as being disabled was primarily undergirded by the lack of choice that had been imposed on him by his having to give up his independent life to live in a residential facility. Seamus had travelled internationally alone; he had lived in his own apartment; he had lived independently and had made most of his own choices. As far as he was concerned, his speech had played no part in defining his independence, as seen in the following excerpt (Seamus, 2, 24-35):

| | |
|---|---|
| Karen | *You have always been independent you were saying. Yes, and so your speech…* |
| Seamus | *My speech never stopped me* |
| Karen | *Ever?* |
| Seamus | *No, you just have to manage and if they don't understand you say it again and again* [laugh] |
| Karen | *But it -* |
| Seamus | *-So you do and then ignore them if they don't understand 'cos there's nothing you can do* |
| Karen | *Ignore?* |
| Seamus | *Well, ignore and move on* |
| Karen | *Um, so are you saying that it has never interfered with your independence? Your speech has never stood in your way?* |
| Seamus | *I have always had a speech impediment and it does not stop me doing what I want to do like my body also. You work around it and force it and make sure you are independent and no one must take that away* |

Hence Seamus saw how he managed his impairments, be they physical or speech-related, as that which defined his being disabled. He said that there was so much that he could not do, but that that was not what defined him.

The indivisibility of communication and other aspects of being is exemplified by Parks. Parks said that his speech did not stop him from participating, but when looking at his descriptions of his participation, I noticed that he enjoyed and was successful in participating and in interacting socially when he could *avoid* communication. Parks had a very restricted communicative life but he had a busy life. He had many opportunities for communication, but engaged rather in his activities in ways in which he avoided communication. He participated in sports, church, rehabilitation, and went out into his community when he could walk.  But in all contexts, he avoided communication. For example, at church he sat away from others, saying that the chairs had no backs and he had to sit on a chair that had a back which meant he sat at a distance from others. He said, *"It's a folding chair he's brought it once or twice, and he's not always there on a… every Friday, but maybe I need him to. Maybe I need to go buy my own chair and take it with me, so I can be part of the group"* (Parks, 2, 212). At gym and other sports he could be with people and do things with people, but did not have to talk to them very much. At work, he avoided social communication, preferring to say at his desk to read the newspaper at lunch time.

However, Parks' choices to avoid communicative situations were not always based on his communication difficulties, but his understanding of himself as a person vulnerable to the harshness of the world, as a person who was responsible for his own actions as a disabled person. The language that Parks used - "I need to", "I have to", "I should" – points to his understanding himself as a disabled person responsible for his communicative functioning in the world, exemplified in this excerpt (Parks, 2, 61-68):

| | |
|---|---|
| Karen | *They kind of turn off.  So at your…. where you are most needy at expressing something, your speech, just the physical speech, stops you from being able to say it.* |
| Parks | *Yes* |
| Karen | *How does that make you feel at that time, in those moments?* |
| Parks | *I feel angry at myself.* |
| Karen | *Angry at yourself?* |
| Parks | *Because I have emphasised my disability.* |
| Karen | *Your wording is "I have emphasised my disability"* |
| Parks | *That's what my parents say.* |

Consider the following statements:

*"…especially with my dad, because he tends to say that because I am disabled, I should make more of an effort to make myself intelligible"* (Parks, 2, 50);

*"I have to learn to or bear the consequences of people turning away from me"* (Parks, 2, 82);

*"I feel like a part of their community, but I need to also make an effort to talk more, sometimes I'm a bit too silent and I think that is an old habit which I need to break"* (Parks, 2, 224).

The inductive route to the theoretical category that was constructed, "living with an embedded communicative self" is depicted in Table 9.

Table 9

*Inductive route to living with an embedded communicative self*

| Focussed codes | Category | Theoretical category |
|---|---|---|
| Recognising disablism<br>Adapting over time<br>Purposefully selecting communicative partners<br>Using humour and cover up<br>Lifelong support<br>Being supported as able in context<br>Success and identity | Able communicative self | Embedded communicative self |
| Being Black<br>Living as a Supercrip<br>Managing effort<br>Feeling powerless<br>Being with disabled people | Trapped communicative self | |
| Having limited choice<br>Choosing words<br>Silence<br>Locus of power | Submerged communicative self | |

## 3. An able communicative self

In some contexts, and at various life stages, the participants saw themselves as desired and valuable contributors to communicative interchanges.

### 3.1 Recognising disablism

Ellie, for example, was adamant that her communication skills were adequate and that the problem lay in the inability of her communicative partners to adjust to her needs. This attitude was tied to her general perception of her identity as a competent and able person who was disabled by those around her. She stated, *"I like to be with able-bodied people. Look I'm no better than they are, some of them are better than I am, but I couldn't care less. I just feel I've got to be with able-bodied people, because I don't, because I don't want to be left out, I want to show them that I'm just the same as they are only I'm, I'm in a wheelchair"* (Ellie, 1, 2).

Later, she stated that not only was she determined to show people that she was a person, and not a disabled person, but that they were to blame for disabling her: *"But, um, you now, you've got to prove yourself all the time, this is what gets to me, um sometimes I've been asked,' are you alright in your head?' And I look at them and I think, now how should I answer that? Do I get angry? Do I laugh? Do I say, ' of course I know what you talking about?' Or you get people saying um… If I've got somebody with me, they'll ask, say my help, 'does she speak? Does she?' And it makes me so mad, because she is also to blame"* (Ellie, 1, 4).

Ellie's ability to remove herself was based on her having gained insight into the understanding of the sources of disablism in her life. Although she had no formal association with a disability group, and had never read on disability issues, she was very aware of disability as a social phenomenon. As a result, she was able to see disablism fairly clearly as the root of her experiences.

Similarly, Tiny expressed that her communication difficulties were based on the communicative partners' ignorance of disability and how to interact with communicatively disabled people. She stated, *"Because I feel sad and tired that they can't just accept me and I have to educate them and that is not fair. I should not have to educate them at all. It is distressing... and annoying"* (Tiny, 2, 96).

She also described scenarios in which people who were familiar with her, including family members, would create the communicative barriers by their negative attitudes towards her. She said, *"My caregivers are intelligent but they don't understand me. It's not that my speech is so bad, it's that they are intolerant"* (Tiny, 2, 106).

Her family had not resolved their own personal issues with the fact that she was disabled. For example, she stated, *"Oh like my brother. He is, he likes to avoid my cerebral palsy"*. Tiny described how her brother compared her to another disabled woman that he knew, saying,

*" 'look at her, she can do everything, she can drive, she can live alone, she is independent, she can even feed herself' and I say, 'no, but … I am cerebral palsied' but he hates that"* (Tiny, 3, 92).

Tiny felt that her family's issues with her being disabled and being cerebral palsied impinged on their communicative interchanges. She also spoke about how her communicative partners' expectations of her were unrealistic and affected her communication with them, as evident in this excerpt (Tiny, 3, 125-133):

Tiny *Yes but I can and you know that this is hard but my mom has these expectations today*
Karen *Does she expect too much of you?*
Tiny *Yes, It's (unintelligible 3s) she says "don't talk like that, talk properly"*
Karen *So she expects you to be able to talk better?*
Tiny *Yes, but ( then?) I just laugh at her*
Karen *So you can laugh when the expectations are too high?*
Tiny *Not always*
Karen *So Tiny, is there a difference between talking to your mom and talking to others?*
Tiny *Yes, you see, they expect so much from me because I don't look CP and then the family and others who do know me because my mom brought us up like that they all have expectations of me*

### 3.2 Adapting over time

Time was also a factor that helped the participants to see themselves as able rather than as disabled communicators. They had lived with their communication impairments all their lives, and in many contexts, and with some people, they were able to resist the internalisation of being disabled because their experience with it had led to them being able to distance themselves. Mary described herself as becoming p-i-s-s-e-d o-f-f (Mary, 4, 41) and that people who could not communicate with her were i-r-r-i-t-a-t-i-n-g and made her m-a-d and she found them i-n-s-u-l-t-i-n-g (Mary, 4, 36), but that she was used to it. Beauty stated, *"Lots of people do that, even my mom. And my sister also says, 'sorry but I didn't hear what you said', and I repeat it. I'm used to repeating all the time"* (Beauty, 2, 113).

Living with lifelong speech difficulties had helped the participants to externalise hurtful experiences. They were able to judge others for their attitudes rather than absorbing the attitudes themselves. They were able to look back and to reflect on their experiences with more insight and less negative emotion, and could protect themselves more from these negative influences. All of them spoke about how they had come to this realisation as adults.

Identity is transitive, and increasing evidence shows how, with time, identity can be refigured and reconstituted in a positive way (Jones et al., 2011).

The excerpt from an interview with Tiny describes the change in her attitudes over time (Tiny, 4, 93-95):

| | |
|---|---|
| Tiny | *I can't live up to their expectations. I used to. I used to try so hard to please them and used (unintelligible 2s.) but now I am me and they have to accept that* |
| Karen | *Has this come to you as you are older?* |
| Tiny | *I am nearly 40 so I decided damn them, I can be what I am and stuff what they think of me* |

### 3.3 Compensating using humour

Ellie was able to stand outside of a situation in which she was made to feel disabled, and interpret it as being ridiculous, in terms of disability in general, as well as her communication difficulties. She said, *"Very easily, 'cos they immediately you know, start asking questions and I'm able to laugh and say you know what's... They say, 'why you laughing? I said, 'because of what you said'. You know, I think this is hilarious, but don't do it to anybody else that's disabled, because they'll probably get so angry that they will fight with you, and that's a whole... that's a good point"* (Ellie, 1. 53).

Ellie used humour to bring people's attitudes to their attention. She stated, *"Well that's why I'm saying now at our church they treat me as a normal person, and I tease them, do you know so... 'can we move you back a bit so we can get so and so in?' or what, and I say, ' don't forget if you don't put me back I'm going to scream'. And they, they shriek with laughter because they know me"* (Ellie, 1, 66).

She also described scenarios in which she used humour as a way of laughing off her disability, and invited others to laugh with her. For example, she said, "*And we had good laughs because he, he says to me, 'now don't put that spoon in your ear', I said, 'if you don't shut up'...* [laugh] *you know, and then we laughed"* (Ellie, 1,6).

Despite the humour, Ellie did become irritated, but she did not internalise this, and did not feel that she was incompetent. Her self-identity was that of an able person, irritated by the doings of others: *"And my mom those days, you used to use the word spastic, and they said, 'oh is she plastic?'... I shrieked with laughter, because I could see little yellow cops (?) and* *all sorts jumping around in front of me, you know,* [laugh] *you know, and it's fun sometimes. But you get irritated if they keep on saying, 'oh you can't do this'"* (Ellie, 1, 66).

In Galvin's (2005) research on the identity construction of disabled people, she found that her participants had developed senses of humour because they preferred to focus on what she called "processes surrounding reconstruction" (p. 400) in order to avoid focusing on the negative aspects of their lives. Ellie's use of humour reflects her use of a strategy that avoided focus on her impairments, and avoided focus on the hurtful attitudes and behaviours of others. Ellie's use of humour, although helping her to stave off the hurt from the comments of people with whom she interacted, was a tactic that she employed regularly. However, this might have served her poorly because she consistently had to act the clown to cover, and to protect herself. She rarely confronted people, and one has to wonder whether this strategy worked successfully for her. Her words that humour *"Is better, than getting angry and upset because, where's it gonna get you?" (*Ellie, 1, 72) make one question whether Ellie had no other – or possibly few – strategies to call on to protect herself from hurt. In addition, consider her acknowledgement that laughter diffused her hurt depending on her *"mood"* (Ellie, 1, 57-62):

Karen *But you can laugh about your disability, but when people have insulted you, you don't laugh about it*
Ellie *No I don't, you know I -*
Karen *Because my question was you know… you say you've got used to it and I think….*
Ellie *It depends, Karen, on what mood I'm in*
Karen *Okay*
Ellie *Like say I've had a hard time having to be patient with staff, and staff are not easy, most of them are, but, they're not easy, especially having multiracial people here, that sometimes I go home and I just (?shake) everybody, so sometimes I think, well it is my fault, instead of saying, 'now, get a move on, I've had enough of you, now just push off', you know, well I'm not that kind of person, but I'm beginning to be like, like that kind of person*

### 3.4 Purposefully selecting successful communicative partners

Serena described the resilience that protected her identity as an able communicator from being eroded. Although Serena experienced very severe communication difficulties in that she was unable to articulate any speech sounds, and had very little voluntary control over her body so that gesturing was very difficult and using her VOCA was very effortful, Serena was able to communicate as an able communicator in many contexts. One of the factors that protected her identity was her segregation from the mainstream. She lived and worked in an institution for people with cerebral palsy. She described herself as able to communicate with the people that she was in daily contact with, and rarely felt that she was a disabled communicator. However, even within the institution, she chose people to be around who understood her, or who were able to use their skills to determine what she wanted to say. One of her close friends was a man who had experienced a traumatic head injury and who had intact speech articulation, but marked cognitive communication difficulties[24] including memory problems. However, he was able to read Serena's messages and was skilled at understanding her gestures. She chose to spend much time with this friend because he was a communicative partner with whom she could personally interact, but also who worked as an effective translator for her in the institution.

### 3.5 Having lifelong support from family and friends

Like Serena, Seamus described his friends and family as resources that kept his view of himself as able. He saw himself as competent and had a strong message communicated to him by his friends that he was no different from them, despite his severe communication difficulties. He had made friends, and had maintained an active social life when he lived independently. Beauty had been given a clear message by her family that she was able, despite being impaired and unable to do certain things. This is evident in the following statement: *"I'm just very lucky, I've always said to my parents I'm one of the luckiest people in the world. I've got such a wonderful family, and my parents said, 'but we couldn't afford all the latest equipment ' and I said, 'I don't care'. Look at me today. I wouldn't be here today if it wasn't for them"* (Beauty, 2, 148).

Nic's support from his family was a key factor in his life. He, like Beauty, reported that his family had told him that he could do anything and be anything. The continual affirmation throughout his childhood and into his adulthood was, for him, the reason why he was able to overcome many barriers.

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[24] The American Speech-Language-Hearing Association (ASHA) defines cognitive communication disorders as difficulty with any aspect of communication that is affected by disruption of cognition. Some examples of cognitive processes include: attention, memory, organisation, problem solving/reasoning, and executive functions. Problems in these areas can affect verbal and nonverbal communication. For instance, speaking, listening, reading, writing, and pragmatic (social interaction) skills may be affected negatively. Problems with cognitive-communication can affect activities of daily living, and academic and work performance (From http://nau.edu/CHHS/CSD/Clinic/Cognitive-Communication-Disorder/).

### 3.6 Being supported as able in context

Context played an important role because some situations were disabling and others not. Beauty's descriptions of her experiences illustrate this point. For example, she described how hard it was for her to manage to heat her food in her microwave. She chose to eat most of her dinners alone in her room because she did not want to eat at 5pm when the dining room served food but preferred to eat later. In this context, communication played no part, but for Beauty, this difficulty stressed her dependency on others which was a dominant part of her disabled identity. She saw herself as ambitious, determined and competent, and felt that her dependency was a slight on against her being.

However, her communication defined her disability in some contexts. For example, she felt that she was not able to argue for her rights in the institution where she lived, such as her need to insist that she be given the right to bathe every day, and it was in this kind of situation that her communication impairments disabled her, and disrupted her sense of self as a person defined by her competency, autonomy and determination. Her communication difficulties challenged her sense of who she was and although she resisted it, she found herself taking on a sense of being compromised, and a sense of being a failure. Notwithstanding the powerful role that communication played here, she still insisted that communication failure was not a part of her self-identity. Her self-identity was that of a determined person, and when she started to feel a sense of failure, she fought it. There was a tension between her experiences – the real, lived experiences of the consequences of her impairments, with her idealised being.

### 3.7 Success and self-identity

Some of the participants had achieved success in many aspects of their lives. This success brought them the strength to resist taking on the social constructions of disability as their own. They described success on many levels and in many domains of life. Beauty had expressed pride in her academic achievements, and her ability to make and maintain relationships, and her independence. She stated *"We really need to get my story out, because the experts of (name of school) say (?said), 'no we don't think you'll ever be able to walk, talk or be able to get an education', and we have got a lot of obstacles, and we want to show South Africans, 'don't give up on your kids'. My mom could easily have given up and just left me at home, and I said, 'enough, I want to go on my own now', and I'm glad that I did 'cos she actually saw how normal I was."* (Beauty, 2, 215). Tiny was proud of her success at work and the fact that she had managed to achieve so much despite going through severe physical deterioration and pain at the time. Nic spoke of his success with modern technology, and of his computer and photographic skills. Lebo spoke of his pride in his work, and in his ability to fit into multi-racial and multi-linguistic settings. Throughout the interviews, there was evidence that the participants saw their success as having been self-driven, and as a buffer against what society might think of them.

Tiny had an interesting interpretation of success. She said that she thought that disabled people cope because they have become experts. She stated (Tiny 5, 57), *"I think that they are in control. They're the experts at this. They have lived with it all their lives and they have it under control"*. She said that despite interminable failure, she had control over failure. She called herself an *"expert at failure"* as in this excerpt (Tiny, 5, 73-82):

| | |
|---|---|
| Tiny | *I don't know how to put in words now but I do have control over my life* |
| Karen | *But not autonomy?* |
| Tiny | *Ja, I have to deal with being dependent and not having choice but I have control over that* |
| Karen | *Are you saying that you are expert at dealing with it and you have control because you can deal with it?* |
| Tiny | *Yes* |
| Karen | *And also…* |
| Tiny | *Control if I can't deal with it – I am still in control of that* |
| Karen | *So* |
| Tiny | *And we get there in the end* |

## 4. Trapped identities

Despite the participants' communicating to me that they felt strong, resilient, mature, and successful such that they could resist the constant hurtful encounters that they experienced, I found evidence in the data of the participants being trapped by powerful contextual influences. By trapped, I mean that they had to work extremely hard, and to call on resources that stretched their human budgets, so to speak, to be able to function as able communicators. Sometimes the resources were available and successful; other times, they were not guaranteed. This state of ambivalence and uncertainty and the fact that the difficulties that the participants faced with their communication were inexorable, persistent and relentless placed the identities of the participants at risk of being hurt.

Given the power of communication in the establishment of the self, one would imagine the lack of recognition shown to the participants, as described in chapter 6, as having the power to create a damaged psyche, a fragile self. Sinason (2010) stated that it is often not the original impairments that create psychological problems, "but rather, the burden of a handicap depletes what resources an individual has, leaving him or her prey to what is internally unresolved or disturbed" (p. 20).  To some extent, the participants had developed resilience – internal and external – which protected them from the harshness of the lack of recognition. The lack of recognition shown to the participants, their communicative isolation and their denigrated status, their being marginalised and stigmatised, and their communicative impairments placed them at risk of developing disabled identities, and of being – and therefore living as – liminal people. They had to work hard to protect their communicative selves from being liminal, from being "suspended in social space without firm identity or role definition" (Murphy et al., 1988, p. 237). Liminality has been described in relation to disability by a number of authors. Murphy et al. (1988, p. 237) defined liminality so: "Liminal people, as the word denotes, are at a threshold. They are marginal to society – poised perhaps to enter, but still outside its boundaries".

### 4.1 Being Black

The experience of disability, communicative disability and the stigmatisation resulting from being Black was evident. The Black participants in this study described the effects of being oppressed as Black people, which had direct consequences for their participation and communicative participation. The experiences of Lebo as a Black person were influenced by his experiences as a Black child growing up under the cloud of Apartheid.  Lebo grew up in a Black neighbourhood, but was educated at a specialised school for children with cerebral palsy. The school's medium of education was English, so he was exposed to a different culture from a very young age. He was segregated from the children in his immediate environment and so his early friendships were affected by his two-fold experience of being labelled different and disabled, and his being isolated from his neighbourhood friends during their schooldays.

He described situations that showed that this segregation had two meanings for him. One the one hand, he was afforded the opportunity for specialised education in a time when facilities for Black children were extremely limited. Regular mainstream schools were significantly under resourced, making it very difficult for teachers to assume their duties with confidence and success. Learners were compromised by the lack of qualified teachers, the large teacher-learner ratios, and other significant educational limitations imposed by the then Apartheid-governed educational policies and immediate post-Apartheid era legacies (Howell et al., 2006). Lebo, however, was educated in a very well-resourced school. He had access to a full rehabilitation as well as small classes with highly qualified teachers. He described himself as lucky to have had that level of education. The downside of his education was, however, that this put him at a level that was way above his peers in the township, and he had to hide his academic success from his peers in order to fit in with them. This is evident in this excerpt (Lebo,2, 180-201):

| | |
|---|---|
| Karen | *And did you have friends at school?* |
| Lebo | *Oh ja, its was a wonderful place* |
| Karen | *mmm* |
| Lebo | *You see, we, well it was hard at first but then it was like we were just all at school. I had a lot of friends there* |
| Karen | *And at home?* |
| Lebo | *Ha* |
| Karen | *What do you mean by "ha"?* |
| Lebo | *Well, you see. Hau, this is a problem* |
| Karen | *Yes* |
| Lebo | *You see, the problem is, the kids at home* |
| Karen | *mmm* |
| Lebo | *They, well, some they did not go to school. It was bad years. Some were poor and the school were shit. I mean, some the teachers not there, the books (unintelligible 1s), but some of the kids do well, really well* |
| Karen | *And* |
| Lebo | *And so you see it is like this. I am brain damaged. Ha, but I can read. I am a very lucky somebody because I can read and do maths and all the schoolwork, and am very clever at school. I had a good opportunity* |
| Karen | *Ok, are you saying that you had it good but a lot of kids from your home did not have good schools* |
| Lebo | *For sure hey. It was like that, ha, so I pretend* |
| Karen | *Pretend?* |
| Lebo | *Ja, I have to be like them or they will not be happy with me* |
| Karen | *So you hid your skills?* |
| Lebo | *Ja, but they all knew I think* |
| Karen | *Lebo, this is an amazing part of history, you know, that I was not aware of* |
| Lebo | *Lots of stories, lots of stories* |

In his neighbourhood as a child there were no fences between houses, the children played freely with one another in the streets, and with the extreme poverty in which most of his neighbours lived, there were no toys, no soccer fields, no parks, and so informal social meetings, wherever they could happen, were the norm. The children played in the local neighbourhood, in the small gardens or in the streets, and in the local soccer field which was a clear, sandy area that was large enough for a group of boys to play soccer. Lebo depended on being taken by the children in his wheelchair to play. He said that he always felt different, always limited in his interactions because of his impairments and his dependency as well as his not being "one of the boys". He felt that the children teased him and often said very cruel things to him, which he felt was the result of traditional cultural understandings of disability. Consider this excerpt (Lebo, 3, 6 – 8):

| | |
|---|---|
| Lebo | *That's the way my people think, and I think we must accept that. For me, being disabled is something like a curse. And the magic, do you know anything about this?* |
| Karen | *Yes, I have heard a bit.* |
| Lebo | *Um. And so the kids treated me ok, but underneath there is always like even today there is this that I am a curse. Yes, and they take good care you see I must not be punished because I am a person. Even if I am a curse. But that still is what the children do. They hear their parents talk and they think its shame and magic, so they not so nice. But they still nice also* [laugh]. *This is very hard to explain.* |

Nic said that being Black was a major limitation for him in terms of his participation. He said that it was very difficult for him to participate in the society in which he grew up as a child, but that later, it was easier as he started to integrate more and more, which was linked to the transformation of the country. His experiences of living and working in multicultural groups had helped him to see that being Black was not an additional limiting factor superimposed on his being disabled as he had experienced growing up. However, he expressed a sense of vulnerability, stating, *"Things changed but you never know. I will always be Black"* (Nic, 4, 118), and gave some examples of contexts in which he felt that he was judged as a Black person. One example was in the workshop where he was employed. He felt that if he messed up, that his co-workers would think it was because he was Black. Other examples that he cited related to his lifelong experiences and the fact that there remain many on-going struggles to transform society two decades after the institution of a democratic government.

Being Black and disabled in South Africa had forced the Black participants in this study to be bilingual. They were educated in languages that were not their home languages, and they struggled to learn the new languages, which impinged on their early educational success. As children they engaged with medical staff at hospitals who did not speak their home languages. The doctors and therapists were all White, and the participants and their families had to communicate in English. Seamus said "*We go to (name of hospital), and that was a very good hospital. My um you see I liked it because I could tell the doctors and therapists my story because I could speak English*" (Seamus, 3, 111).

### 4.2 Living as a super-crip

Beauty said that she was often complimented on her success, on her ability to overcome obstacles, and on her cheerful nature. She was able to live with a strong, able self-identity, but many expectations were made of her. She was admired as the super-crip, as a hero, admired for her courage and her determination (but still othered) (Scully, 2008). Beauty, the super-crip, was the Beauty who was admired. The effort that Beauty had to put into being this cheerful, successful, able communicator was remarkable. For example, she had to limit the time that she spent in communicative interactions with others or she became dry-mouthed and progressively more unintelligible. Speaking took tremendous effort because she worked to concentrate on the content of her speech, as well as the physical effort of communicating as intelligibly as possible.

Moreover, she did not always get clear messages from her communicative partners that she was unintelligible. Often, it was only because the conversation had deteriorated to the point where the broken communication was very obvious that she realised that her listener did not understand her. "*I concentrate so hard on talking and it is such an effort to say what I want to say and I can't concentrate on everything all the time. I hope that people do understand me because if they don't and they don't tell me I'll be very cross*" (Beauty, 4, 266) and later she said "*but I work it out, I can see those blank eyes and sometimes people start looking away and even talk, and even (?saying) something that is nothing about what I am saying"* (Beauty, 4, 387). Thereafter, Beauty had to take responsibility for repairing the situation. She had to tell her communicative partners this, and had to request that they stop talking, and often, she had to request that they get water for her to sip. She therefore had to deal with her dependency and her having to request of others, so as to be able to continue to communicate. This degree of effort was also seen in her physical, day to day functioning as well. In order to manage a day at work, she woke up five days per week at 4.30am so as to be ready to get transport at 7am. She would return to her home between 6 and 7pm, eat dinner at 8pm, do her university assignments thereafter, and get to bed at 11pm. She was exhausted many days - *"and it actually gets to me in the end, in the week I don't sleep enough, when I go home for the weekend, I sleep for hours"* (Beauty, 1, 35), but stated, *"maybe I'm more determined to do things, because I want to prove to myself and to the world that I can do things"* (Beauty, 1, 100).

## 4.3 Managing the effort of communication

The effort of communication for the participants was described in chapter 7 in which I showed that communication required much effort for the participants. Parks' sense of responsibility made him put a lot of effort into his speech: *"I need to make more of an effort to make myself intelligible, and sometimes I do get angry, and when I get angry, I am less intelligible, because I am trying to force my opinion, and I talk harshly and that makes me more unintelligible"* (Parks, 2, 50). I wrote this diary entry after an interview with Serena:

I am so tired. I am having trouble remembering what we spoke about and I have to transcribe the tape now or I will not be able to remember what she did. I wish I could just throw it away. But, if I am tired, what about Serena? Is she as tired?
Effort. This is what it was about today. I had to use every resource available today to interpret Serena's unspecific gestures. She types, but one or two words and I have to interpret those too. And I have to be careful that I don't put words in her mouth and that I don't insult her. Today she told me that interrupting is rude and I interrupt all the time.
Effort. Is this a defining characteristic of communication with her? Is it a defining characteristic of her communication? Does effort stop her from being able to communicate? Well, the effort of communicating with her would stop many people from communicating with her. It's not just time she needs, it's energy – hers and mine.

Did the constant effort that the participants put into their speech help to protect their identities from harm? Or did they see themselves as disabled and that putting effort in was what disabled people were expected to do? Did they put effort in because they put importance on communication in their lives and worked hard to achieve it? The answer to all three questions was affirmative, and it was impossible to tease out the value of communicative success on identity formation. The participants experienced repeated communicative failure. Their efforts at making their speech more intelligible, at initiating communication, at rewording and rephrasing and repeating their utterances were not always successful. There was much guesswork, and little control. They spoke of their reactions to the communicative failure as wearing them down, as exhausting, and as maddening. They also used words like "failure", and expressions like Parks' *"emphasises my disability"* (Parks, 2, 66).

I asked myself how it was possible for the participants to maintain the effort of communication, and there were times when they could not. They were unable to maintain the effort when they were tired, ill, or emotionally excited or upset. They were unable to maintain the effort at the end of some of the interviews although they wanted to have more to say. If the participants could not maintain the effort to communicate, and the experience of failure was so common, did the participants have sufficient resources to protect themselves from hurt and harm, and from starting to believe that it was not worthwhile communicating? The answer, it seemed, was that there were times when coping was easy, and other times when coping was challenging. Tiny answered this question in part by explicating what it meant for her to cope. At the time of this interview, Tiny was experiencing extreme pain (Tiny, 2, 34-41):

Tiny *It is a battle, Karen, this disability. I find it more difficult to manage as I get older. I say manage and not accept. I can never accept this… that is too final. But manage. Accept means, no, I manage… it means I can explore more options but I cannot ever accept this… (unintelligible 2s) … older*
Karen *Accept this as you get older*
Tiny *And hope… (unintelligible 3s)… it will improve*
Karen *Did you say that you lose hope?*
Tiny *As I get older. When you are younger you wait for things to get better and then you think things are going to improve and no I am older in the (past?)*
Karen *Hope?*
Tiny *Lose hope… at the moment you can hear I am not in a… I am in a negative (state?). At the moment I am battling with being CP. I don't mean I wish I was able-bodied. I could be CP but I wish I had less CP and could (unintelligible 3s) walk a bit*
Karen *So you wish you had less CP so you could do things like walk a bit?*
Tiny *Ja*

### 4.4 Being powerless

In many communicative contexts, the participants had reported that they were powerless. This powerlessness came from the lack of recognition by others of their being communicative partners. The participants often could not say what they wanted to. They could not do so because they were not permitted to by others, such as Tiny's mother walking away from her when she did not want to have a conversation about a sensitive topic. They were powerless when they chose to keep quiet. In the following excerpt, Tiny described her disappointment at being excluded from a social activity but also her resignation that she could not retort (Tiny, 3, 84-90):

Tiny *Then they say things like "oh, it's a pity you can't come"*
Karen *So they feel sorry but they don't do anything to help?*
Tiny *Ja*
Karen *And you can't say anything?*
Tiny *No I have to hold back. I can't express what I think or how I feel*
Karen *Because?*
Tiny *Because that's how it is*

Ellie also described how it was best sometimes to keep quiet in some of the scenarios that she described. Serena chose to keep quiet and not initiate or contribute because she felt unable to participate due to the speed and pace of the interaction. Timing made her powerless. Timing rendered Parks powerless. Parks knew that his speech deteriorated when he was intent on saying something, and so he often put off speaking until a later stage. His having to *"put it off and wait until another time…it's cos I'm unintelligible in those circumstances"* (Parks, 2, 111-112) made him unable to achieve his communicative goals. He was shorn of his power in these moments.

Being respectful also rendered Lebo powerless. Both Lebo and Nic spoke of situations in which they were not permitted, by cultural norms, to stand up for themselves. Lebo said, *"No, I just keep quiet. That's the way it is. I must hold my tongue. Respect"* (Lebo, 1, 70). They had to abide by the customs that stopped them, for example, as young men from speaking to an older person before being invited to speak. They were prevented from arguing with their mothers and fathers, or with people in authority, because it was not acceptable. Both of them described scenarios in which the issues at hand were directly attributable to disabling experiences, things that able-bodied people would not encounter. And yet they could not voice their opinions. Lebo did not speak to older people because he did not want them to have to make the effort to communicate with him. He said that that would be disrespectful. He said that older men always spoke to him by directing the conversation through his mother, or spoke about him. Nic did not experience this but said that he avoided conversations with people in authority because of the difficulty that he had, and so he allowed others to speak on his behalf. His "voice" was lost.

Like Ellie, Parks was guided by his deep Christian beliefs, which served to protect and support him, but also to prevent him from being assertive. He wanted to argue with his father. Ellie wanted to tell people off for being rude to her or for laughing at her but they both reported that they held back because of their belief in being Christian. As Parks said, his relationship with his father had improved over the years *"a bit, but I still find it, I can't really be… I can be open to my dad but his way of thinking and my being a Christian conflict a bit"* (Parks, 1, 81).

Ellie experienced powerlessness in many situations. Ellie experienced a kind of domination by her friends, family and work colleagues whom she said thought that they acted in her interests, but which hurt and angered her. She did not have the communicative skills to stand up for herself. She also said that she did not always have the energy to deal with situations that were emotionally taxing for her. The good intentions of others might have been unwelcome but she had few communicative resources to call on so as to state her desires and wishes. Hence, Ellie's communication impairments rendered her powerless.

### 4.5 Being with disabled people

The participants had lived with being labelled as disabled. Some of them lived in institutions that were for "physically disabled people" or "people with cerebral palsy". They were in the company of disabled people all day, in their work contexts and in their residential lives. Nic, Seamus, Serena and Lebo worked on a daily basis in employment centres for physically disabled people. They too were surrounded by disabled people.

Ellie avoided being in the company of disabled people. She said, *"Well I've never, I've had disabled friends and one, I think she's passed away. (Friend's name) and I contact one another when we want to know something, you know and um, you know that's how I am. I don't think I'm better than they are, but I just want to be away from them, not always sitting with disabled people. I really do. And this is where sometimes, I even clash here, because I say, 'you can do it now move on, you know. And I don't want you to be with me, just go and find yourself a seat somewhere', you know"* (Ellie, 1, 4).

Ellie's explanation for why she avoided being with other disabled people was that there was simply no need to be with them. She said that she wished to interact with everyone, and did not want her impairments to define her. She became irritated when people would encourage her to select the company of disabled people because she felt that in that way they were labelling her: she saw herself as a person, not a disabled person. Tiny, on the other hand, sought the company of other disabled people. In her descriptions of the high expectations that people had of her, Tiny wished for more contact with disabled people (Tiny, 2, 159-160):

| | |
|---|---|
| Karen | *Do you think it's because you are in an able-bodied world?* |
| Tiny | *Oh, for sure. The older I am I realise that if I was only with other disabled people they would know and they, and we could all support and understand each other. I would be happier because then I would push myself at my own pace and the expectations would not be so great. I really feel strongly about this* |

## 5. Submerged identities

I came to see the identities of the participants as being submerged beneath a multitude of contextual, situational and personal influences. Some of the participants, like Lebo and Serena, were not able to express their identities verbally, but their identities were also not revealed through their actions and their behaviours. The expression of who we are comes through in our choice of how we think and behave. We see identity in expression through aspects of our lives such as our choice of clothing, our ways of walking, our ways of speaking, and the things that we choose to do. In looking to construct the picture of the participants' communicative identities, the data revealed how submerged their personal identities were.

In a memo that I wrote after an interview with Lebo, I wrote in my diary:

> I was frustrated today in trying to determine who Lebo is as a communicator. He seems confident, but I am not sure that he is being himself, just the Lebo who is talking to a White female, older, researcher. I can't base my research on intuition, but I don't think he can talk to me as he would if he were talking to a man, a Black person, or a buddy. So which of his voices am I representing in my research? Is this really Lebo?
>
> I cannot get to the bottom of it because I can't allow my feelings and intuition in here. What I do know is that he is not able to express who he is, even to me in his role as a man who is Black who is taking part in the research of an older White woman who has known him for about a year. Because his communication skills are so limited, and so frustrating and effortful. Imagine what I would know of him if the conversation could flow smoothly!

And after an interview with Serena, I wrote:

> I wonder if this research is real. I seemed to be in charge of what she was saying. She initiated more than in the previous interview, but I still was the one to interpret, to do all the actual talking. Her gestures are still unspecific for me. Her typing is slow and I interrupt her all the time. Am I representing her? Is it her voice that I am hearing or the voice that I think she is?
> Is this all about me or is it about Serena? Actually, who is Serena? Can she tell anyone?

### 5.1 Limited choice

The participants sometimes had little choice over the kinds of things that express identity. They wore shoes that were easy to get on and off; they wore clothes often chosen for them by others. In one of the participants' descriptions of a very personal relationship in which she could not engage in pillow talk, she expressed how she had always dreamed of having black, sexy, lacy underwear strewn over the floor on the way to the bed like in the movies. Instead, she had her lover undress her, and fold her sensible beige underwear in a neat pile next to the bed. This reminded me of the disabled dolls in the Barbie group, Share-a-Smile-Becky's, who in contrast to the gorgeous, sexy Barbies, are dressed in tracksuits and sensible shoes (Garland-Thomson, 2002). The participants were limited in their choice of personal belongings and activities because of their limited finances. Parks had to limit his physical activities which were very much part of his identity because they drained his financial resources. He loved being a physical man. He loved to participate in sports and firmly believed that keeping fit helped him to remain independent. However, he could not follow through on his desire to participate in sports because he simply could not afford it. Hence, he could not always be what he wanted to be.

In the excerpt presented above, Parks described himself as being *"high maintenance",* wording that is often used to describe people who spend money on clothes and shoes, and who are needy, requiring attention from others. The word is often used in association with women (Urban Dictionary, 2012). Analysed discursively, Parks' choice of wording to describe himself speaks to a construction of himself that is not masculine, contradicting the picture of masculinity and independence that he tried to portray for the world and to himself. This tension between how he described himself versus how he portrayed himself makes one suspect a degree of vulnerability in terms of Parks' self-identity, which was put to the test when his disability was in question.

Similarly, Seamus' desire to be a social person over a beer in the evening with his mates was impossible to realise and so his very being was submerged beneath the institution's construction of how he had to live.

## 5.2 Choosing words

Identity is revealed through the choice of the words that we use. There is literature that has identified the passivity of people with cerebral palsy as communicative partners. Pennington et al. (2009) summarised the research on language development in children with cerebral palsy, illuminating that parental conversations with children with cerebral palsy differ from those with typically developing children. The conversations of parents with their children with cerebral palsy are generally not casual but have a particular purpose; parents take more turns than the children; parents introduce most of the topics, use command and high level questions, and control conversations to prevent breakdowns. Their children with cerebral palsy tend to be passive, use communication for a restricted range of functions, use mostly yes-no responses, make few requests and provide very little information.

Hence, one has to question whether the participants in this study had a sufficiently flexible use of language, and a rich enough vocabulary, to be able to express their identities through what and how they communicated. Furthermore, the participants who used alphabet boards or a VOCA chose their words selectively. They had to select a few words to communicate their ideas, whereas people using oral speech use many more words to express an idea.

Lebo could not express his identity easily at work because he was the only Black man in a workshop of White colleagues. He was comfortable with them but could not speak his home language to them. Nic had to depend most of the time on photographs to express his ideas. The photographs were still, although he wished to communicate action. Moreover, he needed to speak about the photographs so that his ideas would be communicated, but he was trapped if he could not provide his communicative partner with a clue if he did not have a photograph. Consequently, his ability to express his identity was limited to a large extent, to images that he captured, and his limited communication. At least, however, they were his own photographs that he ascribed meaning to rather than pre-printed pictures from a computer programme. This personal meaning helped to reveal Nic’s identity to some extent.

Hence, it would seem that the participants’ true identities were submerged beneath their limited linguistic abilities and linguistic choice.

### 5.3 Silence

Mary’s silence submerged her identity. She expressed that it was her choice to remain silent, but I began to consider whether she was indeed in such control of her communication or whether there were some additional factors at play. Mary was unable to vocalise at all. She had access to AAC but had rejected it. She was literate, and wrote well but did so, in the interviews I had with her, if I asked her to write but rarely used writing spontaneously. Mary agreed to be a participant in the research and was given opportunities to leave the research if she wished, but she did not. She therefore agreed to communicate with me. Mary’s silence was a result of her extreme difficulty with expressing herself, as well as not bothering to communicate with people with whom the effort of communication was too much. However, her silence might have been due to her lifelong experiences with being hurt by communicative partners who did not recognise her as a partner worthy of being communicated with.  Mary’s silence matches what Sinason (2010) referred to as “mild opportunistic secondary handicap” (p 20). Sinason, a psychoanalyst, referred to secondary handicap as a condition in which the “primary handicap” is made worse by exaggerated defence mechanisms. When people are aware of their limitations, they come to be aware of the impact of their impairments on their lives. To protect themselves from this realisation, they develop secondary handicaps as a defence mechanism, to defend themselves against suffering. For Mary, silence – the most extreme form of communication impairment – may have reflected her reaction to the repeated trauma that she had experienced throughout her life as communicative partners failed to connect with her.

### 5.4 Locus of power, resistance and identity

Tiny was prevented from arguing with her mother because her emotional state caused her speech to become more unintelligible. Her mother would walk away from her, telling her that they would talk about the issue later, once Tiny had calmed down. For Tiny, her mother’s walking away meant that she had lost the power of the moment. The thoughts that she wished to express at that moment, as well as the emotion that she wished to express, were trapped. Tiny described how, in these arguments, she behaved in such a way that made her more impaired, and drew attention. She said, *“I flail my arms and make a big noise and my voice goes all loud and squeaky… she can’t walk away, it looks like I’m an epileptic…”* (Tiny, 5, 101-107). In this way, her emphasised impairment provided her with a defence mechanism against the hurt of being controlled, of not being able to express herself, and of not being able to deal with powerful emotions in the moment. Her identity as an able communicator, then, was submerged by her defence mechanisms. Sinason (2010) questioned whether the exaggerated behaviours that disabled people display are, in fact “a terrible caricature” (p. 101) of the original impairment, used by the disabled person to hide who they are.

Perhaps, however, these behaviours were not defence mechanisms, but were the opposite. It is possible that these behaviours were very powerful significances. They turned the situation into one that was most unusual, that absolutely did not fit the script of what typical communication is expected to be (Paterson, 2012), and in so doing, returned the power of the communicative exchange to the participants. In a way, Tiny used her impairments, exaggerated them, turning them into powerful forms of resistance. These performances acted as her “weapons of the weak” (King & Horrocks, 2010) which served her well.

## 6. Conclusion

Communicative participation entails one being recognised as a communicative partner, having permission and skills to enter the communicative exchange as a communicator, and then to communicate. The participants in this study saw themselves as disabled, and although their communication difficulties were severe, they did not identify them as being the core of their personal identity. The findings also show how identity is transient and fluid, depending on context. The overall understanding that I gained was that the participants recognised disablism, but did not always have the skills to deal with this. They were emotionally affected in that they became angry, frustrated, and hurt.

They were in a vulnerable status as communicators much of the time. In some instances, they were unable to express who they were, and for some, the on-going hurt of communicative failure and disablism led to a need for exaggerated defence to be in place which hid them even more. To communicate in social interactions, one needs to see oneself as an equal communicative partner, but self-recognition of being of an equal communicative status was not always evident.

The participants' stories pointed to the lack of recognition, their difficulties with communicating, and their constructions of their communicative identities having being influenced by lifelong experiences. Throughout the interviews, observations and my analyses of the data, it was apparent that communicative participation is not a fixed, static, entity that can be described in one point in time. Instead, the participation of the participants in the communicative world varied. In the next chapter, I present the last of the four theoretical categories, dynamic participation that demonstrates this fluidity, transience and variability through time.

# CHAPTER NINE: DYNAMIC PARTICIPATION

## 1. Introduction

The fourth theoretical category that was constructed from the data was that of dynamic participation. Throughout the interviews, observations, and analysis of the transcripts, I became aware of the dynamism, transience and fluidity of the communicative participation of the participants. Space and time are not fixed dimensions, and communicative participation happens in these changing dimensions. The inductive thread that led to the construction of dynamic communicative participation is illustrated in Table 10.

In the previous chapters, the results that were presented illuminated the dynamism of communicative participation. The results have shown that communicative participation was different in different contexts, with different people. It varied depending on the communicative skills of the participants. Their communicative participation was influenced by the technical support that they had, as well as the support that they were given in their home environments. It was more successful at some points in the participants' lives as opposed to other points. Although the coding of the data showed transience and change in many ways, so as to contain the presentation of the results, in this chapter I will present the idea of dynamic communicative participation with reference only to the lifetime contributions to communicative participation. The participants described how their communicative participation changed over time in their lives, and spoke of the lifetime influences on their communicative participation.

There is a remarkable paucity of information regarding the trajectory of communication development and difficulties experienced by people with cerebral palsy (Levin, 2008). One of the sensitising questions that I used for this research was "What are the issues that you have experienced through your lifetime that have influenced your communicative participation?" I was concerned that the participants would not be able to recall their childhoods and had considered asking their parents or siblings to participate in the research which has been done in previous research (e.g. Dew et al., 2011; Wickenden, 2011). However, I elected to depend on what the participants themselves told me. The reason for this was my growing acknowledgement through the research process of the representation of voice. Asking others to contribute to their lifelong histories might have exacerbated the participants' feelings of being voiceless, of having people speak on their behalf.

There were a few things that I thought about when analysing how the participants recalled the past.  Firstly, I did not focus on the past as the topic of any specific interviews, but rather tapped the memories of the participants throughout the interviews. So, whilst talking about a topic I would ask, ‘has it always been like this?” or “how did this come to be?” As a result, the discussions about the participants’ pasts were always linked to the discussions about their present being. I also became aware of the emotional reactions of the participants as they recalled their pasts, and was concerned about the bias that these feelings would bring to their interpretations, and their representations of their pasts. I was also concerned about the influence that their positioning socially had on what they told me. These concerns, however, reveal the very factors that need to be taken into consideration in any theory of memory that is to be useful for grounding this discussion, and in light of this, I have grounded the discussion that follows in the intersubjective, embodied perspective on memory proposed by Prager (2008)

Prager rejected interpretations of memory that propose that the past is always constructed through the present, because they create a chasm between the past and the present. He also rejected theories that posit that the past is the anchor of the present, which he said did not allow for the past to interact with the present. He suggested, instead, that memory is constructed through the intersection of the past and the present, that the one informs and shapes the other.  However, he also emphasised that research has shown that aspects of memory are resilient, and that there are certain experiences that are constructed on original meanings and do not get distorted by present interpretation.

Prager proposed that social and cultural factors impinge on how one remembers, in other words, that memory is socially, culturally and historically embedded. Prager also considered the memory of people as being in dialogue with others, and so memory, in his theory, is intersubjective where one remembers oneself, and constructs memories of one’s self, in relation to others.  In Prager’s theory, remembering is an embodied process, in which memories are inscribed in people’s bodies through emotion. He suggested that the motivation to remember, to share memories with others, is a result of this emotionally inscribed experience.

Table 10

*Inductive thread to dynamic participation*

| Focused codes | Category | Theoretical category |
|---|---|---|
| Inconsistent<br>Improved<br>deteriorated | Developmental changes in communication impairments | Dynamic communicative participation |
| Poverty<br>Segregation<br>Language | Apartheid | |
| Parental communicative support | | |
| Segregation<br>Access to rehabilitation<br>Communicative opportunities at school<br>Support for families<br>High school<br>Boarding school<br>Friends | Schooling | |
| Decisions regarding occupational choice<br>Attending college<br>Living at home<br>Being at home with nothing to do | Young adulthood | |
| Being unprepared for the future<br>Fearing the future<br>Avoiding talking about the future | The future | |

## 2. Developmental changes in the communication impairments

Some of the participants spoke about the changes in their communication through the years.

### 2.1 Inconsistency

Parks related his communicative participation to his intelligibility. As a young child, he had been markedly unintelligible, but starting in his teenage years had undergone surgery and was then much more intelligible. The effectiveness of the surgery waned over time which had a profound effect on Parks in many respects. He lost confidence, withdrew from social contact a lot more, and was distressed. He underwent surgery repeatedly, and every time this happened, he went through phases of depression and uncertainly to renewed confidence and happiness.

Tiny expressed how her life was affected by her health. Tiny had significant health issues all her life. She had orthopaedic issues and experienced tremendous pain which had progressively worsened over time. Tiny's pain had affected her communication throughout the years. She described the effects of pain on her emotions, as well as on her ability to communicate. At times in her life she had been on medication which affected both her mood and her body, and this affected her communication. Tiny used the term *"enemy"* in relation to her speech. Tiny had said that her speech was relatively less impaired than all her other motor skills, and that she depended on having good communication skills. However, Tiny's speech intelligibility fluctuated significantly. She said that when her speech was clear and intelligible and when she was healthy, she could communicate relatively easily, but when she was ill, her communication let her down. She stated, *"It's my enemy. It's there for me and then it turns on me (laughing)* (Tiny, 4, 145).

### 2.2 Improvement and deterioration

Some of the participants reported an improvement in their speech through the years. Beauty, Tiny, Parks and Seamus reported that their speech had become increasingly more intelligible, and as a result they were more confident in speaking. However, they were not always sure that the increase in confidence came only from being more intelligible, but from their increasing confidence as they matured as people over time.

Nic was the only participant to voice some concern over deterioration in his communication. He thought that he was less intelligible at times, and put it down to weakness. He said that he tired more easily than when he was younger, needed to rest more often, and that speech was more effortful at times.

## 3. Living through Apartheid in South Africa

### 3.1 The effects of poverty

Lebo, Nic and Seamus had experienced the effects of living in poverty, although Seamus' family was relatively well-resourced and both his parents were employed. Nevertheless, they lived in a poor area, and his family shared their resources with the extended family. Lebo's parents always included him in social activities, but he said that this was not always possible. For example, until he was well into his twenties, he had never attended a funeral. In Black South African culture, attendance at funerals is considered essential if one knew the person who passed away. Furthermore, families travel to the homes of people who have passed away where they stay for a few days while participating in the rituals surrounding funerals, paying respect to the person who has passed away as well as the family. It was not that his parents wished to protect him from the gravity and sadness associated with death, but that it was very difficult to have access to cemeteries given the lack of decent roads and the unavailability of transport during the years that Lebo grew up in Soweto. "*The roads are bad, you know, and ja well, I just stayed at home. Even now, but sometimes I go*" (Lebo, 4, 244). Similarly, Nic was excluded from many of the activities that his family took part in because of the lack of accessible transport. Hence, growing up, they were deprived of many of the social activities that children experience simply because of mobility issues and those affecting physical access.

Seamus' family had radios and television, and his mother enjoyed reading, and so Seamus was exposed to literacy from a young age. His mother read to him throughout his childhood, but all the books were in English. His mother always read in English, and did not interact with him in his home language while reading. Lebo's parents were literate but did not engage in reading for leisure. His mother had woman's magazines occasionally but never shared them with her children. " *She had Cosmo. They were by (?her) bed, under the bed. She loved those magazines. She , it was her private, yoh, (?personal)"* (Lebo, 4, 301). They had a television set and Lebo was placed in front of the television for many hours while his mother did housework.

### 3.2 Segregation on the basis of race and disability

Segregation, the core tenet of Apartheid, had a profound effect on the participants. The Black participants experienced segregation in terms of the race and their disability. As described previously, Lebo went to specialised schooling; was better educated than his peers; was bilingual; and was fully literate. These benefits of segregation came with a price in that Lebo was separated from the children in his neighbourhood. He had to hide his skills from his peers in order that he be accepted.

Nic experienced many difficulties with segregation in terms of schooling. There were no local schools that served children of colour, and so he had to leave home. He had to reside in boarding school throughout his childhood, and trips home were rare because of the costs involved in transporting him. So, he lacked intimacy in communication, and had little support from adults in terms of learning to communicate.

He described his school as very conventional, based on strict hierarchies and principles of Christian National Education[25]. Adults were authority figures and rarely engaged with the children on a social level. They gave instructions and directives, but rarely engaged in conversation with the children. He had close relationships with his peers, many of whom were communicatively disabled themselves.

### 4. Persistent parental communicative support

The participants spoke about the dominance of their parents in their lives in their growing years. Parents took on the role as advocates for their children, often providing support with regard to the participants' social interactions, including communicative support. Conversely, their support also served to isolate the participants, and impeded the development of their communicative skills.

Parks spoke about the powerful role that his parents played in establishing his identity as a competent person, always expecting him to try hard and learn to become independent. In this respect, they encouraged him to participate in activities, and were intolerant of any indication from him that he felt unable to achieve the goals that they set for him. However, as a child, Parks' speech was unintelligible to most people, and his mother acted as his translator. Although he was told that he needed to be independent, this independence was not possible because of the extent of his unintelligibility as well as the fact that no alternative means of communication was made available to him. Much of the time, Parks' mother translated for him, but did so in a way that expressed what Parks was attempting to communicate, but she would supplement the conversation. Parks interpreted this as most acceptable in that he did not see his mother's "additions" to her translations, the supplementation of the conversation, as contrary to what Parks would wanted to have communicated. His mother had

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[25] *Christelik-Nasionale Onderwys* (Christian National Education—C.N.E.), as expounded in the *Beleid* of the *Federasie van AfrikaanseKulturele Vereniginge* (Federation of Afrikaans Cultural Societies),in February 1948, aimed at establishing the Nationalists in power forever by indoctrinating all children in Nationalist ideology from the nursery school right through beyond the university or technical college (Dubow, 1991).

communicated like this throughout Parks' life, and he found it to be a supportive means of communication.

This excerpt illustrates the issues that he faced (Parks, 1, 71-77):

Parks *There were only about 5 people who could really understand me*
Karen *Ok so at the age of 17 there were only about 5 people who could understand you*
Parks *Ja, but my mom was one, but my dad wasn't one. He always needed my mom to interpret*
Karen *Your dad needed your mom to interpret for you*
Parks *Yes*
Karen *Did that affect your relationship with your dad at all?*
Parks *I think it has. My mom was more for me, and then my dad tried to counteract it, so that (unintelligible 3s) isn't always (unintelligible 2s) people with disabilities, I think that impacted my relationship with my dad*

Mary's parents had acted as her translators throughout childhood, but unlike Parks' experiences, Mary's parents had not only translated for her, but did not always communicate what Mary intended to say. This was apparent in the use of the VOCA that Mary had as a child. She said that her mother programmed all the information. She described a scenario in which her mother would programme in Mary's daily news which she was expected to share with her teacher and classmates every morning during routine "news time". Mary communicated to me that what was programmed to be communicated to her peers were her mother's ideas, and not hers. Although her mother occasionally attempted to get Mary to express her own ideas, she assumed that what she had decided to enter into the VOCA was what Mary wished to say, and for years Mary accepted that this was how it was done. She never thought to question it, or to ask for it to be different. Throughout her teenage years, her mother spoke for her, and translated Mary's gestures. Just how this lifelong experience of having her "voice" owned by her parents affected Mary is hard to tell. Her communicative passivity might very well have been influenced by her lifelong role of a person whose most intimate communicative partners spoke on her behalf.

Nic, Serena and Lebo spoke about their dependency on their parents to act as communicators for them. Nic said that not only was he unintelligible as a child, but that he found it very difficult to learn to communicate. Similarly, Lebo said that he did not think that that he had developed adequate communication skills as a child because no one expected them of him. He said that he was treated as a baby and just like his parents took care of him physically, they treated him like a baby in respect of his speech. They rarely spoke to him, and most of the time, he was not expected to participate in a conversation. Serena’s parents spoke on her behalf, and Serena acknowledged that much of the time, her parents spoke their thoughts as if they were hers and she was not given much opportunity to correct them. She, like Mary, assumed that this was how communication happened, and it was only in early adulthood that she realised that she could correct her parents, but she said that they persisted with their own translations even if she corrected them. She said that this irritated her, but she had very little contact with her parents and so as an adult this did not concern her any longer.

On the other hand, Lebo said that his parents, with whom he lived all his life, had always spoken instead of him, and that he had assumed a subservient conversational role all his life. He said that in the culture of his home and community, people who are older than oneself, particularly one’s parents, are considered worthier of speaking, and wiser than a child, and it would never have occurred to him to question them. He said his awareness of this came to him only as a young adult, and that there were many times when this dominance over him hurt him, and made him feel that his opinions were being nulled, but that it would have been extremely offensive to his parents, and his father in particular, should he have voiced his disagreement. Hence, the intersection of cultural norms of conversation and disability are evident in Lebo’s experiences of learning to communicate.

Beauty also depended on her parents to act as her translator throughout her childhood, but her description of her experiences was very different from those of Mary, Serena and Lebo. Beauty’s parents acted as her translators throughout her childhood, but Beauty was able to indicate to them precisely what she wanted to say. She said that her mother and father, and later her sibling, respected her “voice” and that she was able to indicate to them if they were translating something that she did not intend to communicate. Her family members were tolerant and always expressed only that which Beauty wished to communicate. In this respect, her parents and sibling co-constructed communication, and so here, Beauty’s parents acted as “animators of talk”, fully acknowledging Beauty’s role as the author of her own talk. In the terms of Simmons-Mackie et al. (2004, cited by Purves, 2009, p. 915), Mary, Serena and Lebo experienced their parents speak “instead of” them, whereas Beauty’s parents “spoke for” her.

Some parents acted as gatekeepers to their children’s communicative opportunities, particularly in relation to being with them in the public. Tiny was excluded from many activities, because of her mother's difficulties with acknowledging that Tiny had cerebral palsy. Furthermore, Tiny's siblings were many years older than her – there was a significant age gap between her and her youngest elder sibling, and so she was excluded because of her age. Tiny described how her social activities in childhood were mostly with her school friends, and most of the time, these interactions were at school only, but that she was not included in many of her family's social activities. She was not included in most social activities in which her mother participated.

Reliance and dependency for communicative purposes on their parents had persisted through the participants' lifetimes. Hence, communication was a challenging experience in terms of the communicative demands of some contexts, and parents still continued to play a role. The participants expressed longing and loss with regard to when their parents were no longer available for communicative support. Ellie's parents had passed away and her brother lived far away. She described herself as having come to depend more and more on her pastor and members of her church, but missed being able to rely on her mother in particular, in challenging communicative contexts.

Tiny's relationship with her siblings was particularly problematic and is illustrated in this excerpt (Tiny, 4, 100-116):

Tiny *And I think also its fear*
Karen *Fear?*
Tiny *Yes, they fear that if they get close to me and get involved with me that they will have to look after me for the rest of my life*
Karen *Gee, you 're saying something very important there*
Tiny *M, I know that's why they avoid me. I just wish they would talk to me about it*
Karen *And they don't*
Tiny *I know I am right but it's a guessing game. I know that this is what they are thinking but they haven't spoken to me*
Karen *Have you ever tried?*
Tiny *No I am not brave enough*
Karen *You seem very brave...why*
Tiny *Because it will lead to a whole family (unintelligible 2s)*
Karen *So it will become a big family issue?*
Tiny *Yes, things always do and then there is shouting and they shout at me and I can't (get to it?)*
Karen *So they often avoid discussing these topics and you say it's fear*
Tiny *Yes, they don't want to be straddled with me for the rest of their lives. They keep their distance*
Karen *That is sad isn't it?*
Tiny *Yes and they could really talk with me about it and we could come to a solution*

As their parents had aged, or had passed away, to some extent the participants' siblings had taken on a more involved role in their lives. The involvement of siblings was not always easy. The participants expressed concerns about being a burden to their siblings, as well as fears about the siblings having to take over a more intimate and supportive role in their lives. For example, Tiny said that she felt that her siblings avoided her because they feared having to take over her mother's role one day.

## 5. Schooling

### 5.1 Segregation

Despite the drawbacks of segregated schooling, the participants described the appreciation that they had for many aspects of this segregation. Beauty was full of praise for the segregated system in her very early years, saying that she was fully accepted, her needs were met; and she had access to high quality, regular multidisciplinary intervention. She had opportunities to make friends who were disabled and who therefore did not judge her. She said that the school environment was structured in such a way that its ethos was one of acceptance and there was no tolerance for any form of discrimination on the basis of disability. This ethos helped Beauty to create her sense of worth and self-confidence.

### 5.2 Access to speech-language therapy and other therapies

The specialised schools offered rehabilitation services including physiotherapists, occupational therapists, speech-language therapists, and often allied personnel including psychologists and social workers. As Tiny said (Tiny, 2, 151-153):

| | |
|---|---|
| Tiny | *Remember, I went to (name of school) and we had the most wonderful therapy. The school was not so good there at (name of school) academically but it was, there were wonderful therapists… (name of speech therapist) and them you see they accepted us. They had expectations but they knew how the cp affected us. The therapists knew cp.* |
| Karen | *Oh yes, they were good* |
| Tiny | *They did push us and they expected a lot but they never pushed us over the edge. Like (name of therapist). I used to drool and now I don't and (name of therapist) worked with me and worked on the drooling and were, you see, there, and we were both determined to make this, and she expected and she would never push me over the edge* |

Tiny expressed her view that the school system created an environment in which the teachers and therapists understood cerebral palsy. For Tiny, this was a very important part of her childhood as expressed in this conversation.

Parks was somewhat critical of this ethos, expressing this opinion that because the children's limitations were accepted, they were not expected to be independent.

### 5.3 School-related communicative opportunities

The schools for children with cerebral palsy, both those for Whites as well as those for Blacks, provided many opportunities for communication and for the development of communicative participation. Children were encouraged to speak and to participate in school activities. The specialised schools provided opportunities for the children to experience a range of communicative opportunities. Many of the schools ensured fairly good access to school transport such as school buses, and schools arranged outings to places of interest; they provided many opportunities for involvement in sports with the support of the South African Sports Association for Physically Disabled[26].

### 5.4 Support for families

Tiny, Beauty and Serena spoke of the important role that the segregated schools played for their parents, and Lebo alluded to this as well. For parents, these schools offered tremendous support. The parents were assured that their children were educated in environments that were nurturing, accepting and as Serena typed, *"emotionally safe"* (Serena, 3, 57). In most cases, the participants as children had had a number of rehabilitation personnel and teachers involved with their lives and thus had the support from a team of personnel. Many times, parents were involved in aspects of the school, such as in fund raising and other communal school activities. The participants felt that specialised schools offered their parents a lot of support, which in turn helped the parents to be more accepting of their children's impairments, and furthermore, the environment gave the parents opportunities to learn skills to cope. Parks was critical of this support system, though, in saying that the parents were provided with support, but that the school system did not help the parents to cope with their children beyond the boundaries of the closed, specialised, personalised school environment.

### 5.5 High school and boarding school

High school (from age 12 to 13 years) brought about many life changing experiences for the participants. The schools for children with cerebral palsy did not all offer high school, and the children had to change schools. For some, this meant leaving home and going into a

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[26] The South African Sports Association for Physically Disabled was started in 1962 and has coordinated activities for disabled children and adults since then. It was fairly progressive with regard to racial policies although it was subject to the segregation laws of the country at the time. ( See http://sasapd.org.za/?page_id=209 for the history of this organisation).

residence. Parks said that this was a very good move for him in that he was forced to become more independent. He had to manage to get by without the assistance and support that his mother had given him all along. However, boarding school was very painful for Parks in some ways. He was unintelligible to most people most of the time, and so he was left alone and chose, many times, to be alone.  He participated in peer activities only because he *"wanted to get out of the hostel"* (Parks, 3, 163). Without the communicative support of his mother, he became lonely, and although he tried to join in with his peers in activities such as youth camps, it was extremely effortful for him because of the extent of his unintelligibility, and he avoided them wherever possible. He described his happiest times as the weekends when he went to say with his parents' friends.

Beauty was made very aware of her being "othered" in the transition to high school. Beauty's parents were determined that she should have the opportunity to attend a school that would offer her a full academic exit level qualification. However, Beauty did not qualify in terms of her diagnosis of cerebral palsy for entry into such a school. Beauty had to go through a series of evaluations to prove that she could cope – even though the school that she was applying for was for physically disabled children (e.g. amputees and polio survivors) but not for children with cerebral palsy.

## 5.6 Friends

One of the limitations of specialised schooling was the segregation from able-bodied peers. Lebo said that his isolation as a child had a significant effect on him. He was not at school with children from his neighbourhood, and so he did not socialise with his friends from school outside school. He said that his communication with his friends at school was comfortable: they had a shared language; they accepted one another's' impairments. He said that in interaction with the children in his neighbourhood, he always felt the outsider because they did not share experiences.

Lebo could not talk to his friends about school activities, and they seemed not to have the same references. Furthermore, Lebo was excluded physically. His mother would not allow him to go in his wheelchair on the poor roads as she was concerned it would get damaged. Instead, he sat in the doorway of the home and watched the children. Sometimes the children would acknowledge his presence by shouting greetings to him.  In addition, most of the time, he was not included in conversation when he was with them physically.

Exclusion occurred on multiple levels. Consider this excerpt (Lebo, 2, 107-129):

Karen *Lebo, tell me about your friends in the neighbourhood, what did you do with them, did you talk to them? I know you watched them and you say they spoke to you*
Lebo *No*
Karen *No?*
Lebo *No, you see I am with them so they talk to me*
Karen *Was it conversation?*
Lebo *No, well, they talk*
Karen *And did you talk?*
Lebo *A bit*
Karen *Did they understand?*
Lebo *No . No, so they talk, and talk a bit and I , well, I am understood but I say and talk and then you know*
Karen *It's hard to put this into words, hey?*
Lebo [Laugh] *Not really*
Karen *Ok, let me ask, did you talk to them a lot?*
Lebo *Not really*
Karen *And did they talk to you, like we are talking, I say something, you say something, then it's my turn?*
Lebo [Laugh] *no*
Karen *No?*
Lebo *Um*
Karen *Did they say things to you every now and again?*
Lebo *Ja*
Karen *Ok, I think they spoke to you to include you but it was limited*
Lebo *Exactly*

The school system both facilitated and impeded the development of friendships for Parks. It was rare, for all the participants in this study, to have had outside contact with the people with whom they went to school. They developed the friendships within school. At school the children had little time to associate with one another – they made friends within the classroom and interacted with one another at break. However, Parks had to be fed by a caregiver at break and so his opportunities for interacting with others were limited in this free time. Serena concurred and said that her free time with friends at school was very limited.

Despite the literature stressing the importance of communicative competence for the development of social skills (Owens, 2012), this research leads one to question whether the route to socialisation for children with significant communication difficulties might be different. The participants reported that they had tremendous support and facilitation by teachers and therapists in the specialised schools; that the environment in which they made friends was very accepting and non-judgemental; and that they made friends through activity and shared experiences rather than through talk. For all the participants, having difficulties with speech in the very early years at school seemed not be have been a problem in relation to making friends.

The later years in school brought about different experiences. Beauty attended a school for physically disabled children. In this school, she had less support from adults. Her speech was problematic, but she said that she thought that making friends in high school was about personality and not ability. On the other hand, Parks experienced significant loneliness through his high school years, and thought that his not being able to communicate with his peers played a very significant role. He said that knowing how to establish close relationships was something that he lacked and he attributed it to not learning the skills in his teenage years, which he was sure was due to his being markedly unintelligible.

Seamus said that he had become aware of his communication difficulties in his teenage years and that this, together with his physical impairments, led to his having experienced many difficulties with making friends. He spoke of the critical role that his parents played during his teenage years. Although he attended a specialised school, his parents made purposeful attempts to help him to befriend teenagers who were able-bodied and who included him in their social activities, and encouraged him to participate in youth activities outside of school. Although he found it difficult, and at times wanted to give up, his parents encouraged him.

## 5.7 Language issues

The medium of education in the specialised schools for Black children was English or Afrikaans, but the children in the hostels and schools came from a variety of language backgrounds, and so they spoke a variety of languages. Nic said that the language that the children developed among themselves was a unique one, tailored to fit the children who were in the school, a mixture of English and Afrikaans as well as a number of vernacular languages. They also used Makaton signs in this pidgin language.

This excerpt from a conversation with Lebo shows the complexity of the issue of the language and schooling in the Apartheid and immediate post-Apartheid years (Lebo, 2, 143-179):

Karen *What language did you speak?*
Lebo *Our own*
Karen *Your own?*
Lebo *Ja, they (come?) and we do mostly Zulu but then we must also use the signs, you now I learned Makaton signs, you know them?*
Karen *Ja*
Lebo *Well, I use Makaton and all the kids also, and we used to make up our own, laughing, like boys, oooh!*
Karen *So you made up your own too?*
Lebo *Mm*
Karen *Rude ones?*
Lebo *Ha, you know me too well [Laugh]*
Karen [Laugh] *And what about English?*
Lebo *Ja that also*
Karen *So you spoke a mixture of everything*
Lebo *Ja, the (unintell 5s )*
Karen *But it worked for you?*
Lebo *I-*
Karen *-I find this very interesting*
Lebo *Mm*
Karen *So it was a language that you kids spoke – did the adults understand?*
Lebo *Ja they also*
Karen *Did you speak it to them?*
Lebo *Um I don't know, no I think we spoke to them in Zulu*
Karen *And?*
Lebo *Also Sotho*
Karen *And what language did you learn in?*
Lebo *Zulu and a bit of Sotho, but they were supposed to teach English*
Karen *And did they?*
Lebo *Ja*
Karen *So your education was in all kinds of languages*
Lebo *Ja*
Karen *And which is your best?*
Lebo *English*

## 6. Young adulthood: restricted communicative opportunities

Young adulthood (18 – 25 years) was a period of uncertainty, loneliness, and frustration for some of the participants.

### 6.1 Decisions about occupations

The decision about future occupation was one that all the participants battled with. Firstly, the participants had not all completed an academic programme at school, and they therefore could not get into educational programmes that they desired. In addition, none of the participants had the funds to pay for post-school education and were not able to access scholarships. For some, educational facilities were not able to accommodate them in terms of their physical needs.

### 6.2 Attending college

Beauty, Parks and Seamus attended colleges that accommodated people with physical impairments and were able to make some choices about their professions. They qualified and were able to secure employment in disability-friendly contexts. Tiny enrolled at college and took courses although she did not manage to qualify, and was not able to get a job. These participants made friends at college and then at work, although they found it difficult to socialise outside of work.

Only as an adult in her late 20s, was Beauty able to secure funds for further education. Beauty was able to go on to university education and during the course of this research obtained a second degree.

### 6.3 At home, with nothing to do

Mary, Tiny, Ellie, Nic, Serena, and Lebo did not have choices. They stayed at home after their school days ended, unemployed and with nothing to do.  Within five years, Mary, Nic, Serena and Lebo attended "sheltered workshops", places of work that were established for disabled people, that offered menial work and very limited remuneration. In her early twenties, Ellie secured a job.

### 6.4 Living at home

All of the participants lived at home in the early adulthoods. They remained friendly with people from school but found that it was difficult to keep contact because they could not talk on the phone, and could not easily get to visit one another because of their limited transport options. Over time, the participants who stayed at home and did not study or work came to depend on a smaller network of people, and described their siblings' friends and their parents' friends as being their friends. They rarely interacted with people of their age, and not with people who were disabled. They described feeling more isolated as young adults.

## 7. Into the future

A striking theme to arise in the research was the absence of talk of the future.

### 7.1 Unprepared

Beauty said, *"You have to do this research. We don't know what's going to happen to us"* (Beauty, 6, 2). Beauty expressed the fears that she had because she had no idea about *"what* *happens to people with cerebral palsy”* (Beauty, 6, 14). Similarly, Seamus said that he had no idea if he was going to be able to keep up his skills.

Serena spoke of how she did not know that she was going to live in an institution and was unprepared for it when it happened. Nic also spoke of how he had not been prepared for the future, and was feeling uncertain of whether his recent move to an institution was going to work out. He said, *“If this is not right, then what? We (haven’t?) spoken this. Mom* (showing picture of institution) *you see, you see, mean, you know what I mean?* (Pointing repeatedly to picture on his phone of his room at his new residence). *This, this, this is where I live now. And and* (pointing to picture of girlfriend on phone) *who knew, my mom (laughing) I have a girlfriend. Who knew? Mom, well, if I can’t live here anymore then, what we do? (unitell 4s). Now me and mom must talk about this, because what is going to happen. I, well, we, you see,* (showing picture on his phone of a room at the residence)” (Nic, 1, 37).

It seems that throughout their lives, the participants had focused their energies, as had their parents, siblings, teachers, and friends, on the management of their day to day concerns, but had not spoken about the future.

## 7.2 Fear of the future

The uncertainty of the future was expressed as fear by some of the participants. Tiny told this story (Tiny, 2, 64-68):

| | |
|---|---|
| Tiny | *When I was about 4, my sister went out with her boyfriend and I asked my mom, “when I will be old enough to go, you know, out with a boyfriend.?” And she said, “when you are old enough” and then I asked her, “ but I can’t walk mom, will he carry me?”* |
| Karen | *Oh my* |
| Tiny | *Ja and I haven’t had a boyfriend for a long time. I don’t. Um. I have never had a boyfriend ever. For a long time. I miss that* |
| Karen | *How did you feel when you said that to your mom when you were four?* |
| Tiny | *It made me scared of the future and I am still scared of the future* |

## 7.3 Avoiding talking about the future

There had been very little talk of the future with the participants. In some cases, the topic of the future was avoided. Tiny put this down to two reasons. In the first instance, her mother and refused to think about the future because she could not cope with the idea. In addition, Tiny said that her mother had repeated experiences of her plans being thwarted. She stated, *“Like moving out of home. She does not want to plan. She never wants to plan because like we were planning she was planning on us going to the UK but I fell and we had to cancel our* *plans because I broke my leg, my femur, and so we could not go and that was awful but so since then she does not plan and she doesn't like to plan. She (ways?) (always?) she will deal with things as they arise* (laugh)" (Tiny, 3 10).

## 8. Evolving into disability

Garland-Thomson (2002, p. 21) wrote that "we evolve into disability", and the experiences of the participants over time show just how their communicative participation depended on the interaction of their bodies with history and the environment. Repeated experiences led to the participants behaving in certain ways and in believing in certain things. An example that stood out through this research was Parks' father's repeated caveat to his son to take heed of the hard world out there. This message from his father, repeated throughout his life, had affected Parks' way of life. However, history also shows the changing influences that were possible over time. He felt that his communicative participation as an adult was easier not only because of his improved intelligibility, but also because he had a more charitable and open attitude to people, and was also more forgiving of their disabist attitudes.

In addition to his religious beliefs, he, like Mary, had adopted a fairly distancing attitude towards his communication and to his being disabled. He avoided communication; he rarely confronted people who excluded him; and he made it clear that this was a learned response from a lifetime of disablism. He had described himself as *"putting up walls"* (Parks, 3. 259) to protect himself from repeated experiences of disablism, from being laughed at, shunned, excluded and avoided. He said that it was easier for him emotionally to keep his walls up and that he was "*I think passive because I wouldn't have been able to cope with the resentment if I gave that to myself"* (Parks, 3, 259).

Lebo, who had experienced the effects of Apartheid on every level – from living in poverty, to being denied equal status, to rehabilitation schooling, the language of learning and work opportunities – had been able to participate in society more freely as an adult because of the changes that he had experienced over time. Nevertheless, it was the repeated lessons of his history that made him feel subjugated, less worthy, and deserving of – in Fraser's (2003) words – the inequality of his status. Throughout his life, Nic had learned that he was "special", the word that his mother used to describe disabled people. Nic said that this word was used in both a positive as well as a negative way. He was not sure if his mother used it as a euphemism to hide her own discomfort with regard to disability, but she referred to him as her "special son" repeatedly. She would introduce him as "my special son" to strangers. He was brought up feeling different, unlike others, and although he had contact with other disabled children at school, in his home environment, he was identified as special and different. As I identified in my analysis of the participants' identity, Nic, as an adult, had come to understand disablism and did not see himself as inferior and damaged. However, he acknowledged that his mother's words had a lifelong effect on him, and his relationship with people, particularly able-bodied people, was influenced by his expectation that all people saw him as "special". He said that as a child he lived up to the label, and depended on his mother and on other adults in the world, and that it was only as a young adult that he realised that he could be more independent, and could enjoy his independence.

Beauty's parents had not allowed her to see herself as different. She was brought up with a strong message that she had to live with her impairments, and try harder. However, her understanding of being disabled came through her schooling which was always specialised and which excluded her from interacting in the mainstream, and from her growing realisation that she was unable to do many of the things that able-bodied people can do. She realised that she had not done ice skating and speech and drama and ballet like other little girls. As a teenager she did not go shopping with her mom to look for clothes, and did not go window shopping with her girlfriends. Her understanding of being disabled came through her own realisations of the experiences that she had been denied.

## 9. Evolving as abled: Being able differently

Who one is, how one communicates, how one chooses to communicate through and with others, depends on patterns of learned behaviours that build up and which change over time. Through their life experiences, part of which included their deprivation and their lack of opportunity, the participants had worked out ways to take part in life's activities. The activities were enacted very differently from the way that an able-bodied person with intelligible speech might enact them, but they were highly evolved and successful means of being. Some of their working it out was conscious, but most of the time, they had come to be what they were through adaptation and through perseverance.

The participants had been denied the opportunities to participate in many of life activities throughout their lives. The did not get to experience drama, ballet and ice skating, eating at the table with the family, playing with the children on the soccer fields, going to movies, going out with the family, or going to funerals. However, although they were denied access to such activities, they had experienced life in different way. Serena introduced this idea to me in one of the early interviews. Serena was passionate about sports, and had been all though her childhood. She said that she had learned about sports by watching it, and had learned that she did not have to do something in order to enjoy it. She loved ballet although she had never been to a ballet and had never danced. For Serena, television and the internet had provided her with the opportunity to take part in all these activities. Her sports were the avenue to much social interaction and conversation. She invited people to her room to watch sports with her and to discuss sports. Serena's inability to communicate easily was overcome by her communicating in a non-verbal way. She included people in her communicative world by her openness and willingness to befriend people; her warmth towards people; and generosity to share her time and space. In addition, as discussed earlier, Serena had developed skills to counsel the people that she lived with. She had never been through counselling, and had never done a course on counselling. Her inability to speak had led her to learn to listen well. People came to her because she listened to them. Although it was very hard for her to express her thoughts and ideas, through sharing her time, space, and self, as well as her willingness to listen, Serena had developed a communicative world and was able to participate in this world on her own terms.

As I got to know the participants more, and became familiar with their communication patterns, it struck me that they had all developed highly sensitive, nuanced, sophisticated ways to communicate. The participants were able to communicate their ideas in ways that were energetic and artistic. They used pauses, facial expressions, arm and leg movements, laughter, eye movements, hand clapping, head shaking, and exaggerated stares. They grunted and squealed and laughed, all of which carried much meaning. These behaviours communicated meaning and also communicated emotion. The participants knew when to keep silent and were able to let me know when to listen, when to ask for clarification.

The participants who used AAC had developed a remarkable ability to select words. They rarely wrote or typed sentences, but chose selected words. They did not have the luxury of talking through an argument, but had to select one or two words that would communicate their meaning. This degree of linguistic sophistication was striking. Nic's love of technology and his adept use of it to complement his communication had developed over time. Despite tremendous difficulties with the fine motor requirements of the technology that he used, Nic had developed strategies to make the technology work for him. Nic's use of his camera was creative, and his pictures were personal and added to his "voice". Mary's silence communicated powerfully her resistance, her determination and often the meaning of what she wanted to say. Parks' involvement in physical activities spoken to his awareness of his body as a man, and communicated a resistance to being feminised. His social activities that allowed him social interaction with restricted oral communication were his successful way of managing his participation in a difficult, communicatively demanding world.

It struck me that my reality of communicative participation was represented by very closed and limited interpretations of communication that come from my medical model background, my traditional linguistic background, and my personal experiences of communication. The reality of communicative participation for the participants was represented by their alternate forms of communication, unlike oral communication and unlike the communication of intelligible people. It required tremendous effort, flexibility, and emotional stability to be able to deal with the effort and the experiences of failure. It required time, effort, familiarity and flexibility on my part as a communicative partner, but resulted in authentic and reliable communication much of the time. Its creativity and artistry offered the participants ways of communicating in social interactions in ways that were unexpected to me as a researcher. There is no question that the participants faced tremendous barriers to communicative participation throughout their lives, and that they continued to experience problems with communicative participation, but their adaptation and construction of their communicative worlds, informed by their pasts, demonstrated resilience that makes one look closely at, and question, normative analyses of communicative participation.

## 10. Conclusion

Having lived with communication impairments all their lives, the participants recalled some of the aspects of their lives that affected their communicative participation as adults. It was clear from their descriptions of their communication over time that communicative participation is developmentally acquired, depending on both ability as well as opportunity through the lifetime. They experienced different patterns of change with regard to their speech intelligibility over time. The participants reported that they were often denied experiences that would have helped them to develop the skills to participate.

Living in South Africa posed challenges to the development of communicative participation for the Black participants, but also for the participants as disabled people who were segregated and othered. In addition, their relationships including their need for and dependence on communicative support affected how they participated in life. Experiencing the effects of barriers such as access to the home language as a medium of learning and social communication played an important role in the participants' histories which impacted on their communicative participation as adults. The participants described their becoming disabled over time by their repeated experiences of disablism as well as their repeated experiences of communicative failure. Their lifetime experiences were characterised by significant issues in being able to make themselves understood, as well as deprivation, exclusion, failure, the experiences of which contributed to the participants becoming artistic and able communicators, participating in life's activities in unexpected but highly evolved and relatively successful ways. They also experienced success in many aspects of their lives, including in their communicative participation, which moulded them, forged their identities, and influenced their lives in innumerable ways.

The changes in communicative participation through the lifetime demonstrate the dynamism, the ever-changing and flowing nature of communicative participation. A wide range of processes and mechanisms come into play, and have different impacts on communicative participation.

We now turn to the final chapters of this study, in which I integrate the results of the study, and on the basis of the four theoretical categories, present a model of communicative participation.

# PART FOUR: COMMUNICATIVE PARTICIPATION

## CHAPTER TEN: SILENCE AND A DYNAMIC RECOGNITION-THEORETICAL MODEL OF COMMUNICATIVE PARTICIPATION

### 1. Introduction: Silence

Distilling the data through the coding processes resulted in a descriptive analysis of the communicative participation of the participants in this study. In this chapter, I take that description forward so as to establish a theoretical understanding of the descriptions. I had immersed this study in a pragmatic constructivist approach to grounded theory (Charmaz, 2006), and taking an interpretive approach, sought understanding of the descriptions and not an explanation. I looked for patterns and connections which using gerunds facilitated (Charmaz, 2006) and in so doing, followed the recommendation made by Charmaz to seek meaning in action. Actions helped me to see sequences and processes. I re-visited the data, re-read the memos, re-read the four chapters of results, searching for the common thread in the themes.

I have shown that communicative participation, a particular form of inclusion in social life, is vulnerable to cracks at many levels within the communicative process. It is indeed the cracks, the breakdowns, the flaws, in the multiple facets of social participation that illuminate the ideals of communicative participation, the needs of people who are communicatively disabled, and the levels at which emancipation can be attempted. I was inspired by Garland-Thomson (2011b, p. 605) to seek a term, a single word that would “invoke an entire, complex, critical conversation”. The term “silence” symbolises the cracks in inclusionary processes. The word silence carries a powerful message. It refers to the negative and although this could be interpreted as a deficit-based interpretation, that is indeed not the intention. On the contrary, in line with the emancipatory ideal of critical disability studies (Meekosha & Shuttleworth, 2009), the intention is to embrace the silence in order to understand it and change it. Like auditory silence, the silence identified in the communicative participation of the participants in this study was not absolute at all times; the there was no all-or-nothing about the cracks. For example, sometimes the participants were fully recognised as communicators, at other times they were not. At times, they had successful communicative support, and at other times, this was mildly lacking and yet for some, often, it was severely lacking. The silence, then, was evident in degrees. Despite there being many successful communicative opportunities for the participants with communicative partners who were supportive, positive, and comfortable, the evidence showed that true communicative participation remained vulnerable. This was one of striking features of the study in that it showed the fragility of communicative participation. In addition, the ephemeral nature of communicative participation for these participants was evident. The layers of silence that were apparent in the communicative participation of the participants in this study are illustrated in Figure 4.

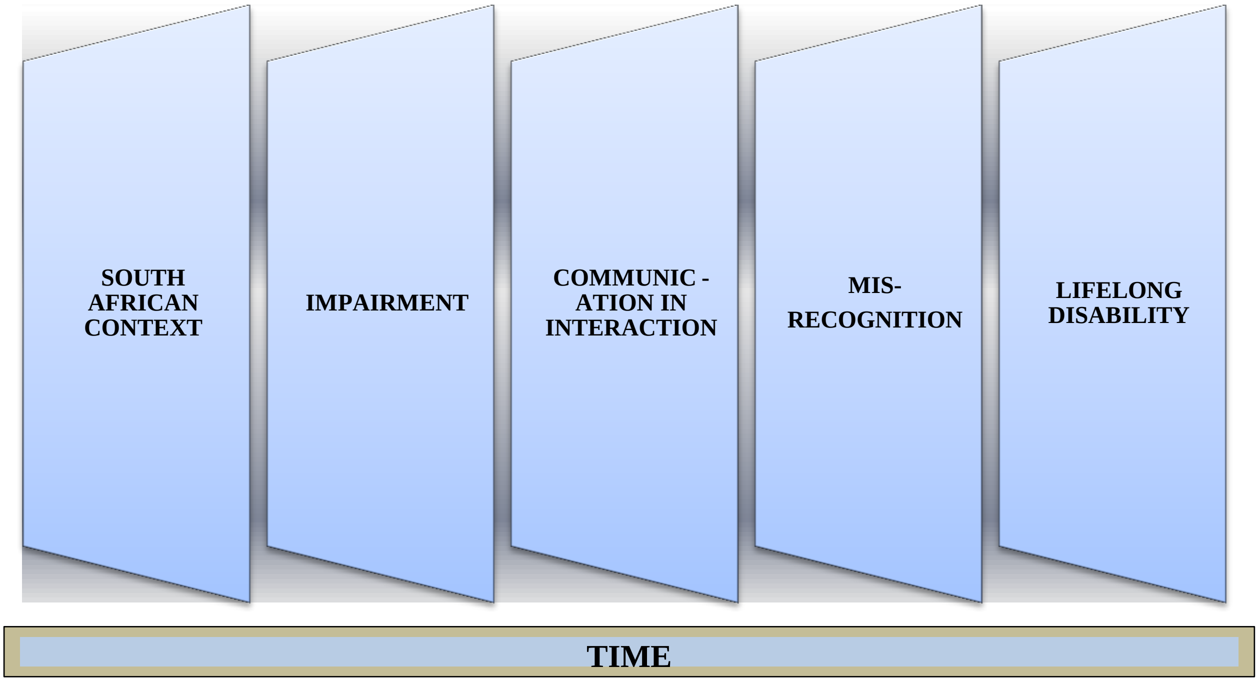

*Figure 4.* Layers of silence

## 2. Silenced by context

The contextualisation of disability has been suggested as crucial to understanding disability (Meekosha, 2008). In the face of the challenges posed by living in South Africa, where accommodations in the broader socio-political frame have not changed all that much, and are unlikely to change quickly, impairments matter. The experiences of the participants in relation to their communicative participation were undergirded by the fact that they live in South Africa, and grew up in South Africa. Many features of this research reflect a particular South African experience, as shown in Figure 5.

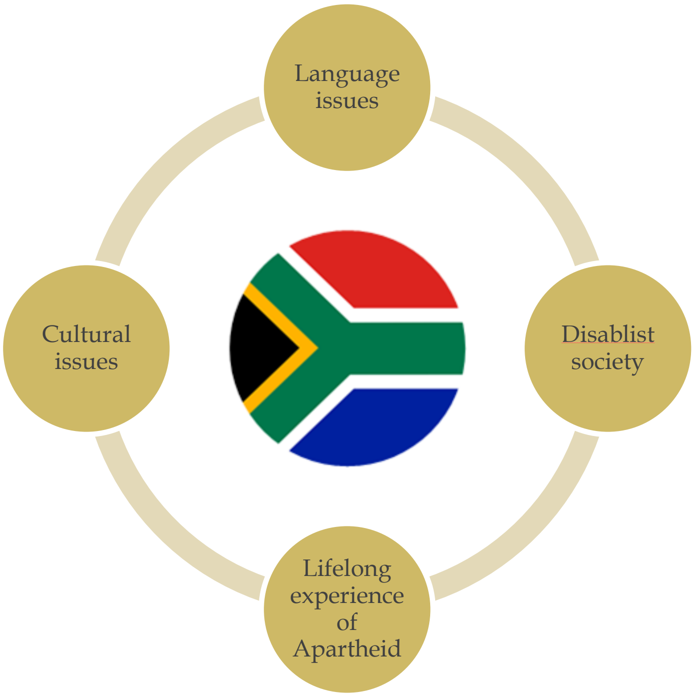

*Figure 5*. Silenced by context

The participants in this study lived in a society that had not adapted all that well to the political rhetoric of disability rights. This was evident in their descriptions of their current living opportunities. Some were able to find work in institutions for the intellectually disabled only. Some lived in institutions in which their autonomy and freedom were significant curtailed. Despite a tremendous amount of rhetoric in South Africa regarding the protection of the rights of disabled people, this rhetoric had not been translated into reality for the participants in this study.

As a result, for the participants in this study at least, there has been little change since the democratisation of the country in terms of distributive justice for disabled people and South African society remains disabist on the whole. The lack of support in terms of resources was apparent. Moreover, they described attitudinal barriers from people that speak to the persistent disabling attitudes in South African society. Under these conditions, the communicative impairments mattered.

The data showed that the experiences of marginalisation, segregation, isolation and discrimination that the participants faced, and continue to face, that are a result of unique issues in the socio-political policies of South Africa are prominent contributors to communicative participation. For example, the fact that residential facilities for disabled people in South Africa are still institution-based unlike many countries that have abandoned this form of residence and adopted community-based living, renders the experiences very different from others. The economic marginalisation exemplified in the lack of employment opportunities, as well as in extreme phenomenon of intellectually competent people having no option but to work in sheltered employment facilities that are designed primarily for people with intellectual disability.

The multi-linguistic backgrounds of some of the participants are not unique to South Africa, but are somewhat unusual particularly given their communication impairments. The participants had experienced unique negotiating language issues in the school system. They had issues managing accent and dialect when speaking in a language other than the home language while at the same time managing intelligibility issues related to dysarthria. They navigated through issues related to communicating about themselves from a marginalised, vulnerable position in which they did not always feel entitled to communicate as a result of their being disabled being intertwined with their cultural representations of themselves in communication (such as a Black disabled person communicating to a White doctor).

Communicative participation was influenced by cultural issues. The respect that Lebo was expected to show to others; his inability to attend funerals which marked him as disabled; and the cultural construction of him as a product of magic are not unique South African experiences, but are unlike the experiences of people described in the communication sciences literature to a large extent. Furthermore, his experiences contrast with those of Beauty whose opportunities and points of access contrasted with his. The multi-cultural nature of South African society, in which people from all kinds of backgrounds share in the experience of being disabled, calls for communicative participation to be examined differently. There is little homogeneity in the experience of communicative participation, exemplified by the South African experience.

The history of South Africa, which played a significant role in the experience of communicative participation for the participants, is unique. Although there are racial disparities in the experience of disability, the racial disparities in South Africa differ. Apartheid was a brutal, enforced political ideology that subjugated the majority of people in the country. It resulted in lifelong experiences that, for the participants in this study, had been felt throughout their adulthoods as transformation particularly for disabled people, is so slow.

### 3. Silenced by communication impairment

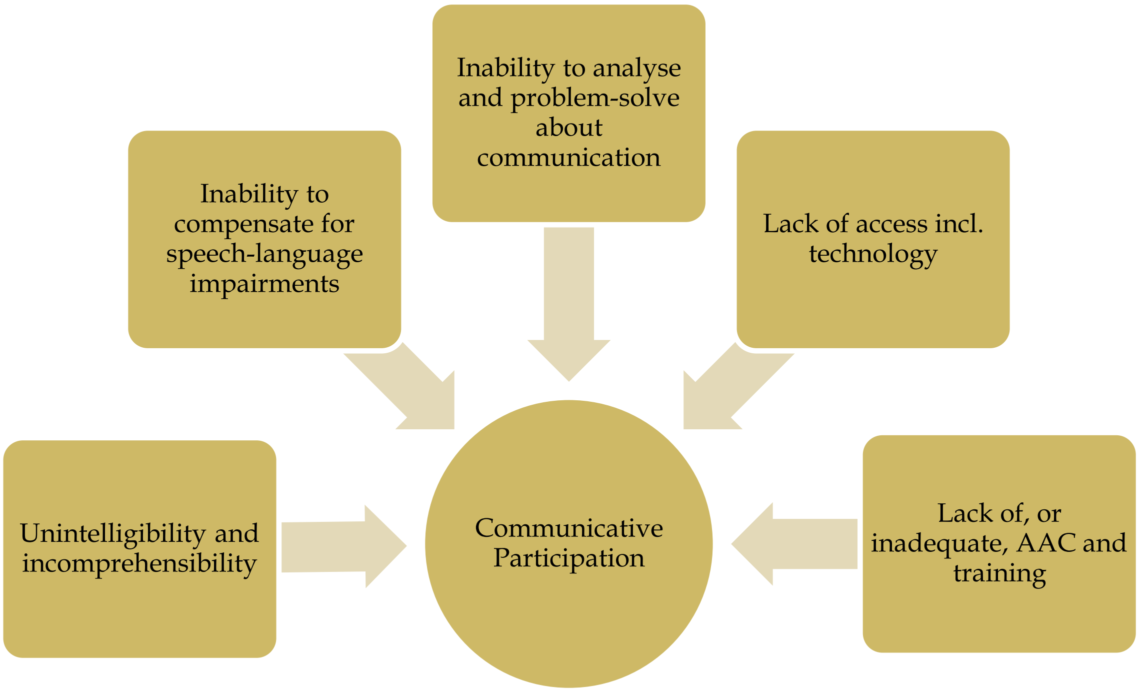

*Figure 6.* Silenced by communication impairments

The participants articulated the powerful role of their speech and language impairments on their communicative participation. This is shown in Figure 6. As Hughes and Paterson (1997, p. 335) wrote of their understanding of impairments, the participants' impairments were not only experienced, but were the basis of their experience..

Theories of disability which remain idealistic and are not rooted firmly in the lived reality of people's lives are bound to silence them. Paterson (2012) stated that how people who live with speech impairments manage in the world is "about the extent to which 'competence' is negotiated in the everyday world" and "this negotiation hinges on carnal factors" (p. 166). There is simply no replacement for the fluid, rapid, oral communication process, and in the absence of environmental support – be it space, time, technology, or accommodating attitudes – the impairments got in the way and limited the participants from being able to take part in and construct the life-world in which communication occurs.

In general, the participants were denied support to mitigate the effects of their communication impairments. The real world of the participants of this study was a disablist one. In terms of the capabilities approach, the participants were not able to access and use support that would allow them to communicate in social settings in the way that they valued because they did not have the freedoms to do so. They did not all have regular, accessible, affordable, modern technical support in the form of AAC, cell phones, and computers. As a general rule, their rights to participate and their rights to communicative participation were not acknowledged by able-bodied members of society. The communicative partners were often untrained and lacked resources to be able to communicate with the participants. These examples show that in the absence of technical, institutional, and interpersonal support, unintelligibility and incomprehensibility influenced restricted communicative participation. That the participants were not able to experience full communicative participation was rooted in their impairments. In the absence of support, they were unable to compensate for their unintelligibility and for some, their incomprehensibility. The dependency of the participants on their parents for mediated communication were very similar to those described in a study that looked at the experience of mediators (Green, Brightman, & Kassner, 2012) in which parents had a very close relationship to their children, and that these relationships remained close. In addition, the researchers found that there was a concern by the parents as to who would mediate for their children when they no longer could. A point that they raised, which was not raised by the participants in this study, is that the parents were able to understand and thus translate their children’s idiosyncratic communication behaviours which other people, particularly unfamiliar people, could not.

In chapter 7, I showed that the participants experienced a range of functional communication limitations that influenced their communicative participation in many ways. Rush was a man with cerebral palsy and significant communication impairments whose autobiography, *Journey out of silence* (2005), included descriptions of the typical communication pattern between his mother and himself. His mother communicated with him by asking question after question. Time, energy, non-specificity, frustration, common failure and a host of other feelings, states and actions characterised this pattern of communication. Rush’s communication impairments governed his communicative participation. Although his mother cared for him deeply, was used to his idiosyncratic speech behaviours, and knew him well, communication broke down often, the consequences of which were both dangerous in terms of his health and safety, as well as hurtful to both parties. I have shown examples of the deleterious effects of inadequate communication in a number of examples in this research. Some participants were abused; others had difficult relationships with family members; one broke up a relationship with an intimate partner because she could not whisper to him. Impairments mattered.

The impairments were significant in that they had been part of the participants' lives forever. They had to create ways of adapting, as well as their own ways of communicating through their developing years. In some instances, some of the participants had not learned skills to help them to negotiate the communicative world because they had been blocked from learning these skills because they did not participate in communicative exchanges in multiple contexts. The participants had not had any form of intervention from speech-language therapists since their early teenage years. Like many adults who have lifelong communication impairments, they were a population of adults who have significant communication needs but who were underserviced by the rehabilitation professions, partly because of the lack of available funding, but also because there is a discontinuity between child and adult services (Levin, 2008).

The participants had a lot of difficulty analysing the components of speech so they could not describe to me how they adapted their speech to enhance their intelligibility. Although this improved over time as the participants became more sensitised to the research topic, and I used vocabulary that they could take on for themselves over time, their ability to describe their communicative participation was limited. When I read Linton's (2008) autobiography, *The body politic,* I was struck by the rich descriptions she gave of how she learned to negotiate the spatial world as a wheelchair user after being paralysed in a motor vehicle accident in her early twenties. Granted, Dr Linton is a professor of psychology and a most expressive person, and through her personal story, she expressed how she adapted to becoming disabled, but also how she negotiated the physical world. The literature produced by people with communication impairments illuminates issues surrounding disablement, recovery, and communication. Books written by adult users of AAC (e.g. Creech, 2003; Rush, 2005) speak to the adaptations to the communicative world as competent AAC users in the context of support, resources, and opportunities. With the support of speech-language therapy colleagues at Connect - The Communication Disability Network, Hussey (2010), a stroke survivor who had aphasia, was able to write about his experience of stroke. His article, published in a scientific journal, described the personal meaning of communication in his life. Lazar, who as a young professor of English studies had a stroke following removal of a benign brain tumour, was able to describe her recovery in poetic vignettes (Lazar, 2011), and later analysed the language used in autobiographical texts on stroke recovery which foregrounded particular experiences of stroke recovery that have not necessarily been apparent though scientific research with people with aphasia (Lazar, 2012). Importantly, the once-aphasic authors of these texts had recovered their language skills and were able to express themselves through the written medium eloquently.

In contrast to these rich descriptions of communication, the participants were not able to speak to the difficulties that their impairments brought to their lives in specific terms. This naivety (not unexpected of lay people, and which I have seen in first-year students of speech-language therapy) may have prevented them from being able to problem-solve around their difficulties.

### 4. Silenced by communication in interaction

*Figure 7.* Silenced by communication in interaction

The participants were silenced in various ways in relation to their communication in interaction which are depicted in Figure 7.

### 4.1 Silenced by auditory exceptionality

Reactions to auditory difference have not been explored in the disability literature. On the other hand, bodies that are visually different have occupied human interest for millennia. Exceptional bodies are evident in Stone Age drawings; people with bodily differences were used as display items and as figures of amusement (Garland-Thomson, 1996); physical anomalies are evident in paintings and sculptures (Siebers, 2012); and there is an enormous amount of physical disability symbolised in literature (Garland-Thomson, 1996). There is a well-established body of research which explores the ways in which the disabled body has been used as an object of titillation and what has been termed “enfreakment” (Siebers, 2012). This emphasis on the visual however, may to some extent have defocussed from the ways in which communication difficulties may also lead to enfreaking reactions.

Communication impairments are auditory exceptions. Little is known about how people react to auditory exceptions. There is information about the psychological reactions to speech-language anomalies, but there is no well-developed discourse that unpacks reactions like the staring discourse has done and continues to do (e.g. Garland-Thomson, 2009; Siebers, 2012). Furthermore, communication impairments are often both visual and auditory exceptions. Parks’ speech was not only unintelligible but when he spoke, he did so with associated movements such as head turning, hyperextension of his neck, and hyperextension of the thorax. He had a “primitive rooting reflex” so if his clothes touched his face, he turned his face in that direction and began to suck involuntarily on his clothes.  He also had a “asymmetric tonic neck reflex” so that if he turned his neck to one side, his arms and leg on that side extended. Parks’ speech was accompanied by extraneous movements such as writhing and inconsistent neck movements[27]. These physical behaviours drew attention to themselves and distracted Parks’ communicative partners. Parks was mostly unintelligible, but the associated movements which drew attention to themselves and which distracted his listeners exacerbated his impairments. They made him less intelligible because intelligibility is not just a matter of being able to understand words. Intelligibility depends on the listener’s linguistic sophistication as well as listening skills. One has to concentrate and focus on the

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[27] I have purposely worded this description in classic speech-language therapy terms to emphasise there can be a place for such descriptions in disability studies that do not minimise the depth of the meaning of disablism, but illuminate the need for impairments to be acknowledged and incorporated into disability discourse.

sounds and cut out any distractions. Most of us do this all the time, but when our listening is challenged by noise – like Parks's associated movements – intelligibility is compromised. The auditory and the visual compete with one another.

Impairments are also inextricably linked to preconceived ideas and constructions of normality and acceptability. Tiny said that she often passed for a spinal injury survivor. According to Tiny, her communication was then considered by her communicative partners as more acceptable because they assumed that the problem was due to an accident and that it was no fault of her own, and that it was her spine that was damaged and not her brain. So it would seem that Tiny felt that by assigning her impairments to her spine, her listeners were more able to listen to her. They were not distracted by constructions of her as brain damaged and incapable. In fact, they were more likely to respond to her as one deserving of their attention because of her tragedy and her blamelessness in what another person – a careless drunk driver, perhaps – imposed on her. And what they thought about her influenced how they took the time and effort to listen to her and communicate with her.

A brain damaged person, as described by Tiny, is less intelligible than a person with a spinal injury. This personal story illuminated the degree of inauthenticity that sometimes characterises communicative participation for people who have to prove to the world that they are capable of being equal communicative partners, and cannot be separated from how their impairments influence their communication. The inauthenticity, the concealing the truth in order to make speech impairments match a stereotypical expectation, has a direct consequence on the communicative partner's behaviours. The danger of this inauthenticity, this passing as less disabled, lies in the fact that Tiny's collusion with the constructed requirements of the able-bodied world (Watermeyer & Swartz, 2008) hid her identity, and so who she was became devalued by others, but also by herself.

Superimposed on the listener's ability to understand what is said are the embodied reactions of the listener. We have, it is thought, a biological need to stare (Garland-Thomson, 2009) and we get to understand our embodied place in the world in relation to people who look different from us (Siebers, 2012). But what of auditory difference? Do we "stare" at people who stutter or do we get away? Do we "stare" at people who we don't understand or do we try to escape their company? Do we have a biological need to "listen" or is different speech a warning signal? The reactions of the communicative partners that the participants in this study reported were escape behaviours. Their communicative partners reacted in ways that were exclusionary, and pointed to a lack of engagement, and a determined expression of not wanting to be in the same social space as the impaired speaker. Their listeners did not stop and stare. Instead, they ran away. Communication impairments evoke a different type of embodied response from different, extraordinary bodies that call one, often, to stare.

### 4.2 Silenced by transactional impairment

Impairment is always viewed as based within an individual who is impaired. When one communicates with a disabled person, one becomes communicatively impaired. I think that the only exception to this is if one can communicate in sign language with a deaf person. In all other interactions with people who have real physical, corporeal communication impairments[28], the impairment becomes shared because the so-called able communicative partner becomes impaired in his or her ability to understand or comprehend what is being said. The impairment is temporary but it is very present. I call this “transactional impairment”. The impairment, then, is not situated in the individual, but in the dyad. This has implications for theorising about the location of communication impairment.

In this study, the participants were not able to participate in communicative interactions partly because their communicative partners were impaired and were not prepared for this, and had not received any form of training with regard to communicating with communicatively disabled people. There are exceptionally few training programmes in South Africa that work on helping communicative partners to better deal with unintelligibility or incomprehensibility, and very few effectiveness studies have been published (Bornman et al., 2011; Goldblum & Alant, 2009).

Psychoanalytic interpretations of disavowal are used to explain the reactions of people to impairments. The premise here is that people look upon disabled people as a reflection of their own vulnerability, their own corporeality, and their own fragility. Marks (1999, cited by Watermeyer & Swartz, 2008) showed the problem with disability is that it disturbs the normative individual. The feelings that one might not be attractive, or might have a shameful appearance, or speak in unacceptable ways evoke deep anxieties in people. Marks showed that the ways to disown these feelings about oneself include oppressing and subjugating disabled people (Watermeyer & Swartz, 2008).

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[28] I exclude here purely socially defined impairments such as a person who is able to speak perfectly being deemed of an inferior status and thus unworthy of participating in communication

I would imagine that experiencing transactional impairment invokes a very deep level of anxiety. At once, one is stripped of one's competency, made to feel weak, insecure, and uncertain. One is forced into real experience over which one has little control. This is not only a psychic reflection of one's own vulnerability and fragility, dependency and corporeality. This is embodied, real, felt. It is unpleasant, threatens one's existential security (Thomson, 2004), and is something that is not owned. It forces one to escape, to run from this experience and from these "others" that cause it. This explains, in part, why the participants in this study were excluded, left alone, and marginalised. However, when their now-impaired communicative partners could not avoid them, or could not run away, it was likely that their anxiety of impairment was felt, was tangible and real. As a result, it seemed that they protected themselves by seeing the disabled person as the "other". In this way, the "other" was accorded a status of being lower, and the evidence in this study showed that the participants were accorded a status of being non- persons, which resulted in their subjugation and oppression.

### 4.3 Silenced by time to communicate

Paterson (2012) explained the behaviours of communicative partners on the basis of time being the fundamental commodity that governs communication. His premise was that the communicatively disabled person interrupts the choreography of life. Timing, pace, immediacy, rhythm, and speech are written into the scripts of what able-bodied communication is expected to be. Communication should flow, be quick, and be efficient. The message should be shared in express time, with expediency. Paterson wrote that when the able-bodied communicator is in the company of an impaired communicator, his or her thought is immediately that he or she does not have the time for this type of communication, a type that does not fit the script of what typical communication should be. The able-bodied person is then positioned as one who cannot waste time and so he or she then looks for a more able communicator.

The notion of insufficient time for communication has been raised in research on communicative participation, such as research in hospital settings on the issues facing nurses and their patients who are communicatively disabled (Hemsley et al., 2011). In this study, the participants identified the denial of time as a crucial part of the disablement.

The question that one is led to ask is whether the issue is one of the commodification of time, where time is a feature of the normative script of communication as Paterson (2012) described, whether time is a currency of social capital or whether it is symptomatic of misrecognition. The extent to which the participants were misrecognised suggests, to some extent, that time was but one of the factors that fed the oppression of the participants by the social world.

### 4.4 Silenced by unreliable communicative support

In most instances, communication disabilities disable both partners in the interaction. The ideas of autonomy and independence are crucial to any critical analysis of communication. In and of itself, communication depends on the interdependence of people upon one another. Despite its obviousness, the notion of dependence in the communicative exchange has not been interrogated, not has interdependence been examined within the context of communication disability. By immersing this discussion in notions relevant to critical disability studies, this important problematic has particular relevance for defining communicative participation.

The assumption is that in the typical construction of communication between adults, the communicative partners provide one another with communicative support in order to initiate and maintain communication. Even if a communicative partner is not unwilling to adapt to the needs of a person's impairments, it may be that the impairments are so severe that no environmental adaptation will render the person fully autonomous, or self-determining as a communicator (Brewster, 2012; Hodge, 2007). This type of scenario was apparent with the participants who used AAC which was not able to replace the speed and accuracy, flexibility and effortlessness of oral speech. The need of communicatively disabled people for communicative support is the essence of the communication training programmes that have been on offer for people with communication impairments. However, the participants' experiences of their communicative dependency beg for questions to be asked way beyond the issues of how communicative partners manage the linguistic or pragmatic functions of communication.

As Scully (cited by Hammer, 2011, p. 168) wrote, interactions between assistants and disabled persons do " not *automatically* enhance the autonomy" (her emphasis) of the disabled person. There are many issues that come into play that warrant attention. Questions need to be asked such as, "Who chose the assistance?", "How is the assistance achieved?"; "Is the assistance patronising?"; "What feelings does the assistance evoke in the communicative partners?" and "How is autonomy determined in the interaction?"

Mainstream work on communication impairments does not take into account the full picture of the factors that influence dependency, including those from the psychological, cultural, social, political, economic and environmental perspectives.

Rather than examine the participants' communication from a dependency aspect, the data lent themselves to being looked at in terms of mutual reciprocity. All of the participants rejected the idea that they were dependent on their communicative partners for communication. They acknowledged that they were dependent on their communicative partners' flexibility and time, but rejected the notion that the burden of communication fell to the partners. What they described was an expectation that their communicative patterns were respected. All of them spoke about the tremendous effort that they put into their communication to try to ensure that they were as intelligible and as comprehensible as they could possibly be.

However, as I have discussed earlier, the participants were not always aware of when their communicative partners had not understood them. So, although the participants put an extraordinary amount of effort into their communication, it broke down when they were not able to identify that there was indeed a breakdown. It was at this point that they expected feedback, and often, they did not get this feedback. Sometimes, communicative partners were authentic, but sometimes they were not.

As well as being inauthentic, the participants described their communicative partners as offering communicative support that was uncalled for, and that in fact, interrupted their train of thought or the communication itself.  It has been proposed  that the need to help disabled people – whether solicited or not – results from the anxiety that is invoked related to sensing the deprivation and loss of the disabled person (Watermeyer & Swartz, 2008).

### 4.5 Silenced by inauthenticity

The participants all described the tremendous effort that it took to make themselves as intelligible and comprehensible as possible. The effort of doing this was remarkable. Not only did it take physical effort because of the difficulty that they had with the physical components of speech, but it took focus and concentration as well. As has been discussed, the participants often were not aware of their communicative partners because they were so focussed on getting their message across.

Hence, paradoxically, the participants took care of their communicative partners, and also shielded them from the difficult experience of communication. These behaviours that shielded and protected the able-bodied communicative partner served to guarantee the status of the able-bodied person, but at a tremendous cost to the participants. Watermeyer (2009a, p. 91) stated,

> disabled people positioned as having to 'deny' imputed loss may be at risk of suffering self-alienation relating to a mode of being which is (necessarily, understandably) preoccupied with 'not being' the personification of stereotype, at the expense of exploring aspects of identity and self.

Hence, like many of the experiences reported by disabled people, the participants in this study were denied the freedom to be who they were, to express their authentic selves. Watermeyer's (2009a) interpretation of this is the denying disabled people the freedom to express loss because they live with the pressure to have to protect others from the feelings evoked by being in the presence of a disabled person. As he stated, for people to feel whole is tied to having the freedom to express ourselves and be known by others. In his theory, loss is an essential part of human growth and development, in that dealing with loss is part of everyday life. However, as shown by the participants, the way in which they dealt with loss was often "perverted and distorted" (Watermeyer, 2009a, p. 93), due to the way in which they responded to how they felt that society dealt with them.

Hence, as per Ikäheimo's (2010b) model, not only does A need to see B as having authority, but B needs to see A as having authority. In this case, authority means that the communicatively disabled person views the communicative partner as a trustworthy and reliable person, who shows respect, love and esteem. Inauthentic or intrusive communicative partners are those who cannot be depended upon to be communicative partners, never mind as partners who offer additional support. There is indeed a crack in the reciprocity that is expected in the communicative process. Mary, in the most extreme reaction to this lifetime experience of mistrust in her communicative partners, had come to devalue communicative partners and refused to interact.  It seemed, for her, they lacked personhood.

### 4.6 Silenced by idiosyncratic communication

Another level at which the participants were silenced was in the lack of recognition that they were given for their communicative efforts. Rather than seeing the face pulling, gesturing, eye widening, squealing, leg kicking, grunting and laughter as communicative, these behaviours were seen as calling attention to themselves. Parks was told by people to try to talk with his neck straight but Parks extended his neck and trunk so as to have more extension and thus more air for speech. The constant repetition, circumlocution and purposefully slow speech which some of the participants used to adapt their speech were seen as part of impairment, and not valued for what their purpose was. In Wickenden's (2010) study with youth who used AAC, she too described the value of these idiosyncratic patterns of communication.

Disabled people themselves have spoken about the ways in which familiar people in their lives develop intimate and clear understandings of what they are trying to communicate (Rush, 2005). This is one of the arguments about facilitated communication where it is assumed that the voice of the person being facilitated is not expressed (Paterson, 2012). However, in the light of a clear absence of research, this is a debatable topic. I increasingly learned to understand the participants because I became familiar with their idiosyncratic communication patterns.

Despite my search through the literature through the process of this study, I have found few analyses of idiosyncratic, successful, alternative forms of communication used by people with severe communication impairments. Hydén & Antelius (2010, p. 588) showed that storytellers with communicative disabilities can be "inventive in finding ways of presenting themselves as competent storytellers even though they may have certain problems vocally animating a coherent, structured story". They suggested that often, people with communication impairments are not considered able to tell their stories because they cannot conform to the norms that have been constructed by researchers as to what constitute "normal narratives". Their analyses showed that idiosyncrasies and different ways of storytelling can indeed do justice to the stories that need to be told. There is, however, very little work like theirs that looks to the ways in which communicatively disabled people construct their communication.

## 5. Silenced by misrecognition

The evidence in this study clearly shows that the participants' claims to being recognised as persons were violated, and that the degree to which they were respected, loved and valued in terms of their contributions were sub-optimal.

Disabled people have been shown to be considered of lesser quality in their personhood (Scully, 2008); the present study showed how and the extent to which communicatively disabled people are misrecognised. The way in which the participants were misrecognised as communicators was inextricably linked to the way that they were devalued as disabled people. For example, Ellie's descriptions of strangers going through her home, passing judgement on its cleanliness and orderliness, was demeaning and she was made to feel as if she were of a lesser value than her intrusive visitors, as if their values were better than hers. Beauty's parents had been told when she was a baby that she was not going to walk or talk or amount to anything, and she had lived her life fighting this lifelong prediction of "valuelessness". These lifelong messages of being of invisible, invaluable, and burdensome, in Siebers' (2012, p. 23) terms, identify the participants as "disqualified" in that they were not seen, symbolically, as quality human beings. The evidence in this study highlighted the processes related to communication that denied the participants the status of being persons.

Fraser (2003) defined misrecognition as an "institutionalised relation of subordination and a violation of justice" (p. 29) that "prevents a person from being able to participate as a peer in social life" (p. 29). There is no question that in most communicative life situations, the participants in this study were not able to exercise their rights to equality in their relationships. They were not able to participate as communicative peers partly because of their communication and other impairments, and partly because of the lack of adaptation to their impairments. However, their lack of participation was fundamentally due to their moral claim to being accorded the status of equal peers being challenged.

The dehumanisation of people has been the topic of scholarship for centuries. Dehumanisation has been recognised as the process that underpins moral exclusion. When people are placed outside the boundaries in which moral values apply, they are morally excluded (Goff, Eberhart, Williams, & Jackson, 2008). The negative responses by the social world to the personhood claims of the participants within the context of concrete interactions were so profound, that it could be said that the participants, most of their lives, had been immersed in a communicative world that was beyond " the moral boundaries in which moral values, rules and considerations of fairness" (Opotow, 1990, cited by Goff et al., 2008, p. 293) applied. The moral claims of the participants for recognition – at least in the context of many communicative interactions – were responded to inappropriately. In terms of the theoretical principles underpinning Ikäheimo's (2010) model, the participants were not seen as persons by their communicative partners and therefore could not participate in society. This is a profound notion that supports the use of, and the power of, the word "silence" to characterise this level of breakdown in communicative participation. They were categorised as non-persons, as objects that were not capable of communicating, and their objectification disallowed them the right to communicate, silencing them.

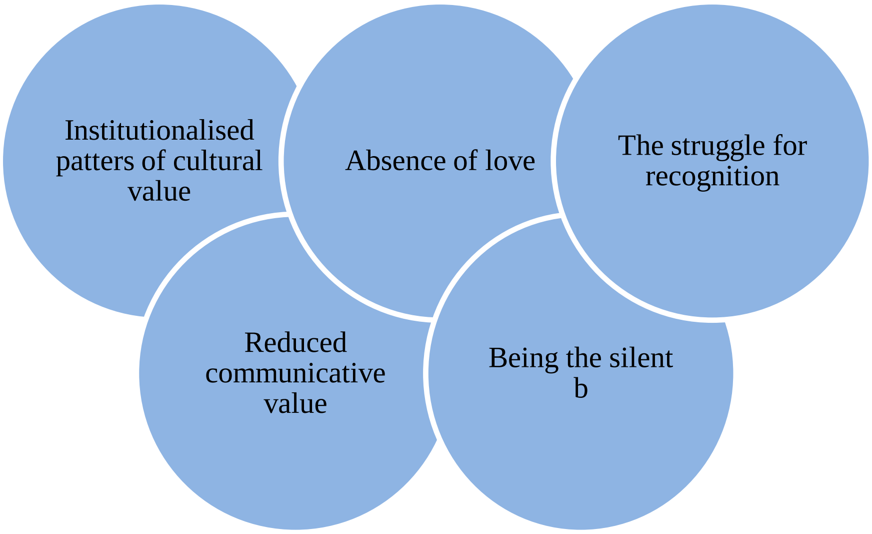

*Figure 8.* Silenced by misrecognition

### 5.1 Silenced by institutionalised patterns of cultural value

Fraser (2003, p. 29) stated that some individuals and groups are denied the status of full partners in social interaction simply as a consequence of institutionalised patterns of cultural value in whose construction they have not equally participated and which disparage their distinctive characteristics or the distinctive characteristics assigned to them.

For decades, the concept of what is culturally and socially normal has dominated the literature. There has been the classic reference to the White, Protestant, male, good looking, sporty, educated, heterosexual (Mollow & McRuer, 2012), but this is an ideal that does not resonate with all groups, and certainly cannot be applied internationally. In response to the difficulty with isolating the precise components of normalcy, Garland-Thomson (1997) coined the term "normate" as "the veiled subject position of cultural self, the figure outlined by the array of deviant others whose marked bodies shore up the normate's boundaries". It is a "constructed identity of those who, by way of the bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them" (Garland-Thomson, 1997, p. 8).

In the social and communicative encounters that the participants had with others, there was clear evidence of the cancelling out of the qualities of the participants, based on the normate's assumptions about the impairments. The participants were reduced  to a "single attribute" (Garland-Thomson, 1997, p. 12). Ellie felt that she had been told that she was 'too brain damaged" to be able to participate in a discussion.  Hence, the judgement of normality for the participants was based on a number of factors, including the fact that the locus of the issue was the brain. The brain is typified in cultural representations as symbolic of intelligence, thought and higher functioning. The participants were rejected on the basis of their perceived deviance from higher thinking. Brain damaged people are culturally represented as infantile and asexual. Seamus being spoken to about his "jamies" (for pyjamas), and Beauty's descriptions of being spoken to as an adolescent typified these cultural responses to the participants.

Lebo and Nic, who experienced the cultural representation of disability as punishment and of having to live with what they considered as being the expression of wrongdoing in the family, experiences which have been described in the literature on interpretations of disability in the South African contexts (Ross, 2011), spoke to representation of disability that differed from the representation of normality in their cultures. Their cultural representation was not only that they were abnormal communicators, but that they were an extraordinary representation of bad and evil, and something magical and spiritual.

Paterson (2012) spoke of communicatively disabled people being denied the opportunities to develop their place in social spaces because they defy their communicative partners' scripts of normal communication.  The participants in this study did not fit with the conventions of communication that they were expected to conform to by their communicative partners. In response, much of the time, their communicative partners acted to gain control. The communicative partners dominated the communication: the participants were unable to take an equal part in the initiation maintenance and termination of communicative acts. The communicative partners controlled topics and acted as gatekeepers.

## 5.2 Silenced by being of reduced communicative value

The participants in this study confirmed that communicative participation depends on communicative partners seeing one another as of communicative value. One of the ways to envision communicative value is to look at it as one of the currencies that contributes to social capital. Bourdieu (1984, cited by Paterson 2012 p. 171) posited that social capital was developed as a notion that spoke to the value that people have in contributing to, and in gaining from, a social interchange**.** Since Bordieu's early work, there has been a significant body of work on social capital, and the notion has been applied to disability (Devine & Parr, 2008; Hall & Kramer, 2009; Holt, 2010; Williams-Whitt & Taras, 2010).

Social capital comprises the resources that are created by relationships, and groups are constructed to produce these resources. People enter networks (in the case of this research, communicative exchanges and networks) so that they can benefit from one another, and have access to the resources of people in their social group. Hence, people enter communicative exchanges in social networks in order to benefit because communicative networks are sources of value for people. As well as enter networks, people create networks in order to benefit from the resources that they can access. Therefore, communicative partners derive capital from the amount and quality of the resources that they can offer and receive from one another in an interchange.

Blackstone and Hunt Berg (2002) developed a tool for the assessment of the social networks of people with communication impairments. The Social Networks Inventory is used to study the composition, density and size of networks as well as also the quality and characteristic features of the communication of both the individuals and their communicative partners and the support provided in and across the networks. This tool was based on the premise that people with communication impartments are at risk of having limited social networks. As has been shown in a number of studies (Ballin & Balandin, 2007; Bryen, 2006; Dattilo et al., 2008), the social networks that the participants in this study described were fairly limited, sometimes foist on them by circumstance. Seamus had his social ties cut by having to move into a residential institution for disabled people; Tiny's family lived in a small town; and Lebo's social networks were very small because of the physical isolation at home when he was not at work. But social networks were also limited by the participants' communication impairments. Parks had social networks in which he participated, but as an outsider, rarely communicating with anyone. He always felt that he was a burden and that he had to take responsibility for his speech, and so his freedom to participate in any given social network was limited. He felt that he contributed little by his being present but silent.

The participants in this study showed that their networks were limited as a result of their reduced communicative capital. Paterson (2012) stressed that people who are communicatively impaired are not considered to have communicative value. They can offer little in the form of communication currency. They cost effort, time, concentration, patience, and comfort. The participants in this study described that they felt that they were a burden on their communicative partners, and that they were dependent on people's willingness and skill to make an effort to understand them. The participants showed how they depended on the resources of their communicative partners. Their functional limitations, their impairments, meant that they were unequal partners in communicative exchanges, depending on the communicative resources of others despite their very active attempts to be as intelligible and comprehensible as possible.

The participants often knew what they wanted to say in an interaction but did not have the skills to do so. Nic's photos were his voice, but sometimes they did not provide enough specificity for the communicative partner to use as a source of reference. The communicative demands stretched the participants' communicative budgets. This phenomenon is well-described in the literature pertaining to the limitations inherent in some AAC systems (McNaughton & Bryen, 2007).

Portes (1998) spoke of the fungibility of different types of social capital, a concept which has a place in the analysis of the communicative participation of the participants. It was clear from the participants in this study that their contributions to their social communicative networks were not primarily communicative per se in traditional terms. At times, the participants used a different form of social capital in order to create and maintain their communicative networks. Serena listened; Beauty used her determination to exploit her super-crip behaviour. When Beauty did not cope, during the times when she could not be the super-crip that she worked so hard to be, when in Williams' (2003, cited by Goodley, 2011a, p. 92) terms, she "corpsed", she gained an enormous amount of sympathy and concern from others. Society continued to welcome her into networks, providing her with credit for those times. Not all of the participants were successful and not all of them had alternative forms of social capital that they could exchange, in part or in whole, for speech and language. In addition, this idiosyncratic use of other forms of social capital to take the place of traditional modes of communicative capital was sometimes successful, dependent on context, and dependent on the communicative partner's flexibility.

### 5.3 Silenced by an absence of love

The stories of blatant abuse reported by some of the participants as a direct result of their not having the skills to communicate effectively, point to the depersonalisation of the participants. Every participant had experienced some degree of verbal abuse. Some of the participants also experienced physical abuse as a direct consequence of their impaired communication. The depersonalisation and was sometimes obvious but most of the time, was more subtle. However, the participants had experienced abuse all their lives. Research on how people define humanness has shown that people define a human on the basis of having complex emotions. It has also shown that people consider the "other" to have fewer, if any, of these unique human features (Haslam, 2006).

Dehumanisation is spoken about in discourse on ethnicity and race, gender and pornography, medicine, technology, education and some other areas of study (Haslam, 2006). The apportioning of person status is a complex issue which remains relatively unexplored. Some social psychological theories speak of the categorisation of people on the basis of their belonging to the in-group or the out-group. The in-group represents the normate. Two forms of categorisation have been identified by Haslam (Bastian & Haslam, 2011; Haslam, 2006). The first is "infrahumanisation" where the members of a category of an out group are considered less human or of lesser status than others. These people are poorer representatives of the normate. The normate represents a group of people who have unique human emotions such as love and contempt. Out-group members have emotions that are shared with animals such as happiness and fear. There was evidence in this study that the participants were considered less human than others, capable of only basic emotions.

The second form of categorisation is "dehumanisation" in which out-group members are viewed as not having human characteristics at all, but are sub-human. According to Haslam (Bastian & Haslam, 2011; Haslam, 2006), there are two forms of dehumanisation. Animalistic dehumanisation involves treating people as sub-human, as not having "uniquely human features" such as insight, cognitive skills, or language. Mechanistic dehumanisation regards people as lacking "typical human features" such as warmth, agency and curiosity. Although the participants in this study experienced both types of dehumanisation, they were all at risk of being considered lacking in unique human features, communication being a uniquely human feature separating one from objects and animals. Hence, communication impairment places one at risk of being categorised as non-person. When one is not considered to have unique features, one is not a person, and one can be objectified. When one is treated as an object rather than a person, one is at risk of abuse (Bastian & Haslam, 2011).

Haslam's dehumanisation theory rests on psychological traits as according one the status of humanness. Honneth's ideas of personhood were somewhat different. Although acknowledging the psychological status making significances, he placed emphasis on moral claims to personhood as well. Most of the time, according to Ikäheimo (2010b), being recognised as persons rests on both psychological and status-making significances. Honneth's (2003) explication of "love" is that persons are able to value themselves in terms of caring about whether they flourish or fail, or to value whether they wish to be miserable or happy (Locke, cited by Ikäheimo, 2010b, p. 82). Sentient vulnerability is to feel pain or be hurt. Eudemonistic vulnerability is to feel happy or miserable, and so the claim to love, the protection of one's eudamionistic vulnerability, is of person-making significance. It is therefore the psychological capacity to be happy or miserable that presents the claim to others. The appropriate response is to be concerned with the welfare of others, but this response only happens if the person who makes the claim is recognised as a person. It would seem that communicatively impaired people are not accorded their moral claim to be recognised as persons.

### 5.4 Silenced by being "the silent b"

Even in the case of communicative patterns that one might not wish to categorise as "abusive", there was evidence of psycho-emotional disablism because the participants were assigned as outsiders. Murphy et al. (1988, p. 237) wrote that disabled people "dwell in twilight zones of social indefinition". They referred to this state of being as "liminality", an inter-structural situation. The participants did not really experience this state in that they were not betwixt and between: instead, they were relegated outside of the polity.

The fact that the participants were able to participate in communicative encounters so rarely, and that most of their encounters were vulnerable to crack, speaks to the "*homo sacer*" analogy used by Reeve (2010, 2012) in her description of disabled people's positioning in social encounters. *homo sacer* was a figure in ancient Roman law who was an outcast, a person who existed but was absent from the polity, a person who had no citizenship. *homo sacer* could be killed but not sacrificed. *homo sacer* was neither part of nor entirely outside of existence. Being in this “zone of indistinction” (Reeve, 2010, p. 204) meant that *homo sacer* had no place, but also was abandoned. The participants in this study were given the status of being outcasts, permitted to enter the communicative space, almost always with conditions being set, and even so, full entrance was rare.

Like the silent b in “lamb”, they were present always, but outside of the spoken world. Living in a state of exception, as present but silent, in which the participants as communicators were placed in most of their interactions must have had an influence on their psychological and emotional development. This study did not probe the psycho-emotional consequences of the participants but there were clear signs of devastating and pervasive effects on the psyches of the participants.

## 5.5 The struggle for recognition

Honneth (2003) claimed that people who are misrecognised feel shame, hurt or indignation. These feelings can be the trigger that show individuals that they are being misrecognised (Honneth, 2003). They are the embodied reactions to the unjust systems in society that prevent misrecognised people from being autonomous. Honneth’s claim was that it is precisely this moral psychological logic that promotes people to “struggle for recognition”. Honneth called this “moral progress” referring to struggles for recognition politically (van den Brink & Owen, 2007). In this study, the participants showed their individualised, personal, meaningful struggles for recognition. Their being able to recognise misrecognition came to them as they matured. Furthermore, their recognition of the ways in which they were not recognised and their revolt against these mechanisms fortified their resistance over time which came to influence their self-identities over time. However, it was clear that earning recognition was a continuous struggle for most of the participants in most communicative social settings.

The changes in the participants’ communicative participation through their lifetimes, together with influences that changed their experiences of communicating, and of their identities and psyches, showed that social pathways are related to history and developmental trajectories. The inclusion of an analysis of the lifetime experiences and contributions to communicative participation reveal that communicative participation is a part of what Elder (1998) spoke of as “lives in motion” (p. 7).

## 6. Silenced forever

Elder's (1998) life course approach has been used to study lifelong experiences for decades. Following his work on studying the transitions of children who grew up through the Great Depression in the USA, Elder (1998) developed a number of principles that constitute his life course theory. Life course approaches to communication disability are rare. In the present study the participants' lives were directly impacted by the historical time and events that came from being in South Africa at the time that they have lived. They had lived in a country in which oppression of persons has pervaded societal structures. Growing up as a person with cerebral palsy in South Africa during the past 50 years had its own meaning for each of the participants as they negotiated the world. The participants' experiences of segregation, of a mostly unchanged disablist society, and of economic circumstances influenced by the history of the country exemplify this historicity. Lebo's experiences of being segregated due to his being a Black disabled communicator, and Serena's experiences of being unable to get the funds to access decent AAC are two examples of this historicity.

Furthermore, Elder's (1998) theory suggested that "the developmental impact of a succession of life transitions or events is contingent on when they occur in a person's life" (p. 3). The lives of the participants were influenced by the timing of different events. The death of Ellie's mother, for example, led her life in a direction in which she became very much more vulnerable having lost her lifelong communication support. The impact of the participants' impairments differed according to their life events such as transitioning through school, making decisions about professions; and decisions about where to live.

Elder (1998) posited that lives are linked and social and historical influences are expressed through these shared networks, which clearly showed through the communicative participation of the participants in relation to people in their lives. The historical events in the lives of the participants and their families affected their lives in numerous ways.

One of the strengths of Beukelman and Mirenda's (2005) Model of Participation is its strong acknowledgement of time. In their model, assessment and intervention always involve consideration of the future communicative needs of the person requiring AAC. Time proved to be a very important component of communicative participation in this study. Studying the communicative participation of a group of people who had experienced lifelong communication impairments revealed the importance of looking at communicative participation as a developmental issue. As Beukelman and Mirenda (2005) wrote, communicative participation is acquired through the lifetime through opportunity and ability. The participants in this study revealed how difficult it was to develop the skills required for participating in life's communicative activities, and how it was their exclusion from communicative participation that denied them the opportunities to develop the skills required. This denial of the loop of learning – participating to learn and learning to participate – had profound implications for the participants. In addition, the participants had experienced exclusion and being othered, being misrecognised and dehumanised, all their lives. This kind of repeated violence against their personhood had tremendous consequences for the development of the participants' identities as well as their psychological well-being. The developmental period through which the participants had lived in South Africa, in which Apartheid as well as societal attitudes to diversity and difference have changed, influenced how the participants were able to participate in society. Ironically, time also acted as a source of well-being in that the participants were able, over time as they matured and developed emotionally, to distance themselves somewhat from being hurt in that they recognised disablism.

## 7. A dynamic recognition-theoretical model of communicative participation

Ikäheimo (2012) made the point that

> As all claims for recognition/inclusion are not necessarily explicitly voiced out, and as the exact content of even the explicitly voiced out ones is often quite unclear – for the addressees as well as to the subjects themselves – the task of collectively assessing the validity of the innumerable plurality of claims with which we are faced in private or public arenas is almost inexhaustibly tangled. (para. 13)

The architecture of communicative participation is extremely complex. In applying his model to the data from this study, it seems that the recognition-theoretical model holds promise for explicating the meaning of communicative participation. Furthermore, the results show that within the context of communicative participation which is social by definition, the different components of Ikäheimo's (2010) model interact and are indivisible, interdependent and interactive. The analysis of the cracks in the dimensions of communicative participation in this study showed that what is needed is a fifth dimension to be added to Ikaheimo's model so as to reflect the central role that time plays in communicative participation, including the ephemeral and changing nature of communicative participation over the lifetime, as well as the influence of time in communication processes. One of the limitations of using Ikäheimo's model is that it does not show that communicative participation is influenced by patterns of development over the lifetime, and that it is a flexible and ever-changing phenomenon. The inclusion of time as a dimension of social inclusion in the model also reflects the fact that disability is a developmental issue (Dew et al., 2011), and changes over time (Scully, 2008). In addition, the model, as it is, does not reflect the dynamism of communicative participation. Communicative participation is not a fixed entity or an end-product. It is changeable, influenced by ever-changing states of the dimensions of the model, from A through E. Although there is no doubt that Ikäheimo did not intend to present his model as such, it could be interpreted from the model as it stands that social inclusion is seen as an end-product and not a process. Time is the dimension in which all communicative participation occurs. My suggestions, then, are to append time as an additional dimension to the model so as to explicate the influence of time on the nature of communicative participation, and to include the word "dynamic" in the title of the model so as to deliberately place the dynamism of the process at the forefront.

I offer the following adaptation to the model, which I would like to refer to as a "dynamic recognition-theoretical model of communicative participation". The model is stated as such:

**Communicative participation is a particular form of social participation in which A interacts with B in C in the manner D with the status E as a function of F.**

In this model of communicative participation, A and B refer to people in communication with one another using any form of communication; C refers to all aspects of social life in which communication occurs or has the potential to occur, and in which people wish to or need to communicate in their life world; D refers to the technical, institutional and interpersonal means that people have to be included in the communicative social world; E refers to the recognitive status accorded to the communicative partners; and F refers to time. These facets are illustrated in Figure 9.

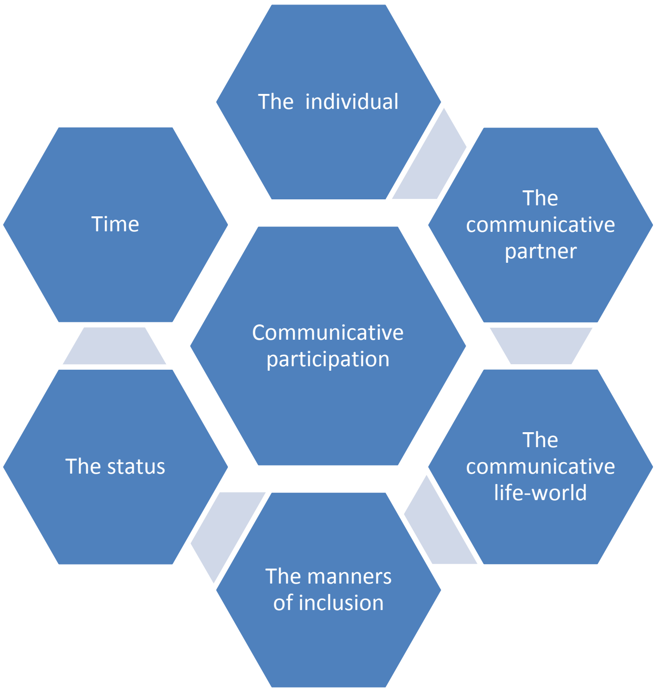

*Figure 9*. The facets of the recognition-theoretical model of communicative participation

The thesis presented is that communicative participation is a particular form of social participation that comprises multiple, interacting and changing levels and domains. Undergirding participation is that certain conditions need to be satisfied in order for people to interact. The fundamental requirement for communicative participation is the moral claim made by the people in the communicative exchange for acknowledgement of their personhood. This thesis articulates with Shildrick's (2012, p. 31) statement:

> disabled people continue to be the targets of widespread discrimination, oppression and alienation, not so much for their differences (both visible and hidden), but because their performativity of embodied selfhood lays bare the pychosocial imaginary that sustains modernist understandings of what it is to be properly human.

Misrecognition was a striking feature of the communicative participation of the participants in this study, motivating for the inclusion of the recognitive status of the communicators as an intrinsic part of any model of communicative participation. When the partners in a communicative exchange recognise one another's claims to moral personhood, then people are able to engage. Without this acknowledgement of personhood, people are not able to participate in society in which they wish to or need to communicate. Once there is co-authority, reciprocity is possible. Once there is mutual respect, the communicators can begin to interact in the communicative world. Recognition precedes communication.

Honneth's (2003, 2007) theory of recognition articulates with the findings of this study in a number of ways. The thesis presented here is that recognition undergirds communication and is not a result of communication. Honneth's theory resonates with developmental theories of communication. Honneth placed emphasis on the earliest development of recognition as germinating in the first months of life when intentional communication develops. He wrote of the infant at 9-months of age who slowly develops inter-subjectivity, and proposed that it then that the claim for recognition begins. Extant theories of pre-symbolic language development propose that the infant develops precursor skills including means-end, object-permanence and joint attention, and is then able to engage in intentional communication. Honneth's theory fits well within with pre-intentional theories. Hence, recognition is a pre-symbolic, pre-cognitive, pre-intentional, human trait. It does not require the attainment of symbolic language.

This thesis proposes that the identity of the participants played a very large role in their communicative participation. Honneth based his model of recognition on the centrality of identity. The psychologisation of recognition is one of the major criticisms levelled at his theory. Fraser (2003) argued that psychologisation is "a short step to blaming the victim" (p. 31). She asserted that Honneth's approach lays blame on the victim for not being able to maintain positive attitudes. She argued further that the failure of social justice cannot be contested politically and socially if self-realisation is a personal battle. In addition, it is extremely difficult to measure self-esteem, self-confidence and self-respect. Honneth (2007) had addressed these criticisms, arguing that recognition should be viewed as something that gives positive value to the person, that is credible to the person, and that relates to the person in the present. Fraser's (2003) alternative however, lacks engagement with face to face encounters, and she only addressed recognition as helpful in achieving participatory parity. I find it very difficult to engage with Fraser's notion of social justice because of the central role that identity was found to play in my analysis of the communicative participation of the participants. Psychoanalytic approaches to disability, such as that of Marks (cited by Goodley, 2011b, p. 719) have positioned the self as" ontologically social": the self of disabled people is formed by its reactions to disablism. When the disabling attitudes are internalised, the self is developed through a process of on-going hurt, and it results in a lowered self-esteem and a lowered belief in one's own value (Goodley, 2011b).

Similarly, though with much more focus on the role of communication in the development of the self of disabled people, the symbolic interactionism perspective focuses on the role of communication through symbolic language on identity development. This is a useful perspective to consider given that communicative participation is the umbrella term for the on-going conversations and dialogues that people carry out in their everyday lives. The symbolic interactionism perspective on the development of the self is based on the foundational assumption that the self is a social construction that develops through interaction with others (Aldiabat & Navenec, 2011). Denzin defined the self as "all the thought and utterances any person has with himself as a distinct object. It is a process and arises out of covert, silent conversations and is behaviourally observed through one's communicative acts, through the conversation of gestures" (Denzin, 1974, p. 270). The concept of the "looking glass self" was proposed by Cooley (1983). He stated,

> As we see our face, dress and figure in the glass, and are interested in them because they are ours, and pleased or otherwise with them according as they do or do not answer to what we should like them to be; so in imagination we perceive in another's mind some thought of our appearance, manners, aims, deeds, character, friends, and so on and are variously affected by it. (p 126)

According to symbolic interactionism, language is the vehicle with which we reflect on our actions, and adapt our responses. The symbols that are used are then used as inner language, as the conversation that one has internally and hence our internal dialogue is an internalisation of the communicative processes that we are engaged with in our social interactions with others (Aldiabat & Navenec, 2011).

Contemporary neuroscience that examines the functioning of mirror neurons[29] suggests that there is a physiological basis to claims by proponents of social interactionism. "The mirror mechanism is a neurophysiological mechanism that transforms sensory information describing the actions of others into a motor format similar to that which the observers endogenously generate when they actually perform those actions" (Sinigaglia & Rizzolatti, 2011, p. 65). Empirical evidence suggests that peoples' responses to the actions of others are evident as neurophysiological responses. This emerging body of neurophysiological research

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[29] Mirror neurons are found in many parts of the brain. They are neurons that become active in response to the actions of others. The mirror neuron thus appears as if it is mirroring the action of the other as if it were doing the action itself (Adapted from Sinigaglia & Rizzolatti, 2011).

lends credibility to the concept of a self that is based on interactions with others. The evidence has also shown that mirroring can also be fallible. For example, if the actions of others are ambiguous or unclear, the responding action may not mirror the action of others, which speaks to the development of the self when interactions are misleading, such as when people pretend to understand communicatively disabled people.

Fraser's (2003) argument is that if we equate the politics of recognition with the politics of identity, then we are likely to be reifying group identities and displacing the politics of redistribution. One of the arguments against the strong social model of disability is it focus on redistribution and its disavowal of personal psychological meanings of disability. In this study, psycho-emotional disablism was one of the ways in which the participants were silenced. They spoke of their distress, anger, pain, and humiliation. They spoke of disappointment, hope, and feelings of loss. These feelings were not incidental, nor were they end products alone. They influenced how, when, with whom, where and if communication in the social world was possible. It seems somewhat absurd to exclude the personal accounts of the meaning of communication disability from a model of communicative participation that acknowledges that a person's participation in the communicative world is a matter of social justice.

In this study, I showed that the personal story of communication disability as well as the participants' visceral, corporeal impairments were intrinsic markers of silence. I cannot imagine how they can be left out of a model of social justice. Impairment is a real and authentic issue. Despite communication impairment being an intrinsically and inherently social reality, it is not only the acknowledgement of personhood and the adaptation of the social world to accommodate the person that matters. The reality is that for many people, no matter how much environmental support is offered, some impairments cannot be compensated for.

Moreover, a realistic perspective needs to be adopted. One of the criticisms of disability studies is that it tends to be idealistic, intellectual and often does not make any difference (Barnes, 2012; Shildrick, 2012). This model is based on the reality of the lives of the participants. The world in which the participants lived was a tough one, challenged by an inordinate amount of factors. In the real world, in the case of this study in a developing context where society itself is undergoing transformation that was unheard of 20 years ago, the transformation of society into a non-disablist one is many years away. Previous experience with strong disability politics showed the powerful changes that activism can bring about (Linton, 2011). However, the day-to-day reality of the communicative lives of the participants in this study was very difficult in many ways. In this context, at this juncture in the country's history, their impairments mattered. In addition, people with communication impairments have been excluded from disability politics to a very large extent. Disability politics, like all other politics, is dominated by people who communicate well and fluently. People who do not have these skills tend to be excluded. Their impairments matter.

As a result, the application of the dynamic recognition-theoretical model of communicative participation is best situated within a realistic paradigm. This paradigm ought to acknowledge that impairments matter. Some, like Barnes (2012), might suggest that this is a dangerous perspective that promises to halt and hinder political change. I don't believe that this need happen as long as those who are involved in bringing about changes remain reflexive and interrogate constantly their positioning in regard to both the discursive analyses, theories as well as the practical implementation of interventions of any kind that make the lives of communicatively disabled people richer. This is one of the challenges of marrying rehabilitation and disability studies.

The dynamic recognition-theoretical model of communicative participation is not essentialist. The model does not support the idea of recognition as the sole source of justice. Full communicative participation requires that the person is provided with opportunities to communicate in all aspects of social life that the person values. Here, the distribution of resources is acknowledged. Participants needed material resources – money for AAC, time to be heard, physical assistance – to be able to participate. There should not be any aspect of social life that a person is unable to access should he or she so choose.  This access requires that the person is afforded technical, interpersonal, and institutional support in all aspects of social life in order that the person may learn the required communicative skills throughout the lifetime and put them into practice. In this way, the model embraces the principles of the capabilities approach. The model offers space for the context in which communication occurs to be examined. Hence, issues around access and support are included.

The model incorporates the communicative partners. Eadie et al. (2006; Yorkston et al., 2008) acknowledged that communication is always between people. Although it is most unlikely that these researchers disregarded the communicative partner, their definition of communicative participation does not specifically include the communicative partner.  As a result, there is risk that analysis of a disabled person’s participation is reduced to the analysis of disabled persons as if they are sole contributors. The model that I propose here places the communicative partners in a conspicuous, visible and prominent position.

The dynamic recognition-theoretical model of communicative participation acknowledges the central role that time plays in the communicative process. Communicative participation is ever-changing. It changes as the dimensions of the model change. Including time as a dimension of the model places emphasis on issues such as the developmental nature of communication.

This model expands upon the existing definitions of communicative participation, offering a broader conceptualisation than has been presented thus far in the literature.

# CHAPTER ELEVEN: CONCLUSION

## 1. Overview of the study

This study was about the communicative participation of adults with cerebral palsy. Nine adults with cerebral palsy living in South Africa were interviewed in serial interviews over a six-month period. Using a pragmatist grounded theory approach, the data were analysed from an interpretive basis. Four main categories were constructed, each of which I shall summarise briefly.

The first category was "being misrecognised as a communicator", which showed that the participants were not recognised by their communicative partners. At some time in their lives, the participants had been excluded from communicative situations completely. At other times, they were included partially, never fully experiencing true communicative participation. I called this position "come on in but not too far", using a line from Devine and Parr (2008). I showed that the participants rarely experienced inclusion in communicative interactions and if they did, they remained in a vulnerable position at risk of exclusion. I attributed the lack of recognition to be the misrecognition of the participants' claims to their personhood. In addition, the communicative partners rarely had any training with regard to how to communicate with their disabled communicative partners. Living in South Africa played a part in that the segregated and crypto-eugenic policies that were so much part of the history of the country during the lifetimes of the participants especially with regard to disablism contributed to their opportunities.

The second category was "contexts for communicating" which showed that the participants lived with significant communication impairments. They had difficulty with a broad spectrum of life's activities as a result of their communication impairments. I identified a number of intrapersonal barriers such as second language issues and those pertaining to particular impairments associated with cerebral palsy. Interpersonal barriers to communicative participation were identified such as issues to do with communicative partners, restricted life's roles, difficulties with interpersonal relationships and dependency within the communicative relationship with others. Those participants who used AAC faced their own challenges. Barriers in communicative participation in context were identified such as difficulties in noise, and some of the peculiarities that affected communicative participation as a result of living in institutions were identified. I was able to show that the participants experienced many difficulties with linguistic-pragmatic aspects of communicating such as having difficulty with negotiating, arguing, joking and phatic communicative functions.

The third category was "an embedded communicative self" which was the term that I used to show that the participants saw their communicative disabilities as embedded within a broader picture of being disabled. I identified three constructions of a communicative self. The "able self" was a construction of the self-identity of the participants as successful and able communicators; the "trapped self" revealed the vulnerability of the self-identity of the participants; and "submerged self" described the submersion of the self-identity of the participants beneath contextual influences. This section showed the circularity of communicative participation: how the participants saw themselves as communicators affected their communicative participation, and so too their communicative participation affected their self-identities.

The final category, "dynamic participation" showed how communicative participation is a fluid, ever-changing process. I substantiated this category through the use of the codes that related to lifelong communication disability. The participants spoke of changes in their communication impairments as well as their skills through their lifetimes. They recounted their experiences of growing up in Apartheid South Africa, with language, segregation and poverty playing important roles in their development. Parents played a part in the lives of the participants in many ways, and continued to play very active roles in terms of communicative participation in the lives of their adult children. Schooling offered both opportunities as well as some very significant restrictions.  These restrictions impinged on their young adulthood in ways such as education choices. In adulthood, the participants experienced many issues with life's situations such as where to live and with their finances, which contributed to, and which were effects of, the participants' communicative participation.

The data resonated with Ikäheimo's (2010b) model of social participation which is based on Honneth's (2003) theory of recognition. In acknowledgement of the central role of time as a dimension through which all communication takes place, as well as the developmental and ever-changing nature of communicative participation, I modified the model, naming it "a dynamic recognition-theoretical model of communicative participation". This novel approach broadens the conceptualisation of communicative participation as it has been viewed to date, builds on the work of scholars who have laid the foundation for understanding communicative participation, and offers an alternative lens through which it can be viewed.

## 2. The value of a critical disabilities studies perspective

Immersing this study in a critical disabilities perspective allowed for this broader conceptualisation of communicative participation to be constructed. One of the reasons why a particular approach to disability studies has come to be called “critical” is that there has been a blurring of disciplinary boundaries. This boundary breaking has allowed different perspectives to come together and to open up ways of thinking. By opening the boundaries, there is opportunity for language to be shared, for ideas to be debated, and for understanding concepts in different ways.

### 2.1 Interrogating issues in disability studies

By working from a critical disability studies framework, I was able to interrogate the meaning of impairment in the lives of the participants and was able to envision the role that their impairments played in their communicative participation. Critical disability studies opened the way for the impairment-disability binary to be interrogated. In addition, critical disability studies offered an opportunity to question the binaries associated with disability discourse – what normal is, what abnormal is; what impairment is, what disability is; what is perceived, what is real; what inclusion is and what exclusion is. This engagement with these dualities helped to form an understanding of communicative participation, as presented in the model, as something that is vulnerable to silence at any level for any person, and is not something that pertains to disabled people only. In no way does this delegitimise or trivialise the experience of disabled people, or as something that anyone at any time could experience. However, it does cast the experiences of disabled people in the light of the social scripts of normalcy. These scripts need to be questioned and debated especially because there is nothing fixed and unquestionable about them (Shildrick, 2012).

In my analysis, I was able to show that the strong social model that requires a defocus on the personal story, on shunning the psycho-emotional effects of disablism in favour of the materialistic philosophies, misrepresents the participants. However, this study also showed that the basic principles of oppression illuminated by the strong social model are real. This study did not reject the social model; on the contrary, it showed that oppression is a major force operating in the silencing of the participants. However, critical disability studies allowed for a much more detailed and nuanced examination of the social processes in operation (Meekosha & Shuttleworth, 2009).

## 2.2 Interrogating the conceptualisation of communicative participation in existing models

Critical disability studies opened the way for the role of the social model in the conceptualisation of communicative participation to be interrogated. The ICF (World Health Organization, 2001) has played a major role in defining communicative participation, as shown in the review of studies in chapter 4. The model is so broad that all that it really calls for is for health and disability to be viewed beyond the level of the individual, for the world in which the person lives to be taken into account. This means that researchers and clinicians who adopt the model do not necessarily interrogate the dimensions of the social model because it is presented by the authoritative WHO as a model that has been researched, that has credibility, that was supported by disabled people, and which is therefore authentic (Threats, 2006; Threats, 2010b; World Health Organization, 2001). In the publications that address issues on communicative participation, those researchers who align their work with the model proposed by the ICF have little engagement with the social model.

The dynamic recognition-theoretical model of communicative participation illuminates the problems of the under-developed notion of participation as is evident in the following example. Researchers who have aligned with the ICF, have developed the Gross Motor Function Classification System (GMFCS) (Palisano et al., 2000) which has been expanded and revised (Palisano, Rosenbaum, Bartlett, & Livingston, 2008) and the Manual Ability Classification System (MACS) (Eliasson et al., 2006) for children with cerebral palsy. These have also been adapted for use with adults with cerebral palsy (McCormick et al., 2007). These tools are used to classify mobility and handling objects respectively, at the ICF activity⁄participation level. These classification systems are used extensively in the literature and in clinical practice, and there has been a need to develop a similar tool for the categorisation of communicative participation. The power of these tools in makes it all the more important to critically evaluate their foundations.  Recently, working with colleagues who developed these tools, a group of researchers have developed the Communication Function Classification System (CFCS) for children with cerebral palsy (Hidecker et al., 2011). The rationale for developing this tool was that there had not been a tool that could be used in comparisons of descriptive cerebral palsy epidemiology studies as well as for the interpretation and generalisability of cerebral palsy treatment studies.

The CFCS is used as a classification of broad communication function, and is underpinned by the authors' definition of communication. They defined communication as occurring when conversation partners establish a shared understanding. "This shared understanding (i.e. communication) results from an interaction among components of ICF activity, participation, and body structure and function (speech, language, and hearing skills) with contextual factors (e.g. setting, conversational partner skills, AAC methods, and cultural backgrounds)." (Hidecker et al., 2011, p. 708)

The broad categories are as follows:

I. Sends and receives with familiar and unfamiliar partners effectively and efficiently
II. Sends and receives with familiar and unfamiliar partners but may need extra time
III. Sends and receives with familiar partners effectively, but not with unfamiliar partners
IV. Inconsistently sends and ⁄ or receives even with familiar partners
V. Seldom effectively sends and receives, even with familiar partners

The CFCS was developed in consultation with children and adults with cerebral palsy, but is based on the transmission model of communication, and although it is not an assessment tool but is a classification tool only, it does not account for participation in social interactions beyond the dyad level.

If the participants in this study were to be classified, they would all be classified as level IV or V communicators, which would deny them their communicative reality. As level IV or V communicators, the participants in this study were able to communicate, were able to participate in situations in which they wished to communicate. They had to do it differently, and had to have communicative support. In this classification, communicative support does not count: only considered is the individual who is classified. This measure then, which claims to be aligned to the participation level of the ICF, effectively ignores communicative participation as I, and others, have defined it. The authors of the CFCS stated,

> The purpose of this study was to create and validate the Communication Function Classification System (CFCS) for children with CP, for use by a wide variety of individuals interested in CP. This required a shift from the traditional focus on body structure and function (i.e. assessing components of speech, language, and hearing problems), to a focus on activity⁄participation, specifically the way in which to classify a person's communication capacity within real-life situations." (Hidecker et al., 2011, p. 705)

However, the CFCS measures the functional communication of the individual, and has little relationship to the notions embedded in understandings of participation, social interaction, and communicative participation which have been identified in this study. Future research on communicative participation may be well served by critique of the situatedness of the research question in relation to the theoretical term "participation". Researchers need to use very specific terminology, and need to pay close attention to the manner in which they align with theories or functional models. This is not to say that the ICF has no place. The ICF has provided a powerful impetus for much of the study of communicative participation, and there is a growing base of research about the access and barriers to communicative participation in the environment as a result. The issue is that the results of this study indicate that how the WHO presents the social model in the ICF is rather narrow, and encourage deeper exploration of the social model and its implications by those who use the ICF. WHO has acknowledged that the ICF is a work in progress (Threats, 2010b; World Health Organization, 2001); studies such as the present one contribute to understanding ways in which the "biopsychosocial" model and its underlying philosophy can evolve.

### 2.3 Incorporating issues of moral personhood in communicative participation

There is a large body of literature that addresses 'attitudes' and 'stigma' in relation to disability, and there is a significant body of literature in relation to communication disorders that acknowledges the forceful role that attitudes play in social participation. Engaging more with issues surrounding disability that have been considered in the tradition of critical disability studies, such as that which is offered by the model that I have presented, may offer a rich perspective on attitudes in relation to communicative participation. Although one of the goals of intervention is to change attitudes – such as proposed in Beukelman and Mirenda's (2005) participation model – those involved with this task have lacked a philosophical theoretical basis to their work (Inahara, 2012). One of the troubling issues that has been identified in this research is the question of the moral claims to personhood by communicatively disabled people. This issue was highlighted to a large extent because of the socio-political and historical social structure of South Africa's past and present. Recognition is a vast topic, and in light of the findings of this study, there is a lacuna of research that addresses the person-making and status-making significances of communicatively disabled people. A philosophical theoretical approach to this study brought about the isolation of recognition as a defining feature of communicative participation.

Acknowledgement of personhood is crucial for people to have autonomy, a sense of self that is separate from the other, and agency. Without personhood being acknowledged, one is thrust into deep anxiety seen in the way in which some disabled people behave (Shildrick, 2012). The participants in this research were placed in positions of vulnerability with regard to their identities, and experienced significant psycho-emotional difficulties. They had developed some degree of resilience through time, but remained, at all times, vulnerable. Engaging with communicative participation as a moral issue, and as a philosophical issue, may well inform us how to go about changing the broader world of disabled people. Working from within a critical disability studies framework permitted me to explore notions that relate to freedom and change. It opened a window to allow communicative participation to be seen as an issue of social justice. Furthermore, I was able to view communicative participation as a matter of social justice beyond the political and materialistic dimensions, but also as a matter of interpersonal relations. Using Ikäheimo's model, and the dynamic model proposed by this study, one is encouraged to see social justice as "psychological, cultural, discursive and carnal" (Meekosha & Shuttleworth, 2009, p. 50).

### 2.4 Marrying communication science with critical disability studies

I have not seen much evidence of researchers in the communication sciences engaging deeply with the field of critical disability studies. I am not surprised by this because disability studies is not accessible to many rehabilitation professionals. In addition, disability studies has not welcomed rehabilitation studies because of the perceived role that rehabilitation has played in medicalising, labelling and treating individuals as tragic persons (Duchan, 2006; Paterson, 2012). Disability studies proponents have argued that only disabled people could truly represent disabled people but this standpoint positioning has been made less intolerant over time. In addition, there is something wrong with the claiming of authority over a field of study in which able-bodied representations and interpretations of disability are not invited to be interrogated (Shildrick, 2012). Critical disability studies opened a space for me to lower my barriers and engage with the understanding that there is mutual benefit for those in rehabilitation studies and those engaged in critical disability studies. There was no reason to privilege one approach over another.

On the whole, from my reading on disability and rehabilitation, the most common trend is for the communication sciences to speak of embracing disability issues, when in fact they mention the issues rather superficially, possibly without understanding what they actually are.

> Yet a troubling trend concerns the co option of some of the language of disability studies that is also taking place. More traditional rehabilitation and special education departments are re-badging themselves as disability studies, but without going far enough in rewriting the script. This is evidenced by courses within universities whose primary allegiance is to medical models, while only weakly acknowledging the socio-political analysis of disability (Longmore 2003; Meekosha and Green 2004). (Meekosha & Shuttleworth, 2009, p. 49)

Duchan (2001b) wrote about this issue over a decade ago, writing that the social approaches to disability and the traditional individualised medicalised approaches to disability in clinical practice at least "do not exist comfortably together. They are fundamentally incompatible" (p. 43). Reading her suggestions for alternate ways to practice rehabilitation, one is struck by the enormity of the shift in thinking that is required. Today, there is a very strong acknowledgement of the need to move social participation into a strong position such that it becomes one of the primary goals when working with people with communication impairments. However, this shift requires much more than a shift to taking the individual with his or her impairments into the real world – as exemplified by the influential Beukelman and Mirenda (2005) model of AAC intervention – but requires instead shifts in ontology, epistemology and ethics. The shifts are philosophical, requiring fundamental changes in approaches and practices (Balandin, 2011; Byng & Duchan, 2005; Duchan, 2001a; Pound, 2011).

Communication impairments have an immediate link to the social world. Communication is of itself, inextricably both physical and social. Hence, I am suggesting here that although there is a very real danger in classifying impairments – dangerous in terms of a return to the dominance of the medicalised approach to disability – there is also a danger in knitting all the strands of all types of impairments together when looking at issues related to disability because they become part of the whole and disappear. While acknowledging Hacking's (1995, cited by Vehmas & Mäkelä, 2010, p. 50) interpretation of diagnoses and classifications as "making up people", and the fact that people start to live in ways that their diagnoses expect, ignoring the peculiarities of different impairments in disability studies masks dimensions of experience. Some activists object to the isolation of one type of disability from another (e.g. Linton, 2008, 2011), arguing that this reeks of medicalisation and detracts from the political meaning of disability (Barnes, 2012). It has been useful politically to group all disabled people under one banner so as to focus on "fixing" society and not the individual (Barnes, 2012), and it has also been assumed that all disabled people experience common issues of disablism (Shakespeare, 2006). There is absolutely no question that the formation of a disability collective proved valuable in bringing people together who shared common ground and who benefited from forming a community (Garland-Thomson, 2007). However, as Linton (2011) said, there is a danger in this approach in that differences become conflated, and at times erased. Her view was that disability movements as a community and collective have an ethos of trying to account for difference, but acknowledged that this aim is not always met. The experiences of the participants in this study showed that there is no doubt that different people experience different types of impairments differently (Reeve, 2012).

The personal stories told by the participants in this study reveal dimensions of disability that are relatively unexplored. Publishing a number of chapters written by people with different types of impairments, the editors of the recently published Routledge Handbook of Disability (Watson, Roulstone, & Thomas, 2012) recognised that the lived experience of people with different types of impairments could inform our knowledge about different dimensions that the impairments revealed. There has been exceptionally little work on communication disability within disability studies (Paterson, 2012) and communication sciences has engaged very little with disability issues (Duchan, 2001a; Pound, 2011), which puts the understanding of communicative participation from a critical disability perspective in a silent place. Paterson (2012) made the observation that disability studies, particularly as promoted by the social models of disability, had focussed on spatial dimensions of disablism. Mobility, and the negotiation of space, was the focus. In addition, he pointed out that when issues of communication disability are raised, the focus has also been on structural barriers. My review of the studies of communicative participation concurs with his observation to a very large extent.

What Paterson’s (2012) analysis of speech impairments offers is a greater acknowledgement of temporal factors in the disabling process. Parr et al. (2003, cited by Paterson, 2012, p. 167) had identified work that had acknowledged ‘tempo’, ‘rhythm’ and ‘pace’, but on the whole, there has been little attention to the ways in which time contributes to everyday existence. Through Paterson’s descriptions of his own experiences of living with a speech impairments, he drew attention to temporal issues in disability. Hence, the particular focus on speech impairment as opposed to other types of impairment has enabled the growth in our understanding of temporal contributions to disability as a whole. The experiences of communicative participation expressed by the participants in this study, like Paterson's autobiographical account of his communication impairments, show that there is danger in not getting a full and nuanced understanding of the meaning of the peculiar experiences of communicatively disabled people. The experiences of people who have communication impairments are unlike those experienced by people with physical impairments, which are unlike the experiences of people who have both physical and communication impairments, and unless we allow and encourage their stories to be told, we are forcing them, so to speak, into a category into which their experiences are not acknowledged.

The dynamic recognition-theoretical model of communicative participation offers promise for further research, for theoretical understanding of communicative participation, as well as for clinical application.

## 3. Using the model to unify and extend the research on communicative participation

My review of the studies on communicative participation shows that there has indeed been established a relatively large base of research on which our understanding of communicative participation can take hold. The review illuminated, however, the variability in the way in which communicative participation is conceptualised. One of the benefits of the dynamic recognition-theoretical model of communicative participation is that it offers promise to unify the research. Communicative participation is a broad term, comprising multiple levels. Some authors have stated their intention to research "the communicative participation" of certain populations of people, which has in some way been misleading. As shown in the model, they have explored only some aspects of communicative participation. Locating one's focus of study or of measurement in much more specific terms, will help to unify the research. It will mitigate to some extent the use of confusing terminology.

The model also points to the gaps that still need to be filled. For example, in this study, the participants were shown to have been influenced by many factors through their lifetimes with regard to learning adult communicative roles. The gap in the knowledge base about how people come to forge their way through their lifetimes is very large. Another example would be the status-making significances accorded people in South Africa within communicative world. The data from this study provided a fairly rich understanding of what it was to be a communicatively disabled person with cerebral palsy; data is needed in different contexts, and with people throughout the country. For example, I did not include Black women, Muslim people, and the participants all lived in Gauteng. In a diverse country like South Africa, it would be worthwhile looking into cultural constructions of status with regard to communication in multiple contexts.

Those of us who wish to contribute to research about people with communication impairments may have to venture further afield than working with communicative partners and the communities in which people who have communication impairments operate (e.g. Côté et al., 2011; Goldblum & Alant, 2009; Kagan et al., 2008; Togher et al., 2006). We have to look at, but beyond, the substantive effects of silence on communicatively disabled people (e.g. Ballin & Balandin, 2007; Struchen et al., 2011). To date, some interventions have made an enormous difference in helping communicatively disabled people to negotiate their social spaces. Paterson (2012) wrote, however, that these interventions are insufficient because they do not necessarily translate as meaningful for disabled people. He wrote that it is not just that their needs have to be met, but that their needs ought to be seen as legitimate. I do believe that some interventions are most certainly legitimate for disabled people (e.g. Côté et al., 2011; Hesketh, Long, & Bowen, 2011; McVicker, Parr, Pound, & Duchan, 2009; Pound et al., 2007). Nevertheless, the transition to these social methodologies is not widespread, and rehabilitation studies has not necessarily engaged sufficiently deeply with issues surrounding disability.

Hence, Paterson (2012) suggested that a phenomenological sociology of impairment is necessary to “carnally re-inform, the (spatio) temporal rules which structure participation so that disabled people are valued, included and legitimized in the choreography of everyday life” (Paterson, 2012, p. 170). I tend to agree with Paterson, in that from my reading, I have become aware of a paucity of discursive analysis of issues around why communication impairments trouble the “normative majority” (Shildrick, 2012, p. 35).We might have to go further to “investigate more deeply what it is that continues to impede the evolution of equitable conditions of possibility” (Shildrick, 2012, p. 32). We may be well advised to look at what maintains the “psychosocial imaginary” (Watermeyer, 2013) to determine what it is that maintains the status of communication disability. There is very little to guide our understanding thus far. Perhaps if we gave ourselves a new name – “critical communication disability studies” – we might feel safer and more liberated to explore ideas that are outside of our borders and that allow us to continue to question extant ways of thinking so as to generate new ideas.

## 4. Clinical implications of the model

The model suggests that the umbrella goal of rehabilitation which is to increase the participation of disabled people, be reframed. The over-arching recommendation that this model suggests – because of how it was developed – is that the management of communicative participation be approached from a critical disability perspective. Hence, the focus is not on the individual , but on the entire process of participation. The model suggests that communicative participation be analysed in terms of its components (illustrated in **Figure 10**), but that the notion of inclusion is not “what can we do to include X in the communicative world?”, but “how can the communicative world include all people, and take into account the particular needs of X and the people in his or her world?” As Inahara (2012, p 50) stated,

> Unintelligible speech, being social and embodied, is dependent upon the practices of subjects in social interaction. The primary concern is not how to distinguish ‘intelligible’ from ‘unintelligible’ sounds, but to establish techniques that enable communication in such a way that the definitional boundary between normal and abnormal speech is questioned.

The model supports the philosophical move away from impairment, and reinforces the shift that is needed to move intervention into a social realm. The model provides a strong theoretical foundation for this, and also provides some guidance as to how to envision the steps that need to be taken.

The model is based on a specific definition of communicative participation that has expanded upon existing definitions of communicative participation. This theoretical foundation provides a stronger base on which to provide clinical services. By envisioning communicative participation as a multidimensional concept, in which the dimensions are interdependent and interact, clinicians can specify which aspects of communicative participation they intend to target, and can better operationalize their aims. In this way, the goal of increased participation is attainable because it becomes more realistic. Similarly, existing models can be looked at in terms of which domains of communicative participation they evaluate.

The model of communicative participation as a multifaceted phenomenon indicates that there is room for the development of trans-disciplinary models of practice so as to realise the goals of participation for communicatively impaired people. To date, the professionals who have been accorded the responsibility for facilitating the participation of communicatively disabled people in the communicative world are, predominantly, speech-language therapists, who are supported by their team members, which include members of the person's family and social networks. However, the number of speech-language therapists is, and will remain, insufficient to serve the world's disabled people. With an 'integrated-compartmentalised' understanding of communicative participation, different members of the team can facilitate aspects of communicative participation and in doing so, lessen the burden on speech-language therapists and at the same time, increase the breadth of the frame in which participation is tackled. There is greater room for the involvement of allied professionally-trained personnel including psychologists, social workers, teachers, nurses. There is room for the involvement of philosophers, economists, and politicians. Communicative participation is an issue of social justice that demands the involvement of the broader society.

The model also suggests that, like Beukelman and Mirenda (2005) did, that all clinical decisions take a long-term approach. Goals might well be set for the present, but need to take into account what the person will require in the future, and steps can then be taken to better ensure that those needs will be met. As a consequence of a long-term view, in this way, perhaps, the high number people who fall between the cracks in the various transitional periods – such as in the transition from child to adult services (Levin, 2008) – will be reduced.

What this model adds is a perspective on the dynamic nature of communicative participation; it reinforces for clinicians the need to constantly modify goals, and to see communicative participation as being different in different contexts, at different times, and with different partners. It demands flexibility.

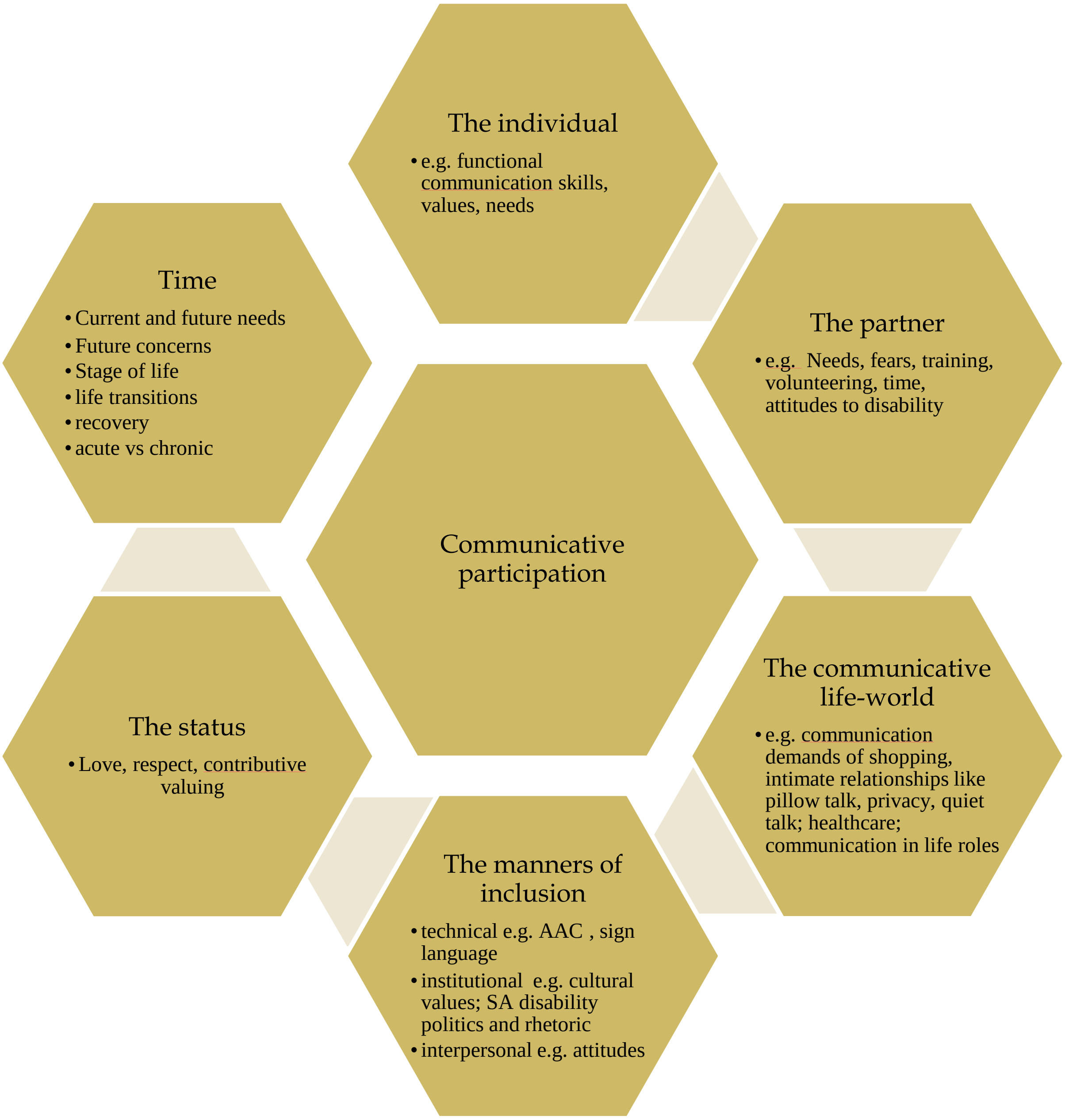

*Figure 10*. Clinical management of communicative participation: an integrated- component approach

## 5. Limitations of this study

The study was limited in a number of respects. Although I wanted to include people representative of all population groups, I did not do so. The group included six White participants and three Black male participants, and the sample was not representative of the people of the country. I discussed the reasons for the bias in the methodology. There is no doubt that different cultures bring different meanings of disability to the page. However, what was clear was that although there were times when gender, race, age and other issues intersected, the overriding issue was the state of the country during the Apartheid years that had an influence on all participants because of crypto-eugenic and segregation policies intrinsic to Apartheid ideology. In addition, the conditions of life for adult disabled people in the country are similar in terms of segregation, financial marginalisation and other forms of oppression and disablism. The privileges of being White in a country that has been racialised for centuries were apparent in that life was more resourced and opportunities were greater. Nevertheless, disablism was experienced by all the participants. A greater spread of cultures, languages and races might offer greater insights.

The bias that I brought to the study from my medical background, and my naivety as regards disability studies may have limited this study. I sense that I have matured sufficiently academically so as to engage with the issues at hand, and suppose that I have done justice to the various discourses. I have spent many hours in reflection about my stance, and am aware that there might have been times when my background influenced my thinking. This is of course inevitable, but I do acknowledge that my professional bias might have been apparent in the interviews themselves.

All of the participants had some degree of difficulty with comprehensibility and intelligibility. I had to interpret single words, idiosyncratic forms of communication, silences, and needed context to work out what the participants were saying. Not only was this difficult, but I am aware that I might have influenced the interviews and the information that I sought as a speech-language therapist. I probed for information about communication and found myself putting words into the mouths of the participants that were based on my interpretations. I have discussed this in the methodology section and acknowledge these limitations.

A topic that I did not explore was 'the future'. Given the prominence that I have given time in the model that I have proposed, this was an omission. It was a concept that was rarely mentioned by the participants, and which I did not bring up, and given the young age of some of the participants, the future in terms of their future needs and aspirations, as well as the future of the country and disability rights and practices, is an important topic. Although I acknowledge that this omission is a limitation of the study, it points to an important notion for inclusion in future research.

## 6. Getting back to Gina and Mike: A concluding statement

The question that I asked myself as I started writing this chapter was, "So, would I know more about how to handle the situation with Gina and Mike having completed this study?" Well, their story fits into the dynamic model of communicative participation that I constructed from the data in this study. They had both lived as disabled people in South Africa which brought unique challenges. They both lived with very significant communication impairments; they had both been denied opportunities throughout their lifetimes to develop communication skills to use in the negotiation of their adult lives. They could not be understood and they could not negotiate and argue and fight for themselves with words. Their impairments mattered. Their communicative partners spoke to them - and cared for them - so long as they fit the normative script of what they expected their charge, child and/or siblings to be. They were expected to "be disabled" and that meant that they were perceived not to have the capacity to determine what was good for them – they could not manage their own "happiness and misery". They were brain damaged which meant that they were not perceived as having the same intimacy and sexual needs of normal people. Hence, they were not seen as having any form of authority over their communicative partners, which was made worse because Gina and Mike did not see their communicative partners as authoritative over them, so there was no reciprocity. They did not have technical support in that they did not use any form of technology to support their communication – it was not available, was too expensive, and actually had never been offered to them. They were denied any form of institutional support – their rights were defined by those who had power over them. Their interpersonal support to participate in life's activities was very limited. They were denied their claims to moral personhood which underpinned all their experiences. They were treated by the people in their world as if their opinions were invalid; they were denied the opportunities to stand up for themselves.

Would I be able to handle this situation today?  There is no doubt that I would be better prepared to assist Gina and Mike. I believe that the description of communicative participation provided by the dynamic recognition-theoretical model provides me with a sound theoretical basis from which to begin to understand their silence. With this foundation, I could harness clinical skill, experience and compassion to make a difference, even if it were not as big a difference as they, or I, might like.

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# APPENDICES

## Appendix 1: Participation Model

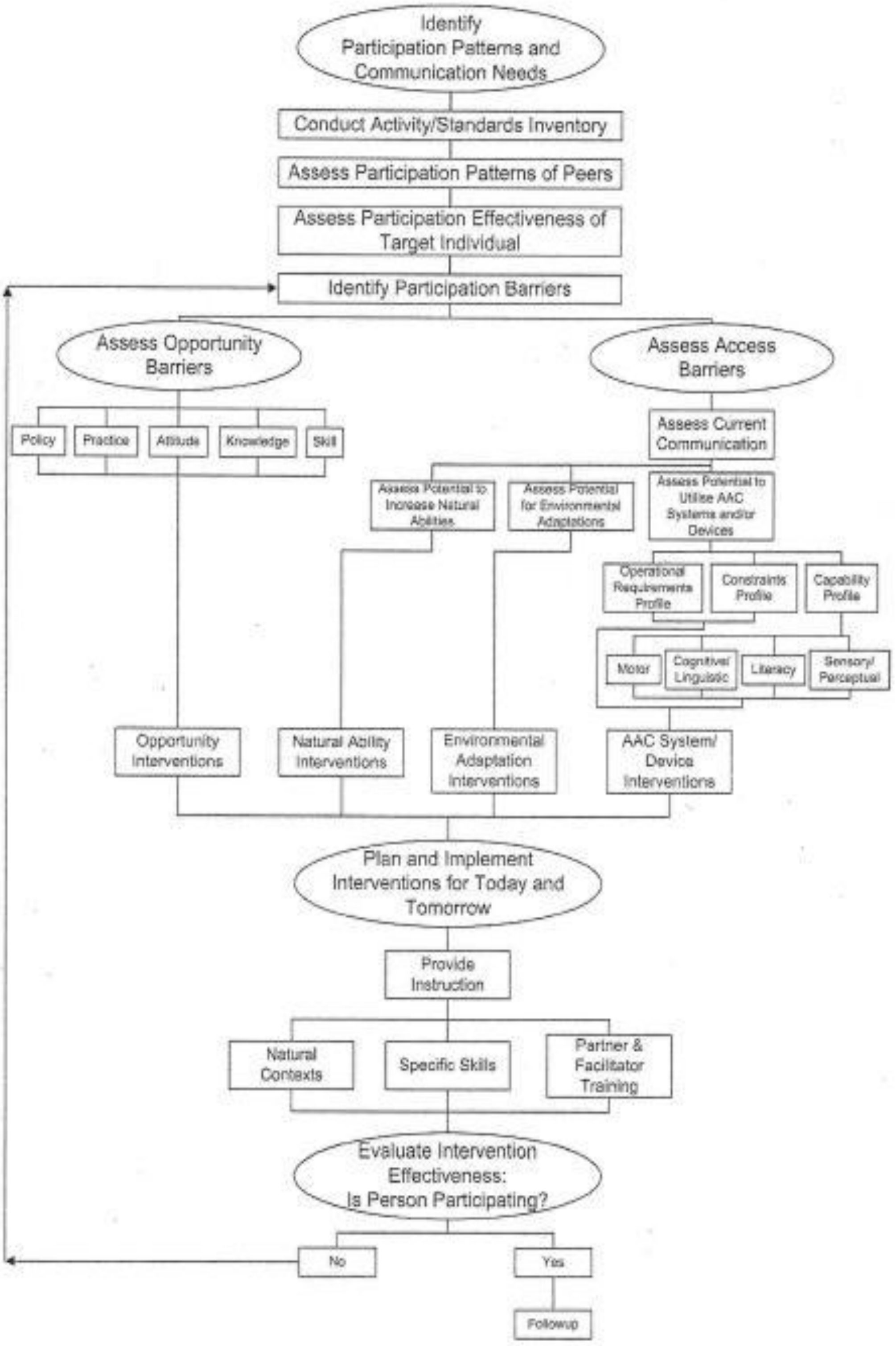


*Figure 11.* Participation Model. From *Augmentative and Alternative Communication: Supporting children and adults with complex communication needs* (1st ed). Maryland: Paul H Brookes, by D.R Beukelman and P. Mirenda, 1992.

## Appendix 2: Participant information leaflet and consent form

## PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

**TITLE OF THE RESEARCH PROJECT: THE COMMUNICATIVE PARTICIPATION OF ADULTS WITH CEREBRAL PALSY**

**REFERENCE NUMBER: N10/08/247**

**PRINCIPAL INVESTIGATOR: Karen Levin**

**ADDRESS: (Home address of researcher provided)**

**CONTACT NUMBER: (Telephonic details of researcher provided)**

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask me any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also **free to withdraw** from the study at any point, even if you do agree to take part. You are also free to select in which aspects of this study you are willing to participate.

This study has been approved by the Health Research Ethics Committee (HREC) at Stellenbosch University and the Health Research Ethics Committee (HREC) at the University of the Witwatersrand and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

### What is this research study all about?

I am researching how people with cerebral palsy communicate and participate in life’s activities. Disabled people can experience many difficulties and I want to investigate what you have experienced in terms of having a communication disability. I also want to determine the ways that you as a disabled person have coped with your communication disabilities and what you have done to overcome them so that you can participate in the world.

## I would like to invite you to participate in the following activities with me.

Personal interview: I would like to interview you in a private place where we can chat about your experiences for two hours, five times over a six-month period. I will video record this interview but only so that I can watch it again when analysing it for my research. No one else will see this video except for the professor who is guiding me.

Observation: I would like to spend a few hours with you in your everyday life to see you participate in the world so that I can better explain the results of the interviews. I will not video record these observations but I will write down my observations in a notebook.

I will be inviting about 14 other adults with cerebral palsy to participate in my research. None of them will be told that you are participating.

You can choose in which aspects of this research project you will be willing to participate, although I would appreciate your involvement in both activities because that is how I plan to get the most amount of accurate information.

## Why have you been invited to participate?

I have invited you to participate in my research because you have cerebral palsy and have lived with a communication disability all your life. I think that you will be able to give me much information that will help me to explain how disabled people in South Africa are able to participate in life.

## What will your responsibilities be?

Your only responsibility in this research will be as follows:

To let me know at any time if you wish to cancel any appointments that we make;

To let me know at any time if you wish to drop out of the research. I will not be upset and I will not tell anyone.

## Will you benefit from taking part in this research?

There are no direct benefits to you except that you might meet with people with cerebral palsy that you have not met before. You might also enjoy talking about your experiences. I am hoping that this research will help us understand how people with cerebral palsy participate so that we can assist disabled people to be more successful in future.

## Are there in risks involved in your taking part in this research?

I do not think that there are any risks to your taking part in this research. However, you may feel upset about talking about some sensitive issues. If necessary, we can talk about this and I will be able to refer you for counselling.

## Who will have access to the videos and information about you?

The only people who will have access to the videos and information will be my supervisor. Your name will be left out of every report. I will not publish anything that reveals your identity.

## What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?

It is highly unlikely that anything will happen to you as a result of this research project. If, in the unlikely event that you are injured, I have insurance to cover me.

## Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study.  There will be no costs involved for you, if you do take part.

## Is there anything else that you should know or do?

You can contact me at (telephone numbers of researcher provided) or (e mail address of researcher provided) if you have any further queries or encounter any problems.

You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by me.

You will receive a copy of this information and consent form for your own records.

**Declaration by participant**

**By signing below, I …………………………………..………… agree to take part in a research study entitled THE COMMUNICATIVE PARTICIPATION OF ADULTS WITH CEREBRAL PALSY.**

**<u>I declare that:</u>**

I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

I have had a chance to ask questions and all my questions have been adequately answered.

I understand that taking part in this study is voluntary and I have not been pressurised to take part.

I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

I agree to be interviewed five times in a six-month period.

**Signed……………………………………….**

I agree/ do not agree to allow Karen Levin to accompany me on my daily activities on one or two days

**Signed…………………………………………**

I agree/ do not agree to allow Karen Levin to videorecord/ audiorecord the interviews

**Signed…………………………………………**

**Signed at (place) ......................…........…………….. on (date) …………....………..**

**Signature of witness…………………………………………………**

**Declaration by investigator**

I (name) ……………………………………………..……… declare that:

I explained the information in this document to …………………………………..

I encouraged him/her to ask questions and took adequate time to answer them.

I am satisfied that he/she adequately understands all aspects of the research, as discussed above

**Signed at (place) ......................…........…………….. on (date) …………....………..**

**Signature of investigator……………………………………………….**

**Signature of witness……………………………………………………**

## Appendix 3: Information leaflet and consent form for participants in observations

## INFORMATION LEAFLET AND CONSENT FORM FOR PARTICIPANTS IN OBSERVATIONS

**TITLE OF THE RESEARCH PROJECT: THE COMMUNICATIVE PARTICIPATION OF ADULTS WITH CEREBRAL PALSY**

**REFERENCE NUMBER: N10/08/247**

**PRINCIPAL INVESTIGATOR: Karen Levin**

**ADDRESS: (Home address of researcher provided)**

**CONTACT NUMBER: (Telephonic information of researcher provided)**

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask me any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are **free to decline** to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part. You are also free to select in which aspects of this study you are willing to participate.

This study has been approved by the Health Research Ethics Committee (HREC) at Stellenbosch University and by the Health Research Ethics Committee at the University of the Witwatersrand, and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

## What is this research study all about?

I am researching how people with cerebral palsy communicate and participate in life's activities. Disabled people can experience many difficulties and I want to investigate what they have experienced in terms of having a communication disability. I also want to determine the ways that they have coped with their communication disabilities and what they have done to overcome them so that they can participate in the world.

I would like to spend a few hours with the participants who have agreed to take part in my research. The aim of these observations is to observe how the participants communicate in their everyday life to see them participate in the world so that I can better explain the results of the interviews that I will be holding with them. I will not video record these observations but I will write down my observations in a notebook.

## Why have you been invited to participate?

I have invited you to participate in my research because you have been identified as the participant in my research as being someone with whom he or she interacts. I think that, by observing your communication with the participant, you will be able to give me much information that will help me to explain how disabled people in South Africa are able to participate in life.

## What will your responsibilities be?

Your only responsibility in this research will be to let me know at any time if you wish to drop out of the research. I will not be upset and I will not tell anyone.

## Will you benefit from taking part in this research?

There are no direct benefits to you. I am hoping that this research will help us understand how people with cerebral palsy participate so that we can assist disabled people to be more successful in future.

## Are there in risks involved in your taking part in this research?

I do not think that there are any risks to your taking part in this research. However, you may feel upset about talking about some sensitive issues. If necessary, we can talk about this and I will be able to refer you for counselling.

## Who will have access to the information about you?

The only people who will have access to the information will be my supervisor. Your name will be left out of every report. I will not publish anything that reveals your identity.

## What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?

It is highly unlikely that anything will happen to you as a result of this research project. If, in the unlikely event that you are injured, I have insurance to cover me.

## Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study. There will be no costs involved for you, if you do take part.

## Is there anything else that you should know or do?

You can contact me at (telephone numbers of researcher provided) or (e mail address of researcher provided) if you have any further queries or encounter any problems.

You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by me.

You will receive a copy of this information and consent form for your own records.

## Declaration by participant

**By signing below, I …………………………………..…………. agree to take part in a research study entitled THE COMMUNICATIVE PARTICIPATION OF ADULTS WITH CEREBRAL PALSY.**

**I declare that:**

I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

I have had a chance to ask questions and all my questions have been adequately answered.

I understand that taking part in this study is voluntary and I have not been pressurised to take part.

I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

I agree to participate in activities in which Mrs Levin observes (name of participant) in his/her communication in everyday contexts in which I am present.

**Signed……………………………………**

**Signed at (place) ......................….......…………….. on (date) …………...………..**

**Signature of witness……………………………………**

## Declaration by investigator

I (name) ……………………………………………..……… declare that:

I explained the information in this document to …………………………………..

I encouraged him/her to ask questions and took adequate time to answer them.

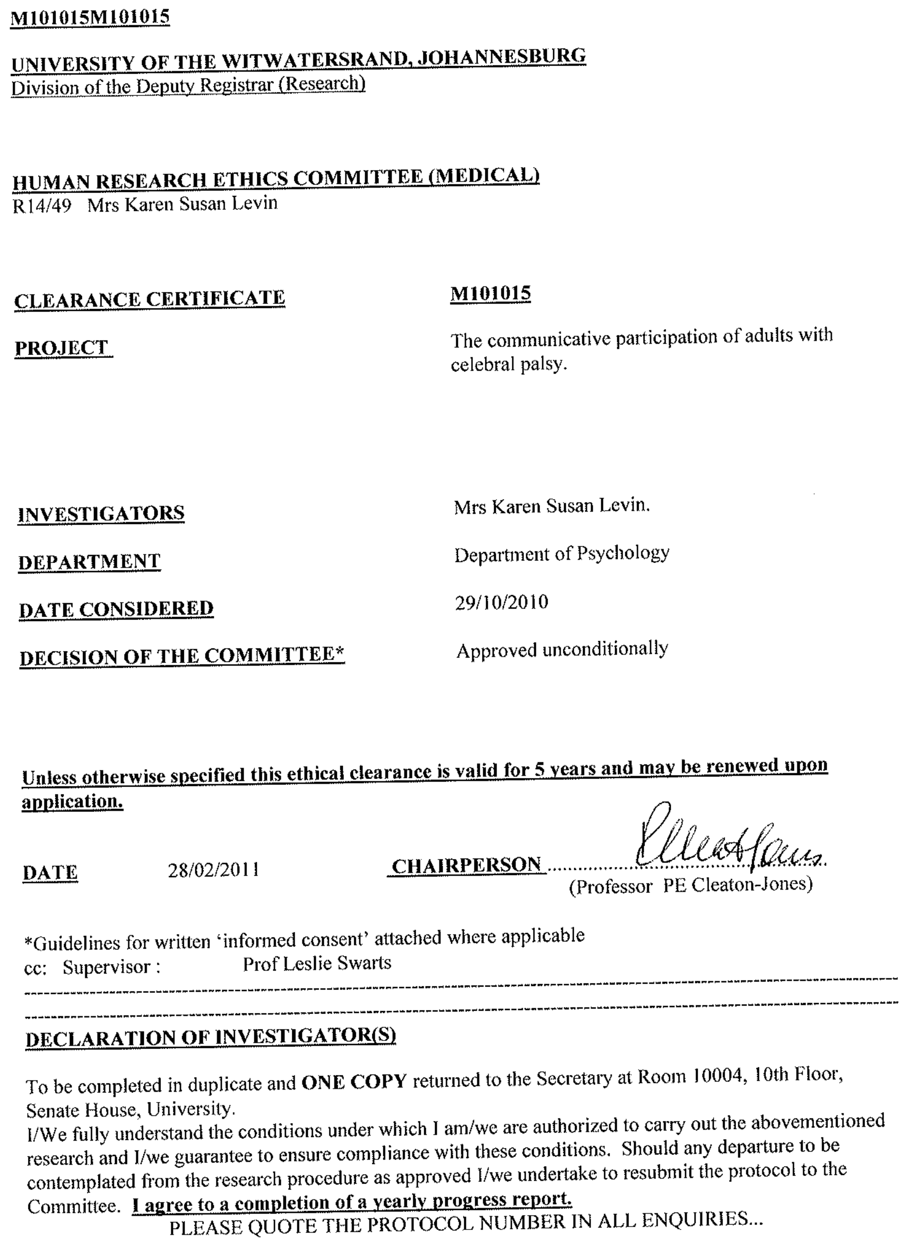
I am satisfied that he/she adequately understands all aspects of the research, as discussed above

**Signed at (place) ......................….......…………….. on (date) …………...………..**

**Signature of investigator………………………………**

**Signature of witness…………………………………**

## Appendix 4: Certificate from HREC, University of the Witwatersrand



**M101015M101015**

**UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG**
Division of the Deputy Registrar (Research)

**HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)**
R14/49 Mrs Karen Susan Levin

| | |
|---|---|
| **CLEARANCE CERTIFICATE** | **M101015** |
| **PROJECT** | The communicative participation of adults with celebral palsy. |
| **INVESTIGATORS** | Mrs Karen Susan Levin. |
| **DEPARTMENT** | Department of Psychology |
| **DATE CONSIDERED** | 29/10/2010 |
| **DECISION OF THE COMMITTEE*** | Approved unconditionally |

**Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.**

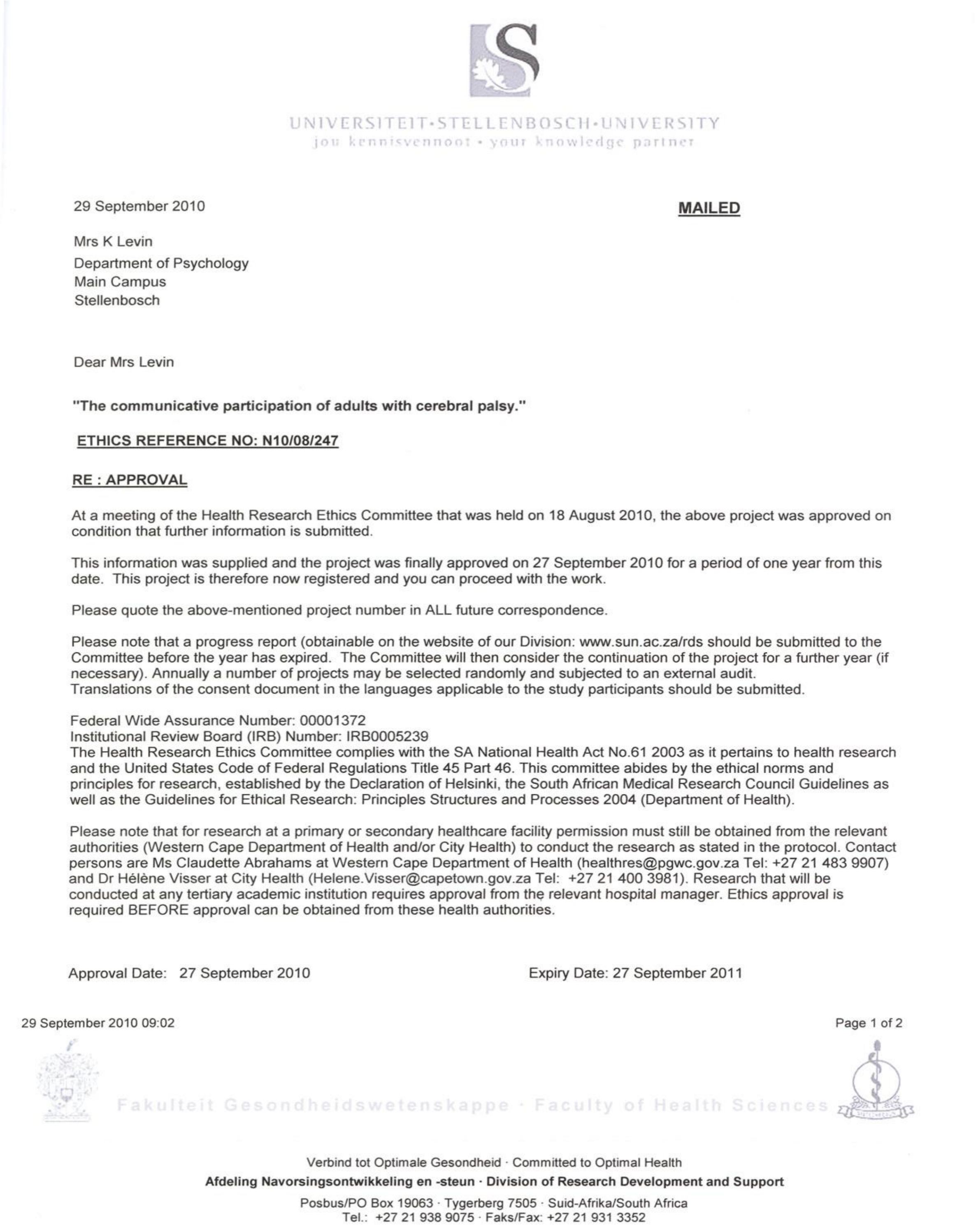
**DATE** 28/02/2011 **CHAIRPERSON** ......................................
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Prof Leslie Swarts

**DECLARATION OF INVESTIGATOR(S)**

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

# Appendix 5: Certificate from HREC Stellenbosch University



UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot · your knowledge partner

29 September 2010

**MAILED**

Mrs K Levin
Department of Psychology
Main Campus
Stellenbosch

Dear Mrs Levin

**"The communicative participation of adults with cerebral palsy."**

**ETHICS REFERENCE NO: N10/08/247**

**RE : APPROVAL**

At a meeting of the Health Research Ethics Committee that was held on 18 August 2010, the above project was approved on condition that further information is submitted.

This information was supplied and the project was finally approved on 27 September 2010 for a period of one year from this date. This project is therefore now registered and you can proceed with the work.

Please quote the above-mentioned project number in ALL future correspondence.

Please note that a progress report (obtainable on the website of our Division: www.sun.ac.za/rds should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.
Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239
The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Hélène Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

Approval Date: 27 September 2010

Expiry Date: 27 September 2011

29 September 2010 09:02

Page 1 of 2

Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences

Verbind tot Optimale Gesondheid · Committed to Optimal Health
**Afdeling Navorsingsontwikkeling en -steun · Division of Research Development and Support**
Posbus/PO Box 19063 · Tygerberg 7505 · Suid-Afrika/South Africa
Tel.: +27 21 938 9075 · Faks/Fax: +27 21 931 3352

## Appendix 6: Examples of initial, focussed and theoretical codes

Table 11

*Examples on initial codes*

| |
|---|
| Being excluded |
| Asking for clarification |
| Expending effort |
| Feeling anger |
| Observing others |
| Standing on the outside |
| Failing to be an employer |
| Taking abuse |
| Being stigmatised |
| Being belittled |
| Waiting for opportunity to speak |
| Hiding one’s disability |
| Passing |
| Having a voice |
| Passing an opinion |
| Engaging in pillow talk |
| Telling secrets |
| Protesting |
| Acting defiantly |
| Arguing a point |
| Expressing intimacy |
| Taking opportunity to speak |
| Revealing vulnerability |
| Interpreting what others think |
| Seeing others as in control |

Table 12

*Examples of focused codes*

| |
|---|
| Being excluded (physically isolated; come on in but not too far; fully included) |
| Half-participating |
| Participating successfully |
| Being recognised |
| Talking |
| Taking roles |
| Being a talker |
| Communication in relationships (roles; friendships; loneliness) |
| Being disabled |
| Living through time |

Table 13

*Examples of theoretical codes*

| |
|---|
| Communicating in relationships (reciprocity, cooperation, recognition) |
| Expressing self (identity) |
| Experiencing inclusion |
| Experiencing barriers |
| Living through time |
| Communicating in context |
| Living liminality |

## Appendix 7: Using the gerund "being" in the initial coding

Table 14

*Examples of the gerund "being"*

| Initial codes | Examples of quotations from participants |
|---|---|
| Being understood | *Going back to childhood, only about a handful of people could understand me* |
| Being rejected | *Found different people approach me differently some run away from me* |
| Being part of the community<br>Being more empowered to talk | *I was more part of the community, and I could talk about many more things with them, because they could understand me easier* |
| Being included<br>Being excluded | *And we play ball… that I'm included in all of the conversation. Whereas before, before the problem was if I'm trying to voice my input into the conversation they immediately changed the subject* |
| Being given a chance to speak<br>Being given a chance to correct | *They just give me a chance to say it again* |
| Being given advice<br>Being cared for<br>Being told to do something impossible | *on the phone…my voice becomes inaudible if I'm upset but my mom says I must stop crying and try again* |

## Appendix 8: Memo 1: *Authenticity*

I went through my transcriptions with (research assistant) this morning, and we discussed the observation that we both have that Ellie and Beauty are both totally unaware of whether their listeners had understood them or not. I am sure that Parks is also not aware – I will have to follow this up with him perhaps.

What can I make of this? I think that Beauty made a point when she said that speaking is so hard for her. It takes tremendous effort. (Research assistant) and I spoke about the deterioration in Beauty's speech as the last interview progressed to the point that we both did not understand most of what she was saying for the last part of the interview, and that I pretended to understand and made comments every now and again and nodded my head. I did not let Beauty know that I was lost. I misled her! I wonder why people do this to unintelligible people. Why did I? I was tired; I did not really care about what she was saying to me at the end! I did not want her to feel uncomfortable? So how would she ever know if people don't understand her if they don't tell her? And if all her energy goes into her effortful speech then how can any be directed to the listener?

I've also done this when I don't understand, and I feel so bad about stopping them all the time to ask them to repeat – it stops the flow and does not let them think things through. So I've nodded and agreed with them even though I have not understood a word. I have done this because I think I am being "fair" but is it?

And Ellie often does not process what I have said to her. (Research assistant) agreed with this. Ellie often talks as if she is talking in a monologue. She says what she wants to say and does not take heed of her listener. I asked her questions and she seemed to go off at a tangent. Is this a part of a language disorder? Is this because she is so used to her listener not understanding her that she ignores the listener? (Research assistant) suggested that they get mixed messages so they just talk, and also thinks that Ellie's pragmatics are poor.

This is a terribly important issue. I ask myself: How can you participate with people when they don't know what you are doing? How much is pretence and false and not true and not authentic about how we interact with them?