The lived experiences of higher education for students with a visual impairment: A phenomenological study at two universities in the Western Cape, South Africa

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DECLARATION

By submitting this dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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ABSTRACT

Introduction: In the last two decades there has been an increase in the numbers of visually impaired students accessing universities in South Africa. However, very few studies have documented the experiences of these students. Through the lens of a phenomenological understanding of disability, this study thus aimed to capture the lived experiences of visual impairment, as recounted by participants from two universities in the Western Cape, South Africa.

Methods: Data were collected and analysed according to the principles of the interpretative phenomenological approach. I conducted semi-structured, in-depth individual interviews with 23 participants, and 13 students participated in focus group sessions.

Results: The analysis yielded important findings. First, participants described the challenges related to the transition from school, namely: orientating themselves to the new physical environment; making new friends; and deciding whether they wanted to disclose impairment. This transition was sometimes closely tied to introspection and a new sense of self. Mainstream versus special schooling experiences seemed to shape this transition and their experiences in higher education to a degree. Second, participants discussed complex social interactions with nondisabled peers, in which the latter reportedly offered help, and avoided or stared at participants, leaving them feeling “not seen”. In response, visually impaired students often denied impairment and concealed their emotional pain. Third, within the learning environment, the participants were sometimes confronted with unwilling lecturers, a lack of communication amongst important role-players, late course material and/or headaches and muscle tension from the effort of reading with limited sight. The students recounted that they commonly self-advocated and took the responsibility upon themselves to get special accommodations. There were also many positive accounts of supportive lecturers and disability units who did more than was required of them.

Discussion: Overall, these findings showed that the experiences of students did not seem to differ according to the institution they attended. Their visual category and/or secondary schooling seemed to have played a more significant role where their experiences differed. The findings also revealed that, in addition to the typical demands of university studies, the participants also took a lot of responsibility upon themselves to manage their studies and their physical and social environment. Participants seemed resilient and innovative, yet the effort sometimes drained their energy and left them frustrated. Despite valuable steps towards inclusion, these visually impaired students were still not fully included on tertiary campuses.

Keywords: visual impairment, inclusion, higher education, South Africa, phenomenology, lived experiences, interpretative phenomenological approach

OPSOMMING

Inleiding: Die aantal visiueel gestremde studente in Suid-Afrikaanse universiteite het oor die afgelope twee dekades toegeneem. Die ervarings van hierdie studente is egter deur baie min studies gedokumenteer. Die studie het dus gepoog om, deur middel van 'n fenomenologiese begrip van gestremdheid, die deurleefde ervarings van visiuele gestremdheid, soos vertel deur deelnemers van twee universiteite in die Wes-Kaap, Suid-Afrika, vas te lê.

Metodes: Die insameling en analise van data is uitgevoer volgens die beginsels van die intertavistiess fenomenologiese benadering. Ek het semi-gestruktureerde, in-diepte, individuele onderhoude met 23 deelnemers gevoer en 13 studente het aan fokusgroep sessies deelgeneem.

Resultate: Die analise het tot belangrike bevindinge aanleiding gegee. Die deelnemers het eerstens die oorgang vanaf skool en die verbandhoudende uitdagings beskryf, naamlik, om hulself te orienteer tot die nuwe fisiese omgewing, om nuwe vriendskappe te smee en om te besluit of hulle hul gestremdheid bekend wou maak. Hierdie oorgang het soms nou saamgehang met self-ondersoek en ‘n nuwe begrip van hulself. Dit blyk ook dat hoofstroom of spesiale onderwys tot ‘n mate die oorgang en algehele ervarings op universiteit gevorm het. Tweedens, het die deelnemers komplekse sosiale interaksie met nie-gestremde eweknieë bespreek. Volgens die deelnemers, word hul dikwels deur nie-gestremde studente aangestaar, vermy of gehelp, wat eersgenoemdd dikwels “onsigbaar” laat voel het. In reaksie hierop het die visiueel gestremde studente dikwels hul gestremdheid, asook hul emosionele pyn, ontken en verbloem. Derdens, was deelnemers soms gekonfronteer met onwillige dosente, kommunikasiegapings tussen kern rolspelers, laat kursusmateriaal en/of hoofpyne en spierspanning weens die inspanning van lees met beperkte visie. Die studente het vertel dat hulle oor die algemeen self-voorspraak doen en die verantwoordelikheid op hulself neem om spesiale aanpassings te verkry. Daar was ook heelwat positiewe kommentaar aangaande ondersteunende dosente en gestremdseenhede wat dikwels meer gedoen het as wat van hulle vereis was.

Bespreking: In die algeheel gesien, blyk dit nie dat die ervarings van studente verskil na gelang van tersiêre instansie nie. Dit wil voorkom dat visuele kategorie en/of sekondêre onderrig ‘n groter rol in die verskille tussen studente gespeel het. Die bevindings dui ook daarop dat, afgesien van die tipiese vereistes van tersiëre studies, die deelnemers baie van die verantwoordelikheid moes dra om hul studies en die sosiale en fisiese omgewing te bestuur. Alhoewel deelnemers veerkragtig en innoverend blyk te wees, het die inspanning hulle dikwels gedreineer en gefrustreerd gelaat. Ten spyte van waardevolle vordering ten opsigte van insluiting, was hierdie visueel gestremde studente steeds nie ten volle ingesluit op tersiëre kampusse nie.

Sleutelwoorde: visiuele gestremdheid, insluiting, hoer onderwys, Suid-Afrika, fenomenologie, leefervarings, interpretavistiese fenomenologiese benadering

STATEMENT REGARDING BURSARIES

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LIST OF ACRONYMS

AHEAD - Association on Higher Education and Disability

ANC - African National Congress

APA - American Psychological Association

CPUT – Cape Peninsula University of Technology

DoE – Department of Education

DoBE – Department of Basic Education

DHET – Department of Higher Education and Training

EWP3 - Education White Paper 3 on The Transformation of the Higher Education System

EWP6 - Education White Paper 6

FOTIM - Foundation of Tertiary Institutions of the Northern Metropolis

INDS - Integrated National Disability Strategy

IPA – Interpretative Phenomenological Approach

NCESS - National Committee on Education Support Services

NCSNET - National Commission on Special Education Needs and Training

NPHE - National Plan for Higher Education

ODP - Office of the Deputy President

SU – Stellenbosch University

UK – United Kingdom

UN – United Nations

UNCRPD - United Nations Convention on the Rights of Persons with Disabilities

UPIAS - Union of Physically Impaired Against Segregation

USA – United States of America

WHO – World Health Organization

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CHAPTER 1

INTRODUCTION

> The most persuasive sociological writing emerges from a personal feeling. Whether it be of anger or delight, it forms into a conviction about something good or bad in society. It unfolds into a story of loss and change, protest or revolution, and then develops into something more abstract, ecumenical, and systematic but recognizably spoken nonetheless, by a voice still breaking with the emotion that first fired it into the world. Such writing is often driven by a desire to proclaim the truth in situations in which power demands "lies, secrets, and silence. (Williams, 2001, p. 123)

1.1 Introduction and Reflections

This study tells my story and yet, it does not. Just like all the storytellers I introduce in this research, I am a student with a visual impairment. Like many of them, I am blind from birth and attended a "special school" for the blind. And, like all of them, I am still studying at a tertiary institution. In many regards, the borders separating our worlds are thin and very permeable; as my taken-for-granted everyday world overlap and merge with theirs. In many ways their experiences are my experiences; their worlds indistinguishable from mine. And thus, in so many ways I want to proclaim, like Leslie Swartz (2011) in his personal memoir of disability in the family, "I have all these things I want to say bursting out of me, threatening to cover every page, to blur and blot with their profusion. I want to say these things because they mean something to me, about me" (p. 13).

Except, these pages are not about me. They are about young men and women who share my disability, but not my life. And, despite the observable and felt similarities between us, our worlds may differ in very distinct and significant ways. After all, "A shared experience does not necessarily mean a shared outlook," (Luff, cited in Beauchamp-Pryor, 2011, p. 14). For example, I may have very fond memories of growing up in a special school for the blind, while some of the participants may not share this sentiment. Yet others might not have attended such a school at all. Having said this, how can I claim to fully “know” and reflect the felt worlds of individuals simply on the grounds that we are all students with a visual impairment? As Frank (2005, p. 967) writes, “One person can never say of another, “this is who such a person is”. One can say, at most, “this is how I see this person now”.

Margrit Shildrick (2009, 2012) warns against this assumption that, as disabled disability writers, we are wholly allowed and best equipped to unveil the absolute truth of disabled lives. Who of us within the field of disability studies is not familiar with the Disabled People International slogan, “nothing about us without us? Hence, with one sweeping statement, able-bodied scholars are excluded from making valuable contributions to our understanding of disability, on the grounds that “they” are the oppressors that would provide a partial view on “us” (Shakespeare, 2014; Shildrick, 2012). Sadly, however, our subjectivity as disabled writers doing disability research does not guarantee that we will discover the “objective” truth (Beauchamp-Pryor, 2014). Even in instances where authors write about themselves, Shildrick (2009) argues, they only provide a portion of the truth. She writes, “we should be deeply suspicious of any claim that disabled people speak the truth of their own conditions (Shildrick, 2009, p. 36). And, after all, does such a “truth” exist? When writing about the biased view of oppressors, Foucault soberly notes, “the partiality of discourse does not imply the existence of some absolute truth that could, under the right conditions, be accessed,” (cited in Shildrick, 2012, p. 35-36). Similarly, the famous philosopher, Merleau-Ponty (1962), writes of the inescapable nature of our personal view on the world. He notes that, even in the use of previously considered “objective” scientific methods, we cannot strip ourselves from our view on the world. He writes, “I cannot shut myself up within the realm of science. All my knowledge of the world, even my scientific knowledge, is gained from my own particular point of view, or from some experience of the world without which the symbols of science would be meaningless" (p. ix).

So does this mean that, given the non-existence of "the whole truth" and my subjectivity, I should abandon this project altogether? I strongly believe not. In a deeply personal, yet philosophical account of being a mother with an intellectually disabled daughter, Eva Kittay (2009) notes, "The close attentive eye needed to care for the dependent individual gives rise to perceptual capabilities that are not shared by those who have at best a glancing acquaintance" (p. 619). Of course, the same cannot be said of my relationship with the individuals participating in this study. But, I want to argue that, just like her relationship with her daughter gave rise to certain perceptual capabilities, I believe my visual impairment also laid the grounds to "look" at the lives of my participants in a certain, dare I say "unique", way? And with this I do not presume that it is the "whole truth"; merely that it is a different part of the truth.

Still, a mere acknowledgement of my subjectivity does not exempt me from striving to provide a clear, unbiased account of the lived worlds of visually impaired students. Eva Kittay (2008) suggests two valuable epistemological principles in making any claims on subjects in research. Firstly, she speaks of "epistemic responsibility". This contains the ethical obligation of knowing subjects before drawing definite conclusions about them. Secondly, she refers to epistemic modesty that serves as a caution to writers to know what they don't know. In searching for "some" truth, this work therefore required a balancing-act; moving close enough to "see" the unique inner lives that came to the fore, while keeping a "safe" and respectful distance so that my world did not became entangled with the unique stories being told. I had to balance being an involved insider with being a distant onlooker; being someone who "knows" it all, with someone who knows nothing.

And so despite, and in many regards exactly because of, my subjectivity, I believe that this work can make a valuable contribution to understand and, where necessary, change the day-to-day lives of visually impaired students.

1.2 Rationale and Significance of the Study

Visually impaired students should be listened to: they can speak directly from their own experiences, their learning strategies employed at school, college and in daily life. They are innovative. They have had to be to progress on into higher education. (Roy, 2003, p. 78)

It is important to know the learning experiences of the students with visual impairment and to use them fruitfully in improving their learning experiences which would eventually make those students with visual impairment to feel proud that they have also contributed to the development of equitable access to education. (Mokiwa & Phasha, 2012, p. 147).

In their pursuit of a tertiary qualification, visually impaired students are often presented with numerous new possibilities and opportunities. Here they can increase their knowledge, make friends, gain a sense of belonging and make important career choices (Beauchamp-Pryor, 2012a, 2013; Getzel, Stodden & Briel, 2001; Hurst, 1996; Scott, 2009; Swart & Greyling, 2011). Moreover, once they graduate and leave the university campus, the benefits of higher education do not end. To the contrary, graduating commonly widens their employment prospects and increases their chances of earning a competitive income (Adams & Holland, 2006; Chataika, 2010; Gajar, Goodman, & McAfee, 1995; Getzel, Briel, & Kregel, 2000; Getzel et al., 2001; Riddell, Tinklin, & Wilson, 2005; Vedeler, 2009; Wehman, 2006). Some studies even show that employment opportunities may double or triple once a student has obtained a degree (Bloom, Canning, & Chan, 2006; Chataika, 2010; Schroedel & Geyer, 2001). In short, a tertiary qualification is often a gateway to a better future for disabled students, including those with a visual impairment (Bell, 2013; Chataika, 2010; Chataika, McKenzie, Swart, & Lyner-Cleophas, 2012; Lyner-Cleophas, Swart, Chataika, & Bell, 2014).

However, before they are able to taste these rewarding outcomes, visually impaired students in higher education commonly have to overcome numerous obstacles along the way (Fuller, Healy, Bradley & Hall, 2004; Getzel, 2008). These challenges include, amongst others, difficulty to access course material (Fuller et al., 2004; Holloway, 2001; Joshi, 2006), inaccessible teaching methods (Howell, 2006) and negative attitudes from peers (Beauchamp-Pryor, 2012a; Hodges & Keller, 1999; Swart & Greyling, 2011) (see also Chapter 3 and Chapter 4). It therefore comes as no surprise that disabled students, including those students with a visual impairment, are at a higher risk of leaving the tertiary institution prematurely compared to their non-disabled peers (DaDeppo, 2009; Getzel, 2008; Madriaga et al., 2010; Wessel, Jones, Markle, & Westfall, 2009). Even though engaging in tertiary education can thus improve the lives of disabled students in very significant ways, barriers may prevent them from reaching their goals and developing their full potential.

In order to correctly identify these barriers to participation, authors are unanimous in their belief that it is critical to listen to the first-person experiences of disabled students themselves. This resonates closely with Kittay’s concept of epistemic responsibility, namely, “to know the subject under study.” When we listen to these students, we will get to “know” their difficulties (Healey, Bradley, Fuller, & Hall, 2006). We will hear their hardships, disappointments, frustrations and sadness, as we delve deeper into their lived worlds. And so we may start to uncover possible areas that need to change. After all, Swartz and Watermeyer (2006) contend that change is only possible if the difficulties faced by people with disabilities are explored and documented. Equally important, however, is to know what needs to remain unchanged. We therefore need to listen to the successes and achievements of these students; to know what and/or whom assisted in their persistence (Mamiseishvili & Koch, 2011).

However, I believe, simply listening is not enough. Their stories of struggle and success should, at the very least, be documented so that their experiences could inform and guide the development of research, policy and practice in higher education (Fuller et al., 2004). As South Africa's former president, Thabo Mbeki, stated in his foreword to the South African Integrated National Disability Strategy White Paper (Mbeki, 1997), "This White Paper represents the government's thinking about what it can contribute to the development of disabled people and to the promotion and protection of their rights. We believe in a partnership with disabled people. Therefore the furtherance of our joint objectives can only be met by the involvement of disabled people themselves" (Mbeki, 1997, p. 2). It is therefore clear that if researchers do not explore the experiences of students with visual impairments, these students will remain silent and change will be inhibited. In this regard, there is a special responsibility placed on insider researchers, such as myself.

Despite a growing body of literature on the day-to-day lives of disabled students, the literature on voices of disabled students in South Africa is still too thin to tell the whole story. The largest study on the experiences of disabled students was conducted across 15 universities by the Foundation of Tertiary Institutions of the Northern Metropolis (FOTIM) in 2011 (FOTIM, 2011). This followed smaller studies like the mixed method investigations across three universities by Crous (2004a, 2004b), as well as the qualitative research of Matshedisho (2010), Naidoo (2010) and Swart and Greyling (2011). Although other studies addressed the situation of disabled students in South Africa, it mostly included the voices of senior managers rather than the students themselves. These studies included the investigations by Howell (2005) and Matshedisho (2007a).

What is more is that very little research in South Africa has been conducted on the experiences of visually impaired students in higher education. In instances where research has been done, it included unpublished works such as the dissertations by Ngubane-Mokiwa (2013), Seyama (2009) and Sukhraj-Ely (2008). The only published articles that could be ascertained on visually impaired students in South Africa are the qualitative studies by Kasiram and Subrayen (2013) and Mokiwa and Phasha (2012). These studies are fairly limited, since they included only the voices of students at one university (mostly the University of KwaZulu-Natal). Having said this, it is evident that most of these studies are fairly recent, suggesting a growing interest in the plight of visually impaired students on tertiary campuses.

A sharp focus on one impairment, like visual impairment, is important, since the barriers and needs of students might differ across disabilities (Alqaryouti, 2010). What is more, is that the experiences of students within one category of disability might also vary (Fuller et al., 2004; Grace & Gravestock, 2009; Roy, 2003). For example, two people with partial sight may have very different experiences and needs at tertiary level, because one of them may have only peripheral vision while the other may have only central vision. Given this fact, it is perhaps more desirable to have an in-depth focus on one impairment with its varying range of experiences and realities, rather than having the potentially confusing task of listening to various voices from a diverse range of disabilities.

In summary, still limited research exists regarding the lived experiences of visually impaired students within the South African context. Such research is essential to pinpoint areas for change and, simultaneously, to highlight effective practice.

1.3 Focus and Aims of the Study

In answer to the call for the personal accounts of disabled students, this study ask, “What are the lived experiences of visually impaired students in higher education?” And “what do these experiences say about their inclusion in higher education?”

Through listening to these students, this research aims to shed light on:

- The lived experiences of visually impaired students at Stellenbosch University (SU).
- The lived experiences of visually impaired students at Cape Peninsula University of Technology (CPUT).
- The lived experiences of individual students through case studies.
- Tentative inferences regarding overlap and differences between students based on differing demographic information. For example, “Does the lived experience of a partially sighted student differ from that of a totally blind student?”

In short, this study will explore the lived experiences of visually impaired students in two tertiary institutions in South Africa. As I aim to explore the day-to-day experiences of these students, I believe their success and struggle, their triumphs and pain, will be illuminated. In this way, it is hoped that this work may facilitate further research that will guide future generations, researchers, policy planners, decision-makers and other important role players to the important areas for change.

1.4 Context of the Study

> Under apartheid, the experiences of disabled people were also the experiences of a deeply divided people living in a profoundly unequal society. The lived experiences of black and white disabled people under apartheid were very different and reflected the

> general inequalities between white and black people in South Africa. For the majority of black disabled people, their lives were about struggling on a daily basis to cope with the poverty, deprivation and violence of the apartheid system, a struggle compounded by their disability. (Howell, Chalklen, & Alberts, 2006, p. 48)

I chose to conduct interviews at SU and CPUT respectively, since these institutions have very different historical backgrounds. Their different histories reflect the racial divide of South Africa's past, as SU was a "Whites only" institution and CPUT was partly a university for Coloured students.

Before 1994, Black, Coloured and Indian citizens rarely occupied the same spaces as White South Africans. In fact the racial divide that was called "Apartheid" could roughly be translated into English as "staying apart". However, racial groups were not only kept apart, but their world also differed in very significant ways. Whereas White persons were enjoying the full wealth of South Africa's resources, the remaining racial groups were struggling on a daily basis with poverty, violence and deprivation (Howell et al., 2006). This racial divide left almost no part of life untouched. In this sense, it also permeated and contaminated the campuses of higher education. Previously "White" institutions, such as SU, were favoured under the country's constitution, while other institutions, such as CPUT, did not enjoy the same privileges (Matshedisho, 2007a). (In the next section I will explain that CPUT was previously two separate institutions – namely a White and Black university respectively). Even though historically disadvantaged institutions may be more resourceful than they were under the apartheid regime, disparities still exist between these institutions in the services they provide and their resources (FOTIM, 2011; Howell & Lazarus, 2003; Matshedisho, 2007a).

And so it was because of this apparent gap that still exists between tertiary settings that this research was conducted at two historically different universities, namely at SU and at CPUT in the Western Cape. Let’s take a quick look at the histories of these institutions and their current approach towards disabled students.

1.4.1 General background of SU and CPUT

The main campus of SU is situated within the oldest town of South Africa. Nestled between picturesque mountains and situated within the heart of the winelands, Stellenbosch is a popular tourist attraction. The town is well-known for its natural beauty and resources, but also for its large student population and university campus. Stellenbosch is thus often referred to as “a student town”.

On 2 April 1918, SU gained status as an independent university that replaced the former Victoria College. It was here that government officials such as H. F. Verwoerd formulated Apartheid policies. It therefore comes as no surprise that the typical Stellenbosch student was White and spoke Afrikaans. Although the university has now instituted transformation, such as including tuition in English and awarding bursaries to historically disadvantaged groups, the process is still slow, and in 2013, 65% of SU’s population remains White.

In part, this history can explain the close ties between SU and the special School for the Blind in Worcester. In the Western Cape, there are mainly two schools for visually impaired learners, namely Athlone School for the Blind in Bellville and Pioneer School for the Blind in Worcester. Historically, these schools were also divided along racial lines – Athlone being the school for mostly Coloured and Black learners, and Worcester being home to predominantly White blind learners. It therefore goes without saying that learners from Pioneer School who went on to tertiary education mostly studied at SU – the only White Afrikaans higher institution in the Western Cape.

CPUT was established in 2005 as a merger of Cape Technikon (now Cape Town campus) and Peninsula Technikon (now Bellville campus). It is the only technical university in the Western Cape and is also the largest university in this province with approximately 32 000 students. The Cape Town campus of CPUT is situated in the heart of Cape Town, with a clear view of Table Mountain. Its history dates back to 1920 when it was established as the then Cape Technical College. The Peninsula campus of CPUT is situated within Bellville, approximately 30 kilometres from Cape Town. It was established in 1962 as Peninsula Technical College in response to a growing number of Coloured apprentices in various trades. In 1979 both institutions were legally established as technikons, the Peninsula Technikon and the Cape Technikon.

Under the Apartheid regime, both technikons were forced to serve a certain race group – Cape Technikon had only White students, whereas Peninsula Technikon served only Coloured students. Therefore Black students were excluded from both these institutions. In 1987 the Peninsula Technikon was opened to all South Africans and, in that same year, the government granted the Cape Technikon special permission to lift the quota on Black students. In 2005, the Cape Technikon and the Peninsula Technikon merged to form CPUT (CPUT, 2010). However, CPUT still has mostly Coloured and Black students who were disadvantaged under the Apartheid regime.

1.4.2 The provision for disabled students at SU and CPUT

In recent years, both SU and CPUT have made efforts to include and welcome students with disabilities on their campuses. In 2006, SU launched the Office for Students with Special Needs/Disabilities, under the division of the Centre for Student Counselling and Development. Two years later, the disability unit at CPUT was launched (Abratt, 2008). Despite their divergent histories, both institutions have very similar goals regarding disabled students. These goals can be summarised as providing for the needs of disabled students, making information and environments accessible for them, and advocating and communicating their needs to relevant staff members.

However, where SU makes it clear that accessibility is contingent on available funds, CPUT specifically states that funds will be procured to provide for the needs of their students. Yet, anecdotal evidence shows that, in the past, SU has invested extensive time and energy in procuring sufficient funds for the support of students (personal communication, Ntsaki Mashele, June 12, 2012). It is therefore unclear where the limits to affordability, as stated by SU on their website, lie.

The success of the inclusion of disabled students is evident in the rise of the number of disabled students at both institutions. Worth mentioning is the steep increase of disabled students at CPUT. In 2012, when I conducted interviews, there were 19 visually impaired students and 175 disabled students in general. In 2014, the number of visually impaired students increased to 41 students and 241 disabled students in general.

As mentioned before, the commitment of both units exceeds access, as they are also concerned with the needs and equal participation of disabled students. They therefore offer services such as:

- Awareness campaigns.
- Academic assistive equipment like JAWS for Windows (a screenreading programme for computers for visually impaired students), Openbook (a scanning programme), Zoontext (a computer magnifying programme) and many more.
- Academic services like staff who convert printed material into Braille and/or large print.

- Facilities, for example, separate computer laboratories where disabled students can do their work.
- Social services like a social club (CPUT) and sporting activities for disabled students like ballroom dancing (SU).
- Training at CPUT. Keeping in mind the historical poverty that spilled over into the democratic South Africa, CPUT employed a direct student support assistant in 2011 to provide training for staff and disabled students. In these two week programmes, students are taught to work on a computer and to effectively use the varying assistive equipment.
- It is thus evident that, despite the historical status of CPUT, their commitment towards disabled students matches that of SU. This confirms the findings by FOTIM (2011) and Howell (2005) that, in spite of resource constraints, other factors like strong leadership can make historically disadvantaged universities very effective in their approach to disabled students. Whether these seemingly effective practices are experienced by students remains to be explored in this research.

1.5 A Note on Terminology

Currently, there are a number of ways of referring to disabled people. These include phrases like “disabled people” or “people with disabilities”. The sixth manual of the American Psychological Association (APA) (2010), prefers the latter phrase, as it places the person first, thereby recognising that the disability is not the sole identity of the disabled person.

However, APA admits, along with other critics, that this way of writing may become cumbersome and awkward. Paradoxically, this unnatural way of writing, may potentially draw more negative attention to the disability (Vaughan, 2009). Furthermore, asserting that a disability is not part of the self and merely an appendix, denies the fact that disabled people might see their disability as an integral, positive part of their identities; a part that inevitably shaped who they are (Beauchamp-Pryor, 2011; Overboe, 2009). Widdel writes about her disability in the following way, “I cannot wish that I have never contracted ME, because it has made me a different person, a person I am glad to be, would not want to have missed being, and could not imagine relinquishing, even if I were ‘cured’” (1996, p. 83). In the largely British social model of disability, the term “disabled people” is preferred, as according to this model, people are disabled by social exclusion and discrimination (see for example Oliver, 1990).

In this thesis I will use these terms interchangeably, including “visually impaired person” and “person with a visual impairment”, in order to ensure easy reading. Furthermore, I believe that both phrases are acceptable in this work, since using a number of terms is supported by the phenomenological framework of this study. Phenomenology entails listening to the day-to-day experiences of people – irrespective of whether these experiences are shaped by biology or society. It also entails respecting and, where appropriate, using people’s varied self-ascriptions.

1.6 Structure of the Thesis

The thesis consists of 10 chapters. Chapters 1 to Chapter 5 lay the theoretical and methodological foundation for Chapter 6 to Chapter 8, while Chapter 9 gives an overall conclusion.

Chapter 2 will situate this study within a theoretical framework. Firstly, it will provide a closer look at the medical and social models of disability, including their origins, definitions and the critique against them. Lastly, the phenomenological formulation, as framework for this study, will be discussed.

In Chapter 3, I will review relevant literature regarding education and disability. This encapsulates a general look at the progress towards inclusion worldwide, as well as the experiences of disabled students in higher education. The chapter concludes with suggestions forward.

Chapter 4 will shed light on the situation of disabled students in South African tertiary institutions. It will include a glimpse into the history of disability in South Africa, as well as policy developments post-1994. Furthermore, it will take a look at the outcomes of policies with specific reference to the experiences of disabled and visually impaired students.

Chapter 5 provides a broad overview of the methodological paradigm and technique of the thesis, namely the interpretative phenomenological approach (IPA). It goes on to show the way in which this approach informed the collection and analysis of the findings. It also introduces the reader to the participants of this study.

The analytical findings of the study, combined with relevant literature, are presented in Chapter 6 to Chapter 9. Chapter 6 to Chapter 8 comprise a holistic, thematic overview of the data, while Chapter 9 provides a detailed look through four individual case studies.

Chapter 10 concludes the thesis. It draws on the findings of this work in order to discuss implications of this thesis and to make informed recommendations.

CHAPTER 2

SITUATING DISABILITY WITHIN A THEORETICAL FRAMEWORK

2.1 Introduction

Over the past 40 years, theories on disability have expanded, establishing disability studies as a discipline within its own right (Barnes, Oliver, & Barton, 2002a; Roulstone, Thomas, & Watson, 2012). This chapter gives an overview of the most prominent theoretical models within the disability studies arena during this time. In particular, it sheds light on the medical, social and phenomenological models of disability. It discusses the way in which the medical model placed disability within the biology of the objective body and, in response, how the social model de-emphasised biology by situating disability within societal structures.

Within the growing field of disability studies, there are probably no disability-formulations as well-known and widely cited as the medical and social models. If policy documents, academic books, scholarly articles and personal accounts are not inundated with arguments for and against these understandings of disability, they almost always acknowledge the history of these models as its starting point. Likewise, even though this dissertation aims to frame disability within the phenomenological paradigm, I still provide a comprehensive overview of the medical and social models of disability.

In my view, the unwritten requirement for describing and acknowledging these two models are twofold. Firstly, these two models still serve as a benchmark that measure the progress, or lack thereof, within societal structures. In other words, the models provide a lens through which we can see whether higher education settings, for example, made any progress in addressing disability-related problems. As will be evident in the following sections, the application of these models has real consequences for people with disabilities (Smith & Erevelles, 2004).

As will be discussed later in this chapter, when the social model was introduced in opposition to the medical model, it marked an important turning point for how disability was understood for decades. In essence, it laid the foundation for the disability movement and the development of disability studies as a discrete discipline (Watermeyer, 2013). The social model thus initiated dialogue amongst disability scholars, resulting in the expansion and elaboration of additional theories explaining disability-formation.

In this chapter, each model is illuminated in terms of its differing definitions of disability, what it signifies and the way in which it shapes our understanding around the origins and construction of impairment (Coleman-Fountain & McLaughlin, 2013). Furthermore, the implications of the respective models will be discussed, along with the nature of the progress made within the model and critiques against it. I deemed it essential to position this chapter early in the dissertation, since it will aid our understanding and shape our lenses for the proceeding chapters. Let us now turn our focus to the various models that shaped disability research and initiated the disability debate.

2.2 The Medical Model

> . . . things were going along quite well, at one time. Sure people had accidents or contracted diseases, and sure, some people were disabled by these things and there were some who were even born disabled. However, there were special places where they could live, special schools that they could attend, special places where they could work and all kinds of special stuff that they could do. Now, this was not disturbing to anyone, well, maybe to them, but they were already disturbed. It was

> not as though they were not being taken care of they were with their own kind and, moreover, with our help they are living the best kind of life their limitations allow. This is the best situation for all concerned. (Michalko, 2009a, p. 99-100)

2.2.1 Definitions and critique

Until quite recently, what has been termed the medical model has been the predominant, seemingly uncontested, way of thinking about disability (Barnes, 2012; Oliver, 2009a; Oliver & Barnes, 2012; Schneider, 2006). It framed disability as an individual problem that rests solely on biological deficits (Abberley, 1996; Howell, 2005; Priestley, 2006; Rieser, 2006; Smith & Erevelles, 2004; Watermeyer, 2013; Williams, 2001). More specifically, as elegantly captured by Longmore (2003), through the medical gaze disability was seen as "a series of physiological, psychological, and functional pathologies originating within the bodies of individuals" (p. 1). Responding to this narrow view of disability, many writers took issue with this model's failure to consider contextual matters such as social, economic, historical or political factors in the development of disability (Abberley, 1996; Barnes, 1990; Barnes et al., 2002a, 2002b; Barnes & Mercer, 2005; Oliver, 1986; Reindal, 2008; Smith & Erevelles, 2004). Individuals, critics argued, were understood to be simply the tragic victims of "failed" biology that left them with the inherent, incapacitating "problem" of a disability (Barnes, 2012; Fernie & Henning, 2006; Howell, 2005; Michalko, 2002; Oliver, 2009b; Reindal, 2008). From this perspective, professionals were expected to cure or, at the very least, take care of these helpless "patients" (Beauchamp-Pryor, 2011).

Even though, at first glance a stance informed by a medical imperative to provide care and rehabilitation may seem beneficial to disabled individuals, the worldwide disability movement increasingly illuminated the adverse effects of this individualistic, biologically orientated perspective (Oliver, 1990; Swartz & Watermeyer, 2006).

Implicated in the medical view, with its sharp focus on remedy and cure, is the clear distinction between what is deemed normal and abnormal. When the body or intellect of individuals deviated from socially recognised norms and they were unable to perform "normal" activities, they were considered abnormal (Beauchamp-Pryor, 2011; Howell, 2005; Thomas, 2002); as a "body-gone-wrong" (Michalko, 2002, p. 120). For example, a student with a visual impairment in higher education (bodily deviance), who uses an assistive device for reading (deviant activity), would, in this light, be viewed as disabled and abnormal. In response to this deviance, rehabilitation was aimed at correcting bodily dysfunction and appearance so that it could "measure up" to the "normal" standards of the human body (Edwards & Imrie, 2003; Hughes, 2002). This curing often included excruciating surgery and therapy ((Beauchamp-Pryor, 2011; Borsay, 2005). If the body, however, is beyond "repair", the disabled person had to cooperate fully in an attempt to retrieve at least some form of normality (Barnes, Mercer, & Shakespeare, 1999). The message was clear: being disabled is not desired or acceptable. In fact, being disabled renders one flawed, inferior, lacking and not quite human (Campbell, 2008, Disabled People's International, 2001; Loja, Costa, Hughes, & Menezes, 2012). This curative practice left no room for the consideration that a person might have wanted to be disabled and that being disabled might have been a desired part of their identities (Beauchamp-Pryor, 2011; Wendell, 1996). Morris (1996) summarises this in the following way,

> That our lives are a burden to us, barely worth living. . . . That we crave to be 'normal' and 'whole'. . . That we don't have, and never have had, any real or significant experiences in the way that non-disabled people do. . . That we desire to emulate and achieve normal behaviour and appearance in all things. That we are ashamed of our inabilities, our 'abnormalities'. . . That we should put up with any inconvenience,

> discomfort or indignity in order to participate in 'normal' activities and events. And this will somehow 'do us good'. (pp. 19-21)

Interwoven within the separation between normal and abnormal bodies are oppressive levels of dependency, exclusion and power. The task of "restoring" the disabled body to acceptable levels of "normality" were left to those who were in power, like medical professionals (Oliver, 2009a; Oliver & Barnes, 2012). From the medical gaze, they were considered experts in curing the "biological insufficiency" of disability, (Longmore, 2003, p. 42). Moreover, the role of professionals mostly transcended the curative level, as their assessments directed the entire lives of people with disabilities (Rieser, 2006). Their evaluations determined, for example, where disabled people went to school and whether and where they should work. Unfortunately, solely adhering to expert advice and practices meant that people with disabilities became dependent, medical patients, with limited agency (Barnes, 2012; Beauchamp-Pryor, 2011; Fernie & Henning, 2006; Longmore, 2003; Priestley, 2006; Reindal, 2008; Smith & Erevelles, 2004). It is no wonder then that Garland-Thomson (1997) argues that people with disabilities, within the medical view, were situated "within a hierarchy of bodily traits that determines the distribution of privilege, status, and power" (p. 6).

This unfair distribution of physical and social capital was further reinforced by the confinement of people with disabilities to institutions such as special schools (Barnes, 2012; Hughes, 2002; Priestley, 2006). Here, at the margins of society, victims of disability experienced "social death" where their human rights were denied and they were subjected to oppressive practices of professional care (Barnes, 1990). In this light, Rieser (2006, p. 135) rightfully proclaims, "The medical model view of us creates a cycle of dependency and exclusion which is difficult to break". Professionals thus played a prominent role in steering the lives of disabled people, leaving them with no control over their own destiny. Instead, their voices were faint and unheard as they inevitably became the "invisible objects of charity" (Longmore, 2003). However, the power not only lay with professionals, but also with able-bodied people who met the standards of normality and who, upon this, monopolised political, social and physical capital to which the biologically disabled had no access (Gottfried, 1998).

Left with nothing but an identity of abnormal, voiceless dependence, we can safely assume that disabled people felt inferior to their normal counterparts and to those "competent, adequate, superior professionals. Disabled people may therefore have internalised the negative views of others, resulting in low self-esteem and a warped sense of worth" (Rieser, 2006).

Probably the most disconcerting consequence of medical model thinking is the justified, unquestioned grounds it creates for discrimination. Simply put, if disability is construed as stemming from biological deficits only, the contextual grounds in which disability is rooted and created is simply brushed over. The unfair distribution of power, privilege and status remains unexamined as the social and economic marginalisation of people with disabilities goes unnoticed (Swartz & Watermeyer, 2006). The focus is sharply and unwaveringly turned to care and cure, rather than restructuring of society. In this way, discrimination can continue without the slightest ripple of disturbance so long as it is securely kept hidden under the cloak of biological cause and effect. Similarly, South Africa's history of Apartheid is marked by countless examples of such nonchalant, unexamined, careless discrimination, and the similarity here between issues of racism and those of disablism is not coincidental.

In short, the medical model conceptualised disability as an inherent biological defect of the individual, without considering the context of that person. This rendered disabled people dependent on the care and goodwill of professionals and, as a direct consequence, left the disabled without any control or say over their lives. The medicalisation of disability furthermore separated people with disabilities from mainstream society, since it constructed them as deviant from socially constructed norms. Being defined as abnormal objects of charity often left disabled people feeling devalued and inferior. Seeing biology as the root of disability also created the foundation for society to continue their seemingly justified discriminatory practices against people with disabilities.

2.2.2 The manifestation of the medical model in education

Within the educational domain, medical model practices were no different. When the assessments of professionals indicated that a child had a disability, the logical next step was to segregate that child to a “special school”. True to the medical paradigm, at these schools the problem was understood to be “within the child”, and, the message was clear: learners with disabilities were considered tragic, dependent and different (Priestley, 1999). Within the South African context, “learners” refer to school-going individuals, typically from the age of six to 18.

As Gerber (1996, p. 159) describes the special school philosophy, “segregating, insulated, self-protecting, racially biased philosophy and array of practices, a product of . . . misguided scientific positivism, or merely as an ineffective, overblown problem to easily solvable school problems” which can be ascribed to “deficit-bound psycho-medical paradigms of individual pathological defects” (Slee, 2004, p. 47). Consequently, as seen before, professionals were appointed in “expert” roles to “care for” and “cure” the sick victims of impairment (Goodley, 2011; Slee, 1996; Swart & Pettipher, 2011).

Some authors are of the opinion that the medical model is still, perhaps more subtly than before, the dominant way of thinking about disability for everyone who works within education (Swart & Pettipher, 2011; Ware, 2004). As Swart and Greyling (2011) writes, “it is deeply ingrained into the thinking of generations of teachers, parents, professionals and legislators and is not going to change rapidly, even though it is argued that it is discriminatory and limiting” (p. 6).

However, the introduction of the revolutionary social model in the 1980s, started interrogating this way of thinking and set in motion a political agenda for change.

2.3 The Social Model

2.3.1 Origins and definitions

Although the social model was formally articulated by disabled scholar, Mike Oliver, in 1983 (Roulstone et al., 2012), its earliest roots lies in the disabled people’s movement that started in the mid-1970s in Great Britain (Barnes & Mercer, 2005; Fernie & Henning, 2006; Howell, 2005; Priestley, 2006; Swartz & Watermeyer, 2006; Thomas, 2002; Watermeyer, 2013; Williams, 2001). It marks the time when disabled activists started speaking out against their exclusion from mainstream society and their enforced poor economic circumstances (Thomas, 2002). In particular, disabled activists in a small British organisation, the Union of Physically Impaired Against Segregation (UPIAS), spoke about their situation in the following way: “In our view, it is society which disables. . . . Disability is something imposed on top of our impairments; by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society” (UPIAS/Disability Alliance, 1976, p. 3). This extract is permeated by the first traces of critique against the medical model and thus introduced the transition to a new, social understanding of disability.

The social model defines disability as: “The loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers” (Finkelstein & French, 1993, p. 27).

In these two definitions, it is clear that the social model introduced a significant shift to the understanding of disability. No longer was disability seen as a product of functional limitations and biological deficit within an individual, but rather as caused by the external physical, attitudinal and political barriers directed towards and imposed upon people with disabilities (Ash, 1984; Barnes & Mercer, 1997; Beauchamp-Pryor & Symeonidou, 2014; Longmore, 2003; Oliver, 1983, 1990, 2009a; Oliver & Barnes, 1998; Priestley, 2006; Rieser, 2006; Schneider, 2006; Swartz & Watermeyer, 2006; Thomas, 2002). In the words of Oliver (1981), “This new paradigm involves nothing more or less fundamental than a switch away from focusing on the physical limitations of particular individuals to the way the physical and social environment impose limitations upon certain categories of people” (p. 28).

In her reflective paper, “Blind rage”, Georgina Kleege (an academic with a visual impairment), describes the experience of her disability in the following way:

> . . . ninety nine % of my days are just fine. I get up, I go to work, I teach, I read, I write. The fact that I use aids and assistants to do some of these things is not really central to my consciousness. When everything works, I consider myself "normal." My blindness is just a fact of life, not an insurmountable obstacle blocking my path. I work around it. I ignore it. On a lot of days, it matters less than the weather. (Kleege, 1998, p. 62)

This quote clearly illustrates the premise of the social model – that disability is imposed by society. If everything in her environment works well, her disability is not disabling and barely reaches the edges of her awareness.

In tandem with the gaze that now turned away from physical deficit, the focus of intervention also changed direction. The aim switched from normalising the "defective" individual, to social restructuring and political emancipation as intervention for difficulties associated with disability (Barnes & Mercer, 2003; Oliver, 2009b; Reichart, 2014; Rieser, 2006; Shakespeare, 2014; Swartz & Watermeyer, 2006). In this light, instead of the individual, society needed to change.

Having said this, social model theorists did not disregard the biological nature of disability entirely. In their distinction between "impairment" and "disability", they left room for both societal and biological influences (Loja et al., 2012). Impairment refers to the physical or medical basis of a disability that encapsulates the limitations of physical, sensory or psychological function. On the other hand, the term "disability" was used to describe the social exclusion and barriers imposed on people with disabilities (Barnes & Mercer, 2005; Disabled People's International, 1981; Shakespeare, 2014; Watermeyer, 2013). Social model writers therefore regarded disability as the interaction between an individual impairment and the socio-political environment (Ryan & Struths, 2004).

However, even though they recognise that a disability cannot exist without the foundation of a physical impairment, they still emphasise and perceive the disabling agents to be rooted within societal structures. In other words, a person might have an impairment, but it is society that determines whether the impairment will develop into a disability. As Barnes (2012) noted, "For advocates impairment may be a human constant but 'disability' need not and should not be" (p. 18).

This external, environmental starting point created a platform for disabled scholars to challenge and unhinge the veiled discriminatory practices against them (Fernie & Henning, 2006; Oliver, 1990, 1996; Shakespeare, 2014; Watermeyer, 2013). The social model thus brought hidden discrimination to the foreground, mobilising people with disabilities to take political action (Watermeyer, 2013). To a certain extent, the social model "woke" people with disabilities to the implications of medical formulations, and inspired them to develop new theories and models explaining disability-formation. Shakespeare (2014) captures this neatly when he writes,

> Suddenly, people were able to understand that it was society that was at fault, not them. They did not need to change; society needed to change. They did not have to feel sorry for themselves; rather, they could be angry. . . . They became empowered to mobilise for equal citizenship. Rather than a demeaning reliance on charity, disabled activists could now demand their rights. (p.13)

It is no wonder then that the social model laid the foundation for disability studies as a distinct and discrete discipline (Swartz & Watermeyer, 2006). In addition, as Barnes (2012) extensively describes, the social model laid the foundation for disability legislation and equality, prompted a growing number of literature around disability-related matters, for example the establishment of the academic journal *Disability and Society* (formerly *Disability, Handicap and Society*) and led to the initiation of various organisations offering services to people with disabilities in the UK and around the world. Organisations working with disability-related matters in the UK, furthermore, almost always have social model-based policies (Barnes & Mercer, 2010; Shakespeare, 2006). This social model rhetoric is also explicitly mentioned and/or implicitly implied in the policy documents of South African higher education settings.

In summary, the social model exposed and challenged the various layers of the medical model. Firstly, it stripped the medical understanding of disability from its biological roots. Instead, it argued for a socio-political definition of disability, wherein people with a biological impairment are enabled or impeded through societal structures. Hereby, the responsibility for change was transferred from the shoulders of the biologically impaired body, to the “broken” limbs of the social and political structures. In this move, the medical model’s discriminatory practices became clear and, flowing from this, disability studies as an emancipatory discipline was established, and political action was mobilised (Watermeyer, 2013).

2.3.2 Social model and education

Undoubtedly, one of the most notable contributions of the social model is its influence on the educational setting. Alongside the shift in disability paradigms of the late 1970s and the early 1980s, disability theorists started recognising the medicalised “within child” understanding of special education (Reindal, 2008). Hand-in-hand with new social understandings of disability, educational policies and conceptualisations moved away from the “specialness” of the child and “special” care, to the removal of societal barriers that hindered equal participation within the education milieu. The emphasis on the social model thus helped to shape and restructure primary, secondary and tertiary education (Rieser, 2006; Swart & Pettipher, 2011).

Within higher education, the move to social model thinking also translated into the acknowledgment and removal of environmental barriers (Howell, 2005). Although tertiary settings were rarely divided into “mainstream” and “special” environments, medical thinking still permeated higher education campuses (Riddell, 1998). These campuses thus remained substantially inaccessible for students with disabilities and were mostly beyond their reach. A new understanding of education thus required a radical change in attitudes, policies and institutions (Swart & Pettipher, 2011).

In this way, the social model opened up the way for the emergence of inclusive education – a concept that is considered today a theoretical framework in its own right (Goodley, 2011). This theory, along with its implications and influence on South African higher education, will be discussed in the proceeding chapter (see Chapter 3).

2.3.3 Critique against the social model

Although the social model undeniably contributed immensely to disability dialogue and discussion and, thereby, opened and illuminated oppressive ideology of the past, it has recently come under sharp scrutiny. Critics approach the social model from various angles, but all of them agree on one central point: that the social model places more emphasis on the political, while overlooking the personalised, individual reality of disability. From this universal point of departure, it flows naturally that the social model is criticised for its over-socialisation of disability, its relative inattention to the unique personal attributes of the individual and, lastly, for its failure to reflect and acknowledge the emotional, personal lived worlds of individuals with disabilities. "The greater good" of political emancipation overshadows other concerns.

2.3.3.1 Over-socialising disability

> I consider this opposition (social) model oversimplistic, because even the most utopian barrier-free environment will leave people with disabilities disabled. No amount of change in attitudes will alter the fact that the person with a certain type of spinal cord injury loses all or most of the movement and sensation in their body below the level of the injury; nor will it alter the fact that people with sensory impairments lose out on much of the interplay and interchange of language in the case of the deaf, and gesture,

> expression, body language and much else in the case of the blind. There are realities about disability that we cannot get away from. (Popplestone, 2009, p. 129)

Embedded in the philosophy of the social model, is the underlying assumption of a “utopian barrier-free environment.” Given this tacit understanding that such a society is within our grasp, we can all look forward to an environment where disability would simply evaporate and cease to exist in the face of social reconstruction (Rieser, 2006; Tregaskis, 2004). As Crow (1996) proclaims, “It wasn’t my body that was responsible for all my difficulties, it was external factors, the barriers constructed by the society in which I live. I was being dis-abled – my capabilities and opportunities were being restricted – by prejudice, discrimination, inaccessible environments and inadequate support. Even more important, if all my problems had been created by society, then surely society could uncreate them” (p. 56).

In direct opposition to this view, critics argue that, despite the most successful efforts to remove societal obstacles from the environment, some traces, limitations and certain realities of a biologically informed disability would still remain (Bury, 2000). Even if all environmental barriers were removed, many people would still live with substantial consequences of what the social model terms “impairments”.

Flowing from this, many disability authors argue for a middle ground understanding of disability, wherein the socially constructed impositions, as well as the impact of inherent functional restrictions, are recognised and addressed (Beauchamp-Pryor, 2012a; Fernie & Henning, 2006; Howell, 2005; Popplestone, 2009; Rieser, 2006; Watermeyer, 2013). Of course a person with disability is confronted with societal barriers, oppressive attitudes and so on, but impairment, as it stands alone, also carries within it the innate potential for restriction. Take, for example, a visually impaired student entering the tertiary environment. Now, we would be justified in assuming that unfamiliar routes and inaccessible course material can be remedied through societal intervention. Someone can simply be appointed to convert material into an accessible format and an orientation programme prior to commencement of the academic year can assist in familiarising the student with the new physical environment. However, if the biological disability were not present, such intervention and restructuring would have been pointless and unnecessary. Similarly, even while technology may have brought the previously impossible within reach, the necessity of using this technology is still based on the inherent biological nature of the disability. To take an example from my own experience as a student in a higher education context: consider a blind person "looking" for her equally blind friend on a university campus. She might walk right pass her friend, without realising the friend's presence. Now the question remains, is this mutual inability to see each other socially imposed? Quite frankly, it would not seem so.

In conclusion, a quote that describes this beautifully:

> No matter how conveniently a paraplegic might move around in a town there would be problems about trying to keep up with a party climbing in the Himalayas – and it would be difficult to attribute this to any kind of social construction. And if such problems appear in thought experiments about one particular disability, they appear far more when you consider the endless types and degrees of disability that exist, and imagine trying to construct environments that could cope with them all. (Richards, 2002, p. 710)

2.3.3.2 Exchanging unique lives for collective action

Disability writers within the social model paradigm to a degree severed disability from the impaired body in an attempt to create a collective, politically unified voice against oppression (Scott-Hill, 2004; Shakespeare, 2014; Watermeyer, 2013). They argued that a collective voice of sameness is necessary since, after all, all disabled people shared in the predicament of oppression (Oliver, 1990). However, in skirting around personal diversity in favour of a political agenda, something of the intricately unique life of each individual gets lost.

Disabled feminists also criticised the social model for its disregard of unique and diverse lives. In doing so, they argued, additional, potentially oppressive identities, will remain hidden and unrecognised under the all-encompassing collective identity of disability (Morris, 1989; Thomas, 1999; Wendell, 1996). They urged that the model should include the space wherein other intersecting oppressed identities such as class, gender and race could become visible. This critique echoes the premise of intersectionality, first conceptualised by feminist writer, Kimberlé Crenshaw, in 1989. In this theory, the intersection of various societal factors affecting each individual must be considered when thinking about oppression. Goggin (2008) writes about intersectionality in the following, all-encapsulating way, “A body or mind that is disabled is also one that is raced, gendered, trans/nationally sited, aged, sexualised and classed. Disability is imbricated with other categories of difference, experiences of marginality and forms of political activism” (p. 1).

Contrary to the emphasis on differing identities that intersect to form unique lives, disabled people were expected to collectively fit and match the realities dictated by early disability theorists (Marks, 1999a). Marks (1999a) notes that these realities pertained in large part to White, middle-class, Western, male, wheelchair users. Confirming this notion, authors noted that disability studies did not adequately consider disabled people from sexual minorities (Shakespeare, Gillespie-Sells, & Davies, 1996), from diverse ethnic backgrounds (Stuart, cited in Goodley, 2011) or people with disabilities other than mobility impairment, such as psychiatric, sensory and/or intellectual disabilities (Morris, 1992). It should be mentioned that disability studies and other fields of identity research were mutually exclusive. Not only did

White male wheelchair users fail to consider other intersecting identities, but the acknowledgment of disability remained absent from mainstream research and debate around class consciousness (Davis, 1995), race (Goodley (2011) and feminism (Ghai, 2006; Morris, 1992, 1996).

In their attempt to formulate a model that could replace the individualistic approach of the medical model, theorists therefore moved to the direct opposite end of the continuum. Instead of leaving some room for contemplation and exploration of unique aspects of individual lives, they primarily focussed on the collective identity of disabled people as a group. They barely left any chance for traces of the individual to filter into thought or to permeate consciousness, but rather abandoned difference in favour of the "greater good" of political emancipation (Low, 1996). No wonder then that some authors conceptualised the social model as a political tool, rather than a theory (Watermeyer, 2013). Even social model thinkers themselves, like Oliver and Barnes (2012), state, in response to critics, "Almost to the point of boredom, we have constantly stated that the social model is a tool to be used to produce changes in society and is not and was never intended to be a social theory" (p. 7).

2.3.3.3 Overlooking personal lived experience

> There is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability – and do indeed disable us – to suggest that this is all there is to it is to deny the personal experience of physical and intellectual restrictions, of illness, of the fear of dying. (Morris, 1996, p. 10)

Inextricably tied to the disregard for unique disabled identities lies the main critique against the social model – its failure to reflect the personal and emotional content of disabled lives (Beauchamp-Pryor, 2011; Hughes, 2002; Hughes & Paterson, 1997; Morris, 1991; Reeve, 2002; Shakespeare & Watson, 1997). Watermeyer (2013) vividly describes the existing and “alive” inner worlds of people with disabilities. He writes, “Disabled lives carry every aspect of human complexity; of relationship, uncertainty, self-regard, loss and hope” (p. 44), and elsewhere, “It is becoming clear that the world of disability has human reach which extends way beyond the material and rational, beyond tangible barriers, to the recesses where these are mirrored in psychic life” (p. 44). However, in contrast to this moving acknowledgement of human complexity within the psychological lifeworlds, social model writers deliberately overlooked the personal and emotional experience and pain of a body that is impaired (Shakespeare, 2006; Shakespeare & Watson, 2001; Thomas, 1999, 2001; Watermeyer, 2013).

Often, this disregard for the personal stemmed from a fear of the gloomy consequences of medicalisation (Watermeyer, 2013). Early disability writers who vividly remember medical discourse and oppression, may be cautious that a focus on the personal inner struggles of people with disabilities would subsume any political agenda. It may have been their belief that, if dependency and vulnerabilities of people with disabilities become known, this would confirm disabled stereotypes. Hence, they were concerned that vulnerability and personal acknowledgement of struggle would counter political action and thereby, inevitably, lead us back to domination and control over our lives. In denying social systems’ role in the construction of disability, they argue, people with disabilities will return to the margins of society (Abberley, 1987, 1996; Barnes, 1990; Oliver, 1986, 1990). Shakespeare (1996) captures this fear when he writes, “to mention biology, to admit pain, to confront our impairments has been to risk the oppressors seizing on evidence that disability is really about physical limitation after all” (p. 40).

Watermeyer (2013) acknowledged that these fears were not entirely ungrounded. Indeed, stories of personal tragedy tend to overshadow accounts of discrimination. However, he argues, we should not brush over these inner worlds, not least because they reveal very real experiences and painful effects of disablism (Watermeyer, 2013). Therefore, he continues his warning, excluding the psychological from disability theories may be impoverishing and even dangerous. Separating the experiences of the impaired body from the political agenda might lead disabled people to disown their personal feelings or hide them for political gain. They might get to believe that showing their vulnerabilities will be toxic and render the political movement ineffective. Hence, they might trade authentic acknowledgment of inner feelings for political emancipation (Watermeyer & Swartz, 2008). In hiding the painful, bereaved parts related to disability, we deny others the chance to know us fully and we stand the risk of self-alienation (Watermeyer, 2009).

Underscoring this belief, feminist writers such as Morris (1991, 1992, 1996), and Wendell (1996) call this alienation of personal experience an injustice. In conjunction with feminist theory, they claimed that the personal is also the political (Reichart, 2014). These feminist writers argue that impairment involves some form of suffering, pain and loss and that it is politically honest and valuable acknowledging these bodily experiences rather than reducing them to the removal of societal barriers (Hughes, 2004).

From this it flows naturally that recent disability authors started arguing for a theory that would capture and reflect their embodied, psychological experience (Crow, 1996; Howell, 2005; Morris, 1993; Schneider, 2006; Shakespeare & Watson, 1997; Watermeyer & Swartz, 2008). Some authors even claim that it is possible to understand disability as both a political struggle and phenomenological experience (Turner, 2001; Williams, 2001), since it is both individually and socially caused (Schillmeier, 2008). While social model writers have responded to this criticism by claiming that the social understanding of disability does make room for bodily experience through its distinction between biological impairment and societal disability (Shakespeare, 2014), Watermeyer (2013) proclaims, “The social model movement, like other revolutionary formations, is incomplete without an account of the personal and psychological, but simultaneously unable to accommodate one” (p. 39). In this distinction between extreme opposites, the biologically impaired body is similar to the medical model’s body. In this conception, the body has no history or meaning, but is thrown into the world with only biology as its essence. It is timeless, physical and separated from the self and culture. Hughes and Paterson (1997) write, “It also posits a body devoid of meaning, a dysfunctional, anatomical, corporeal mass obdurate in its resistance to signification and phenomenologically dead, without intentionality or agency” (p. 329), and further “. . . within disability studies the term “body” tends to be used without much sense of bodiliness as if the body were little more than flesh and bones” (Paterson & Hughes, 1999, p. 600). Opposing this view, Paterson and Hughes (1999) point out that the impaired body is an active agent in political change, rather than the passive victim of fate. According to Shakespeare (2014) the biological impairment and societal disability is always intertwined and simply cannot be separated into two neat categories. It is therefore no surprise that Hughes and Paterson (1997) plead for a realignment of the impaired and disabled body.

In other accounts, social model authors argued that emotional and psychological pain and discomfort should be viewed as a direct consequence of political marginalisation (Abberley, 1993; Finkelstein & French, 1993; Oliver, 1995). However, in my inability to see my husband’s face, to appreciate in all sensory fullness the impressions of nature; if all these losses make me sad – can I blame social oppression for it? Could I hold others, albeit political figures or close friends, accountable for these unremedied parts of my impairment? In the face of these undeniable and often inescapable realities, I want to agree with Watermeyer (2013) when he writes about the social model's conception of psychological issues. He writes, "It is . . . inaccurate to accuse social model authors of completely ignoring the psychological realities of disablism, but it is undeniable that the model allows for the most awkward of spaces to examine these issues" (p. 39).

2.3.4 Conclusion

Now, we may very well ask ourselves, what is the future of social model thinking and how do we view its past? Does the criticism against it leave it ineffective and powerless? Should we, as Shakespeare (2006) suggest, abandon the model completely and, can we agree with Bury (2000) when he writes,

> I do not believe that the 'social model' has really engaged with the real issues facing the vast majority of disabled people, and, despite its rhetoric and undoubted attractions for some, it has not produced a cogent approach which can serve the real practical needs of disabled people, or indeed the research community. (p. 1075)

In my view, the model has been useful and most effective in opening up a debate around the taken-for-granted, unquestioned formulation of disability as an individualistic illness. It aimed to place disability on the political agenda and to overthrow accepted ways of engaging with disabled people. In its rigorous aim for a strong, united voice against marginalisation, it momentarily denied and shied away from psychological vulnerability and dependency that also shape the realities of disabled people. However, would writers all over the world, including me, be writing about disability, its theories and disabled lifeworlds if the social model had not questioned the medical model in the first place? Perhaps it is necessary for a scale tipping more to the opposite side if it rested for decades on the side of injustice and marginalisation. In this way, Shakespeare (2014), in his most recent book, referred to the development of the social model as, “one of the most brave and transformative moves in the history of political thought, because it goes against deep-seated intuitions” (p. 17).

Since the time of our departure from the medical model and the consequent development of the social model, we can now finally return to the disabled body with all its complexities and humanity. However, this time, we will be mindful and aware of social oppression and the injustice this might hold.

2.4 Phenomenology – Returning the Body to Disability

. . . there is the social model and there is the medical model and somewhere in between there is the real life of the disabled individual. (Popplestone, 2009, p. 129)

> . . . the ability to think about disability as both a “personal trouble” and a “public issue,” as hurt and prejudice, and to write about it with a vivid sociological imagination marks out the most interesting work in the field, by both medical sociologists and disability theorists. The trick is to see the thing nondualistically, to recognize impairment/disability not as something that is either-or but as simultaneously and ontologically both personal and public – to see it, therefore, as something that requires methodological lenses to help us change focus easily, without feeling that talking about one excludes or even betrays the other. (Williams, 2001, p. 123)

2.4.1 The call to bring the body back

Even though the body was never quite absent from disability theory, the social and medical model both cast it into the marginal shadows of meaningless biology. Whereas the medical model simply depicted the disabled body as a passive, voiceless entity, the social model severed it from its biological roots through its impairment-disability separation. In essence, this distinction also left the “impaired” body as nothing but its physiology. In both accounts, the body was therefore devoid of meaning, history, culture or agency; nothing but a “corporeal mass” (Hughes & Paterson, 1997, p. 329).

Ironically, this understanding of the disabled body was in direct contrast to the discovery of the body in other arenas of sociology interested in the effects of oppression, such as feminism and queer theory (Hughes & Paterson, 1997; Shilling, 1993). In this post-Cartesian “somatic society” (Turner, 1996, p. 1), theories started acknowledging that both political and personal struggles meet within the body and are expressed through it (Goodley, 2011; Hughes, 2002). However, since the 90s, disability scholars progressively started moving alongside the somatic turn in a growing urge for bodily recognition and experiential accounts within the disability movement (Hansen & Philo, 2009; Hughes, 2002, 2004; Hughes & Paterson, 1997; Paterson & Hughes, 1999; Watermeyer, 2013). However, this call was for a body that would not exclusively consist of biology, but that would also encapsulate its political stance (Morris, 1991; Thomas, 1999, 2001; Wendell, 1996), its historical roots (Hughes, 2002, 2004; Turner, 1996), as well as its personal and emotional felt worlds (Hughes, 2004; Reeve, 2012; Watermeyer, 2013). Some of these theories included attempts at placing disability within the contexts of psychoanalysis, (Marks, 1999a, 1999b; Watermeyer, 2006, 2013), postmodernism (Corker & French, 1999; Tremain, 2002; Shakespeare, 2006), intersectionality (Marks 1999a; Stienstra, 2012; Thomas, 2007) and phenomenology (Hughes & Paterson, 1997; Paterson & Hughes, 1999). The call was therefore for the return of the body, but in an altered form.

It may thus seem, at first glance, that we have come full circle – from the depiction of disability as biological failure, to the rejection of this body in favour of disabling societies and, now, returning to the body. Yet, currently, authors argue for a different understanding of the disabled body. This new understanding of the body moves away from the purely biologically created entity, to a body that is changing over time, that has personal and emotional facets (Hughes, 2004), that is culturally created and influenced and that is the host of deeply meaningful experiences.

In this section, I will argue that phenomenology provides an effective framework for this new understanding of an altered, deeply meaningful body.

2.4.2 Why phenomenology?

> On the phenomenological account, illness is no longer seen merely as biological dysfunction to be corrected by medical experts. Because of phenomenology's focus on the subjective experience of the ill person, it sees illness as a way of living, experiencing the world and interacting with other people. Instead of viewing illness as a local disruption of a particular function, phenomenology turns to the lived experience of this dysfunction. It attends to the global disruption of the habits, capacities and actions of the ill person. (Carel, 2013a, p. 10)

We may very well ask ourselves, "How can a phenomenological understanding of disability give a meaningful account of the impaired body?" The answer to this question is two-fold: phenomenology leaves room for a cultural, historical, deeply meaningful and physical body (Paterson & Hughes, 1999) through its (a) focus on the exploration of lived experience, and (b) its claim of the body as both object and subject. It was for the following reasons that phenomenology was chosen for this study: First, it restores the body to the disabled person, and second, it provides fertile grounds for a rich narrative of "the real life of the disabled individual" (Popplestone, 2009, p. 129).

2.4.2.1 Phenomenology as lived experience

Phenomenology is concerned with the sensitive task of examining human experience (Husserl, 1927). It explores the day-to-day lives of individuals in the search for a meaningful account of their "lived experience" (Carel, 2013a; Smith, Flowers, & Larkin, 2009). As the term suggests, lived experience encompasses the daily activities, thoughts and impressions comprising an individual's world within a specific context (Creswell, 2007). Lived experiences are experiences, exactly as they appear to us (Carel, 2011, 2013a). Since we cannot leave our bodies in our perception of the world, things, as they appear to us, are subjective (Merleau-Ponty, 1962). The way things appear to us are therefore not necessarily the way things are objectively.

However, phenomenology provides more than a simple account of daily activities and perceptions. It delves deeper into the meaningful amalgamation of emotions, thoughts, culture and bodily experiences of an individual (Carel, 2011; Creswell, 2007; Henning, Van Rensburgh, & Smit, 2004). It is concerned with how it is to exist in the world (Carel, 2011). A phenomenological account of the lived experiences of visually impaired students would thus tell of their hopes, joys, but also of their fears, hardships and anger. In short, lived experience pertains to the taken-for-granted world, our perceptions of it and the experiences we have in it (Husserl, 1970).

Listening to the voices of disabled persons as they tell their stories is a powerful means of validation and empowerment (Symeonidou, 2014). Instead of the passive role of victim, phenomenology allows disabled persons to be active agents for change in their own lives. As Overboe writes, "our lived experience would be an integral part of the atmosphere and tone for any change within our lives and our interaction with others, whether they be disabled or non-disabled" (Overboe, 2009, p. 81). This concurs with the notion of the liberation of the oppressed as defined by Paulo Freire (1978). He stipulated that, when deprived of dialogue, an individual is oppressed. However, only through dialogue can the oppressed be liberated.

As an example, Dan Goodley (2012) explores the phenomenological enquiry of disabled human experience on the basis of the writings of Rod Michalko. Being blind, Michalko (1999) gives a deeply moving account of his intimate, everyday experiences with a guide dog. These stories are not merely superficial narratives that skirt over deeply felt worlds, but rather shed light on his relationship with his dog and their encounters with the social world. He provides concrete examples of how he and Smokey, his guide dog, often encountered awkward situations and exclusionary comments and reactions from able-bodied strangers. We can see how these life-stories illuminate not only Michalko's (1999) perception and experience of disability, but also expose societal practices and exclusion. "This being-in-the-world is a phenomenological position that may well give very different understandings of disability to those that already exist in the community" (Goodley, 2012, p. 317).

This example of Michalko's (1999) lifeworld clearly illustrates how we may come to understand disabled bodies as personally meaningful and socially influenced. And it is exactly this notion that introduces the second rationale for a phenomenological understanding of disability – the fact that it portrays the body as both subject and object in an inseparable unity. An exploration of the life-worlds of individuals is therefore also a way of overturning the notion that the body is merely a biological object whose being-in-the-world can be diagnosed and explained in terms of a complex network of physiological causes. Traditional psychology has often followed this "natural science" route by its tendency to lean on quantitative impirical data alone in explaining human experience. The meaningfulness and freedom of human experience were thus often overlooked in an attempt for "scientifically rigorous" findings. With phenomenology, there is thus a move towards understanding the qualitatively rich phenomena of our daily lived experiences (Carel, 2011).

2.4.2.2 The body-object; the body-subject

“The strict separation between an internal realm and an external world does not make sense when we think about how we actually experience our body and the world, as a seamless unity” (Carel, 2013a, p. 26).

“. . . people are disabled by society and by their bodies and minds” (Shakespeare, 2014, p. 5).

Phenomenologists within the field of disability followed in the footsteps of Merleau-Ponty (1962) by claiming that the body simultaneously appears as object “*korper*” and subject “*leib*”. Not only is the body a physical, medical, experienced “impaired” object, but it is inextricably intertwined with the experiential, meaningful, animated living “disabled” body as subject (Bendelow & Williams, 1995; Carel, 2011, 2013a; Goodley, 2012; Hughes, 2004; Slatman, 2014). As “*korper*” the impaired body cannot escape its cultural roots or meanings and its social context. Likewise, the hurt and suffering of social oppression and prejudice (*leib*) become embodied as they permeate the impaired body “*korper*” (Hughes & Paterson, 1997). Hence, impairment becomes social and disability is embodied (Goodley, 2011, 2012; Hughes, 2004; Hughes & Paterson, 1997; Kleinmann, 1988). And so, the social model’s Cartesian distinction between impairment (body as object), and disability (body as subject), collapses under the weight of the unified, phenomenological body. “. . . disability is experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning” (Hughes & Paterson, 2006, p. 101).

The body as both object and subject takes centre-stage in our knowledge and attachment to the world. In fact, it orientates us in the world (Carel, 2013b). The objective body is my home, the place which separates me from other physical bodies, but, at the same time, it is my source of subjective knowledge about the world and the site where meaning is created (Bendelow & Williams, 1995; Hughes, 2004; Hughes & Paterson, 1997). “It [my body] is both a physical object, made of matter, and the seat of consciousness” (Carel, 2013b, p. 351). Thus, my knowledge of the world is also informed by my physical body. *Leib*, in other words, is not disembodied, since it starts from a place of localised, bodily sensations. The sensations of the body, or lack thereof, inform the living body, while the living body draws on corporeal messages in its subjective experience and knowledge of the world. Slatman (2014) therefore argues that it would be wrong to assume that lived experience only pertains to *leib*, without consideration of *korper*. That which I perceive is thus part of the world, but also inevitably part of myself. My body and the world therefore imply each other and are of the same nature. We are within and part of the world and the world is an extension of our bodies. As Hughes and Paterson (1997) so elegantly points out, “One’s body is one’s window on the world” (p. 335). In this way, phenomenology invites and welcomes both the political and the personal within the “home” of the body (Goodley, 2011).

Given the centrality of our bodies, it is no wonder then that a change in a bodily function changes one’s whole being-in-the-world. The taken-for-grantedness of the world is cast away and one’s entire world is rearranged. Similar to pain (Bendelow & Williams, 1995) and illness (Carel, 2013a, 2013b), a disability is not only biological; it is a being-in-the-world. It thus leaves no part of life untouched as it alters the world. It infiltrates our relationship with ourselves and with others, and our lived space and time. It changes our environment, our judgment and goals. Disability changes us.

2.4.3 The phenomenologically impaired body

This rearrangement of our worlds, together with the notion of body as subject and object, is neatly captured by the phenomenological frameworks of illness (Carel, 2013b) and of the impaired body (Paterson & Hughes, 1999; Reeve, 2012). In particular, Paterson and Hughes (1999) and Reeve (2012) used the concept of dys-appearance in explaining the phenomenal experience of disability, while Carel (2013b) explained illness as being a limit case that distances us from our bodies and opens us to philosophical reflection. Reeve (2012) also includes a consideration of the psychological dimensions of having a disability. In the discussion which follows, I am strongly influenced by Carel's (2013a, 2013b) work on illness and disability, not because I believe that illness and disability are the same, but because Carel, as a philosopher living with a chronic illness, has produced an exceptionally clear critical account of phenomenology from the perspective of a person living with a non-normative body.

The discussion below on the phenomenologically impaired body is subdivided into two broad sections, namely, (a) the dys-appearing body and its psycho-emotional effects and, (b) the ill body. In the dys-appearing body, I will define dys-appearance and how it can be used to capture the experience of disability. Secondly, I will shed light on the psycho-emotional effects of the dys-appearing disabled body and disablism, as described by Donna Reeve. In the second part of this section, I will discuss Havi Carel's (2013a, 2013b) phenomenological understanding of the ill body and how it could be applied to encapsulate the experience of disability.

2.4.3.1 Dys-appearance

2.4.3.1.1 Dys-appearance – an embodied understanding of disability

“Bad days feel like death. On bad days my body closes in on me, reminding me constantly of my inability to do so many things” (Carel, 2013a, p. 42).

Paterson and Hughes (1999) used Leder’s theory of dys-appearance in the development of their embodied understanding of disability, or, as they called it, “the sociology of impairment”. According to Leder (1990) and Merleau-Ponty (1962), our bodies often disappear into the depths of consciousness. Usually, we perform our daily activities, we move about in the world, without conscious attention or awareness of our bodies. As Taylor Carman (1999) writes, the body “plays a constitutive role in experience precisely by grounding, making possible, and yet remaining peripheral in the horizons of our conceptual awareness” (p. 208). At times, however, this casual mode of living, this comfortable being-in-the-world, is disrupted and we become acutely aware of our bodies. For example, when experiencing physical pain, the body moves to the forefront of our awareness and “dys-appear” (Bendelow & Williams, 1995). In Greek, this suffix “Dys” means something bad, hard or ill; in other words dysfunctional. In Latin, however, “dys” means to pull way, to pull apart (Leder, 1990). Dys-appearance therefore pertains to the Latin meaning; since it captures the appearance of the body in an alien way. In dys-appearance, the body thus moves to the forefront of our awareness, but, paradoxically, at the same time it is experienced as being apart from and foreign to the body.

Now, the question may arise: what makes the body dys-appear? What wakes it from its unconscious “sleep” to the unforgiving place of alien self-recognition? For Leder, the roots of dys-appearance could be intracorporeal or intercorporeal. The former refers to biologically localised discomfort within the body like pain or illness that serves as a constant reminder of our bodies' physicality. On the other hand, the latter refers to "outside-of-the-body" experiences like social interactions wherein the body dys-appears. An example of such an intercorporeal dys-appearance may be when someone goes to a casual party, only to realise that they are over-dressed. Intracorporeal experiences are therefore closely tied to the experience of "*korper*", whereas intercorporeal refers to the "leib" of embodiment. When the body dys-appears, whether it be intra- or intercorporeal, it demands attention by bringing the body into sharp focus. And, in turn, this unyielding demand for attention may lead to self-interpretation.

Hughes and Paterson (2006) and Paterson and Hughes (1999) argue that the dys-appearance of the disabled body is intercorporeal, since the body dys-appears as a result of disabling environments. The impaired body may fall back into a place of non-recognition; into the comfortable shadows of oblivion. However, when confronted with social and/or physical barriers, the impaired body rushes into the vivid unforgiving light of dys-appearance and presents itself to us. At once, the body is confronted with itself, "the external and the internal collide in a moment of simultaneous recognition" (Paterson & Hughes, 1999, p. 603). In this moment of recognition our impaired bodies dys-appear, and we are faced with the uncomfortable realisation that our impaired bodies do not belong to and are alien in this world (Hughes, 2004; Paterson & Hughes, 1999).

After all, this world is created by and for the taken-for-granted lives of able-bodied people (Hughes, 2002; Imrie, 2000). Hughes (2004) captures this beautifully when he writes, "The social and physical world has been made by and in the image and likeness of nondisabled people. It is a home for their bodies" (p. 67). Implicating in the notion of "home", is the belief that the world provides a place of physiological and psychological comfort for able-bodied individuals; a place wherein their carnal bodies rarely reach the borders of active consciousness (Hughes, 2002). In stark contrast to this comfortable worldly home, impaired bodies do not fit into the world. In fact, they frequently experience discomfort through physical and social inaccessibility, in a place which is clearly not their home (Paterson & Hughes, 1999). Garland-Thomson captured this when she said that when the shape of a body does not fit the shape of the world, there is a misfit (2011).

Marks (2000) observes that even where efforts are directed to make physical places accessible for people with disabilities, little attention is paid to important details such as the privacy, sociability, aesthetics and comfort of these places. Moreover, the impaired body often recognises itself as alien in the world within social encounters. Often the very structure and norms of social interaction exclude the impaired body. For example, eye-contact and body language are considered crucial aspects for effective communication, yet people with visual impairments cannot participate in these subtle, yet essential modes of interaction. In these interactions, the body becomes an awkward presence as it "sees" itself as an outsider and simultaneously is objectified by others (Hughes, 2002; Paterson & Hughes, 1999). ". . . as long as the other treats me as a subject – that is, experiences with me to the world in which I dwell, mutual incorporation effects no sharp rift. However it is different when the primary stance of the other is highly distanced, antagonistic, or objectifying" (Leder, 1990, p. 96). In such instances, the impaired body dys-appears in the knowledge that it is left out in the cold amongst people that feel welcome in their worldly homes.

And so, in this light, the body as object "*korper*" and subject "*leib*" becomes evident in the amalgamation of deeply painful experiences and alien social positioning. For, as it is oppressed and excluded from mainstream living, it recognises its position through the body's dys-appearance. Physical and social inaccessibility serve as reminders of the biological body and its homelessness. Tying all lose ends together, Hughes and Paterson (1999) remark, “The disadvantaged corporeal status of impaired bodies cannot be understood without the wider material and social position of disabled people, but neither can it be divorced from the painful intimacies of the lebenswelt” (p. 606).

2.4.3.1.2 The psycho-emotional effects of dys-appearance

“It is disturbing to be marginalized in a world in which your heart is firmly entrenched, in a world you experience as your homeland” (Michalko, 2009a, p. 100).

Donna Reeve (2002, 2012) is interested in the emotional effects of dys-appearance, and what lies at the root of it. She believes that disablism causes sticky social interactions and inaccessible environments, causing the dys-appearance of the impaired body. Carol Thomas (1999) defines disablism as “a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being” (p. 73). Hereby two types of disablism are implied, (a) structural disablism, such as inaccessible buildings, and (b) psycho-emotional disablism which refers to disabling barriers that undermine the emotional well-being of disabled persons. It is similar to other arenas of oppression such as racism, ageism and so on, in which disabled people are discriminated against (Madriaga, 2007; Thomas, 1999). This discrimination against disabled people often stems from a belief that they are not “normal” (Davis, 1995; Madriaga, 2007), not “perfect” (Glassner, 1992), and therefore they are biologically inferior and do not belong in this world (Hahn, 1985; Hughes, 1999; Hughes & Paterson, 2006; Loja et al., 2012; Michalko, 2009a; Morris, 1991).

Of particular interest to Reeve (2012) are the emotional responses of disabled persons to disablism that make their bodies dys-appear. She categorises these reactions into indirect and direct psycho-emotional disablism.

2.4.3.1.2.1 Indirect and direct psycho-emotional disablism

Indirect psycho-emotional disablism may arise alongside structural disablism (Reeve, 2002, 2012). The dys-appearance of bodies resulting from social or physical barriers, may elicit feelings of shame, hurt, not belonging and so on. The material world, for example, lack of transport, may thus frequently remind someone with a disability, “you don’t belong” (Kitchin, 1998). Reeve (2012) notes further that structural barriers have very real consequences for someone with a disability. For example, lack of transport may limit employment options and inaccessible academic courses may place a lid on the range of course choices typically available to able-bodied students.

On the other hand, direct psycho-emotional disablism arises from relationships that the disabled person has with other people or themselves. As mentioned before, people with disabilities may have “sticky” relations with nondisabled people, as they are invalidated through stares, hurtful jokes, and so on (Reeve, 2002, 2006). Furthermore, they may be avoided due to a prejudicial belief that disability is contagious. These behaviours typically stem from feelings of pity, curiosity, fear and/or disgust in the minds of nondisabled people (Carel, 2013a; Hughes, 2012; Loja et al., 2012). Of course, these social encounters may leave a person with a disability feeling shameful, hurt, and awkward.

> . . . it is only a matter of time before another person – a drunk on the street or a rude teenager – will say something that will bring tears to my eyes, something that will make the true horror of my condition appear in broad daylight, my carefully constructed but fragile defences crumbling before it. (Carel, 2013a, pp. 59-60)

Many writers agree that these reactions towards disability often reflect a deep-seated fear of one's own vulnerability and mortality. As Michalko (2009a) writes, "They (nondisabled people) patronize, pity, and even ignore us. People know that the membership category disability is always open and is open to anyone. The presence of disability reminds people of this fact and this, too, is disturbing," (p. 101). In response, disabled persons often learn that it is not permissible to talk about the painful parts of their disability, but that it is preferable to fabricate bravery (Carel, 2013a; Watermeyer, 2013; Watermeyer & Swartz, 2008). This way of relating to others is "not real" (Watermeyer, 2013) and comes at a high cost to the disabled person. This leads Carel (2013a) to proclaim, "I sometimes think that what is tragic about being ill is this silence" (p. 67). When reading Watermeyer (2013) and Watermeyer and Swartz (2008) this "tragedy of silence" becomes clear. They warn that this silence about the painful parts of a disability might have two compromising effects. First, disabled individuals may lose the feeling of being fully accepted by another human being in their entirety and, secondly, they might be left with insufficient time and space to understand their own experience. This leads us directly to a consideration of the second part of Reeve's direct psycho-emotional disablism.

Reeve (2002, 2012) added an intersubjective dimension to the intercorporeally dys-appearing body. Direct psycho-emotional disablism may also occur in the relationship disabled individuals have with themselves. This is called internalised oppression (Reeve, 2012) (see also Abberley, 1993; Priestley, 1999; Wendell, 1996). Internalised oppression means that the disabled person internalises prejudices of disability; thereby invalidating themselves. As a result, their disabled bodies never dys-appear, because they view social stereotypes of disability as normal and right (Reeve, 2012). In this way, they might come to believe, for example, that not pursuing a tertiary education, not marrying, not having friends, being stared at, etc., are right for people of their "dysfunctional" nature. These messages from society, would not bring their bodies to the foreground of their consciousness, because they have resigned themselves to the inevitable fate of disability. However we can see how this internalised oppression and lack of dys-appearance may have grave implications for people with disabilities. In believing that they are indeed inferior, they may limit the choices of who they can be, for example, student, wife, friend, and so on (Reeve, 2012). Reeve (2012) calls this state of internalised oppression “false consciousness”. “We harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, everyday of our lives,” (Mason, 1992, p. 27). “. . . disability is a life lived before a looking glass that is cracked and distorted by the vandalism of normality” (Hughes, 2012, p. 67).

At the other end of the spectrum within internalised oppression, Reeve (2012) describes the phenomenon of “double consciousness”. The disabled person desires to be seen as a worthy, complete human being with abilities, hopes and dreams. Instead, they face chronic dys-appearance of their bodies (Reeve, 2012), since society fails in affirming their worth. They are “chronically” reminded that they are inferior and, indeed, not quite human (Young, 1990). In this way, disabled people are constantly aware of their bodies as presence-as-alien-being-in-the-world (Paterson & Hughes, 1999, p. 603).

2.4.3.1.2.2 Additional ways of dys-appearance and psycho-emotional effects

Reeve (2012) describes two additional ways of dys-appearance and its psycho-emotional effects. These include (a) instances where disabled people have to reproduce themselves as disabled, and (b) instances where the “normal” subject is reproduced.

At times people with disabilities find themselves in the compromising position of having to make their own bodies dys-appear (Reeve, 2012). For example, in applying for a social grant, people with disabilities are required to foreground their disability so that it is socially recognisable. This might be particularly applicable to South Africa, with its recent focus on affirmative action and equal rights for all. For example, in South Africa, disabled people qualify for specifically allocated bursaries within higher education. It will therefore be essential to explicitly state one's disability in applying for these funds. However, Reeve (2012) warns that this emphasis on one's disability may impact negatively on psycho-emotional well-being. Having to reconstruct oneself as disabled for financial assistance, for example, directly flies in the face of one's usual attempts to escape society's stereotypes of the disabled as dependent and lazy (Reeve, 2012).

"Passing" is another conscious attempt to foreground the dys-appearing body (Reeve, 2012). This refers to the efforts of some disabled people to pass as able-bodied by behaving like their nondisabled counterparts. As Reeve writes (2012), "the body is behaving according to cultural norms of able-bodiedness rather than being free to adopt any mode of behaviour and movement that is 'normal for them'" (p. 88). Even though this might mean that people with invisible impairments would be protected against invalidation like staring, they walk with the ever-looming risk of being "find" them "out" (Reeve, 2002, 2012; Thomas, 1999). In this way, they always face the possibility of dys-appearance and, consequently, psycho-emotional disablism. However, when people with invisible impairments decide to disclose their disability, they might face very unique challenges. For example, people might not believe that they are disabled, because it cannot be seen. As a solution, they might use visible markers of disability, like a cane in order to prove their disability. However, as stated before, this may also have an emotional cost in publicly identifying as disabled (Reeve, 2002).

And so Donna Reeve (2012) concludes, ". . . passing and exposure are both forms of dys-appearance because of the impact they have on self-identity as disabled, non-disabled or something in between" (p. 88).

However, despite the potential negative effects of chronic dys-appearance, it may also encourage resistance (Loja et al., 2012; Reeve, 2002, 2012) and healing (Leder, 1990). Faced with the knowledge of the-body-as-alien-in-the-world, a disabled person might deliberately step out of social norms; countering the prejudicial beliefs of others. For example, a disabled person may decide to use social encounters as a platform to educate others about disability. Writing this dissertation can also be viewed as an end product of chronic dys-appearance. Higher education exposed me to being alien-in-the-world, resulting in a dissertation through wanting to change the lives of people with disabilities in tertiary institutions.

2.4.3.2 The ill body and its relationship to disability

Havi Carel (2013b) formulates the ill body as being a limit case that distances the ill person from his/her body and making it available for philosophical reflection. In the following section, I will apply her formulation of illness to a phenomenological understanding of disability.

It may seem that likening disability to illness is a dangerous step towards the medical model. However, Carel's formulation of illness leaves room for a phenomenological, embodied understanding of disability, while considering the effects of the environment.

2.4.3.2.1 The body as limit case

Carel (2013a, 2013b) argues that illness imposes limitations on the body and hereby pushes it to its limits. In so doing, illness sheds light on aspects of life that usually go unnoticed. In this way, we can see the close ties between Carel's body as limit case to the dys-appearing body as described by Paterson and Hughes (1999).

In terms of limitations imposed on someone with a visual impairment, Carel would argue that losing one's eyes would be the limit case of seeing. However, in-between seeing and total blindness, more moderate forms of limitation exist, such as near-sightedness, using glasses, partial sight, detection of movement, and so on. Each of these, she goes on to argue, illuminates other parts of the phenomenon of seeing through modifying certain aspects of it (reading, assisted mobility and so on).

Just like illness, the later acquisition of a disability removes us from our familiar, ordinary life. It unhinges the taken-for-granted structure of our experience and, in so doing, reveals our normal being-in-the-world by pushing it to its limits. However, unlike illness, people with disabilities do not always have a familiar, nondisabled past to reflect upon. Often, they are thrown into the world with their already constructed disabled bodies. Using Carel's conception, I argue that for people who were disabled from birth, their "out of the ordinary worlds" become evident, not in "felt worlds", but in the limitations imposed on them. Furthermore, seeing how nondisabled people go about the world also highlights these limitations to the disabled person. Yet, imposed limitations are also felt by people with acquired disabilities, but they experience it in tandem with the disruption of their taken-for-granted bodies.

Usually, we have an unquestioning, taken-for-granted trust and certainty in our body's ability to perform everyday tasks of daily living. We go on living, thinking and doing; secure in the knowledge that our bodies will readily yield to our demands. In the words of Edmund Husserl (1970) "To live is always to live-in-certainty-of-the-world" (p. 142). This is what Heidegger calls, "being able to be" (cited in Carel, 2013a). However, when confronted with imposed limitation, the body's functioning is disrupted and the certainty of our bodies move to the forefront of our awareness (the body dys-appears).

This certainty in our bodies, also encapsulates the trust that each movement or perception of our bodies carries with it the innate horizon of possibilities. Typically we have the option of choosing amongst a range of possibilities; accepting some and rejecting others. When walking past a library, for example, I may choose to enter or walk past it. If I decide to enter, I have the choice of searching for a book, going directly to the librarian, working on the computer, and so on. If I choose searching for a book on my own, I can go to the shelf, search for the book and start reading through it. Now, I am presented with the option of taking it out or putting it back on the shelf. However, when I cannot see – when I am blind – my horizon of possibilities shrinks. Walking past the library, I may not even be aware of the existence of the library – thus leaving me with no option of entering it. However, let us say I am deliberately walking to the library. Upon entering the library, I may not be able to search for the book directly, since I would be unable to see and find the book. If the computer does not have a screen reader, this option might also be closed to me. So, I will have to ask the librarian or someone else for assistance finding the book. When, finally, I have the book, I cannot simply open the book and read it. I will have to take it out, ask someone to scan it into an accessible format for me, read through it and then decide whether I want it or not. In this example, we can see how not only possibilities are limited, but time is also altered. It therefore comes as no surprise that Hass (2008) argues that a limited horizon of options changes one's entire existence. In other words, being unable to see does not mean only the loss of physical sight, but also entails a narrowing of possibilities that changes one's being-in-the-world. And suddenly one becomes "unable to be" (Carel, 2013a).

Disability, like somatic illness, also shrinks the innate possibilities of typically useful objects (Carel, 2013b). A practical tool, like a pen, loses its usefulness as a ready-to-hand-entity and morphs into a present-at-hand entity, which confronts us with its empty meaning and uselessness. For example, the typical purpose of a pen is writing (ready-to-hand-entity).

However, in my sightlessness, I have no mainstream use for it. I cannot write with it, I cannot see what someone else wrote with it; in my hands it becomes a useless object without meaning. Of course I can retain some meaning by using the pen as a hairpin; but in this, the main purpose of the pen in its everyday usage is lost.

Once again, one’s entire being-in-the-world is altered, for the loss of meaning does not pertain to a single object; it changes one’s entire interaction with objects in the environment. It is not just that book, that library or that pen that become useless and unattainable, but the entire environment becomes hostile and uninviting. As Paterson and Hughes (1999) pointed out in the section on dys-appearance, the disabled body realises that this world is not its home.

And so, it should come as no surprise that the limitations imposed on someone with a disability often do not fail to contaminate social worlds (Carel, 2013a). For example, a visually impaired person may not be able to participate in social activities such as football or tennis. Furthermore, the reactions of others, as discussed before, may cause the disabled person to withdraw from socialising and/or from speaking freely about the disability. In this way, spontaneous social interactions are limited; as it is clouded by the reality and imaginings of disabled life. This leads Carel (2013a) to write movingly, “It is not only physical possibility that suffers in the hands of illness. It is ways of being and ways of being-with that suffer” (p. 64). “I shall never be able to board a train, walk down the street or smile at a stranger in a way that would be unfettered by my illness” (Carel, 2013a, p. 63).

Another issue that needs consideration is the reality of limited choices for disabled people in South Africa (Watermeyer, 2013; Watermeyer & Swartz, 2008). For example, the public transport in South Africa is mostly dangerous and inaccessible, leaving disabled people dependent on others.

It is thus clear that often people with disabilities, like those who are ill, have to face various limitations, either inherent to their disability or imposed on them by society.

2.4.3.2.2 The distancing effect of disability

Carel (2013a, 2013b) uses writings by Merleau-Ponty to show that illness distances us from our bodies. This resonates closely to the disabled body that pulls away, “dys”, when it recognises its alien-being-in-the-world.

The limitations imposed on the disabled (or ill) body divorces it from its everyday or desired routines, goals and habits. Instead of cooperating to meet the person’s goals, the disabled body comes to the fore as it is unable to work towards the desires of the subjective, lived body. There thus appears a rift between our biological body in what it can do and the subjective body in “what it wants to do”. And in this way disability, like illness (Carel, 2013b), creates a distancing effect. For example, as a blind person I might be filled with dreams of becoming a medical doctor. Yet my biological body that is blind obstructs this life project, leaving me unable to pursue my goals.

In Merleau-Ponty’s terms, the biological body interferes with the intentional arc of the person. Not only our minds, but also our bodies intend to something. In other words, if I want to pick up a book, my hands stretches out towards it, my fingers flex to pick it up, my back arches driving me closer to the book. An intentional arc connects my body to the book. “It is this intentional arc which brings about the unity of the senses, of intelligence, of sensibility and motility. And it is this which ‘goes limp’ in illness” (Merleau-Ponty, 1962; p. 136).

The disabled body becomes the host of difficulty, limitations and struggles. It becomes an obstacle, instead of the safe space I inhabit. Instead of the natural orientation of the body being the null-centre, the perceptual centre of my experience, with my attention directed away from it, my attention shifts to my body as I objectify it. This sharpened focus on the body creates a distancing effect. The natural sense of "I can" now makes room for an unwelcome "I can not" (Kesserling, cited by Carel, 2013b). The physical world becomes hostile, inaccessible and difficult. Certain activities take up more time or have to be forsaken altogether.

The disabled body thus fails in yielding to our demands, while the environment fails in accommodating our body's disability. And so, in this way, the cleft between the body and the self, and the body and the environment, is created.

2.4.3.2.3 Illness as philosophical motivation and method

Carel (2013b) argues that reflecting on one's life is typically a choice. However, disability, she goes on, "barges" into life worlds, disrupts everyday lives, imposes limitations and demands attention. Many projects in the world can no longer be performed in the conventional way and new ways of being-in-the-world need to be explored. In this way, disability force its hosts to reflect on their lives. It is not the polite invitation to reflection; the usual subtle allure of self-examination; it is a rude, violent, forceful call to reflect upon bodies and day-to-day habits.

Carel (2013b) cites Merleau-Ponty when he writes, "True philosophy consists in relearning to look at the world" (p. 56). However, Carel (2013b) states that illness (like disability) transcends a mere new outlook on life; it also involves coping, to the best of our ability, within an environment filled with constraints. However, in coping with limitations, phenomena might be revealed to us in a philosophical manner.

And in this way, once again, disability may illuminate that which usually goes unnoticed.

Carel (2013b) ends her discussion of reflection by arguing that illness (like disability) illuminates normalcy. She writes, “And because the end product (normalcy) seems so natural, so perspicuous, we need cases of pathology to expose the underlying process which gives us normal, stable, experience” (Carel, 2013b, p. 356).

2.4.3.2.4 Disability and the good life

So, should we now conclude, given this rather gloomy picture, that someone with a disability is “doomed” to be unhappy? Certainly not. Carel (2013a) refers to adaptability and creativity as a positive outcome from illness.

Regarding adaptation, Carel (2013a) writes about the adjustment to the disruption of the body. This could also be applied to the disabled body. Even in instances where someone has been disabled throughout their lives, there are mostly always new limitations to overcome. For example, going to university or starting employment might bring new obstacles to the fore for someone with an “old” disability. The lifeworlds of many disabled people will reflect the creative ways in which they overcome obstacles and confront day-to-day life. For example, finding some social activities “closed down” to them, disabled people may find new activities that they can participate in, like chess, and so on. Adaptability is also evident in the ability to find meaning in the journey with disability and even embracing the disabled identity as something positive. Apart from adaptability and creativity, I also discussed how dys-appearances and imposed limitations can be actively resisted by disabled people (Reeve, 2012). Through these processes, Carel contends that the rift between the biological and lived body could be restored.

And so Carel (2007, 2013a) concludes that it is possible to be happy in illness/disability, "but their uncovering requires a new set of conceptual tools (such as health within illness, adaptability) and a metaphysical framework that gives precedence to the experience of illness and to the embodied nature of human existence" (Carel, 2013a, p. 103).

In this, we should be careful not to place all the responsibility onto the disabled person to change. Garland-Thomson (2011) warns that disabled persons should not change to fit the world, but rather that the world should adjust and meet the needs of disabled persons. This section should be seen as merely a view on the resilience of disabled people in the face of inherent and imposed limitations and should not detract from the responsibility of society to accommodate them.

2.4.4 The debate – critique and conclusions

Critics of the recognition of the body within the disability arena argue that the merger of impairment (*korper*) and disability (*leib*) are devoid of any significant theoretical, practical or social value (Barnes, 2012; Thomas, 2007). Along the same lines, Thomas (2002) claims that, thus far, these studies have failed in making a notable contribution to disability. These writers warn that a focus on the personal lives and troubles may have a damaging effect on the collective lives of people with disabilities, as it steers attention away from wider social structures that lead to exclusion and shun impaired bodies to the margins of society (Barnes, 2012; Thomas, 2002, 2007). Finkelstein (cited in Barnes, 2004) calls these personal accounts "inside-out research", whereby research becomes so invested in the inner lives of individuals, that the social origins of these subjective worlds are brushed over and barely noticed (Thomas, 2002). It is, however, important to note that Thomas (2002, 2007), whilst noting these concerns of disability scholars, also urged for the full theorisation of impairment, wherein disability and impairment would be acknowledged.

It is evident that these authors are deeply concerned that the gaze of disability scholars will turn inward; leaving the political and social progress of the social model null and void. Of course, given the history of medicalisation and marginalisation, their caution that embodiment will leave the impaired body once again disempowered is not completely ungrounded and maybe even somewhat plausible. However, there also lies a personal danger in denying the reality of the body, with its joys, pain, laughter and tears (Paterson & Hughes, 1999).

Connolly (2013), citing Merleau-Ponty, points out that it is our subjective bodily experiences that connect us to the world and make it meaningful and real. For Winnicott (1988) this unity of body and psyche is a fortunate achievement. He writes, “How easy it is to take for granted the lodgement of the psyche in the body and to forget that this again is an achievement. It is an achievement which by no means falls to the lot of all” (Winnicott, 1988, p. 122). In “dislodging” the impaired body from disabled social reality, we face the risk of dissociating people from their very real emotional struggles (Watermeyer, 2013) in a collective push to deny these experiences. And this dissociation, in its reduction of the body to a purely objective entity, threatens to leave the world we live in empty and devoid of all meaning (Jung, cited in Connolly, 2013). Connolly (2013) warns that this feeling of meaninglessness, that there is nothing worth living for in the world, may become a fundamental psychic problem.

Paterson and Hughes (1999) argue that phenomenology, in its portrayal of the body as both object and subject, can expose oppressive societal structures, while capturing lived experience. After all, they contended that it is mostly societal structures that make the body dys-appear. The dys-appearing body, as a limit case, could reveal the way in which “disability is embodied and impairment is social” (Hughes & Paterson, 1997, p. 336).

Phenomenology therefore allows the space for accounts of hurt and suffering, while removing these narratives from charitable discourse by illuminating oppressive practices. Suffering now becomes balanced between pain and oppression and it “helps one think more clearly about disability (as oppression) becoming embodied as suffering” (Hughes & Paterson, 1997, p. 336).

I would thus argue that phenomenology offers a lens through which we can see how the impaired body dys-appears. We remain aware of our own feelings of pain, and yes, personal tragedy, while remaining ever mindful of how the “*leib*” of experience are drenched with oppression and societal structures that may exclude us. This is felt, however, not only in the subjective body, but also in our very core, in our bodies. It thus remains a balancing act, knowing that societal structures are embodied and the body becomes social. Phenomenology, at best, offers a way of avoiding the dangers predicted by social model authors, while leaving room for the voices and very unique experiences of people with disabilities.

CHAPTER 3

INCLUDING DISABLED STUDENTS IN HIGHER EDUCATION – A REVIEW OF THE LITERATURE

> It is one thing for institutions to provide improved access for people from non-traditional groups such as those with disabilities, but if there is no change in the ideology of the institution, its staff and its curriculum then the problems will remain. This is the difference between rhetoric and reality, between the policies as set out in institutional plans etc., and the practices as experienced by applicants and students on courses. (Hurst, 1993, pp. 355-356)

3.1 Introduction and Overview

Prior to the 1990s, relatively few disabled students had the opportunity to study at a tertiary institution. However, in the last two decades there has been a growing international commitment to include these students in higher education (Fuller, Riddell, & Weedon, 2009a; Hadjikakou & Hartas, 2008; Suubi, 2014). This ideological transformation was influenced by, and followed in the footsteps of, the disability movement of the late 1970s (see also Chapter 2) (Bell, 2013; Swart & Greyling, 2011). As disability scholars rejected the medical understanding of disability in favour of a sharper focus on societal barriers, the educational gaze also needed to be adjusted. In primary and secondary schools, this meant replacing the former dual education system where disabled students were segregated, towards unified classrooms where disabled learners could attend their neighbourhood schools (Allan, 1999, 2004a, 2004b; Allan & Slee, 2008; Graham & Slee, 2008; Slee, 1996, 1997). Unlike the schooling system, higher education had mostly not been subdivided into institutions that catered for disabled and nondisabled students separately. What needed to change in higher education was that barriers to access and participation needed to be interrogated (Hadjikakou & Hartas, 2008).

Thus, on all levels of education, the focus had to move away from the medicalised welfare perspective of the disabled person as the “problem” to be “cured”. Instead, the new gaze had to interrogate the “deficits” within regular schools and universities (World Health organisation [WHO] and World Bank, 2011). Once these “deficits” were removed, disabled students would be able to access and participate fully in a mainstream environment such as a tertiary setting (Adams & Brown, 2006; Fuller et al., 2009a; Grace & Gravestock, 2009; Howell, 2006; Rieser, 2006).

As Howell and Lazarus (2003) wrote, “Increasing access and participation is not about trying to make ‘others’ fit into an existing system. Rather it is about changing the system so as to accommodate a larger and more diverse student population” (p. 61). Such a cultural shift would require a refocus; from what cannot be done, to ways to make higher education more accessible for disabled students. In this way, Adams and Brown (2006) and Howell and Lazarus (2003) argue, these students will be better equipped to achieve success.

This change in the ethos of learning environments is well known as “inclusive education”. Its definition is neatly captured in the World Report on Disability (WHO & World Bank, 2011). It reads, “Inclusive education entails identifying and removing barriers and providing reasonable accommodation, enabling every learner to participate and achieve within mainstream settings” (p. 210). Not only did this report identify the need for the removal of barriers, but it also pinpointed the provision of reasonable accommodations such as conversion of printed material into an accessible, electronic format for visually impaired students (Konur, 2006). The provision of support has been identified as one of the cornerstones of inclusive education (Hadjikakou & Hartas, 2008). The United Nations

Convention on the rights of persons with disabilities (UNCRPD) (United Nations [UN], 2006) described reasonable accommodations as “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms” (Article 24). It is thus evident that one of the main aims of inclusive education was attainment of equality (Beauchamp-Pryor, 2013).

While ideas and debates could certainly serve as the cornerstone for change, persuasion alone was simply not sufficient to improve the support and to ensure the inclusion of disabled students. In essence, legislation was required to provide the necessary pressure and impetus for change (Beauchamp-Pryor, 2012b; Taylor, 2004). As Taylor (2004) wrote, “the number and experiences of students accessing HE will invariably be influenced by changes in legislation” (p. 46). This need was captured in Article 24 of the UNCRPD (UN, 2006). They stipulated, “States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities” (p. 16). Since the onus now rested on higher education and governments to accommodate disabled students, many nations developed policies in an attempt to make discrimination unlawful, increase the access and widen the participation of disabled students in higher education. Interestingly, political responses were evident not only in high income nations like the United States of America (USA) (Beauchamp-Pryor, 2012b), Australia (Ryan, 2011) and Europe (Beauchamp-Pryor, 2012b; Magnus & Tøssebro, 2013), but also in the developing world such as southern Africa (Moswela & Mukhopadhyay, 2011). Yet, Moswela and Mukhopadhyay (2011) stipulated that progress in southern Africa, despite policy changes, still lags behind that of the developed world. To some extent, attention will be given to this aspect in the following chapter on education within South Africa. Nevertheless, at minimum, the move from the medical to the social understanding of disability permeated the educational sector at policy level (Hadjikakou & Hartas, 2008; Swart & Greyling, 2011; Swart & Pettipher, 2011).

What is more, statistical data showed that the number of disabled students entering higher education was increasing across the world (Crous 2004a, 2004b; Hadjikakou & Hartas, 2008; Hong, Ivy, Gonzalez, & Ehrensberger, 2007). This increase was documented in, to name only a few, Northern Ireland (Nicholl et al., 2013; Redpath et al., 2013), Scotland (Riddell & Weedon, 2014), Australia (Ryan, 2011), Canada (Fichten, 1995; Fichten et al., 2003; Mullins & Preyde, 2013, the United Kingdom (UK) (Adams & Holland, 2006; Pumfrey, 2008; Tinklin, Riddell & Wilson, 2004) and Southern Africa (FOTIM, 2011; Moswela & Mukhopadhyay, 2011). This increase, at least in part, could be ascribed to non-discriminatory legislation (Beauchamp-Pryor, 2013; Crous, 2004a, 2004b). Having said this, a number of authors caution that this seemingly rosy picture might be somewhat misleading. Firstly, Beauchamp-Pryor (2013) and Hopkins (2011) observed that, in the UK, the increase may simply be due to a higher number of disclosed disabilities. In other words, in the light of anti-discrimination legislation and improved support for disabled students in higher education, these students may be more willing to disclose their disabilities. Secondly, when taking a closer look, it appears that this increase was more prominent for students with less visible disabilities like learning impairments, rather than students with sensory disabilities such as a visual impairment (Beauchamp-Pryor, 2013; Hopkins, 2011). Thirdly, a quantitative increase did not automatically translate into the attainment of equality and inclusion. Many studies showed that, despite the rise in numbers, disabled students are still underrepresented in higher education worldwide (Chataika, 2010; Howell, 2006; Moswela & Mukhopadhyay, 2011; Nicholl et al., 2013; Redpath et al., 2013; Ryan, 2011; WHO & World Bank, 2011). Yet, documenting this increase and what it might mean, reflects the newfound awareness around the inclusion of disabled students. And in this awareness, change is already evident.

Moreover, as I have suggested earlier, inclusion is far more than the mere increase in numbers. It also involves the quality of the social and learning experiences of disabled students once they have gained access to higher education (Fuller et al., 2004; Jacklin, Robinson, O'Meara, & Harris, 2006). It includes feeling like a welcomed member of the tertiary environment; a member that truly belongs and whose contributions to the diversity of the university are valued and celebrated (Adams & Brown, 2006; Beauchamp-Pryor, 2013; Swart & Greyling, 2011; Thomas & Loxley, 2001). In his definition of inclusion within schools, Rieser (2002) placed a lot of emphasis on this "valuing" part of inclusion. He wrote, "Inclusion is valuing all children irrespective of their type or degree of impairment, or reconstructing the institution to remove barriers so teaching and learning take place so all children can be valued for who they are, participate, interact and develop their potential" (p. 132). In other words, a high number of disabled students in higher education did not automatically translate into an ethos of being valued or a feeling of "belonging" and being "wanted" (Beauchamp-Pryor, 2004, 2013). Hence, the effectiveness of policies cannot be measured simply against the statistical standard of large numbers of students in the system.

So now we are left with the question, "How can the effectiveness and implementation of policies be assessed?" A key component of this evaluation is gaining understanding of how disabled students experience the tertiary environment viscerally, in their flesh and bones. It is partly, and crucially, through the lens of their lived realities that the ability of universities to implement inclusive policies will be illuminated (Brandt, 2011; Fuller, Riddell, & Weedon, 2009b; Riddell et al., 2005). For example, a university may have a strong policy, rooted in the social model, but if disabled students still encounter barriers on campus, this policy is clearly not implemented effectively (Dowrick, Anderson, Heyer, & Acosta, 2005; Swart & Greyling, 2011).

However, listening to the voices of disabled students is not enough. Ideally, listening should lead to action. For too long disabled students have had no voice in policies and practices affecting their lives (Borland & James, 1999; Hall & Tinklin, 1998; Hurst, 1993; Riddell et al., 2005). In other words, the individual accounts of disabled students should influence and shape legislation and policies; thereby improving their lives (Beauchamp-Pryor, 2012c; UN, 2006). In the words of Fuller et al. (2004),

> . . . it is important that the experiences of disabled students in their full variety and their lived knowledge of teaching, learning and assessment in higher education should input and mould the development of policy and practice to a much greater extent than is currently the case. (p. 316)

As long as the development of policies is undertaken only by nondisabled individuals, power relations will remain unchanged and the ethos of the medical model will prevail (Beauchamp-Pryor, 2013).

Let us now turn to the literature on the experiences of disabled students and reflect upon what it says about the current strides towards inclusion.

3.2 Experiences of Disabled Students in Higher Education

The literature on the experiences of disabled students will be clustered under five headings, namely, (a) transition and entry into higher education, (b) disclosing a disability, (c) social experiences, (d) physical access, and (e) academic life.

3.2.1 Transition and entry into higher education

Moving to the wide-open spaces of a tertiary environment, filled with new experiences, opportunities and challenges, could be stressful and overwhelming for any student (Beauchamp-Pryor, 2012a; Gencoz & Or, 2006; Hopkins, 2011; Jacklin et al., 2006; Macaro & Wingate, 2004). In many instances the transition marks the first break from the parental homes and, alongside it, introduces the first major step towards adulthood and independence (Beauchamp-Pryor, 2012a, 2013; Daniels, 1982; Goode, 2007; Parker, 1999; Scott, 2009; Weedon & Riddell, 2009). Although they shared some challenges with their nondisabled counterparts, this walk to independence was often more complicated for disabled students (Beauchamp-Pryor, 2013; Durlak, Rose, & Bursuck, 1994; Eaton & Coull, 1999; Eckes & Ochoa, 2005; Hopkins, 2011; Reed et al., 2009; Reed & Curtis, 2011; Reed, Lewis, & Lund-Lukas, 2006). It often entailed (a) choosing the “right” university, (b) renegotiating family relationships, and (c) time-consuming preparation and orientation. Let us briefly look at each of these challenges in turn.

3.2.1.1 The requirements: “what they have to do” for the transition

For the disabled students in the study by Beauchamp-Pryor (2013), independence meant “finding a place where they fitted in and were included in their own right” (p. 126). In selecting a university where they could “fit in”, disabled students often had to consider various aspects, such as the physical lay-out of the institution (McBroom, 1997). Mobility impaired students, for example, could not study at an institution where the buildings had only stairs and no elevators or ramps (Hadjikakou, Polycarpou, & Hadjilia, 2010; Redpath et al., 2013; Shevlin, Kenny, & McNeela, 2004). So even though some students might have wanted to study at a specific university, physical inaccessibility might have made this very difficult or even impossible. Furthermore, as could be expected, some students also based their choice on the apparent ability of the university to provide adequate disability support such as extra time for examinations (Fuller et al., 2004; Goode, 2007; McBroom, 1997; Mullins & Preyde, 2013; Shevlin et al., 2004). However, in some cases, the way students felt on their first visit to a university weighed even heavier than its disability support provision (Goode, 2007). In other words, for some students the determining factor in their decision was whether they felt welcomed by university staff (Goode, 2007; Hopkins, 2011). This confirmed that the feeling of being wanted comprises an important segment of inclusion (see 3.1).

In addition to deciding on which university to attend, some disabled students also had limited options with regards to academic courses (Beauchamp-Pryor, 2013; Fuller et al., 2004; Riddell et al., 2005). For example, some universities discouraged these students from studying certain academic programmes (Beauchamp-Pryor, 2013), while some students independently chose an academic course in light of their disabilities (Fuller et al., 2004; Riddell et al., 2005). For example, in the study by Fuller et al. (2004), students with dyslexia deliberately chose academic courses that required minimal written assessments.

These narrowed choices for disabled students seem to reflect traces of an ongoing medical ideology in some tertiary institutions. Where universities failed to remove barriers to access and participation, disabled students had to adapt by choosing academic institutions where they would be included. And, once again, the student was perceived as the “problem” who needed to adapt and find a suitable place, whereas some universities remained out of reach for them. In short, since not all universities were accessible to them, they had to choose the “path of least resistance” and they were still discriminated against (Beauchamp-Pryor, 2013; Hopkins, 2011).

However, the ability or inability of a university to provide for disabled students was not always the only factor that determined the students’ choice. In many cases, disabled students chose an academic institution that was close to the support network of their parental home (Beauchamp-Pryor, 2013; Elliot & Wilson, 2008; Fuller et al., 2004; Hadjikakou et al., 2010; Shevlin et al., 2004). For the visually impaired students in her study, Beauchamp-Pryor (2013) found that, being in close proximity to their family and friends meant that support was more readily available. This support entailed (a) transport from and to the university, and (b) back-up in case disability support at the university failed.

However, as stated earlier, independence also meant "being included in their own right" (Beauchamp-Pryor, 2013, p. 126). In order to become independent, disabled students therefore had to renegotiate their familial relationships. In some cases, students therefore accepted the support from family members (Adams & Holland, 2006), but without asking for their help with all difficult matters (Beauchamp-Pryor, 2013). Getzel (2005) suggested that a gradual shift of responsibility from parents to the disabled student would be preferable.

It is evident that the transition to higher education was often hard work for disabled students – and harder work than for many of their nondisabled counterparts. Apart from the extensive preparation beforehand such as contact with disability staff (Elliot & Wilson, 2008) and researching the lay-out of the campus (Goode, 2007; Hopkins, 2011; McBroom, 1997), they also had to orientate themselves upon arrival. For visually impaired students, this orientation entailed, amongst others, getting to know the routes to their classes (Hopkins, 2011; McBroom, 1997; Vancil, 1997). This required extra work that nondisabled students did not have to perform (Hopkins, 2011).

3.2.1.2 Influences on the transition

In addition to the hard work involved in the move to a tertiary institution, how smooth this transition went was often influenced by other factors. These included previous education, type of impairment and the personality traits of disabled students.

In some cases, where disabled students had attended a segregated "special school", such as a school for the blind, the transition was often more complicated than for those who transitioned from a regular school (Beauchamp-Pryor, 2012a, 2013). This seemed to be closely tied to the level of support that was available to students during their school-going years. Since students received extensive support in segregated schools, they were often ill-prepared for the leap to the mainstream "self-catering" setting of a university (Beauchamp-Pryor, 2012a; Hopkins, 2011; Wagner, Newman, Cameto, Garza, & Levine, 2005). On the other hand, disabled students from mainstream schools had commonly not received specialised support at school and therefore learned to "fight for their rights" from early on (Beauchamp-Pryor, 2012a, 2013).

For students with hidden disabilities, the transition also often seemed more problematic than for those with more visible disabilities (Elliot & Wilson, 2008; Weedon & Riddell, 2009). In some instances these students did not define themselves as disabled (Fuller et al., 2004). Therefore, they missed important information on disability support and/or disability staff remained unaware of them (see following section) (Elliot & Wilson, 2008; Weedon & Riddell, 2009). It would therefore be safe to assume that, for visually impaired students, the visibility of the disability could have an influence on their move to independence.

3.2.1.3 Conclusion and reflections

Studies have shown that in their transition to higher education and independence, considerable responsibility still rested on the disabled student – they had to prepare in advance, they had to make an informed decision regarding the university they wanted to attend and they were disadvantage by previous educational segregation. And so, already at entry level, it is clear that some disabled students were still not fully included on tertiary campuses.

What is more, we know very little about the entry experiences of disabled students who did not transition from their parental homes. For example, gaps in research still exist regarding students who transitioned from boarding schools or who enrolled for studies later in life.

So, it seems that (a) some universities were still not fully inclusive of disabled students, and (b) more research is needed on the transition of disabled students to higher education, particularly those who did not transition from their parental homes.

3.2.2 Disclosing a disability

3.2.2.1 The importance of disclosure

Studies have shown that disabled students disclosed their disabilities to the university at a range of times. Some disclosed on the application form, some at registration, some during the course of their studies and some not at all (Jacklin, 2010; Jacklin et al., 2006; Kranke, Jackson, Taylor, Anderson-Fye, & Floersch, 2013). Although when and whether to disclose was and should be the student’s choice, they were formally entitled to support only upon disclosure (Gardner, Barr, & Lachs, 2001; Getzel, 2008; Gil, 2007; Hadjikakou & Hartas, 2008; Houghton, Piggott, & Armstrong, 2006; Jacklin, 2010; Konur, 2006; Lovett, Nelson, &

Lindstrom, 2014; Roberts, Ju, & Zhang, 2014). In other words, universities were obliged to provide support only when students declared their disabilities and needs. A clear example of this could be found in the study of three visually impaired students by Orsini-Jones (2009). In this study, teaching staff were often frustrated by the lack of disclosure from the students. Even though they could see the students' disability, they could not provide support where students did not ask for it.

Yet, a simple self-reported declaration was often not considered sufficient proof of an existing disability. It needed to be substantiated through medical and/or psychiatric assessments – depending on the type of disability (Beauchamp-Pryor, 2012b). This process is not as simple as it might seem. Apart from being costly and time-consuming, it was also sometimes emotionally draining for students (Hopkins, 2011; Lovett et al., 2014).

In 2012, however, the Association on Higher Education and Disability (AHEAD) (2012), based in the USA, provided guidelines suggesting that self-reports should carry far more weight than they currently do. They stipulated that these self-declarations should be treated as the primary proof of a disability and should therefore be considered more important than clinical impressions (secondary) and external medical documents (tertiary). Lovett et al. (2014) were cautious of this approach. They argued that mere self-disclosure might be too thin to serve as adequate evidence of, in particular, hidden disabilities like psychiatric, cognitive and learning impairments. They pointed out that these students might (a) not be able to accurately describe their disabilities and their impact on learning, and (b) fabricate disabilities in an attempt to get special accommodations like extra time for examinations. In fact, in the study by Lehmann, Davies, and Laurin (2000), disabled students expressed the need for more assessment since they felt ill-equipped to explain their needs adequately.

However, at close examination it seemed that AHEAD (2012) did consider and attempt to safeguard against “false” self-disclosures. They suggested that, in situations where disabilities were not apparent or comprehensively described, universities may make use of clinical impressions (secondary documents) and objective medical assessments (tertiary documents). In other words, if universities were not fully satisfied that they understood or could see a student’s disability, they could take further measures to support such a student’s claims. However if a student’s disability was fairly obvious, like with total blindness, tertiary documents would simply have been an unnecessary, burdensome process. Therefore, AHEAD (2012) advised that, instead of taking a one-size-fits-all approach, the unique circumstances of each student should be considered. As Elton (2000) stated: “I cannot think of anything more unfair than to treat all students as if they are the same when they are so manifestly not” (p.1).

Yet, whichever pathway universities decided to follow, mere self-disclosure or external documents or a combination of these, one thing still remained – disabled students still had to self-report in order to qualify for special accommodations (Getzel, 2008; Jacklin, 2010; Konur, 2006; Lovett et al., 2014).

3.2.2.2 Determinants of disclosure

Since they qualified for often much needed reasonable accommodations and financial support, it is easy to assume that disabled students would not have hesitated to declare their needs. However, despite the potentially grave academic implications, many students decided not to disclose their disability (Jacklin, 2010; Jacklin et al., 2006; Magnus & Tøssebro, 2013; Orsini-Jones, 2009; Riddell, 1998; Wagner et al., 2005). In some cases, students even extended the duration of their studies, rather than reveal the “secret” of their disabilities (Magnus & Tøssebro, 2013). Now, we may very well ask ourselves, “What influences their decision not to disclose?” and “Why were some students so reluctant to disclose their needs?”

The answer to this question is not a simple one. It seems that nondisclosure often centred around (a) how disabled students saw themselves and how they wanted to be perceived by others (disabled versus nondisabled identity), (b) their level of choice (visibility of the disability), and (c) the perceived cost/consequences of disclosure. Let us look at each one in turn.

The decision whether to disclose was sometimes closely tied to the disabled or nondisabled identity of the student. In those instances where students accepted a disabled identity, they were often more willing and comfortable to tell others about it (Evans, 2013; Jacklin, 2010; Wagner et al., 2005; Waters, Stevens, Holland, & Madriaga, 2012). For example, in interviews with 12 students with dyslexia, Evans (2013) found a distinction between students who embraced and those who resisted a disabled identity. His findings showed that those students who saw themselves as disabled (embracers), did not hesitate to tell others about it, while those who resisted (resisters) the disabled identity did not reveal it. In her interview with Anna, a student with epilepsy, Jacklin (2010) had similar findings. Anna was a nondisclosing student who did not like the term “disabled” student. She therefore preferred spaces where it was possible for her to hide her seizures.

Apart from not seeing themselves as disabled, some students also did not want others to define them as “disabled” or “a special case” (Jacklin et al., 2006). Keeping silent about the disability was therefore a way of appearing like all the other “normal” students (Atkinson & Owen-Hutchinson, 2013; Low, 2009; Tinklin & Hall, 1999). As Low (2009) writes, “Uppermost in their minds is negotiating a non-disabled identity. Their greatest desire is to be seen and treated as just another normal student” (p. 242).

This choice whether to display a “normal” or a “disabled” identity was often influenced by the visibility of the impairment (Beauchamp-Pryor, 2011; Fuller et al., 2004). While those students with an invisible disability such as dyslexia had the option to “pass as normal” (Goffman, 1963), those with a very noticeable disability did not always have this option (Magnus & Tøssebro, 2013; Riddell et al., 2005). Herein we see the distinction by Erving Goffman (1963) between the “discredited” and the “discredible”. The discredited refers to persons with visible disabilities who are immediately recognisable as disabled, whereas the discredible are those individuals with an unseen impairment who have the option to “pass as normal”. Once again, Anna, the student with epilepsy, is a good example of this (Jacklin, 2010). Anna would conceal her disability in instances where it was possible. However, whenever she knew that she might get a seizure, she would disclose her disability, because it would have been revealed anyway. However, this does not mean that students with very apparent disabilities did not try to conceal their impairments. Goode (2007) postulated that these students knew that they could not hide their disabilities, yet they attempted to “play it down”, thereby avoiding “extra-visibility”. For these students, masking the severity of their disabilities or even trying to “pass as normal” involved strategies like not asking for help (Orsini-Jones, 2009), not sitting in front of classes, or hiding their assistive devices such as magnifying glasses (Goode, 2007; Low, 2009). So, in some instances, even students with very visible disabilities, like those with low vision or blindness, had the desire “to be seen and treated as just another normal student” (Low, 2009, p. 242).

In many instances this desire to hide a disability went hand-in-hand with the perceived or real consequences of telling others about it. For many, the social and academic cost was simply too high (Hadjikakou & Hartas, 2008; Riddell, 1998). These consequences will be discussed at length further in this chapter, but let us briefly look at it here.

Socially, students sometimes feared that the knowledge of their disability would overshadow all their other qualities, allowing others to see only their disability (Magnus &

Tøssebro, 2013). And, they feared that when others "saw" their disability, they would be pitied, stereotyped and excluded from social groups (Elliot & Wilson, 2008; Kranke et al., 2013; Magnus & Tøssebro, 2013; Roberts et al., 2009). As will be discussed in the following section, this fear was not ungrounded, since students were sometimes excluded based on their disability. However, in instances where students had a sense of belonging and strong ties with a social group, they felt safer to disclose their disability (Jacklin, 2010; Madriaga, 2007). Anna, the student with epilepsy in Jacklin's (2010) study, disclosed during her undergraduate years, because she felt part of the university. Yet, during her postgraduate years she did not have a sense of belonging and consequently remained silent about her seizures. It is therefore no wonder that the encouragement by others, like peers, could prompt students to step forward about their needs (Jacklin et al., 2006; Roberts et al., 2009). It might be that the involvement by peers "normalised" the disability and made them feel accepted despite their disabled identity (Roberts et al., 2009).

Students also had concerns regarding the academic consequences of disclosure. Even though being open about their disability meant that they were entitled to reasonable accommodations, the very real fear of discrimination and exclusion sometimes outweighed these benefits (Madriaga, 2007; Riddell, 1998). They were afraid that the knowledge of their impairment would compromise the relationship with their lecturers and that these staff members would be unsupportive and not consider them for future opportunities (Jacklin, 2010; Kranke et al., 2013; Leyser & Greenberger, 2008). However, the fear of discrimination in the tertiary environment was even evident before students started their studies. Many students did not indicate their disabilities on the university application form, because they were concerned of not being accepted for their chosen academic course (Beauchamp-Pryor, 2013; Vickerman & Blundell, 2010). This was not an ungrounded fear, since disabled students could be discouraged from studying certain courses (Beauchamp-Pryor, 2013). Even more extreme, Jacklin (2010) found that Anna, the student with epilepsy, was accepted for post-graduate studies at the only university where she did not disclose her disability.

However, it goes without saying that, whether they took on a “normal” identity or had an invisible disability, this concealment did not erase their disability or its effects (Mullins & Preyde, 2013). Some of these students still needed special accommodations. However, often asking for this support meant accepting, at least in part, a disabled identity (Low, 2009). Some students therefore decided to confide in some trusted people or only in those individuals who needed to provide them with support (Jacklin, 2010; Magnus & Tøssebro, 2013; Mullins & Preyde, 2013). Some others disclosed only when academic problems became too overwhelming (FOTIM, 2011; Getzel, 2008; Getzel & Briel, 2006; Getzel & McManus, 2005; Kranke et al., 2013; Roberts et al., 2009). It is therefore not surprising that in some cases, students with an unseen disability wished for a concealable visible marker of their disability (Mullins & Preyde, 2013). In other words, these students wanted to be able to show lecturers physical proof of their disability, but, when needed, they wanted to be able to hide this evidence.

3.2.2.3 Concluding remarks, and the question of universal design

Evidently, deciding whether and when to disclose was not an easy choice. No matter what the decision was, it had the potential to result in exclusion. If students remained silent about their needs, universities did not regard them as disabled, leaving these students without any specialised support. In essence, this meant that nondisclosing students could not be valued for who they were, because some part of their lives remained obscured. On the other hand, when they disclosed, they faced the very real threat of being rejected on their chosen academic course, while their information was not transferred onto relevant staff members. These continual disclosures, coupled with the potential for discrimination, did not reflect an ethos of inclusion and directly flew in the face of the stipulations of the UNCRPD (UN, 2006, Article 24) where it read, “States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others.” So, whether students disclosed or not, it seemed like they always faced the potential for exclusion.

Many writers argue that it should not be necessary for students to disclose in order to get some support (Beauchamp-Pryor, 2013; Hall & Stahl, 2006; Madriaga, 2007; Scott & McGuire, 2005; Shaw, 2007). For example, if teaching staff always reads out what is written on the white board, blind students would be able to follow in class without alerting the lecturer to their disability. These inclusive practices are called universal design for instruction (Scott & McGuire, 2005) or universal design for learning (Hall & Stahl, 2006). Recently, many educators worldwide have proposed that universal design strategies provide effective guidelines for the successful inclusion of disabled students (Fuller & Healey, 2009; Getzel, 2008). It means providing flexible teaching methods, employing various teaching methods and varying the presentation of information so that it would accessible to all students (Getzel, 2008). However, as seen before, inclusion also involved the recognition and respect of individual differences between students (Fuller & Healey, 2009; Grace & Gravestock, 2009; Hall & Stahl, 2006).

Even though more and more disabled students disclosed to be eligible for reasonable accommodations, this is not to say that disclosing students always got what they hoped for (Getzel & Thoma, 2008; Lightfoot & Gibson, 2005). To the contrary, many of these students were disappointed and frustrated with the outcome of their disclosures (Borland & James, 1999; Goode, 2007; Roberts, 2009). In the following sections the outcomes of their disclosures will be highlighted.

3.2.3 Social experiences

Some authors have stated that friendship lies at the heart of the student experience and, when friendships are formed between disabled and nondisabled students, these may create a sense of "togetherness" (Beauchamp-Pryor, 2012a; Taylor & Palfreman-Kay, 2000). This form of friendship might furthermore strengthen the self-concept of disabled students, influence their persistence in higher education (Hodges & Keller, 1999) and, on a broader level, challenge their exclusion (Beauchamp-Pryor, 2012a). However, as mentioned before, some disabled students feared that confiding in others about their disability would lead to social barriers and exclusion, rather than a sense of belonging and togetherness. Of course, we may very well ask ourselves whether this concern had any grounds or whether it was a somewhat irrational concern. There exists no one answer to this question, as the experience of friendship, social encounters and level of acceptance were dependent on many factors and sometimes differed from student to student and from one relationship to the next.

In some instances, disabled students have experienced stereotyping, labelling and pity from their nondisabled counterparts (Joshi, 2006; Low, 2009). For some nondisabled persons, a disability equated to "inability" or "being stupid" (Dowrick et al., 2005; Low, 2009). Interestingly, even in some cases where the disability remained "a secret", students were indirectly exposed to what others thought of disabled people. Perhaps because able-bodied people did not know of the student's disability, they felt comfortable commenting that disabled students, especially those with psychiatric disabilities, were "bad", "unstable" and that they did not belong in higher education (Mullins & Preyde, 2013). It is therefore no wonder that some disabled students experienced social alienation and rejection (Goode, 2007; Joshi, 2006; Shevlin et al., 2004).

In the study by Beauchamp-Pryor (2013) one quarter of participants felt that they were excluded from their social group, compared to the 12.5 % in the study by Jacklin et al. (2006). It would therefore be a gross generalisation suggesting that all relationships between students with and without disabilities were strained, as disabled students often had positive and meaningful relationships with peers (Hadjikakou et al., 2010; Jacklin et al., 2006; McBroom, 1997). In fact, in some studies, disabled students pointed to their nondisabled friends as an invaluable source of emotional and practical support (Beauchamp-Pryer, 2012a, 2013; Dowrick et al., 2005; Swart & Greyling, 2011). This support included sighted students helping their visually impaired friends with finding books in the library or by taking notes for them during class time (Beauchamp-Pryor, 2013).

Variation also existed in the relationship disabled students had with one another. Some disabled students found companionship and support in their friendship with disabled peers (Elliot & Wilson, 2008). Older disabled students, in particular, seem to have been an invaluable source of information and guidance for younger students (Swart & Greyling, 2011). In contrast, some students deliberately distanced themselves from their disabled peers (Low, 2009). According to Low, this could be seen as an attempt to get or maintain a nondisabled identity. As she wrote, “Students distance themselves from their disabled identities by expressing dislike for, attributing negative attributes to, and/or keeping physical distance between themselves and other students with disabilities” (Low, 2009, p. 247).

These mixed social experiences leave us with many questions. Some of these are, “Why did some students have positive social experiences while others remained marginal to their peer group?”, and “Why did some people have both positive and negative social encounters?” These questions lead to one overarching question, namely, “What were the ingredients for strong relationships between people with and without disabilities?" Although there is no definite answer to these questions, analysis of the literature showed some suggestions.

The past experiences of both disabled and nondisabled students sometimes had an influence on whether they became friends (Beauchamp-Pryor, 2012a). Social interactions between students with and without disabilities were sometimes awkward, because the latter did not have prior contact with disabled students and generally lacked awareness of disabilities (Erten, 2011; Mullins & Preyde, 2013; Shevelin et al., 2004). This concurs with Erving Goffman (1963) who postulated that, in interactions with disabled people, those people without disabilities would become "wise". However, the theory that nondisabled people "simply know no better", may stretch even deeper. As explained in Chapter 2, ableist emotions in the nondisabled person's imagination, like pity, fear and disgust (Hughes, 2012) may stem from the belief that, because the disabled body does not measure up to the standard of a "normal" body, it does not deserve the same treatment and does not belong in a "perfect" and "normal" world (Loja et al., 2012). According to Beauchamp-Pryor (2012a, 2013) these attitudes towards disabled persons reflect prevailing medical model thinking around disability within wider society; that disabled people have "deficits" that need compensation and care. It is therefore no wonder that these reactions towards persons with disability often resulted in a distance between disabled and nondisabled people (Hughes, 2012).

As stated in the previous paragraph, the previous experiences of disabled students also sometimes had an influence on their interactions with nondisabled peers. If disabled students experienced friendships during their school-going days, they seemed to be more likely to make friends in higher education (Beauchamp-Pryor, 2012a, 2013). This stretched even further to include friendships with nondisabled friends. In other words, if disabled students attended a special school where they had only disabled friends, they would be less likely to befriend nondisabled peers in higher education compared to those students who formed friendships in a mainstream school (Beauchamp-Pryor, 2013; Polat, Afroditi, Boyle, & Nelson, 2001).

In many instances, it appeared that successful interactions depended largely on the initiative of the disabled student. Disabled students therefore often “took the lead” in interactions with nondisabled students (Goode, 2007; Hodges & Keller, 1999; Jacklin et al., 2006; Swart & Greyling, 2011). In fact, in the study by Hodges and Keller (1999), visually impaired students saw “taking the initiative” as the strongest contributor to social involvement. This initiative included, amongst other aspects, assertiveness and managing the discomfort of sighted students. However, this “emotional work” was sometimes emotionally draining for disabled students (Goode, 2007).

However, it was not always internal factors that caused social exclusion; sometimes external circumstances also played a contributing role (Kilmurray & Faba, 2005). These circumstances included, amongst others, (a) where students lived and, (b) whether they could read printed notices. When they lived in a university residence, students were more likely to feel included in a social group (Swart & Greyling, 2011), while those who lived off-campus had limited time to make friends (Hodges & Keller, 1999; Hanafin, Shevlin, Kenny, & McNeela, 2007; Jacklin et al., 2006). For the visually impaired students in the study by Hodges and Keller (1999), it was very difficult to participate in social activities. These events often took place after five o’clock in the evening, at which time the students were already at home. Since they were unable to drive, they could not return to campus to attend these socialisation opportunities. Furthermore, visually impaired students were unable to read printed notices on campus of upcoming social events; hereby missing out on social events (FOTIM, 2011; Hodges & Keller, 1999; Jacklin et al., 2006; Joshi, 2006).

These previous two barriers are clearly related to visually impaired students. It is therefore no wonder that, in the study by Beauchamp-Pryor (2012a), the visually impaired students were the group who spoke most at length about their difficulty with social encounters compared to students with other disabilities.

In the light of these difficulties, coupled with the perceptions of nondisabled peers, it comes as no surprise that visually impaired students often did not feel included in the social aspects of tertiary life. Moreover, once again a lot of the responsibility rested on them to “smooth out” social interactions. Of course, the questions remained, “What happened to those students with less assertive personalities?”

3.2.4 Physical accessibility

The UNCRPD (UN, 2006) regarded accessibility, including the accessibility of the physical environment, as an important aspect of the ability to participate fully in all facets of life. To this end, they stipulated that,

> To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment. . . . These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia: . . . buildings, roads, transportation and other indoor and outdoor facilities . . . (UN, Article 9)

However, as seen previously, some universities remained out of reach for disabled students, because of inaccessible physical lay-out (Redpath et al., 2013; Riddell, 1998). Once they were there, some students also encountered physical barriers (Hanafin et al., 2007; Holloway, 2001; Moswela & Mukhopadhyay, 2011; Redpath et al., 2013; Riddell, 1998). As the UNCRPD

(UN, 2006) stipulation assumed, these physical barriers sometimes spilled over into other areas of life; affecting students' ability for "full participation". One of these potentially "affected" areas was the academic performance of students (Hanafan et al., 2007). If, for example, a mobility impaired student needed to go to the bathroom during assessment, but the only wheelchair accessible bathroom was in another building, it might have caused anxiety; resulting in poor academic performance (Hanafan et al., 2007). Inaccesible physical environments could also inhibit social participation (Hodges & Keller, 1999; Jacklin et al., 2006). For example, where social events were held in places without ramps or lifts, mobility-impaired students were unable to attend these events. Riddell (1998) also noted the potentially negative impact on self-esteem when students were not able to access the physical environment completely.

Although, as could be seen from the examples in the previous paragraph, physical accessibility often related to the difficulties experienced by mobility-impaired students, Hurst (2009) noted that visually and hearing impaired students might also find the environment inaccessible. For example, in the South African study by FOTIM (2011), partially sighted students mentioned that they were unable to read signs on the campus. Those visually impaired students who had no depth perception also reported that stairs posed a particular challenge to them, as they did not know when the stairs ended.

It is thus evident that, in some cases, disabled students still experienced the physical lay-out of universities as non-inclusive. Firstly, inaccessible lay-outs limited their scope of options regarding universities and, secondly, once they were there, their full participation could be stifled by physical barriers.

Once again, universal design strategies provided useful thinking around the physical environment. In fact, the concept of universal design, as coined by Robert Mace early in the

1970s (Scott & McGuire, 2005), originated from architecture and product design. It meant that products and the physical environment were designed, from the outset, so that they could be used optimally by everyone (McGuire, Scott, & Shaw, 2006; Scott & McGuire, 2005; Shaw, 2007). For example, if there were more speed bumps at road crossings, it would be safer for all students – disabled and nondisabled alike – crossing the road. Buzzers at traffic crossings would help not only students with a visual impairment, but also people who could not see well at night, those who had colour blindness and students with attention deficit disorder. In short, universal design would mean that disability and an inclusive environment would become part of the taken-for-granted lifeworld and natural common-sense attitudes of everyone.

3.2.5 Academic experiences

The successful inclusion of disabled students often entailed the provision of reasonable accommodations (see 3.1) (UN, 2006; WHO & World Bank, 2011). For some disabled students, these accommodations were imperative for achievement in the academic terrain (Kranke et al., 2013; Madriaga, Hanson, Kay, & Walker, 2011; Mullins & Preyde, 2013). These accommodations included, amongst others, adjustments to (a) printed information/course material, (b) teaching methods, and (c) assessment techniques. Let us briefly look at each one in turn.

3.2.5.1 Adjustments

Nowadays, assistive technology has made it easier for disabled students, especially those with a visual impairment, to access the written word (Burgstahler, 2005; Soorenian, 2014). "Assistive technology is a term used to refer to products that can help disabled students to undertake aspects of their work" (Grace & Gravestock, 2009, p. 99). For visually impaired students, one of these important products is called a screen-reader. With the Braille or voice output of a screen-reader, it became possible for visually impaired students to follow the entire content that was displayed on a computer screen (Cooper, 2003; Fichten, Asuncion, Barile, Ferraro, & Wolforth, 2009). So, it became possible for visually impaired students to read notes and books, as long as it was in an electronic format (Scott & McGuire, 2005).

However, assistive technology should not be confused with general technology. Ironically, technological advances sometimes made it more difficult for visually impaired students to read electronic texts. For example, Lee (2014) pointed out that some Google applications and kindle e-readers were inaccessible to visually impaired students. Trends towards e-learning also posed some setbacks to the accessibility of the written word (Fichten et al., 2009). For example, some websites and text formats like Powerpoint might be difficult, if not impossible, to read with the aid of a screen-reader (Fichten, et al., 2009).

So, assistive technology did not solve the problem of inaccessible materials completely. Additionally, the conversion of printed materials into an accessible format often took some time since publishing houses were sometimes unwilling to provide students with the electronic format of books (Whitehouse, Dearnley, & Murray, 2009). And so, numerous studies revealed that the learning of some disabled students, including those with a visual impairment, were still stifled by limited and delayed access to course material (Bishop & Rhind, 2011; Frank, McLinden & Douglas, 2014; Hanafin et al., 2007; Holloway, 2001; Joshi, 2006; Kilmurray & Faba, 2005; Klinkosz, Sekowski, & Brambring, 2006; Madriaga et al., 2010; Reed & Curtis, 2012). Ideally, students wanted these materials before classes started (Hopkins, 2011; Hurst, 2009; Madriaga, 2007) in order to follow effectively in class (Borland & James, 1999; Fuller et al., 2004; Newland, Boyd, & Pavey, 2006; Tinklin & Hall, 1999).

This difficulty with printed material extended beyond the classroom and was very evident when visually impaired students visited the library. In 2004, Bolt (2004) estimated that only 5% of the materials in libraries were accessible for these students. Surrounded by books, articles and dissertations that they could not read, it is no surprise that going to the library could be stressful for these students (Elliot & Wilson, 2008; Fuller et al., 2004; Holloway, 2001; Scott, 2009). One student in a study by Scott (2009) emphasised that there was something inherently unequal about the library experiences of a visually impaired student compared to that of their sighted counterparts.

Apart from adaptations to written materials, it was often necessary for lecturers to adjust their teaching style. It was often difficult, if not impossible, for visually impaired students to see presentations, such as transparencies, as displayed by lecturers (Bishop & Rhind, 2011; Borland & James, 1999; Fuller et al., 2009b; FOTIM, 2011; Reed & Curtis, 2012; Swart & Greyling, 2011). Similarly, it was difficult for hearing impaired students to lipread when teaching staff did not face the class (Fuller et al., 2004). Not being able to follow in class often had a ripple effect on adequate note-taking (Healey et al., 2006; Madriaga et al., 2010; Mullins & Preyde, 2013; Roberts, 2009). Students therefore preferred a variety of flexible teaching methods (Claiborne, Cornforth, Gibson, & Smith, 2011; Roberts, 2009; Swart & Greyling, 2011), instead of a one-dimensional teaching style directed to one type of learner (Mullins & Preyde, 2013). For example, lecturers could provide verbal explanations of their displayed notes.

Finally, many disabled students needed reasonable accommodations at the time of assessments (Fuller & Healey, 2009a; Vickerman & Blundell, 2010). These accommodations included extra time for the completion of examinations and changes to procedures like the conversion of test materials into an electronic format or writing in a separate room (Fernie &

Henning, 2006; FOTIM, 2011; Fuller & Healey, 2009; Hadjikakou & Hartas, 2008; Hall & Stahl, 2006; Healey et al., 2006; Madriaga & Goodley, 2010; Mullins & Preyde, 2013; Quick, Lehmann, & Deniston, 2003; Swart & Greyling, 2011).

Paradoxically, even though these accommodations were considered an important way of including disabled students, it made some feel like “outsiders” (Michalko, 2009b). As previously described, asking for these accommodations meant disclosing their disabilities (Low, 2009); something that potentially made them feel “extra-visible” and different from their nondisabled counterparts (Fuller & Healey, 2009; Goode, 2007; Mullins & Preyde, 2013; Roberts et al., 2009). For example, in the study by Mullins and Preyde (2013), some students found it awkward explaining to others why they wrote exams in another room. So the exact measures that were aimed at including disabled students could serve to alienate and exclude them.

3.2.5.2 Whose responsibility was it anyway?

Although disability support personnel often facilitated the accommodations to disabled students (Erten, 2011; Mullins & Preyde, 2013), students frequently regarded the support and understanding of lecturers as an essential component in their academic success (Erten, 2011; Joshi, 2006; Scott, 2009; Wilson, Getzel, & Brown, 2000). Getting this support, however, was often not as straightforward as it might seem. Firstly, in some instances disabled students did not want to inform each individual lecturer of their needs. They therefore hoped that the disability support personnel of the university would transfer their relevant information to lecturers (Erten, 2011). In many instances this did not happen, because staff members wanted to protect the confidentiality of each student (Beauchamp-Pryor, 2013; Borland & James, 1999). So in these instances, unless the students disclosed to each one of their lecturers, teaching staff remained unaware that disabled students were attending their classes

(Beauchamp-Pryor, 2013; Borland & James, 1999; Crews & Keil, 2005; Dowrick et al., 2005; Fuller et al., 2004; Fuller et al., 2009b; Jacklin et al., 2006; McBroom, 1997; Redpath et al., 2013; Shevlin et al., 2004). This meant that, in order to get the required support, disabled students often had to disclose more than once, since they had to inform individual lecturers of their needs (Crews & Keil, 2005; Fuller et al., 2009b; McBroom, 1997; Scott, 2009; Shevlin et al., 2004; Swart & Greyling, 2011). Of course, this continual disclosures felt to be a "constant battle" for some students (Goode, 2007; Lightfoot & Gibson, 2005); a battle that some with more reserved personality traits were not willing to fight (Roberts et al., 2009).

However, even in instances where lecturers were aware of disabled students, the required support was not guaranteed. All too often there were variations in the responsiveness and practices between departments and from the one lecturer to the next (Beauchamp-Pryor, 2014; Borland & James, 1999; Brandt, 2011; Elliot & Wilson, 2008; Fuller et al., 2004; Hadjikakou & Hartas, 2008; Holloway, 2001; Hopkins, 2011; Jacklin et al., 2006; Madriaga, 2007; Magnus & Tøssebro, 2013; Mullins & Preyde, 2013; Riddell et al., 2005; Roberts, 2009; Swart & Greyling, 2011; Taylor, 2004; Tinklin & Hall, 1999). What is more, is that the same lecturer or tutor could vary in their responses over time (Hopkins, 2011; Shevlin et al., 2004). In other words, one tutor sometimes had an inclusive approach, only to revert to an old style of teaching later. The unwillingness of some lecturers to adapt teaching methods was related to various factors. Some of these included a fear of giving these students an unfair advantage over their nondisabled peers (Brandt, 2011; Lehmann et al., 2000; Mullins & Preyde, 2013; Vickerman & Blundell, 2010), suspicion regarding the validity of the disability (especially when it was unseen (Kitchin, 1998; Magnus & Tøssebro, 2013), a lack of prior experience in working with disabled students and lack of time (Erten, 2011; Hurst, 2009; Lehmann et al., 2000). It is thus clear that disabled students were still very dependent on the subjective discretion and "good" graces of lecturers, rather than on policy alone (FOTIM, 2011; Hanafin et al., 2007; Mullins & Preyde, 2013; Riddell et al., 2005; Shevlin et al., 2004; Tinklin & Hall, 1999). And, in instances where special arrangements were made, it often happened on an ad hoc basis; as the need arose (Fuller & Healey, 2009; Fuller et al., 2004; Hadjikakou & Hartas, 2008; Robson, 2004).

In many instances, students had to assert themselves continually and had to repeat their requests for accommodations (Elliot & Wilson, 2008; Goode, 2007; Holloway, 2001; Hopkins, 2011; Reed & Curtis, 2012; Shevlin et al., 2004). For some students, this continued assertiveness provided them with a sense of control and power over their own lives (Riddell et al., 2005), while some even became activists for change (Goode, 2007). Unfortunately, outweighing these benefits were the negative consequences of constantly reminding teaching staff of their needs. Firstly, other barriers sometimes left students so emotionally drained that they were unable to battle for their needs (Goode, 2007). For those who did "battle", repeating their demands was experienced as stressful, frustrating, anxiety-provoking (Holloway, 2001; Hopkins, 2011; Madriaga, 2007) and even demeaning and shameful (Beauchamp-Pryor, 2012a). Renegotiating also sometimes took considerable time, detracting from time to study or participation in social activities (Elliot & Wilson, 2008; Jacklin et al., 2006). It, therefore, came as no surprise that some of these students came close to dropping out of a tertiary education institution (Goode, 2007) or that students left the university environment for one year (Hanafin et al., 2007).

3.3 Conclusion

Now, after the close examination of the lived experiences of disabled students, we are able to answer the question whether they are currently included in tertiary institutions. We saw that, while an inclusive commitment is evident through policy developments, the lived experiences of disabled students sometimes told a different story (Adams & Holland, 2006; Bell, 2013;

Beauchamp-Pryer, 2012a, 2013; Dowrick et al., 2005; Holloway, 2001). Individual needs were still met with ad hoc arrangements, variation existed in the level of support and a seemingly disproportionate amount of responsibility rested on students in procuring necessary support. In addition, they had to choose tertiary institutions and courses in light of their disabilities, renegotiate family relationships, disclose their needs continually, initiate social interactions with peers and manage the physical environment. Even the measures intended to include disabled students, such as reasonable accommodations, marked them as “abnormal”, hereby excluding them.

Since the responsibility of inclusion often fell on disabled students themselves, there exists the very real concern regarding those students who do not have more forceful personalities. Some students might want to self-advocate, but might not have the necessary skills to do so (Lehmann et al., 2000; Taylor, 2004). Especially during their first year, students might not know how to get much needed support or whether they are illegible for accommodations (Borg, Maunder, Sharpling, & Abson, 2008; Cawthon, 2008; Nightingale, 2007). In these students’ “falling through the cracks”, it is difficult to see an ethos of appreciation for the difference amongst students.

In the light of these lived realities, Beauchamp-Pryor (2012a) described the tertiary approach towards visually impaired students as “included, but not inclusive” (p. 181). In short, this meant that the growing number of disabled students in higher education did not necessarily imply wider participation once they were there (Beauchamp-Pryer, 2012a, 2013; FOTIM, 2011; Goodley, 2011). In fact, gaps between policy and practice still exist, leaving students without adequate support (Fuller et al., 2004; Madriaga, 2007; Riddell et al., 2005). These gaps extend the mere “unwillingness” of lecturers and rather points to a prevailing disablist society (Madriaga, 2007).

Of course, the accomplishments of inclusive education should not be overlooked or denied. After all, it led to policy development, greater numbers of disabled students accessing higher education and, most importantly, rethinking around how to include disabled students.

Despite great strides having been made in the inclusion of disabled students, much remains to be done (Bell, 2013; FOTIM, 2011). This research, with its focus on the experiences of visually impaired students, is an attempt to further this objective.

CHAPTER 4

DISABILITY AND HIGHER EDUCATION IN SOUTH AFRICA – A LITERATURE REVIEW

> Education is the great engine of personal development. It is through education that the daughter of a peasant can become a doctor; that the son of a mineworker, can become the head of the mine, that the child of farm workers can become the president of a great nation. (Mandela, 2005, p. 112)

> Let us work together to nurture our people with disabilities so that they also experience the full excitement and joy of learning, and to provide them, and our nation, with a solid foundation for lifelong learning and development. (Department of Education, 2001a, p. 4)

4.1 Introduction

This chapter will give a broad overview of the developments regarding disabled students within South African tertiary institutions over the last two decades. The chapter will start with a short glimpse into the history of education within South Africa, since “The progress made in South Africa must be measured against its own unique political, social and legislative background” (FOTIM, 2011, p. 14). Thus, following a brief outline of the educational divide prior to 1994, initiatives aimed at correcting the inequities of the past will be highlighted. This will include an overview of government policies on disability in higher education, as well as a critical appraisal of services that tertiary institutions currently offer.

As I have emphasised before, exploring the experiences of disabled students is valuable, not least because this can give an indication of how effective policies and practices are. Therefore, the second part of the review will place the day-to-day lives of disabled students, as provided by literature, under a microscope. Since this study has a specific focus on visually impaired students, the chapter will also include an overview of visually impaired students' current situation in tertiary settings in South Africa.

Lastly, the chapter will conclude by looking at recent policy developments, 2010 – 2013, in the field of disability in higher education. Through the goals of these policies, it will be possible to determine whether the experiences of disabled students, as reflected by research, have been taken into account.

4.2 Historical Background

"A historical glimpse into previous educational dispensations and practices also helps to deepen our understanding of present educational practices in South Africa" (Swart & Pettipher, 2011, p. 14).

Before 1994, many disabled students could not obtain a tertiary qualification in South Africa. In those rare instances where they made it into higher education, they were confronted with numerous obstacles that impeded their full and equal participation on these mainstream campuses. According to the literature, two aspects should be considered when talking about limited access and participation for South African disabled students. These are (a) the schooling system, and (b) the structure and functioning of tertiary institutions. These two factors and how they related to disabled students will be discussed in the following few paragraphs.

The first factor that played a major role in the restricted access to higher education for disabled students was the multiply divided schooling system of South Africa. As in most other countries, disabled learners did not attend the same schools as their nondisabled peers. Instead, they were segregated in special schools, often far removed from their parental homes, where professionals were employed to “care” for them (Nel, Engelbrecht, Nel, & Tlale, 2013). In instances where they went to regular schools, they were commonly placed in “special” classrooms, where they were still “kept apart” from their “normal” peers (Howell, 2005, 2006; Howell & Lazarus, 2003; Swart & Pettipher, 2011). Keeping this medical ideology of care and cure in mind, it is no wonder that this peripheral system often did not prepare disabled learners to enter the mainstream life of higher education. In fact, many of these institutions did not offer a syllabus that could equip learners for tertiary education and, even worse, many did not offer tuition up until matric (school-leaving) level (DoE, 1998). It is as if professionals at special schools did not expect disabled learners to pursue a tertiary qualification and therefore did not prepare them for it.

In addition to the exclusion of disabled learners from regular classrooms, the South African schools were also divided along racial lines. In other words, Black and White learners, including those with disabilities, did not attend the same schools (Chataika et al., 2012; Howell, 2005, 2006; Howell & Lazarus, 2003). This division was not unique to the educational milieu, since Black and White people did not occupy the same neighbourhoods, use similar public facilities, and so on. This separation, however, went deeper than a mere physical division of racial groups. This separation reflects the reality of the people of South Africa under the Apartheid regime where Black, Coloured and Indian citizens did not enjoy the same material privileges, safety and rights as did their White compatriots (Howell et al., 2006). The Apartheid system did not start school segregation by race – racial segregation in schools in South Africa and many other countries has a much longer history – but it entrenched and formalised segregationist practices on an unprecedented scale. In short, the Apartheid division imposed inequalities between White and Black citizens, where Black people were treated as subordinate to the privileged White minority. And so, Black children had to learn in educational environments with very few resources, compared to the relatively well-resourced special schools that served White disabled learners (DoE, 1998; Naicker, 2005). Even more disconcerting was the estimation that, in 2001, more than 80 % of disabled learners were not attending any schools (DoE, 2001a). Unsurprisingly, the majority of these learners were Black children from rural areas (FOTIM, 2011; Swart & Pettipher, 2011).

And so, in the light of the failure of the schooling system to reach all children and to adequately prepare learners for further education, it is not surprising that the DoE (1998) found that not many disabled learners accessed higher education.

Moreover, as stated before, the educational system was not the only factor that prevented disabled students from accessing, participating in, and tasting success in higher education. The structure and functioning of universities themselves were often to blame for the limited number of disabled students crossing their borders. In many instances disabled students were not selected for certain academic programmes because they were believed to be incapable of meeting course requirements. In this discriminatory selection, the dominance of medical ideology was evident. In other words, the universities did not adapt to accommodate disabled students in certain programmes, which left the student as the possessor of the “problem” of a disability. Moreover, physical barriers, such as limited access to information, also made some universities unwelcoming environments for disabled students who were there (Howell, 2005, 2006; Howell & Lazarus, 2003). This reflects global trends discussed in the previous chapter.

Furthermore, just like primary and secondary schools, tertiary institutions also served specific racial groups under the Apartheid regime (see also 1.4). For example, SU was a “White university” with a large wealth of resources at its disposal. On the other hand, what has since become CPUT were two separate technical colleges, namely Cape Technikon for White students and Peninsula Technikon for Coloured students. In this sense, Peninsula Technikon, along with all other tertiary institutions for people of colour, was under-resourced in comparison to their White counterparts (FOTIM, 2011; Howell & Lazarus, 2003; Matshedisho, 2007a).

It is thus clear that, before 1994, universities remained out of reach for many disabled students. But the question as to what happened after 1994 still needs to be answered, along with the question whether the educational system changed at all.

4.3 Policy Responses in the Period 1994-2001

The year 1994 marked an important turning point for the previously marginalised citizens of South Africa. This was the first year, after the decades of Apartheid, that everyone over the age of eighteen had the right to vote. Following the democratic elections, the African National Congress (ANC), under the leadership of President Nelson Mandela, was introduced as the new governing party of South Africa. The ANC, comprising mostly previously disadvantaged citizens, took on the liberating yet challenging task of correcting the “wrongs” of the past (Naicker, 2005). Hereby they wished to establish a country where everyone, including disabled people, would be free from discrimination and would enjoy the protection of equal rights for all (Swart & Pettipher, 2011). The new constitution, which was approved in 1996 (South African Government, 1996), was clear: “The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth” (The Constitution of South Africa, 1996, Article 9[3]). Thus, the state formally committed itself not to discriminate against disabled people.

Apart from the protection against discrimination, the new government also emphasised the equal rights of disabled people in their 1997 White Paper on an Integrated National Disability

Strategy (INDS) (Office of the Deputy President (ODP), 1997). Thabo Mbeki, the then deputy president, stated, “This White Paper represents the government’s thinking about what it can contribute to the development of disabled people and to the promotion and protection of their rights. We believe in a partnership with disabled people. Therefore the furtherance of our joint objectives can only be met by the involvement of disabled people themselves” (ODP, 1997, p. 2). So not only were disabled persons’ rights acknowledged, but it was recognised that they should have a voice in matters affecting their lives (Howell, 2005; Matshedisho, 2007b). The INDS furthermore underscored the social model of disability when it stipulated, “The Social Model, therefore, implies that the reconstruction and development of our society involves a recognition of and intention to address the developmental needs of disabled people within a framework of inclusive development (ODP, 1997, p. 11).

It would thus appear that the INDS, along with the principles of the new constitution, laid the groundwork for the inclusion and participation of disabled people in all spheres of life. In this regard, the educational domain was not forgotten. As a baseline, the constitution stipulated that all people, including those with a disability, have the right to education: “Every person shall have the right to basic education and equal access to educational institutions” (South African Government, 1996, p. 16). What manifested form this were policies that were specifically tailored to disabled people in all levels of education.

In 1996, the new government of South Africa appointed the National Commission on Special Education Needs and Training (NCSNET) and the National Committee on Education Support Services (NCESS). They were required to conduct research and, based on their findings, make suggestions on ways to benefit disabled South Africans over the whole spectrum of the educational domain. Their final findings were contained in the 1997 report, “Quality

Education for All: Overcoming barriers to learning" (DoE, 1998). Regarding higher education for disabled people, this report was clear:

> The primary challenge to higher education institutions at present is to actively seek to admit learners with disabilities who have historically been marginalised at this level, providing them with opportunities to receive the education and training required to enter a variety of job markets. Alongside this is the challenge to develop the institution's capacity to address diverse needs and address barriers to learning and development. This includes not only learners with disabilities, but all learners. This requires that adequate enabling mechanisms be put in place to ensure that appropriate curriculum and institutional transformation occurs, and that additional support is provided where needed. (DoE, 1998, p. 126)

The report therefore clearly pinpointed two main challenging aims for the inclusion of disabled students in higher education, namely, (a) to admit more disabled students, and (b) to facilitate their full participation (Howell, 2005, Matshedisho, 2007b). These aims showed the move from the medical understanding of disability towards the inclusive social model perspective that the environment must change to accommodate disabled persons. At least at policy level, the onus thus shifted from the disabled student to institutions for higher education. And so, in response to these challenges, policies were developed to facilitate equal access and participation for disabled students in higher education (Howell, 2005, 2006; Matshedisho, 2007a, 2007b). These policies included: Education White Paper 3 on The Transformation of the Higher Education System (EWP3) (DoE, 1997), the National Plan for Higher Education (NPHE) (DoE, 2001b) and, directly flowing from the NCSNET and NCESS report: Education White Paper 6: Special Needs Education: Building an Inclusive Education and Training System (EWP6) (DoE, 2001a).

In addressing the inclusion of disabled students, these three policies clearly indicated that disabled students should have fair and equal opportunities to access and succeed in higher education (DoE, 1997, 2001b). EWP6, in particular, provided guidelines to meet these goals. These guidelines could be summed up into two main proposed strategies namely, (a) removing all obstacles that hindered access and participation, and (b) strengthening the ability, and capacity of tertiary institutions to respond to the diverse needs of disabled students (Howell, 2005). An example of the latter could be well-planned and cost-effective support services to disabled students through regional collaboration (DoE, 2001a). The NPHE went beyond these aims as it made provision for accountability when it stated, "The Ministry therefore expects institutions to indicate in their institutional plans the strategies and steps they intend taking to increase the enrolment of these categories of learners, including clear targets and time-frames" (DoE, 2001b, p. 28).

A quick note on the schooling system is also necessary, since a greater number of disabled children completing matric could possibly result in more learners accessing higher education (Howell, 2005). With EWP6, the then Minister of Education, Professor Kader Asmal, committed South Africa to an inclusive education system (Naicker, 2005). This entailed a 20 year plan in which time the divided education system had to be transformed into a unified system for all. In other words, he stipulated that regular neighbourhood classrooms should accommodate disabled and nondisabled learners in a welcoming environment where difference would be celebrated and accommodated (DoE, 2001a).

It is therefore clear that the new government post-1994 considered the situation of disabled students in all spheres of the educational landscape. However, while on paper these policies may seem impressive and efficient, the real question is whether it was effectively put into practice. For even the most well thought out policy will lose its power if it is not echoed in the day-to-day lives of disabled students.

4.4 The Experiences of Disabled Students Post-1994

The following section will give an overview of the experiences of disabled students in South African universities after 1994. Four aspects will be discussed namely, (a) general support structures, (b) internal facilitating factors, (c) access to the written word and the role of technology, and (d) interaction with nondisabled persons. While the first two headings pertain to the experiences of students across the entire range of disabilities, the last two sections will shed light on the particular experiences of visually impaired students. I chose to structure this section in this way, because these aspects show how the experiences of these students might differ from students with other disabilities.

4.4.1 General support structures

The sparse literature on the experience of disabled students in tertiary education in South Africa has indicated that the students largely depended on disability units and lecturers for academic support (Crous, 2004b; FOTIM, 2011; Matshedisho, 2010; Naidoo, 2010; Swart & Greyling, 2011). As will be evident from the following section, these experiences were generally not just positive or negative, but rather hinged upon the simultaneous mixed realities of gaps in provision and strides towards inclusion.

4.4.1.1 Disability units

Analysis of the literature shows that South Africa has gained significant ground since 1994 regarding the inclusion of disabled students in higher education. Not only did the number of disabled students increase on these campuses (Howell, 2005), their participation was also facilitated through support services offered by the majority of tertiary institutions (Department of Basic Education (DoBE), 2010; FOTIM, 2011; Matshedisho, 2010). These services, provided by so-called disability units, included the conversion of printed material into Braille and large print, audio-recorded textbooks, the provision of extra time for examinations, computer centres with special software like JAWS for Windows (special screen-reading programme), mobility training, sign language interpreters and many more (FOTIM, 2011; Howell, 2005; Matshedisho, 2010). Apart from this technical assistance, staff of disability units typically also played a mediating role as they had to communicate the needs of disabled students to faculty. They furthermore advocated for these students and helped them with day-to-day challenges on campus (Howell, 2005; Matshedisho, 2010).

The importance of disability units was echoed in the accounts of disabled students, as they commonly believed that disability units played a central role in their inclusion on some tertiary campuses (FOTIM, 2011; Matshedisho, 2010). For example, in the study by Matshedisho (2010), 25% of disabled students said that they felt comfortable and welcome on their first day at university. It is probably no coincidence that these were also the students who had the support of their respective disability units. On the other hand, the 75 % of students who felt uncomfortable on their first day at university reported that they did not have the support of a disability unit. It is evident that, in order to facilitate full inclusion, these units generally provided more than mere academic support, but also helped with the adjustment to university life and, for example, finding a residence (Matshedisho, 2010). Finding new friends and forming a social network was sometimes a fortunate by-product of these units (FOTIM, 2011). This often happened since disabled students spent a considerable time at these units and therefore often met other disabled students there. In short, many disabled students attributed their adjustment to the support of disability units (Matshedisho, 2010).

Encouragingly, the growing recognition of these units as an important vehicle for inclusion has been mirrored in the establishment of HEDSA – Higher Education Disability Services Association; a body that represents disability units in South Africa. HEDSA is concerned with matters around the achievement of equity, diversity and inclusion of disabled students on tertiary campuses and therefore were involved with the Green Paper (DHET, 2012) on post-school education of 2012 (discussed later in this chapter) as well as the expansion of funding for these students. What is more is that HEDSA's board includes two student representatives, which left room for their voices to be heard.

Despite this progress towards the full inclusion of disabled students, disability units were, and still are, restricted in the services they offer. Firstly, they were commonly not autonomous, as they often fell under student counselling or student affairs. They were therefore often unable to develop and implement programmes, since they were bound by the restrictions of their overseeing departments (FOTIM, 2011). The nature of these departments, for example counselling centres, was also problematic since their focus on pathology and rehabilitation may have reinforced the notion of the medical model of disability (Lyner-Cleophas et al., 2014). The disability unit model, paradoxically, also played a role in keeping disability separate from other transformation and diversity issues and therefore out of the mainstream (Department of Higher Education and Training (DHET), 2012, 2013; FOTIM, 2011).

In addition, financial constraints continued to be a very tangible reality for these units, especially for historically Black institutions (DHET, 2012, 2013; FOTIM, 2011; Howell, 2005; Matshedisho, 2007a). For disabled students at the University of KwaZulu-Natal, this meant that disability units did not have enough permanent staff and sufficient equipment to provide for their academic needs (Naidoo, 2010; Sukhraj-Ely, 2008). As a result, their accessible course materials were often delayed, which left them with very little time to prepare for assessments (Naidoo, 2010). Furthermore, the available computers and scanners were often not enough so that all students could work simultaneously, which meant that a lot of time was wasted (Sukhraj-Ely, 2008).

In many instances, disability units therefore had to raise external funds to make the environment more accessible for disabled students (FOTIM, 2011; Howell, 2005; Matshedisho, 2007a). This lack of funding shed light on universities' lack of recognition of the importance of these units for disabled students and reinforced the medical charity view of disability (FOTIM, 2011).

Despite limited funding, some small disability units still go out of their way to make the university a positive experience for disabled students (Howell, 2005; FOTIM, 2011).

4.4.1.2 Lecturers

While disability units could often not provide all the necessary services due to financial limitations, disabled students thought that lecturers' inability to provide accommodations was due to their lack of awareness around disability issues (Crous, 2004a, 2004b; Matshedisho, 2010; Swart & Greyling, 2011). For example, in his study of the experiences of disabled students at three South African universities, Crous (2004b) found that 67.3 % of disabled students believed that their lecturers had limited knowledge of disabilities. Where lecturers thus seemed unhelpful, students often related it to their lack of awareness regarding disability rather than a pure unwillingness to help them (Matshedisho, 2010; Swart & Greyling, 2011). Since the level of awareness differed from lecturer to lecturer, it should come as no surprise that in general there was no consistency across departments. At SU, for example, students in the Humanities and Social Sciences experienced more support and adaptations than students in the Natural and Economic and Business Sciences (Swart & Greyling, 2011).

In some studies, students suggested that lecturers should be trained to work with students with disabilities (Crous, 2004a; Matshedisho, 2010). At some universities there was evidence that showed that some institutions made efforts to raise awareness on disability. At the University of Cape Town, for example, awareness was built into students' medical training. In a study by Amosun, Volmink, and Rosin (2005), medical students were asked to use wheelchairs for a week in an attempt to gain insight into the lives of disabled students. At SU, disabled students themselves were actively involved with advocacy and raising awareness. These students, through the student association body for students with disabilities (Dis-Maties), held an annual "Dinner in the dark" function, in an attempt to make people aware of living with a visual impairment. Yet, it seemed like these efforts at awareness were mostly directed to fellow able-bodied students, rather than making provision for lecturers.

Yet, sometimes lecturers did not provide disabled students with support because they were simply not aware that a disabled student was attending their classes. In the study by Crous (2004b), 63.4% of participating students did not disclose their disability to lecturers. There are various reasons for this. First, students were sometimes under the impression that disability units or the university administration would transfer their information to relevant lecturers. Yet, in many instances this did not happen (Crous, 2004b; Naidoo, 2010) and in instances like these, disabled students had to mediate and communicate with disability units and lecturers (Naidoo, 2010). Other students did not inform their lecturers or the disability unit of their disability because they were afraid of their prejudices and possible discrimination (Crous, 2004a; FOTIM, 2011).

In other instances, lecturers and disability units remained unaware of disabled students on university campuses because disabled students were not aware of the existence of support services (Bell, 2013; Crous, 2004b; FOTIM, 2011). The FOTIM (2011) report, for example, found that students, especially those from mainstream schools, often “stumbled” upon disability services of the university by chance. This suggests that disability units should make a greater effort to market their services and to make it visible for disabled students.

Despite these negative experiences with lecturers, there were also accounts where lecturers went out of their way to accommodate disabled students (Swart & Greyling, 2011). At SU, students reported that friendly, patient and kind lecturers really made a positive difference in their lives.

Worryingly, however, is the underlying thread of the reliance on lecturers and disability units, rather than an acknowledgement of the rights of visually impaired students. Matshedisho (2010) ascribed this focus to the distance between formal and real rights for disabled students in a country, such as South Africa, where human rights were violated for centuries. He goes on arguingwhere political power is still unbalanced and where a country is still plagued by poverty, it is difficult to enforce formal rights. Therefore disabled students are still dependent on the attitudes of individual lecturers and disability support staff.

4.4.2 Internal facilitating factors

Given the gaps in service provision, largely as a result of financial constraints and limited awareness, students sometimes had to take some initiative in negotiating their environment (Naidoo, 2010; Swart & Greyling, 2011). In the study by Naidoo (2010), students frequently served as the intermediary between the disability unit and lecturer – communicating their needs to both these important role-players. At SU, students commonly believed that they had to take some responsibility for their inclusion and success on campus. For them, factors like self-advocacy, disclosure assertiveness and problem-solving were important skills for success (Swart & Greyling, 2011).

However, as seen in Chapter 3, this might imply that students who did not have these skills and/or had more reserved personalities, had a lesser chance of being included on tertiary campuses. Furthermore, Lyner-Cleophas et al. (2014) warned that the ability of some students to develop effective coping mechanisms should not be used to stall governmental and institutional processes towards inclusivity. When effective policies and practices are implemented, disabled students would not have to face the rather unfair task of becoming superheroes in their effort to juggle usual academic work alongside disability-related challenges (Chataika, 2010).

4.4.3 Access to the written word and technology

The few studies that have been conducted on the experiences of visually impaired students in South Africa show that they have very similar challenges to the disabled population at large. Like students with other disabilities, they also face social difficulties and have to confront academic barriers. Yet, probably the most prominent difference between the learning needs of visually impaired students compared to students with other disabilities, is their challenge to access the written word.

As described in Chapter 3, Information and Communication Technology has, in many ways, made it easier for visually impaired students to access written material (Mokiwa & Phasha, 2012; Ngubane-Mokiwa, 2013). The software, JAWS for Windows, made it possible for blind students to work on computers, to read electronic books and to browse the Internet. Similarly, students with partial sight use the programme, Zoomtext, to magnify any electronic information on a computer (Crous, 2004b; FOTIM, 2011; Mokiwa & Phasha, 2012; Ngubane-Mokiwa, 2013; Seyama, 2009; Sukhraj-Ely, 2008). As seen before, disability units were often responsible for the conversion of these texts into an electronic format (Sukhraj-Ely, 2008).

Although these technological advances were, and still are, a positive way of enhancing access to written material for visually impaired students, it could also, paradoxically, hinder accessibility. The first two factors were briefly mentioned in this chapter. These were: the late conversion of texts; and limited availability of resources. Often, visually impaired students received their course material late, due to the time-consuming nature of conversion, compounded by the few staff at disability units (Ngubane-Mokiwa, 2013; Seyama, 2009). So, whereas sighted students received their materials immediately, visually impaired students had to wait for the conversion of their materials, yet they were still expected to submit assignments at the same time as their sighted peers (Crous, 2004b; Seyama, 2009). A participant in the study by Seyama (2009) captured the domino effect of this dilemma in the following way, "unfortunately one was expected to submit on the same date as the sighted students . . . extension of time for submission was the only option for us, but then it meant putting up with a backlog as the assignments are not from one module" (p. 55). Having said this, the FOTIM report (FOTIM, 2011) suggested that there might have been other reasons for this delayed access to course material. In this report, staff from disability units stated that, at times, visually impaired students failed to bring their printed material to the disability unit on time. For example, they might only bring a textbook to be scanned one week before a test.

A further factor that hindered access to the written word was the fact that some visually impaired students were not familiar with assistive technology and therefore did not know how to use it (Sukhraj-Ely, 2008). This was especially true for students who had attended a mainstream school (FOTIM, 2011). As seen in 1.4, the disability unit at CPUT made provision for this potential problem, through the provision of a training course on technology and assistive technology for first year students.

Moreover, at times, assistive software like JAWS for Windows, was incompatible with the electronic format of the text. For example, JAWS could not read mathematical and scientific signs or graphic material (Mokiwa & Phasha, 2012; Ngubane-Mokiwa, 2013). In the study by Mokiwa and Phasha (2012), a participant described it as follows, “The words were seen as individual letters and not as any conceivable word within the English language. The other document was seen as a picture by my screen reader and as such I had no choice but to have the invigilator read the paper to me” (p. 145). In this last quote, the loss of independence when technology was ineffective, is evident. However, it sometimes went further than a mere loss of independence. Some students in distance education did not finish their examinations because their screen-readers could not read certain text styles (Mokiwa & Phasha, 2012).

Lastly, as seen in Chapter3, technology was generally experienced as a barrier when it was used by lecturers in their classrooms. For example, lecturers often used power point presentations or other visual aids in their lectures; forgetting that visually impaired students could not see them (Seyama, 2009; Sukhraj-Ely, 2008). As one participant in the study by Seyama (2009) said, “some lecturers forgot that some of us could not see, they kept on saying as you can see this and that, pointing at something, maybe a chart . . . one felt lost and definitely not benefiting anything” (p. 56).

It is therefore evident that in South Africa, as is the case across the world, technology enhanced access to the written word for visually impaired students. Yet, technology also disadvantaged and, at times, excluded visually impaired students in various ways.

4.4.4 Interaction with nondisabled persons

The three studies on the social experiences of visually impaired students in South Africa revealed very disturbing findings. These investigations, conducted at the University of South

Africa (UNISA) by Ngubane-Mokiwa (2013) and at the University of KwaZulu-Natal by Kasiram and Subrayen (2013) and Sukhraj-Ely (2008), were layered with accounts of bullying, prejudicial beliefs and sexual exploitation. Worryingly, no positive relationships were reported in these studies.

4.4.4.1 Perceptions of others

Studies showed that the attitudes towards visually impaired students primarily centred on perceptions of incapability (Sukhraj-Ely, 2008). In particular, they experienced that others, peers and lecturers, sometimes thought that they were incapable of pursuing a tertiary qualification. For example, in the study by Ngubane-Mokiwa (2013) one participant spoke of this prejudicial belief and its emotional effects on her, “The first day I went to university for registration the security guards blocked me in the gate and they said that I am not supposed to be there. One said, ‘This is not a place for people like you’. That statement does not leave my memory. It keeps flashing and it hurts” (p. 200). Furthermore, lecturers and peers sometimes did not value their contributions in class. As one person overheard someone saying, “she is blind, let’s ask her a stupid question,” (Kasiram & Subrayen, 2013, p. 69). Another example could be found in a person recalling that her lecturer told her, “I do not believe you wrote this . . . there is no blind person who can type . . . who typed this assignment for you?” (Ngubane-Mokiwa, 2013, p. 201). Since visually impaired students were viewed as inferior, helpless and incapable, it is no wonder that peers were often over helpful towards them (Sukhraj-Ely, 2008).

These perceptions of incapability often had very real consequences for the students, especially regarding their future. Firstly, they were denied places on certain courses, because of the belief that they would not have been able to meet the course requirements and/or that they would not have been able to follow their chosen career path (Kasiram & Subrayen, 2013;

Ngubane-Mokiwa, 2013). An example of this, cited by both Kasiram and Subrayen (2013) and Ngubane-Mokiwa (2013), was when students wanted to study social work. They were told that, because they were unable to travel or read body language, they would not be able to pursue this career path. In these perceptions, there was no acknowledgement that visually impaired students could sense emotions through other means and that they could make their own arrangements for travelling. In this way, the possibility of agency and initiative of visually impaired students were overlooked.

Similar results were found in the study by Mayat and Amosun (2011). They observed that disabled students in South Africa were still excluded from certain academic fields like engineering and science. They therefore conducted a study through which they explored the perceptions of five lecturers in these course programmes. Even though the five participating staff members expressed willingness to teach disabled students, they clearly showed some reservations. Their initial thoughts centred around the perceived limitations of these students as they expressed concern that these students would not be able to meet all the course requirements. One lecturer even wondered whether these students would not be an embarrassment to their able-bodied peers. This study therefore showed the entrenched nature of medical model thinking, as lecturers saw the disability as the problem, rather than thinking of strategies to adapt the course. These discriminatory attitudes were neatly summarised by a participant in the study by Howell (2005), when she said,

> An interesting issue for me is the refusal of academically sound students for courses that they qualify for, on the basis of disability. Disability is the only category of people who get refused entrance to courses who would academically qualify, which to me makes them an interesting category of people. (p. 37)

Then, when finally they were applying for employment, the perception of incapability followed them, “Prospective employers believe that due to having a disability, the brain does not function so how can you achieve” (Kasiram & Subrayen, 2013, p. 70). It should therefore come as no surprise that some students did not declare their visual impairment on the university’s application and/or registration form (Ngubane-Mokiwa, 2013; Seyama, 2009).

At times, it seemed that the negative perceptions towards disabled students and the consequent narrowed career paths were exacerbated by their race. As one participant in the study by Ngubane-Mokiwa (2013) proclaimed,

> They said a blind person cannot do Maths and Science. When we reasoned with them that the blind white learners were allowed in their school for the blind to do Maths and Science, they said we should remember that we are black. That was the most painful experience for me; we had to stop doing Biology. (p. 196)

It is therefore clear that a medical model view of disability is still reflected in the perceptions of incapability directed towards visually impaired students. As seen from this section, this view is not only a perception, but it often holds real consequences for visually impaired persons. It may narrow their options and, as a result, keep them at the margins of society. Furthermore, it threatens the full inclusion of students in higher education and, even more disconcertedly, it may jeopardise their emotional well-being. This exclusion and its psycho-emotional effects, is reflected in the following quote, “For the past 44 years, my disability followed me every day. I am an outsider at home and feel like hanging myself” (Kasiram & Subrayen, 2013, p. 68).

In some extreme instances, the attitudes towards visually impaired students resulted in emotional, physical and sexual abuse.

4.4.4.2 Abuse

Disturbingly, in the study by Kasiram and Subrayen (2013), visually impaired students recounted instances of physical, emotional and sexual abuse. For example, some students said that they were frequently insulted and assaulted by family and peers. In residence, peers sometimes abused their power by insisting on payment when they helped visually impaired students. Even more disturbingly, was the fact that some visually impaired women felt powerless against sexual abuse.

It is thus clear how negative attitudes towards disability may have very real consequences for someone with an impairment.

4.5 Where We Are Now and the Way Forward

In 4.3, we saw that the "Quality Education For All" report of 1997 identified two aims for the inclusion of disabled students in higher education. These aims were directed towards equal and increased access and participation for these students on tertiary campuses. Now, in the light of the experiences of disabled students, we can review the progress since the release of this report.

4.5.1 Participation

Despite strong policies and the positive strides towards supportive structures for disabled students, their experiences revealed that practices did not change overnight. In some important ways, some students are still excluded from full participation in all spheres of campus life (Chataika, 2007; DHET, 2012, 2013; DoBE, 2010; FOTIM, 2011). In part, this slow move towards inclusion could be ascribed to the initial focus on the inclusion of other previously marginal groups, such as racial groups and women (Chataika, 2007; FOTIM, 2011; Howell, 2005, 2006; Howell & Lazarus, 2003; Matshedisho, 2007b; Morrison, Brand, & Cilliers, 2009).

It seems that the DHET, in their Green Paper (DHET, 2012) and White Paper (DHET, 2013) on post-school education and training, identified the gaps in provision very accurately. I will highlight the two most important issues here, namely, funding and awareness.

Firstly, the DHET recognised the lack of funding for disability units, particularly at previously Black institutions. Apart from being the result of the Apartheid regime, they stated that this problem was a result of the way in which institutions were funded. In the past, the state did not provide subsidies for disability grants; disability units had to raise funds from external sources. But, in the Green Paper of 2012, the DHET (DHET, 2012) responded to this issue. In this paper they made a commitment to determine the financial needs of various disability units and, hereafter, to allocate resources based on the needs of each unit. In their White Paper of 2013 (DHET, 2013) it became clear that this commitment was not empty. In fact, the DHET provided funding for infrastructure audits at each of the 23 universities and allocated R130 million to improve accessibility on campuses. The amount that was allocated to each university depended on whether disability was a priority for that university and whether they had the capacity to address disability. While this plan seems sufficient and effective, it is not clear what is meant by "capacity". In other words, what would make a university not eligible for funding due to capacity? And would this criterion not serve to exclude some previously disadvantaged universities?

The second issue that was prominent from the experiences of disabled students, was the lack of awareness regarding disability. Once again, the DHET did not overlook this problem. In their Green Paper (DHET, 2012) they stipulated that, through the teaching of accessible teaching methodologies, disability awareness will be enhanced for lecturers and able-bodied students. In the subsequent White Paper, disability awareness was not directly addressed, but rather full integration of disabled students was addressed through the aim to develop a strategic policy framework.

In their White Paper (DHET, 2013) the DHET identified the need for a strategic policy framework. Such a policy, they argued, would provide clear guidelines for universities on how to improve the access and success of disabled students on their campuses. This framework would require that all institutions develop clear plans to address disability within their contexts. It furthermore would attempt to define and give guidelines on “reasonable accommodations” for disabled staff and students. Lastly, they aim to provide standards and norms for the inclusion of disabled staff and students in all spheres of campus life, including academic, sport and culture. It thus appears that this framework will serve as a benchmark against which universities would be able to measure their standards regarding the inclusion of disabled students. It would also ensure a less fragmented and a more integrated approach across universities.

It is thus clear, in the light of the current literature on the experiences of disabled students, that the DHET pinpointed gaps in provision quite correctly. However, since the FOTIM report of 2011 (FOTIM, 2011) also found minimal involvement of disabled students in the functioning of disability units, the DHET could also take this into consideration in their strategic policy framework. For example, they could suggest a disabled student representative for each disability unit.

4.5.2 Access

Despite a growing number of disabled students in higher education, equitable access has not yet been obtained. In 2011, across 22 of the 23 public universities, only 1% of the entire student population was disabled (FOTIM, 2011). This proportion showed that, in 2011, many disabled students of school-leaving age were still not enrolled for tertiary programmes. In fact, in 2010 and 2011, only 47% and 55% of the DHET allocated funds for disabled students were used (DHET, 2013). So, in spite of available funding for their studies, many disabled students still did not pursue a tertiary qualification.

These figures could largely be ascribed to the exclusionary practices within schools that largely remained unchanged after 1994. In 2010, the DoBE (DoBE, 2010) stated that, of the two billion rand that was initially allocated to expand inclusive education, more than 50% was utilised for other priority areas. As a consequence, regular schools continued to refer disabled learners to special schools, without any legal implications. As seen before, these special schools commonly upheld a medicalised view of disability and thus did not prepare learners for life beyond its borders (Howell, 2005, 2006). What is more, access to basic education post-1994 was still not guaranteed for disabled learners. Although the constitution made it clear that all children had the right to basic education, statistics painted a different picture (DHET, 2013). In 2007, 44 847 children between the age of 7 and 18 still did not attend schools, because they were disabled (DHET, 2012). These continued practices in schools were problematic, since primary and secondary education is an indispensable channel towards higher education.

In 2010, the DoBE (DoBE, 2010) restated their commitment to increase the number of disabled learners in schools where they could receive quality education and support. In this regard, they particularly targeted children from poor and rural communities. They stipulated that special schools should only serve children with “high needs”. Steps have already been taken to improve the infrastructure and service delivery within special schools. For example, funding, more than 20 million rand, has been allocated for assistive devices for disabled children, such as laptops and wheelchairs.

It is thus hoped that, through the increased access to schools, the number of disabled students will increase on the terrain of higher education.

4.6 Conclusion

South Africa has clearly come a long way in the inclusion of disabled students since 1994. The establishment of disability units, in particular, served to better the lives of these students on the tertiary terrain. However, despite policy aims for equal access and participation, the voices of disabled students told a different story. In many regards, they felt alienated as lecturers and peers were not informed regarding disability. Furthermore, support was often delayed and inadequate due to budget constraints.

Fortunately, these gaps in provision have not been overlooked. In fact, as we have seen in the previous section, the DHET already took steps to promote and ensure inclusion for disabled students and learners.

So, although South Africa clearly still has a long way to go in terms of the inclusion of disabled students in higher education, this fact is recognised by important governing bodies. Furthermore, steps are currently being taken to put policy into practice.

CHAPTER 5

METHODOLOGY

5.1 Research Design

For this study, I chose the interpretative phenomenological approach (IPA), because of its perfect fit with phenomenology and the accounts of lived experience. IPA, as developed by Jonathan Smith (1996), has its origins in three approaches. These are phenomenology, hermeneutics (interpretation) and ideography (Smith, 2011; Smith et al., 2009).

Phenomenology is interested in the unique day-to-day lives and experiences of individuals (Carel, 2011; Creswell, 2007; Larkin, Watts, & Clifton, 2006; Yin, 2011) (see Chapter 2, section 2.4). Due to it being impossible to leap out of ourselves and see the world purely objectively, phenomenology extends the mere account of experiences (Merleau-Ponty, 1962). It also includes our interpretation of, and the meanings we attach to, our own experiences (Smith, 2011; Smith et al., 2009). In short, phenomenology is concerned with the way people make sense of their experiential worlds.

Just like the participants, researchers also see the world through their own eyes. They therefore see the experiences of participants through the "lens" of their own interpretations (Brocki & Wearden, 2006; Palmer, Larkin, de Visser, & Fadden, 2010; Smith, 2011; Smith, Jarman, & Osborn, 1999; Smith et al., 2009). This interpretation often entails drawing on the context of the participants and trying to understand their lifeworlds by conceptualising them within a theoretical framework (Larkin et al., 2006; Smith, 2004; Smith & Osborn, 2003). It is therefore commonly a speculative process, whereby the researcher thinks and conceptualises what the experiences of participants mean and how they are experienced by them (Larkin et al., 2006). Smith (2011) described this process of IPA as, "engaging in a double hermeneutic, whereby the researcher is trying to make sense of the participant trying to make sense of what is happening to them" (p. 9). IPA therefore contends that research outputs are a combined product of the analyst and the participants. Of course the main concern of the analyst is the lived experience of the participants, but the analysis will always be suffused with how the analyst thinks the participant is thinking (Smith et al., 2009).

In this sense-making process, IPA researchers also employ the ideographic stance. This means paying close attention to detail (for example, examining a single case), as well as generalising these particularities across various cases (for example, in finding themes) (Brocki & Wearden, 2006; De Visser & Smith, 2006; Smith, 1999; Smith et al., 2009) (see 5.5 for a detailed explanation). For IPA researchers, it is thus important to see the smallest piece of the puzzle, while simultaneously having a panoramic view of the entire picture.

In short, through the lens of IPA, I aimed to provide readers with a full, clear, close-up perspective, instead of a distant, panoramic view of the students' experiences. Hence, it is hoped that readers of this dissertation will be transported into the lifeworlds of the students; feeling as if they are walking in their shoes. It is furthermore hoped that readers, while engaging with this text, will be able to exit their own taken-for-granted, intuitively given lifeworlds and enter the often marginal taken-for-granted lifeworlds of students with a visual impairment. In gaining such an insider's perspective, able-bodied and other disabled individuals might gain an understanding of these students; making the lifeworlds of the students clear and inviting these lifeworlds into the mainstream, common-sense world of able-bodiedness.

5.2 My Taken-for-granted View on the Research

As IPA suggests, the search for knowledge is inextricably tied to our position in and view of the world (Heidegger, 1962; Merleau-Ponty, 1962). Therefore, researchers cannot help but to bring their preconceptions, for example, their prior experiences, ideas and assumptions, to the phenomena they investigate (Smith et al., 2009) (see also Chapter 1, section 1.1). Similarly, it would be naive to deny that I brought my experiences and beliefs to this investigation. After all, there was a lot of overlap between my world and that of the participants. Just as they do, I have a visual impairment and, just as they do, I am currently studying. It can almost be said that I had “too much” of an insider’s perspective, threatening to cloud my objectivity. My perspective, shaped by my own experiences and ideas, might have prevented me from divorcing my reality from those experiences of the participants. The danger thus existed that I might have shaped the realities of participants, both during the interview process and during the interpretation of the stories, through the lens of my subjective world. Thus, I needed to employ strategies to “bracket” my experiences and ideas.

Even though Merleau-Ponty and Heidegger believed that the fore-structure is always there, Edmund Husserl stipulated that, through bracketing, we can at least attempt to keep these preconceived ideas to a minimum. According to Husserl (1927), bracketing means putting to one side the world that I take for granted, in order to clearly see my perception of that world. If I take my eyes off the objects in my world and direct my gaze inwards; reflecting on my perceptions of these objects, I could be said to have gained the phenomenological attitude. Thereby, I would become aware of my preconceptions of being a student with a visual impairment within a tertiary setting, without making my taken-for-granted world disappear.

Although I also believe that one can never fully separate new stimuli from personal preconceptions, I aspired to bracket my preconceived, taken-for-granted lifeworld and approach the research with the phenomenological attitude to the best of my ability. In this pursuit, I had many strategies helping me to achieve and maintain this attitude.

Firstly, I am a counselling psychologist. During my training and my professional career, I have learned the important therapeutic skill of listening with empathy. Empathic listening entails putting one's own preconceptions aside and engaging sensitively and primarily with the client's lifeworld. I believe that this skill has been central in assisting me to bracket my preconceived ideas. The second strategy formed an integral part of the procedural phase of this research (refer to 5.4 for a detailed description). Following all interviews, I presented the research findings to the participants, in order to ensure that I had "heard" their stories accurately.

While the first two strategies ensured a greater degree of objectivity during the interview process, the third strategy was an attempt to safeguard the interpretation phase against my fore-structures. Prior to the general thematic analysis, I analysed each individual interview separately (see 5.4). Husserl (1927) also referred to this strategy and called it "the method of reduction". He stipulated that, through reduction, we should examine the descriptions and reflections upon each small particularity of a phenomenon. For him, each reduction provides a different perspective on the phenomenon at hand. Most importantly, Husserl postulated that reductions will lead a researcher away from the distractions of their own preconceptions and assumptions, and lead them back to the essence of their experience of a given phenomenon. I thus hoped that my own subjectivity would be kept to the minimum through attention to the smallest details of the participants' lives.

Fourth, I tried bracketing my experiences through self-reflection. Reflexivity refers to the ongoing critical reflection on oneself as researcher and the acknowledgement and exploitation of one's subjective reality (Smith, 2006) (see also 5.6). Lastly, supervision also assisted in helping me to acknowledge my pre-conceptions, and therefore consciously attempting to keep them from influencing the research findings unduly.

In summary, Smith (2007) captured these encounters with research participants beautifully when he explained the concept of the hermeneutic circle. In the following extended extract, he wrote,

> I start where I am at one point on the circle, caught up in my concerns, influenced by my preconceptions, shaped by my experience and expertise. In moving from this position, I attempt to either bracket, or at least acknowledge my preconceptions, before I go round to an encounter with a research participant at the other side of the circle. Whatever my previous concerns or positions, I have moved from a point where I am the focus, to one where the participant is the focus as I attend closely to the participant’s story, facilitate the participant uncovering his/her experience. This requires an intense attentiveness to, and engagement with, the participant as he/she speaks. . . . Having concluded the conversation, I continue the journey round the circle, back to where I started. So I return home to analyze the material I collected from the perspective I started from, influenced by my prior conceptions and experience. However, I am also irretrievably changed because of the encounter with the new, my participant and her/his account. Then I engage in movement round a virtual mini-circle where, in my home location, I mentally take on again a conversation with my participant, as I rehear his/her story, ask questions of it, try to make sense of it. Indeed the various actions inherent in the hermeneutic circle between part and whole . . . take place in this cognitive space at home base. (Smith, 2007, p. 6)

5.3 Participants and Sampling

5.3.1 Finding participants

IPA researchers typically use purposive sampling in the recruitment and selection of their participants (Smith & Osborn, 2003). In this vein, I invited students to participate in this study through a purposive sampling technique. This meant that a clear outline of my target population informed the inclusion criteria for potential participants (Babbie & Mouton, 2001; Silverman, 2013). I invited all participants that fitted the following inclusion criteria:

- They had to be students at SU or CPUT.
- They had to have a visual disability.
- They had to be able to understand and speak Afrikaans or English.

The only exclusion criterion was that they should not have any major disabilities other than their visual impairment.

The recruitment process differed slightly between the two universities. At CPUT, I obtained a list of the students with a visual impairment from the head of the disability unit, Dr. Nina du Toit. Thereafter, I contacted all prospective participants telephonically, inviting them to participate in the current study. At SU, contacting the prospective participants directly was prohibited by the ethics committee at the university. Therefore, I e-mailed the invitation letter (see Appendix A) to the appropriate subdivision of the Centre for Student Counselling and Development, namely the Office for Students with Special Learning Needs/Disabilities. Upon receipt of this, Mrs. Marcia Lyner-Cleophas, head of the office, kindly distributed the invitation letter (see Appendix A) and the informed consent form (see Appendix B) to students with a visual impairment. Having received the invitation, the prospective participants had the option of responding to her e-mail or contacting me directly. Apart from being an ethical requirement of the university, I believe that this stipulation was especially useful since I knew some of the prospective participants prior to this study. I believe that as I did not contact them directly, they would probably be more comfortable to refuse to participate in the study should they wish to.

5.3.2 Participant information

The task of this section is to analyse the demographic information of the participants and to draw possible inferences from it. For this purpose, I looked at the students who participated in this study. I also obtained information on the demographic information of those students who did not participate in this research. For a more concise lay-out of these demographic details, refer to Table 5.1 and Table 5.2.

Table 5.1 provides a concise lay-out of the demographic information of research participants. It shows pseudonyms of participants, their sex, age, race, language, visual category, onset of disability, tertiary affiliation and academic level and category.

To protect the privacy of participants, I masked their identities with the use of pseudonyms and by clustering their academic courses into categories. In other words, I did not disclose their academic course or year, since this might have compromised the confidentiality of the study. Their level of study is indicated by only disclosing whether they are at under- or post-graduate level. Academic courses were clustered into six overarching categories:

- Art and culture (BA Humanities and BA Language and Culture).
- Helping professions (BA Law, B. Education and BA Social Work).
- Creative art (music and fashion design).
- Public relations (marketing, tourism and public management).
- Numeracy (accounting and socio-informatics).

- Other (chemical engineering, computer science and sport science).

In order to be concise, abbreviations will be used throughout the Table (refer to list of abbreviations

Table 5.1

Demographic Information of Participants

Pseudonym	Sex	Age	Race	Lang	VI	Onset	Institution	Course category	Year	School
Zandile	M	21	B	X	PS	Birth	CPUT	Public relations	UG	SS
Xavier	M	24	B	X	PS	Birth	CPUT	Public relations	UG	SS
Ryan	M	22	B	X	PS	17	CPUT	Public relations	UG	MS
Bongani	M	28	B	O	PS	27	CPUT	Public relations	UG	MS
Nandi	F	23	B	X	PS	Birth	CPUT	Numeracy	UG	MS
Ginny	F	23	B	X	PS	16	CPUT	Other	UG	MS
Queenie	F	26	B	X	PS	Birth	CPUT	Helping professions	UG	MS
Yolandie	F	23	W	A	PS	Birth	CPUT	Creative art	UG	MS
Vicky	F	27	C	A	PS	2	SU	Helping professions	UG	MS
Denise	F	25	W	A	PS	Birth	SU	Helping professions	UG	MS
Tracey	F	23	W	A	PS	Birth	SU	Art and culture	UG	SS
Ashley	F	23	W	A	PS	Birth	SU	Helping professions	UG	SS
Emma	F	22	W	A	PS	16	SU	Numeracy	UG	MS
Frank	M	21	W	E	PS	Birth	SU	Other	UG	SS
John	M	29	W	A	PS	Birth	SU	Creative art	PG	MS
Lisa	F	25	W	A	BL	Birth	SU	Creative art	PG	SS
Haily	F	22	W	A	BL	Birth	SU	Art and culture	UG	SS
Sue	F	20	W	A	BL	12	SU	Art and culture	UG	SS
Mia	F	20	W	A	BL	Birth	SU	Art and culture	UG	SS
Ilse-Marie	F	19	W	E	BL	Birth	SU	Art and culture	UG	SS
Carla	F	28	W	A	BL	Birth	SU	Art and culture	UG	SS
Petro	F	34	C	E	BL	24		Art and culture	UG	MS
William	M	23	W	A	BL	Birth		Other	UG	SS

Note: Sex= Female (F) and Male (M); Language= Afrikaans (A), English (E), Xhosa (X), other (O); Race= Black (B), White (W), Coloured (C); Visual category= Visual impairment (VI), blindness (Bl), partial sight (PS); Year= Under-graduate (UG), post-graduate (PG); School: Mainstream (MS), special school (SS); Institution = (CPUT), Stellenbosch University (SU)

Table 5.2 provides an outline of the participation rate of the research participants in each interview. For example, it indicates which students participated in one, two or three interviews. Simply put, it shows whether a student participated in interview 1, whether that individual came for a follow-up interview and whether he/she went on to the focus group interview.

Table 5.2

Participation and Retention Rate

Pseudonym	Institution	I1	I2	F1	F2	F3	F4
Zandile	CPUT	Y	N				
Xavier	CPUT	Y	N				
Ryan	CPUT	Y	N			Y	
Bongani	CPUT	Y	Y			Y	
Nandi	CPUT	Y	Y				
Ginny	CPUT	Y	Y				
Queenie	CPUT	Y	N				
Yolandie	CPUT	Y	N				Y
Vicky	SU	Y	Y		Y		
Denise	SU	Y	N				
Tracey	SU	Y	Y				
Ashley	SU	Y	Y				
Emma	SU	Y	Y		Y		
Frank	SU	Y	N				
John	SU	Y	Y				
Lisa	SU	Y	Y	Y			
Haily	SU	Y	Y		Y		
Sue	SU	Y	Y		Y		
Mia	SU	Y	Y	Y			
Ilse-Marie	SU	Y	Y		Y		
Carla	SU	Y	Y	Y			
Petro	SU	Y	Y	Y			
William	SU	Y	Y		Y		

Note: I1 = individual interview 1, I2 = individual interview 2 and F = referring to focus group interview with its corresponding number; Y = Yes, N = No; Participants could have participated in both individual interviews, but they were assigned to only one focus group session; Institution = (CPUT), Stellenbosch University (SU)

5.3.2.1 Number of participants

Twenty three students volunteered to participate in this study. This is in agreement with Polkinghorne (1989) who recommended interviewing 5 to 25 individuals who have all experienced the phenomenon under study. The 23 students comprised eight from CPUT and 15 from SU. At face value it may seem that fewer students from CPUT participated, yet at SU, less than a quarter of the students known to have a visual impairment volunteered to participate (15/63), while almost half of those at CPUT were willing to be interviewed (8/19).

Various reasons could explain the higher participation percentage from CPUT. I hypothesise that, firstly, a larger percentage of students from CPUT took part in the study because I contacted them directly. Various studies have highlighted the benefits for recruitment rates of direct contact with prospective participants. For example, Simpson et al. (2005) and Wong et al. (2013) found that telephonic follow-up yielded better results for participation compared to recruitment invitations through mail. Individuals who did not agree to participate in these studies when contacted by mail, were more likely to agree to participate in studies following telephonic contact.

Secondly, the majority of students at SU who did not volunteer to participate had partial sight. In Chapter 7, I will discuss how students with partial sight often want to hide their mostly invisible disability. The fact that all the students from CPUT were partially sighted, yet still agreed to the interview process, could be explained in terms of the recruitment process. Since I contacted them directly, they may have realised that I was already aware of their disability, thus there was no reason for them to hide it. However, at SU, potential participants were contacted via the Centre for Student Counselling and development; hence they might have thought that, by not responding, their disability might remain concealed to me.

5.3.2.2 Visual category of participants

5.3.2.2.1 Definition and category

The legal definition of blindness in the USA refers to best corrected visual acuity 20/200 (6/60) or less in the better eye with limited field vision. The vision field's widest diameter has a maximum angular distance of 20 degrees (Jernigan, 2005). This means that individuals who see less than 20/200 are unable to discern any letters below the (E) at the top of an eye chart (Watt, 2003). The visual ability of individuals who see less than 20/400 is measured through their ability to perceive light, to count fingers or to detect hand movements at a certain distance (Watt, 2003).

Jernigan (2005) contends for a more functional, instead of the medical, definition of blindness. He suggests that individuals are blind in so far as they have to employ alternate techniques to perform the tasks fully-sighted individuals are typically able to complete. If the lives of individuals are significantly changed through the use of such alternate techniques, they can be considered blind. In his definition of blindness, Kruger (1988) largely focused on alternate techniques to discern between various levels of visual disability. He distinguished between total blindness, severe visual impairment and partial sight. The totally blind individual will have no visual perception. Braille is typically the medium of instruction for the written word, and physical assistance is required from others to a lesser or greater extent. Nowadays, a screen-reading programme makes it possible for totally blind persons to access the electronic written word. In his second category, Kruger defines visual impairment as ranging from only the ability to distinguish between dark and light to the ability to read large print through electronic devices. Individuals with visual impairments usually read Braille and rely on their sight for mobility only. Lastly, partial sight refers to individuals who are able to read ink print and who are largely independent.

In this study, visual ability was grouped into two broad categories, namely blind and partially sighted students. Blind students referred to those students who use Braille or audio assistance for reading and who use assistance to walk independently, for example, with a cane or a guide dog. Partially sighted students referred to those individuals who read large print and who use no assistance while walking.

5.3.2.2.2 Participation

Fifteen students were partially sighted while eight were blind. Interestingly, all participants from CPUT were partially sighted - even those who did not agree to participate. At the time of the interviews, there were thus no blind students at CPUT. This can be ascribed to the technical and hence visually inaccessible courses at CPUT (personal communication, Dr N. du Toit, April 25, 2012). Dr du Toit furthermore recounted that blind students are often ill-prepared by secondary schooling and therefore fail to adhere to the minimum admission requirements. (As will be evident in Chapter 6, only two out of the eight students from CPUT attended a special school for the blind).

At SU, the percentage of blind students who participated was much higher than that of the students with partial sight. Almost one half of the blind students volunteered participation (8/19), while just over a sixth of the students with partial sight agreed to take part in the interview process (7/44). Once again this could be ascribed to students with partial sight electing to hide their disability (see Chapter 7).

5.3.2.3 Race of participants

Noteworthy was the racial distribution of the students. Taken together, the majority of the participants were White (14), followed by seven Black and two Coloured students. Thirteen of the White and both of the Coloured students were studying at SU, while all seven of the Black students were studying at CPUT.

If we look at these institutions in relation to race, a definite skewed distribution is still evident. This supports the notion that there still might exist racial divide between previously privileged White and previously disadvantaged Black and Coloured institutions. For example, in Section 1.4, I mentioned that, during the Apartheid regime, racial divide was prominent within higher education settings. In particular, SU was predominantly White, while the Peninsula campus of CPUT mostly had Coloured students. Apart from the specific participants, the overall statistics of the students with a visual impairment also confirms this hypothesis. At the time of the interviews, there were 16 Black and three White students with a visual impairment enrolled at CPUT. At SU, on the other hand, 48 of the students with a visual impairment were White, 12 were Coloured and three were Black. These figures roughly reflect the ongoing racial profile at the institutions, but with an over-representation of White students with visual impairment at SU, for historical reasons mentioned earlier.

The majority of visually impaired Coloured students were partially sighted (2/12). As mentioned before, SU students with partial sight were less likely to participate in this study, since (a) they might have wanted to hide their disability and, (b) I did not contact them directly. Hence, this could explain the very few Coloured students that participated in this study.

5.3.2.4 Language of the participants

Directly related to the racial distribution and divide mentioned above, was the home language of the students. However, as stipulated by the inclusion criteria of the current investigation, all the participants could talk and understand English (even if it was their second language). If

English was not a participant's home language, I frequently reflected their narrative back to them in order to confirm that I understood them correctly. I also did not hesitate to ask for clarification when I felt uncertain whether I understood them. I also encouraged them to ask me for clarification whenever they could not understand me. Furthermore, as will be discussed in the following section, following the interviews I went back to the participants to ensure that I understood their stories (unfortunately, very few of the CPUT students attended this session). I therefore employed various strategies in an attempt to bridge the possible language barrier.

Although some people might argue for the use of an interpreter in a study like this, I decided against it. I believe that it might have compromised the rapport and trust I wanted to establish between me and the interviewees. The presence of a third party in the rather personal interview might have resulted in an alliance between two of the parties (Swartz, 1998). As Swartz (1998) pointed out, an interpreter might have developed an alliance with me as interviewer, but, on the other hand, an alliance was also possible between the interpreter and the interviewee, since they share the same language and most likely similar social backgrounds. It is a reality that there are very few trained research interpreters in South Africa able to converse in indigenous languages apart from Afrikaans, and the use of an untrained interpreter is associated with a range of potential difficulties (Swartz, in press).

5.3.2.5 Gender of the participants

Almost two thirds of the participants were women (16), while only seven men agreed to be interviewed.

The lower participation rates amongst men is not a novel occurrence. Oliffe and Thorne (2007), for example, found it is more difficult to recruit men to participate in health studies than their female counterparts. This also happens in my work as a psychologist. I work for a community-based organisation, Good Hope Psychological Service. For the last six months of 2013, I saw eight male and 28 female clients. In other words, men constitute less than 25 % of my clientele, despite the national data for mental disorder showing a much more even male:female ratio (Seedat et al., 2009; Williams et al., 2008).

Affleck, Glass, and Macdonald (2013) and Macdonald, Chilibeck, Affleck, and Cadell (2010) offered a useful explanation for these low participation rates amongst men. It is widely recognised that men often find it difficult expressing their emotions. This relates to an unwillingness and difficulty in revealing their vulnerabilities and/or difficulty in adequately expressing their emotions verbally (Kelly, 2014; Levant, Hall, Williams, & Hasan, 2009). Therefore the level of emotional discussion often required by a long, in-depth, semi-structured interview, may be intimidating for some men (Affleck et al., 2013). The prospect of having to discuss a possibly sensitive topic such as their lived experiences may be uncomfortable to some men and, as a consequence, may explain why they refrained from participating in this potentially threatening study (Affleck et al., 2013; Macdonald et al., 2010). Furthermore, it could also be that women identified more with me than men, because, like them, I am a woman, too (Kelly, 2014).

The greater percentage of women participating in this research is also reflected when measuring it against SU’s whole list of students with a visual impairment. Twelve of the 35 women with a visual impairment known to be enrolled at SU participated in the study (almost a third), while three of the 28 male students agreed to be interviewed (just more than one tenth). Interestingly, this pattern was not echoed in the CPUT data. Here, almost half of the complete list of both male and female students with a visual impairment participated in the study (4/10 of females, 4/9 of males). Something else to consider is the fact that at SU, 23 of the overall 28 males were White, while 5 were Coloured. No Black males with a visual impairment were listed on the SU database. At CPUT, eight of the nine males were Black, while one was White. Although no definite explanation for the higher participatory percentage amongst Black men in this study can be provided, something could be said for the fact that a greater percentage of female students also participated in the study compared to those from SU. Once again, I believe that the direct approach to recruitment that I used at CPUT largely contributed to the higher percentage of both male and female students. However, further investigation is needed, since this occurrence may also be a result of other factors. For example, it may be due to racial or institutional factors. It also leaves me with the seemingly unexplored, unanswered question: Are Black men more willing to talk about their emotions than White men? This is an intriguing question which has to an extent been dealt with by other researchers (see, for example, Morrell, 2003; Ratele, 2009; Shefer & Mankayi, 2007), but it is beyond the scope of this dissertation to explore this in any detail.

5.3.2.6 Age of the participants

Interestingly, despite other variations, there were very few differences between the age groups of the participants from the two retrospective universities. At both institutions, the median age was 23 while the average age at CPUT was 23.75 and the average age at SU was 23.9. At SU, however, the age range was slightly wider, 19 to 34, compared to an age range at CPUT of 21 to 28. This may be due to the fact that more students from SU took part in the study, resulting in a wider age range.

5.3.2.7 Academic details of the participants

If we turn to the academic information of the students, it is clear that the students from CPUT took various courses that were generally representative of the academic programmes studied by all visually impaired students at this institution. On the other hand, the academic courses studied by the SU participants were not as representative of the entire visually impaired student population of SU. The majority of the participants at SU (10), followed a BA programme. Although the majority of visually impaired students at SU are enrolled for a BA programme, quite a number of students are also studying financial/accounting, engineering and BSc courses. None of these students, however, volunteered to participate in this research.

I can offer two hypotheses in an attempt to explain the presence of mostly students from the BA faculty in this dissertation. Firstly, those participants studying towards the non-represented courses were mostly partially sighted. As mentioned previously, in Chapter 7 the unwillingness of partially sighted students to participate will be clarified. Secondly, as indicated previously, some of the students knew me prior to this investigation. I am studying within the Faculty of Arts and Social Sciences, which awards the BA degree, therefore I am familiar with some of these students. Knowing me might have established rapport and trust before the interview process, making it easier for students to volunteer to participate in such an exploration of their lived experiences.

At CPUT, no post-graduate students with a visual impairment participated in the study and, congruent to this, there were none indicated on the student list. This raises the question whether no students with a visual impairment further their studies at post-graduate level at CPUT or whether they are less likely to disclose their disability. If the former is true, an investigation into the reasons for not continuing on the academic path within this technical setting is needed. At SU, only two of the 15 post-graduate students took part in the study. The reason for this is unclear, but we can speculate that, since they have come so far in their academic careers, they are already adjusted to a tertiary setting and its accompanying challenges. Another plausible explanation could be found in the type of institution. Since

CPUT is a technical university, the courses offered provide students mostly with a professional qualification, for example, engineer, teacher and so on. Many of the students at SU, however, studied a BA degree, which does not offer a professional qualification on its own. It could therefore be assumed that furthering studies at graduate level may be more important and essential for students at SU. As a research-driven university, furthermore, SU has a high proportion of postgraduate students in general; the proportion is far lower at CPUT.

5.4 Procedure

As indicated in 5.3, potential participants were invited to the study via e-mail (SU) or telephone (CPUT). As soon as they accepted the invitation, we scheduled the first interview at a time that was most convenient for them. Before the first interview I e-mailed the informed consent form to them so that they had enough time to read through it.

At SU, the individual interviews took place within the Education Building and the focus group/member-checking sessions were conducted in the Centre for Student Counselling and Development. There were two venues for interviews at CPUT. On the Cape Town campus, all data-collection procedures were conducted within the Student Counselling Centre, while all the interviews on the Bellville campus took place within the Disability Unit. These venues were very centrally located on the respective campuses.

As Silverman (2013) prescribed, all interviews were captured on two audio recorders. I transcribed the interviews in order to stay close to the data and to assist data analysis (Henning et al., 2004).

I decided on a variety of data-collection methods because this increased the rigour of my research design and provided me with a deeper insight into the lived experiences of visually impaired students (Affleck et al., 2013; Yin, 2011). Hall and Rist (1999) compared the use of a single method to relying on the "precariousness of the one-legged stool" (see p. 291). Similarly, it has been argued that one empirical method of data-gathering is not sufficient to capture a phenomenon in its entirety (Patton, 2002). Therefore, I used the data-collection methods of a biographical questionnaire, two individual interviews (an initial and follow-up interview) and a focus group interview that also served the purpose of member-checking. In the following sections, I will provide a clear outline of each one of these methods. This will encapsulate a clear description of each technique, situating it within the IPA paradigm. Following the description of each method, the number of students from each institution who participated in that particular procedure will be stated and discussed.

The entire data-collection phase stretched over six months – February to July 2012. In this time I conducted 43 interviews of which 23 were initial interviews, 16 were follow-up interviews and four were focus group/member-checking interviews.

5.4.1 Informed consent and biographical questionnaire

The informed consent form (see Appendix B), was e-mailed to the students prior to the first interview. At the first meeting, before I proceeded to the interview questions, I asked the students whether they understood the content of the informed consent form. Even if they did, I still explained the most essential parts, for example, that they were allowed to withdraw from the study at any time without any consequences and that they were not obliged to answer any of the questions. After I was certain that they understood the form and what it meant for them, I asked them to sign the form if they agreed to its content. For those who could not or preferred not to sign, there was the option of agreeing verbally on the audio recorder. None of the participants refused to give their consent, albeit orally or with a signature. Partially sighted students mostly signed the form, while the blind students preferred oral consent.

After the informed consent form was signed, I proceeded to the biographical questionnaire (see Appendix D). All 23 students completed this questionnaire. I conducted this questionnaire orally, audio-recorded it and filled in the form after the interview. In terms of the content of the questionnaire, I included items that I suspected might have an impact on the results of the study. As will be discussed in Chapter 6, some of the information provided in the biographical questionnaire proved useful, especially that of visual category. An item that I included later was schooling. During the first few interviews the students always referred to their type of secondary schooling (special or mainstream). Early in the data-collection phase I therefore became aware of the potential importance of this item; hence its inclusion into the questionnaire.

Based on the data obtained from the biographical questionnaire (Appendix D), I have provided a comprehensive discussion of the demographic information of the participants in 5.3.2 and included a brief outline of this information in Table 5.1. Following the biographical questions, I proceeded to conduct the first interview (see Appendix E for the interview schedule).

5.4.2 Individual interviews

5.4.2.1 Description

All the students who volunteered to participate in this research were invited to take part in two individual interviews (see Appendix E for the interview schedule). I particularly chose semi-structured interviews with open-ended questions, since these facilitate rapport and empathy and thus leave space for participants to freely talk about their stories, thoughts and concerns (Creswell, 2009; Henning et al., 2004; Palmer et al., 2010; Smith, 2004; Smith et al., 2009).

As Smith et al., noted, “One-to-one interviews give participants the space to think, speak and be heard” (2009, p. 57).

A further, strong motivation for using semi-structured interviews was to give a “voice to the voiceless” (Atkinson & Silverman, 1997, p. 311). It is widely noted that, where research about people with disabilities does exist, it often alienates them by a failure to reflect their own perspectives (Goode, 2007). In this study, students with disabilities were asked to give their own perspectives and share their life stories. In so doing, the misrepresentation, alienation and under-representation of students with disabilities could be counteracted (Affleck et al., 2013). This concurs with the view of Sandelowski (2002) that interviews serve as a vehicle to include previously vulnerable groups, like students with disabilities. As he so eloquently writes, “The interview has become the politically correct method to redress the wrongs of both positivism (which ostensibly give no voice and no entrée to the private or authentic) and prejudice (which it does not care to give)” (p. 105).

The interview schedule was treated as a loose guide to the interview. In order to accurately hear the in-depth, lived narratives of the previously unheard voices of students with a visual impairment and to provide them with the most suitable climate to relate these accounts, I allowed them to direct the dialogue between us where it deemed necessary (Silverman, 2013). For example, I asked open-ended questions and, when they spoke about something that was not on the schedule, but still related to the research question, I followed up through questioning and/or reflective responses. I also did not necessarily keep to the sequence of the interview questions, yet I ensured that all questions were asked if the issues covered by the questions did not naturally arise during the interview. It flows naturally from this that I regarded the questions in the interview schedule as a flexible guide; as something that indicated important topics to be covered, yet not as a restrictive guide to be followed rigidly

(Silverman, 2013). As Yin (2011) stated, “as with all of qualitative research, nothing is linear” (p. ix). I therefore approached the one-to-one interviews as a conversation, but one in which I mostly listened while the participants recounted their experiences (Smith et al., 2009).

As mentioned before, the students were also invited to participate in a second, follow-up one-to-one interview. I used the first interview as a guide to explore and discuss overlooked and unexplored aspects that arose from the first interview (Smith, 1994). I furthermore attempted to build trust and rapport during the first interview thereby laying the foundation for deeper exploration during the second interview.

5.4.2.2 Participation

The interviews ranged from 45 to 90 minutes. Overall, all 23 participants took part in the first interview, while 16 agreed to the follow-up interview. Of the 16 who took part in the second individual interview, 13 were from SU while only three were CPUT students.

The high attrition rate of the CPUT students could be explained from two angles – first by looking at the explicit reasons given by them and, secondly, by trying to understand the underlying meaning of their explanations. Explicit reasons for not attending the second interview included a busy schedule and heavy workload. In the light of the next chapter, this is a very plausible explanation. In Chapter 8, I will indicate the academic pressure on visually impaired students, especially for those with partial sight who commonly experience extensive reading difficulties. Interestingly, and confirming this hypothesis, both students from SU who did not attend the second interview had partial sight (all the blind students therefore took part in the follow-up interview). Furthermore, as will be explained in Chapter 7, partially sighted students often hide their disability. One in-depth interview might therefore have been overwhelming for them.

The language barrier could also explain the attrition at CPUT. English was not the first language of any of the participants who did not participate in the follow-up interviews. However, the question then remains why three participants did not view this as a barrier and continued with the next interview.

I ruled out a lack of rapport and trust, since some of the students who did not attend the follow-up interview relayed very personal and sensitive experiences to me during the first interview. As some of the students at SU knew me prior to the interviews, this may have enhanced the feeling of rapport, thereby motivating them to continue with the interview process.

In conclusion, it seems most likely that attrition rates were linked to visual category, but the specific reason for this needs further investigation. Furthermore, the other hypotheses cannot completely be ruled out and also need further consideration.

5.4.3 Focus group and member-checking interviews

5.4.3.1 Description

Concluding the data-collection phase of the research, all participants (including those who did not agree to a follow-up interview), were invited to take part in one focus group interview that simultaneously served as respondent validation. Although I initially wanted to separate respondent validation from the focus group interview, I realised that the students had time constraints and many academic obligations.

Two focus group interviews were held at each university and participants from SU could choose which interview time was most convenient for them, while one focus group interview was scheduled on each one of the two campuses of CPUT. I decided to divide the participants into two separate groups, since focus groups should preferably not exceed five individuals (Smith et al., 2009). According to Smith et al. (2009) four to five individuals are sufficient to generate a discussion, yet small enough to be managed effectively.

I decided to use focus group interviews, since I believed that the interaction between the multiple voices of participants could facilitate more information and stimulate additional thoughts (Creswell, 2009; Palmer et al., 2010). Focus groups are also congruent with the IPA method (Palmer et al., 2010).

As with the follow-up individual interview, I used the analysis of all the one-to-one interviews to inform the focus group interviews. I thus reported the tentative findings of the study and invited further discussion around these topics so that I could confirm and refine my results (Silverman, 2013). The focus group interviews thus also served as member-checking. In doing this, I was hoping to verify the accuracy of my qualitative data (Creswell, 2009).

5.4.3.2 Participation

Finally, 13 of the original 23 students attended the focus group/member-checking interview. These students comprised 10 from SU and only three from CPUT (refer to Table 5.2). I scheduled two focus group interviews at SU. Participants could therefore choose a group that would have been convenient to them. There were no time limits on these interviews. The first interview was three and a half hours, while the second stretched over two and a half hours. Four students attended the first one and another six took part in the second focus group. Overt reasons given for nonparticipation were (a) heavy time schedule, and (b) being away from SU for practical work.

At CPUT, one interview was held on each campus. The students were consulted on what times would suit them best and the time for the interview was scheduled accordingly. Even though three students indicated willingness to participate in the Cape Town interview, only two attended the interview. This interview lasted two hours. Similarly, while two students agreed to the focus group interview on the CPUT Bellville campus, only one student attended. This interview lasted two hours, and was in its nature an individual member-checking interview. At CPUT, two students could not attend the focus group interview, since they were away from the campus for six months for practical work and one stated a busy time schedule.

Once again, all the students who did not attend the focus group interview, even those from SU, were partially sighted. The same reasons provided in 5.4.2 therefore can be applied in this situation. However, here we also have to consider the reality of practical work and the inevitable restrictions it imposed on this study. As up to six months sometimes lapsed before the focus group was conducted (I first had to transcribe and analyse the data), the students were at different stages in their course which imposed different restrictions on them.

5.5 Analysing the Data

In keeping with my aim for a rich, detailed account of the lifeworlds of the participating students, all 43 interviews were analysed according to the principles of IPA. This consisted of both within-case analysis and across-case analysis (Creswell, 2007). The former analysis refers to a detailed description of a few single cases and the themes within them, while the latter implies the thematic analysis across all cases (Smith, 1999, 2011). This is in keeping with Yin's (2003) suggestion that an analytic process may involve the identification of themes within individual cases, followed by a mapping of common themes that would transcend the cases.

Whereas the within-case analysis primarily served as the foundation for the across-case analysis, its results were also used to provide four in-depth case studies. Throughout the individual case studies and cross-case analysis, I also included many extracts from the interviews in an attempt to deepen the analysis and to validate my findings. This analysis thus shed light on the shared experiences of students with a visual impairment, while allowing for their individual voices to be heard through verbatim quotes and individual case studies (Brocki & Wearden, 2006). “In a good IPA study, it should be possible to parse the account both for shared themes, and for the distinctive voices and variations on those themes” (Smith et al., 2009, p. 38).

In the following sections, I will give a fuller explanation of these constructs and how they pertained to this research analysis.

5.5.1 Within-case analysis

I analysed the interviews of each participant individually, in order that the findings would reflect the detailed, deep layers of their experiences (Smith, 2011; Smith et al., 2009). In other words, the idea was to discover and reveal the heart of the lifeworlds as experienced by the individuals who are living it. For this purpose, I followed the IPA steps as suggested by Smith et al. (2009).

I believe, along with many other researchers, that thorough preparation is essential when embarking on a qualitative analysis. Therefore, reading and re-reading an interview transcript is considered the first step in this endeavour. This step enabled me to become acquainted with the content of the interview and helped me to recognise possible patterns and connections within the text. Furthermore, reading the same text repeatedly increased the likelihood of the participant becoming the centre and focus of the analysis (Smith et al., 2009). Repeated reading thus assisted in subduing my voice, allowing the voice of the participant to be heard (see 5.2). Through this process, I slowly began entering the lifeworld of each participant.

When I felt sufficiently comfortable with the explicit content of the transcript, I moved to the next analytic step. This involved re-reading of the text and adding notes and comments to it. For this process to be successful, I had to engage in what Smith et al. (2009) call "analytic dialogue". In other words, I had to establish what each line of the transcript meant to me, while trying to understand what it meant to the student. This required paying close attention to the context of each student's lifeworld and the content of their language (use of specific words). As a result, the comments started to reveal the meaning of experiences for the student, identified and recognised similarities and contradictions within the transcript and informed the development of abstract concepts (Smith et al., 2009). As can be expected, this process increased my familiarity with the text and, moreover, enhanced and deepened my understanding of the student's lifeworld.

Next, I was ready to develop themes that emerged from my notes and the transcript. Despite the suggestion that themes should solely rest upon the researcher's notes, (Smith et al., 2009), I used the original transcript in conjunction with the notes in order to reflect the data accurately. As a further precaution, I included verbatim quotes in support of each theme and as validation that I did not stray too far from the original text. It is thus evident that the themes reflect not only my interpretation, but also the original words of the research participants.

Identifying themes required the fragmentation and re-organisation of the original text. This represents the hermeneutic circle, since the whole transcript is fragmented into various parts, but is eventually reconstructed into the write-up as a whole (Smith et al., 2009). With the development of themes, I aimed to reflect interconnections and patterns between parts of the interview and the accompanying comments. Moreover, it provided me with an understanding of what was important in the comments and transcript.

By this time I knew the data adequately enough to find connections between themes. This meant that I steered away from the order in which the themes were presented to me. Rather, I re-arranged the themes so that they told the interpreted story of the student. This step completed the analysis of the first case and, subsequently, I moved to the next case and started the process again. Here I needed to bracket the ideas and themes that emerged from the first case to be able to give an unbiased account of the unique lifeworld of the next participant.

Upon completion of all 23 cases (39 individual interviews and four focus group interviews) the actual write-up of the analysis involved two different processes. Firstly, four of these within-case analyses resulted in individual, detailed case studies. Secondly, each one of the analysed transcripts, including the four that were used for case studies, also formed the basis of the across-case analysis. Hence, I will describe each of these two analyses in turn.

5.5.2 Across-case analysis

In the across-case analysis, I had the task of looking for patterns across the analysed cases. This involved the grouping of similarities and differences across the cases, restructuring and relabeling the original individual themes, so that patterns of meaning became clear in a final account of their shared experience (Smith et al., 2009).

5.5.3 Case studies

“But do we always have to find out universal truths of behavior? Sometimes, surely, it’s enough to explore the life of a unique individual” (Rolls, 2005, p. 2).

Case studies can be conceptualised as examining a particular case such as an individual with a visual impairment, within clearly defined boundaries such as two selected universities (Creswell, 2007, 2009; Henning et al., 2004; Stake, 1995, 2005; Yin, 2009).

Case study analysis is in direct alignment with IPA's commitment to idiography. Therefore it could provide rich, particular details of a particular case (Bramley & Eatough, 2005; De Visser & Smith, 2006; Smith, 2011; Stake, 1995, 2005). This means that, by looking at a single case, it will be possible to get a sense of their lived experiences. It goes further by illuminating how these individuals make sense of and attach meaning to their experiences (Creswell, 2007; Smith et al., 2009). Lastly, case studies enable a researcher to draw connections between accounts and sense-making processes. As can be expected, this process assisted me in becoming intimately familiar and involved with the narrative of each student. Hence, it is no wonder that Smith et al. (2009) reported single case studies to be powerful.

In this research, case studies resulted from the within-case analysis. In other words, I followed all the steps in the within-case analysis and used this re-organised compilation of the interview transcript and notes as case studies. All the cases were thus developed using the same procedure (Yin, 2003). This left me with the task of choosing four case-studies amongst 23 completely developed cases. First, I selected cases that provided a variety of interesting and unusual perspectives and experiences. This procedure is called purposeful maximal sampling (Creswell, 2005). In the second instance, I based my decision on the depth and width of detail provided by the student. Lastly, I chose cases that were not similar, in order for the reader to get a sense of the variety of lived experiences of visually impaired students.

I believe that the four case studies deepened and widened the across-case analysis and facilitated a deeper understanding of individual students' lifeworlds (Creswell, 2009; Henning et al., 2004). It thus allowed the reader to hear individual voices amidst the multiple voices of shared experience.

5.5.4 Summary

In conclusion, the data analysis of this study lead to rich, thick descriptions of the findings and provides the reader with an insider's perspective. This was achieved through a thorough description of the research setting, four thorough, in-depth case studies and a thematic analysis containing extracts from interviews.

5.6 Trustworthiness

In pursuit of the qualitative trustworthiness of the study, the four criteria as proposed by Guba (cited in Shento, 2004) were considered. These four criteria correspond to positivistic research methods and include: (a) credibility (this corresponds to internal validity), (b) transferability (this is similar to the quantitative construct of external validity), (c) dependability (this corresponds to reliability), and (d) confirmability (this is better known as objectivity by the positivistic researcher). I will discuss how these four criteria were applied in this research dissertation.

Credibility is achieved when the findings of a study are communicated in such a way that they reflects reality (Morrow, 2005; Shento, 2004). Many researchers suggest that reflexivity enhances and strengthens the credibility of qualitative studies (Shento, 2004; Smith, 2006). Reflexivity refers to the ongoing critical reflection on oneself as researcher and the acknowledgement and exploitation of one's subjective reality (Smith, 2006). In 1.1 and 5.2, I reflected upon my subjective taken-for-granted lifeworld and the way it might have compromised or enhanced the credibility of my findings. For example, having a visual impairment might be beneficial to the study, since participants may feel more comfortable talking to me and rapport building may be easier. I may, therefore, gain valuable inside information from the participants due to my obvious insider's perspective. On the other hand, the danger exists that I may shape the realities of participants, both during analysis and collection, through the lens of my subjective world. However, I tried maintaining credibility through open acknowledgment of my biases within the research, ongoing reflexive commentary in the study and a reflexive journal (Shento, 2004). As mentioned before, I believe that my therapeutic skills also assisted me in bracketing my subjective experiences. Lastly, supervision and a member-checking session also helped me to measure my subjectivity to the objective worlds of my participants. In the same light, confirmability refers to my objectivity as researcher. Although I acknowledge that it is impossible keeping the research findings completely free from my own perspectives, the disclosure of my biases once again lends confirmability to this study.

A study is transferrable if readers are able to generalise the findings to the context (Morrow, 2005; Shento, 2004). This research is transferrable since I provided contextual information on both universities, including their background and disability policies (see Chapter 1, section 1.4) (Morrow, 2005; Shento, 2004). In addition to a clear description of the context, I also provided detailed, demographic information on each participant, without compromising their privacy.

Dependability was obtained through an explicit and detailed report of the research process that made it possible to repeat the study (Morrow, 2005; Shento, 2004). In this study, an unambiguous, step-by-step description of the research design and methodology, including data-collection and analysis procedures, were discussed as well as a reflective appraisal of its effectiveness (Shento, 2004).

5.7 Ethical Considerations

In the light of the potentially sensitive and emotionally-laden content of the interviews with possible vulnerable individuals, it was essential that I obtain ethical clearance to proceed with this research. Ethical clearance was obtained from the ethical committees of SU and CPUT in August and September 2011 respectively. Consequently, potential participants were invited to be part of this research from November 2011 (see Appendix A for invitation letter).

As soon as students agreed to participate in the interviews, I e-mailed them the informed consent form (see Appendix B). I had a hard copy of this form at each first interview. After I was certain they understood their rights, I asked them to sign the consent form. The content of the informed consent form and, in particular, the parts I emphasised verbally, included the voluntary nature of participation and their right to withdraw from the study at any time without adverse consequences for them or anyone else. Furthermore, I ensured that they understood that they could refuse answering any of the interview questions.

The research participants were also informed that I would take precautionary steps to protect their identities. One of these steps included that only my research supervisor, Prof L. Swartz, and I had access to the raw data. The raw transcripts were stored on my computer, requiring a password to access it. Moreover, audio recordings were destroyed following the data-analysis. Lastly, pseudonyms were used when I referred to the participants in the dissertation.

In supervision, my research supervisor was also available when I had to discuss ethical uncertainties.

5.8 Summary and Limitations

The aim of this study was to explore the lived experiences of students with a visual impairment and this clearly required a qualitative, IPA research design. For this purpose, two interviews and a focus group/member checking interview were conducted with 23 students from CPUT and SU retrospectively in order to gain a full, in-depth understanding of their lifeworlds. The data obtained through these interviews were transcribed and analysed before the write-up of the findings. Analysis had to reflect the shared experience, as well as the individual voices of the students. Therefore the analysis included four in-depth case studies and a thematic, across-case analysis. Ethical conduct was optimised through written ethical clearance from both investigated tertiary institutions, a clear and comprehensive informed consent form and supervision. Furthermore, trustworthiness was primarily enhanced through my reflexivity on my bias as a researcher who shared many of the investigated qualities of the research participants.

One of the main limitations of this investigation was the non-representativeness of my sample. For example, at SU, very few male students participated in the study and most students were representative of the humanities faculty. At CPUT, the sample was more representative of the entire visually impaired student population. The data gathered was limited, because of the cross-sectional, self-reported nature of this study. In other words, following the students longitudinally from school to their transition to higher education and beyond would have given a clearer picture of their lifeworlds. Moreover, listening to important role-players such as school educators and disability support staff could have assisted in a wider understanding of issues discussed by the participants.

A further unfortunate limitation was the high attrition rate of the research participants following the first interview. Even though attrition was also evident at SU, it showed more of a gradual decline than the attrition rate at CPUT. A further limitation was my inability to speak the home-language of the majority of the CPUT students.

In hindsight, I could have applied for ethical clearance to send out the invitation to all SU and CPUT students. Hereby, I could've ensured that even nondisclosing students had the opportunity to participate in this study.

The last limitation was my subjectivity as a student with a visual impairment. On face value, my taken-for-granted world might seem very similar to that of the research participants, because of our seemingly shared lifeworlds. Although my objectivity could thus have compromised my findings, I believe that this limitation also lent strength to my study (see 1.1 and 5.2). Exactly because of our similarities, the participants could have felt more comfortable talking to me (Beauchamp-Pryor, 2014).

We now turn our focus to the research findings, produced by the methods of this research design that included a combination of the voices of the research participants and my interpretation.

CHAPTER 6

RESULTS AND DISCUSSION PART I:

THE PRE-TERTIARY ENVIRONMENT

6.1 Introduction and Lay-out of Emergent Themes

Within the early stages of this research project, I decided to conduct interviews with students at two historically different universities. CPUT and SU met this criteria, because, unlike CPUT, SU was a predominantly White and wealthy university during the Apartheid years (see Chapter 1, section 1.4). In the light of the possible residues of the unfair distribution of resources between these universities, I strongly expected to see a clear difference between the experiences of students from CPUT and SU. However, interestingly, the differences between these students were minimal. Where differences between students were evident, these seemed related mostly to aspects such as visual category or type of schooling. For example, in some regards there were many similarities amongst the students who attended a special school and amongst those who went to a regular school, irrespective of their tertiary institution. In each theme, these differentiating aspects will be highlighted.

The across-case analysis of all the life stories resulted in three broad themes. These were:

- The pre-tertiary environment (Chapter 6).
- The social environment (Chapter 7).
- The learning environment (Chapter 8).

The description and interpretation of these themes stretch over three chapters; each of which consists of two main parts. Firstly, the respective chapters will provide a clear and detailed description of a theme and its supporting subthemes. Secondly, drawing on theory and previous works, the results will be interpreted.

As strongly suggested by IPA, the descriptive part of each chapter was drenched with verbatim quotes from the participants. In order to place each quote in context, I used certain indicators before each extract. The first indicator was the initial of the participant's pseudonym. After this initial, the rest of the information followed within parenthesis. The first of these indicators was the initial of the tertiary institution of study; in other words C indicated CPUT while S indicated SU. Next, the type of interviews followed; I pertaining to an individual interview and F to a focus group interview. Lastly, if the participant was Afrikaans, a number indicated the cross reference of the original quotation in Appendix F. Consider the following example. An individual interview with an Afrikaans speaking student called Mia, who was studying at SU and whose interview was the third translated from English, will be indicated as follows: M(SI3).

Let us now start with the first theme: the pre-tertiary environment.

6.2 The Pre-tertiary Environment

A clear distinction was evident between the experiences of the students who attended a special school (11 from SU and two from CPUT) and those who remained in a mainstream environment (three from SU and four from CPUT). Although more students from SU thus attended a special school, their experiences overlap considerably with those of the CPUT students who transitioned from a special school. The same trend was also seen in those who attended a mainstream school. Three students (one from SU and two from CPUT) attained their visual disability after their school years and were thus not accounted for by this theme.

Although this theme did not, in all accounts, address the experiences of disabled students in higher education, it was still very important to describe and discuss these experiences. The reason for this is because this theme showed how previous educational experiences might have influenced some parts of tertiary life. It furthermore shed light on the progress towards inclusive education.

Four subthemes emerged from the stories related to the pre-tertiary environment, namely:

- The shared experience in a special school.
- The isolating experience in a mainstream school.
- The decision to study.
- Renegotiating the new environment.

Each one of these themes will be described in the following sections.

6.2.1 The shared experience in a special school

> I discovered that many other children shared my world and, despite the harshness of institutional life, I felt relaxed, made lots of friends, became more confident and thrived socially. For the first time in my life I was a standard product and it felt very good. (French, 1993, p. 7)

Not all the students who attended segregated education went to the same schools. Two students went to Prinshoff School in Pretoria, nine students went to Pioneer School in Worcester, while both students from CPUT went to Athlone School for the Blind in Bellville. Only Pioneer School in Worcester has extended their support to other impairments, specifically learners with a learning disability. Notwithstanding the fact that not everyone attended the same special school, the overlaps across the recollected experiences of all these students were remarkable.

The story of shared experience and even “sameness” emanated from the voices of all the students who attended a special school. Apart from their most visible common attribute – visual disability – they shared much more than this obvious physical trait. Their shared experiences were also shaped by (a) their lack of exposure to nondisabled peers, and (b) the one-size-fits-all treatment they received from school professionals.

Regarding the lack of exposure to sighted peers, it seemed that the boundaries of all special schools were rather impermeable. In other words, opportunities for exploration beyond these walls and infiltration from outside were rather limited, T(SI1): “We never really had contact with other people, large groups of people who could see normally or whatever.” It flows naturally from this that visually impaired learners[1] often only had contact with one another, L(SI2): “In school you had contact with only a certain group of people. For example, in primary school you could say you only had contact with the visually disabled. And in high school also just with the same people every day.”

Within this social bubble of the special school, it seemed that learners had a strong feeling of “sameness”, Z(CI): “At special school like we are all the same more or less; like everyone understood everyone else’s problem.”, and, X(CI): “In Athlone school you are confined to seeing the very same people every day. You have the same challenges.”

On the positive side, it seemed that this level of sameness meant that they were a cohesive group, M(SI3): “We were literally this blind community, because we never had contact with anyone else.” However, it also meant that they were kept apart from the social trends of the

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[1] In South Africa, the accepted and legislated word for a school pupil or scholar is “learner”.

mainstream world, L(SI4): “Because your peers are basically blind people who are as limited as you are. So, you know, you develop according to other terms. I mean, because we are not necessarily interested in things like fashion or MTV’s latest music video, there are many aspects we are not aware of, that we don’t understand, that we are not interested in. You know, like that. So in this environment you basically cultivate social conventions that simply don’t exist in the outside world.” And exactly this marginal nature of special schools is what sometimes made adjusting to a new environment somewhat problematic (see 6.2.4), C(SI5): “On the one hand I think it is good growing up like that [in a special school]. Yet, you have to get exposed to other people, to other things, uhm, otherwise you are going to struggle so much more in adjusting.”

Moreover, as stated before, this sameness between the learners seemed to have been further perpetuated by the uniform treatment by school professionals. From the narratives it appeared like educators failed to acknowledge the different realities, personalities and strengths of each learner, M(SI6): “If you are in this community you sort of don’t have your own personality, they kind of tar all with the same brush.”

So, what did this treatment look like? Firstly, students recalled that they were very protected, T(SI7): “At school you are kind of safe and you moved in a small environment and there were always someone who could help you.” For some learners this protection did not mean safety, but rather translated into strict control over their lives that limited their worlds, I(SI8): “It was probably nice for some of us to be in such a protected environment. For me and some of my friends it was frustrating. We didn’t like that we were constantly nannied. You know? We didn’t like the fact that we were always under strict control. . . . Not that we were mature adults while we were in school, but we found it very limiting; we sort of weren’t allowed to broaden our horizons.”

This strict control often spilled over into their academic lives. The students recalled that they were never encouraged to excel academically. To the contrary they were often encouraged to "shrink" their abilities in order to fit the one-size-fits-all mould of expectation, I(SI9): "When I went for career counselling, I was discouraged from taking difficult subjects like Mathematics and Natural Sciences. Uhm, and with other friends, other friends of mine who had the ability to take seven subjects were encouraged to only take six subjects."

Some students felt that this protection, and the imposed limitation of their academic abilities, meant that special school staff did not believe that they could achieve academically or pursue a tertiary qualification, F(SI10): "The problem is that they (special school staff) don't expect people with visual impairments to go and study. They don't expect it. And unfortunately they'll have to start realising that people, uhm, people want to . . . people are ambitious. They aren't going to sit around just because they are disabled." In fact, they felt that the professionals at special schools wanted to keep them institutionalised, X: (referring to special school staff) "And the people are always having . . . they are more people with extraordinary care, than people who would just like you to go out there, grow, learn to live.", and, I(SI11): You get there [school] when you're five, you go to pre-primary, you spend your entire school career there. If you are done, you are encouraged to go to the Department for Career Development, which is also an initiative of the institute. Then you go and work for the institute. Then you go to the old age home for the blind, Brevis House, and then you die.

Fortunately, all the students in this study did not follow this path, but rather chose to further their studies (see 6.2.3).

6.2.2 The isolating experience in a mainstream school

Much unlike the experiences of students from special schools, the students who attended a mainstream school recalled very alienating and lonely experiences. In stark contrast to a cohesive community where experiences were shared and understood, these learners felt like they had nothing in common with their fellow learners. Emma described this feeling in the following way, E(SI12): "I didn't fit in at all. I literally fell into a foreign world and I simply did not fit in. I just couldn't make friends."

"Not fitting in" sometimes stretched further than a mere lack of commonalities and not making friends. In fact, four students recalled outright ridicule, N(SI): "From where I come from, there are names, you know? A Xhosa name in my own language. Someone will call you something that you never wish you were called in, because I will ask them, "Is that the only way you can call me?" That's how I grow up. They will tease me and bully me in that name, because even at school that was the thing I had to struggle with.", and, Y(CI13): "At school people incessantly teased me about my glasses. My glasses were so thick that I had huge eyes and I was overweight and my teeth were crooked.", and, V(SI14): "School days are teasing and those things. The children really literally tease you."

As could be expected, these accounts of ridicule and alienation were layered with feelings of exclusion and emotionally laden memories, Q(CI): "Sometimes you see other people who like to tease and yah, you get hurt." Apart from emotional pain, these consequences included distrust in people and lowered self-esteem, Y(CI15): "And so I developed this complex. I just felt people are nauseating and cruel,", and, N(CI): "There are days when I will go and go into the bedroom crying and crying. You feel like why?! Why is the world so?! Why did you create me like this? Someone will make a joke with you. Like I said in my own language they will call you something and it's more like you can't even call that to a dog. . . . All I can say is that it brings down my self-esteem. You know ever since I was a child my eyes are what put down my self-esteem."

It is therefore clear that students had very painful memories of their life in a mainstream school. Yet, they did not recall any academic difficulty.

6.2.3 The decision to study

From the narratives of the students it seemed that their previous schooling did not play a major role in their decision to pursue a tertiary qualification. (Of course, this is a selected group – I interviewed only students who accessed higher education). Instead, aspects like future plans, previous financial background and limited options were cited as the factors that influenced their decision. Yet it is interesting that, despite the inadequate preparation and lack of encouragement from school professionals, students from a special school still decided to study.

Every one of the students wanted to study with the aim of obtaining a "Good Employment", Z(CI): "I knew I had to [study] in order to get a good job." For some, a "good" job meant breaking away from the traditional careers for visually impaired adults, like working on a switchboard, S(SI16): "In all honesty, I didn't want to go and sit behind a switchboard after school. I just want a degree and I want a job and I want to say, okay, I've really worked hard for this, studied hard for this and now I'm here." For others, a good job meant freeing themselves from the grasp of poverty, G(CI): "I'm not coming from a good background from home, so I want to improve."

For some, the choice to study was borne out of a restricted range of options. Firstly, some students felt that, in the light of their disability, it was possible to obtain a good job only when they acquired a tertiary qualification, T(SI17): "I didn't know what else to do, because, really, what work can you actually do if you can’t see?”, and, L(SI18): “And I know for people in my position, blind people, university is pretty much one of the best options, because you can’t scrub ship decks or that type of thing.”

Three students, after struggling to find a job, decided to study because it was their last choice, C(SI19): “I struggled to find a job. . . . I sort of said studying was my Plan B and finding a job was my Plan A.”

It is therefore clear that there existed a range of reasons why students decided to study. Whether there was a difference between students from a mainstream and special school was not evident.

6.2.4 Renegotiating the new environment

When focussing on the initial adjustment to tertiary life, it seemed that the students from a mainstream school experienced a smoother transition to the new tertiary environment compared to those who transitioned from a special school. After all, they were used to social alienation and exclusion and thus this experience was nothing new to them, G(CI): “Coming to university? No, it was not that difficult.”

This transition seemed to have been much more difficult for the students from a special school. The two aspects that were initially difficult for them were finding their way and making friends.

Particularly overwhelming for them was getting acquainted with the physical environment. Unlike the lay-out of a special school, the wide-open spaces of a tertiary setting were foreign and not designed with disabled students in mind. Some students made an attempt to prepare themselves for the physical challenges of walking alone. They visited the campus beforehand

and paid for an orientation and mobility instructor to teach them the routes to class. Even though these preparations were somewhat helpful, they did not prepare them sufficiently for the day-to-day challenges of walking the campus. For example, Sue recalled that visiting the university beforehand did not prepare her for walking amongst large crowds, S(SI20): “I came here to see what it looked like, not on an open day, but just on a usual day. But still, it isn’t the same like being surrounded by thousands of students. It’s kind of a different experience.”

Apart from walking amongst crowds, they also sometimes found the physical environment to be potentially dangerous, in sharp contrast to the safe, protected environment of the special school. These obstacles included the threat of motor vehicles and obstructions in the environment, A(SI21): “The other day I was at a pedestrian crossing, then I saw a car that seemed rather far away, but he clearly drove fast. And he just came. He didn’t stop. He was, I think if he drove a centimetre further he would’ve drove over my foot.”

It is therefore no surprise that students with a visual impairment, especially initially, experienced strong emotions when thinking about or facing walking independently. These students felt uncertain, scared and extremely worried (sometimes the worry inhibited sleep). They often experienced these emotions when even just anticipating walking alone. In the morning, some students had to gather themselves and find enough courage before walking to class, I(SI22): “It takes a bit of my energy to find my way to places. Each time it’s like, okay, okay, I pluck up the courage, here I go. Uhm, so I so I get by, but each time it’s a bit of an emotional experience.”, and, M(SI23): “It sounds very very lame and probably childish, but for the first two weeks of my academic year it was my greatest concern. Not how I would manage in class, but how I am going to get where I want to be and how am I going to find my way between classes.”

Mia recalled that she avoided going back to the hostel for lunch, for fear of walking independently amongst hundreds of students, M(SI24): “It was terribly difficult for me to . . . later I simply didn’t go to the residence for lunch, because, you know, it was terribly difficult with my cane . . . I don’t even knew my way properly, then I had to try and find my way back to the residence amongst countless students.”

However, this difficulty negotiating the physical environment was mostly only evident during the first few weeks of tertiary life. As they became more confident in mastering their routes, their worries mostly dissipated, M(SI25): “It was difficult, but later . . . one morning you get up and you realise, but listen here, I’m doing it without thinking about it.”

Not only did they have to manage a new physical environment, but for these students from a special school the tertiary environment meant separating from their usual cohesive shared identity. Within the wide-open spaces of a university campus, free from the boundaries that shaped their worlds and identities, they were overwhelmed by numerous new experiences and knowledge. They were surrounded by students from all walks of life – disabled and nondisabled. They were stripped from those individuals who shaped their group-identity and they were thrown into a world of sudden anonymity, Z(CI): “It was quite a shift, because already at a special school like we are all the same more or less; like everyone understood everyone else’s problem.”, and, T(SI26): “And so when I got here, it was out of the protected environment and everything is so big and so many people and I knew no-one. I had to walk amongst thousands of people and in the streets to get to various classes. Big buildings. And it’s large classes with a lot of people. The lecturer don’t know you and no-one else knows you.”

It is therefore no wonder that some students felt very alone at first, M(SI27): "And at a stage it felt terrible, because I felt completely unsafe and kind of like an orphan if I can put it like that. Because nobody, nobody knows and nobody cares."

Without the feeling of sameness, without the cohesion that in a sense shaped their identities, some students felt like they didn't know themselves, M(SI28): "We were literally this blind community, because we never had contact with anyone else. And suddenly it is like you don't know who you are." And so, some students did a lot of self-examination and introspection in an effort to get to know themselves within this new environment, L(SI29): "University is such an overwhelming experience for a blind person, because in university a lot of self-examination takes place and so on. And it's a time when you really discover a lot. So you really learn so much about yourself. . . . You really learn so much about yourself which, in the end, causes you to rebuild your identity. That which people always said about you, you choose for example not to believe it."

However, even though the initial entry into the university seemed to have been more difficult for students who attended a special school, their stories suggested that, in the long-term, they adjusted better to tertiary life compared to students from a mainstream school. For example, although it took some time, students from a special school always made disabled and nondisabled friends, L(SI30: "Socially I learned that, hey, I can actually make friends with sighted people, you know, we do have things in common."

On the other hand, very few of those students who came from a mainstream school, excluding those who could see during their school years, made any nondisabled friends during their tertiary years, E(SI31): "My two best friends, you know, are visually impaired. So you get used to making friends with people who understand you, therefore you always target someone with the same problem as yourself." In extreme circumstances, some students did not make friends at all, V(SI32): “There is not one person I could really call my friend.”, and, Y(CI33): “I only had two best friends throughout my entire life. But I just feel that people can be very cruel, so it’s better to keep your emotions to yourself.”

In addition to the social adjustment, it seemed like students from a special school were more likely to ask for special accommodations than those who transitioned from a mainstream school. For some students from a mainstream school, it was difficult asking for special arrangements, because they didn’t know what they were entitled to receive, J(SI34): “I didn’t want to ask for exceptions. See, I think it was because I didn’t wanted to be a burden. And perhaps I was afraid that people would think that I’m using it as an excuse.” Others didn’t ask, because they didn’t know what was available and whether it would help them in any way, Y(CI35): “So I never knew that I could get the assistance. And I also always thought, what assistance could they give me, really? It’s not like they could make my work easier. It’s not right.” Some others considered the social consequences of disclosure, E(SI36): “Sometimes you really just want to fit in.” Lastly, some students didn’t ask for accommodations, because they didn’t see themselves as disabled and wanted to pass as normal (see Chapter 7 for a discussion of these matters), N(CI): “I didn’t want to go to the disability unit, because of the word “disability”.”

However, all the students, whether they came from a special or mainstream school, eventually experienced a sense of pride and accomplishment in their abilities, C(SI36): “It was literally like two worlds. From school where you had everything and all of a sudden you are here in a self-catering world. Yes, so I think it was quite a big leap. But it was also a good thing. I think it was a good learning curve, uhm, for me as a person and I think it gave me more self-confidence and I saw that actually I could do this.”, and, L(SF37): “It takes a lot to adjust and so on, but yet you have this feeling of accomplishment. You know when you pass your first year and you make friends, that sort of thing.", and, N(CI): "I'm a hero to myself, you know?"

This theme showed that, although the students from a mainstream school generally experienced a smoother transition to the tertiary environment at first, some evidence suggests that they struggled more in the long-term.

6.3 Discussion

6.3.1 The move from special school to university

The stories of the students revealed that the ideology and practices of medical model thinking continued in special schools after 1994. Under this protection and specialised care, the students reflected that they were very limited. They could not explore life beyond the borders of the school and they were not encouraged to excel academically. In fact, they often had to shrink their abilities in order to fit the one-size-fits-all mould of expectation of the school professionals. Even when they had the ability to take difficult subjects or to take more than the minimum modules, they were discouraged from doing so. In this spirit of perceived limited capabilities, the learners were not adequately prepared or encouraged to pursue a tertiary qualification. These stories of the participants of this work overlap with the findings by FOTIM (2011) and Howell (2005).

In this way it is evident that an environment that does not pose structural or social barriers does not automatically translate into an environment that is barrier-free. To the contrary. The fact that the special schools were outside mainstream life and that there was minimal encouragement to leave the borders of this marginal environment, made dys-appearance a very tangible reality for the students. They recognised their bodies as alien in this marginal world, because they knew that they were capable of higher academic achievements and of leaving this world. In fact, exactly because these students were able to see the imposed limitations of the special school and still recognised their abilities, hopes and dreams, Reeve (2012) would argue that their bodies chronically dys-appeared (double consciousness). Chronic dys-appearance means that someone, like a student, longs for recognition and belonging in this world. They realise their abilities, but simultaneously recognise that the environment and others undermine and do not recognise their worth. They are therefore confronted with their bodies as alien-in-this-world. In other words, they could clearly see the oppression as it was happening to them. This is confirmed by the participant, Ilse-Marie, who said that she and her friends were frustrated by the strict control and supervision of school professionals.

Hence, it would appear that dys-appearance was not always an undesirable occurrence. It seemed like this chronic dys-appearance or double consciousness mobilised these students to step out of the boundaries and limitations of the special school and move into the wide-open spaces of a mainstream environment. Through the recognition of their abilities and strengths, they deliberately turned the prescribed “you can’t” of the environment into a definite “I can”. And so, against the odds of these limiting prescriptions, the students in this study decided to utilise their capabilities through tertiary studies.

As stated before, this determination to study did not mean that the transition was problem-free. In fact, similar to the findings of Beauchamp-Pryor (2012a, 2013), it was more difficult for these students to transition from a special school to tertiary life compared to those who came from a mainstream school. After all, as other studies also showed, these students received extensive support and protection during their school years and thus the move to university was experienced as a rather big leap (Beauchamp-Pryor, 2012a; Hopkins, 2011; Wagner et al., 2005).

Although they might have recognised their abilities whilst in the special school, it was like the new environment “woke” them to the reality of their disability, as their certainty in their bodies and the environment dissipated. As with the acquisition of a new illness, the sudden confrontation with their “old” disabilities within a new environment initially rearranged their entire being-in-the-world. Without the support of the special school, without the habitual going about in the world and in the face of new limitations, they suddenly did not know who they were. This phenomenon of not knowing who they were, is referred to by Carel (2013b) in her work on chronic illness, as “the distancing effect of illness” (p. 350). In other words, in some instances the students could not go about their worlds in the way they were used to, for example, knowing everyone and socialising freely. They therefore had to introspect to uncover new and hidden aspects of themselves.

Eventually, we saw that the students from a special school adapted to life within a mainstream environment. As they learned their physical routes, as they made friends and as they got familiar with the learning environment, they started to gain a sense of accomplishment in the knowledge that “I can”. In other words, their biological and lived bodies realigned. This supports Carel’s (2013a) notion that, when confronted with illness (disability), people have the ability to adapt and to live a happy life.

Having said this, the resilience of these students should not result in a careless dismissal of the oppressive practices that still dominate the lives of many disabled learners. After all, I only interviewed those who transitioned to university, but not all learners make it into higher education. How many school learners decided against tertiary studies, because they internalised the “you can’t” of the environment? How many faced limited opportunities because they were advised to take subjects that did not allow them to transition to higher education? Clearly, the practices of these schools should continue to be interrogated and further research in this regard is much needed.

Although beyond the scope of this dissertation, it is interesting to note that the renegotiation of identity is a "normal" part of later adolescence (18-22 years) (Erikson, 1968). During this time adolescents commonly rid themselves of the group identity of early adolescence (age 12 to 18), and start finding their own personal identity. So, even though visually impaired students faced rather unique challenges in their transition to tertiary life, the processes of identity-formation and the history of group identity was not a novel occurrence.

6.3.2 Previous social experiences and the transition

As shown in 6.2.1 and 6.2.2, the social experiences of learners in a special school differed considerably from those in a mainstream environment. The students reported that they gained a sense of cohesion and belonging within the special education setting. Learners took comfort in their commonality. Here they were known and they knew everyone. Here they knew what was expected of them and how they were being defined. Cook, Swain, and French (2001) also found that learners in a special school often form strong friendships and gain a sense of belonging and inclusion in this setting.

On the other hand, in the mainstream environment children were often reminded of their disability through teasing, ridicule and complete social exclusion (intercorporeal dys-appearance). French and Swain (2004) also noted the embarrassment of learners in a mainstream school, since they feel different to their peers. "Adolescence is a time when pressures to conform to group norms are particularly intense and anything which singles out young people as being different from their peers is likely to be resisted by many of this age" (Franklin, Keil, Crofts, & Cole-Hamilton, 2001, p. 112). Young people want to blend in with the crowd; something which is very difficult when they have to receive special help (French

& Swain, 2004). It is therefore no surprise that the differentness of the students in this study, compounded by the ridicule from peers, left them with low self-esteem and self-confidence. These findings overlap with those of Beauchamp-Pryor (2013), but are contrary to those of Topping and Maloney (2005) who found that a fair amount of social integration was experienced by children in a mainstream school.

The current study seems to suggest that these previous experiences were important since they influenced friendships later in life. Coming from a place of cohesion and belonging, visually impaired students from special schools eventually made nondisabled and disabled friends. This is unlike previous studies that found that, coming from a special school where there were only disabled peers, disabled students would find it very difficult to make nondisabled friends in university (Beauchamp-Pryor, 2013). On the other hand, those students who experienced a great deal of ridicule from peers in a mainstream school rarely made any friends and, when they did make friends, it was often disabled friends. We can theorise that students from a mainstream school rarely made nondisabled friends in university, because they did not have the prior experience of making friends and some even learned that, as Yolandie stated, “people are cruel.” On the other hand, students from a special school had the experience of friendships and knew what it was like making and having friends. Even though it therefore took time making nondisabled friends, this was not impossible for them since they commonly had confidence that they could do so.

The developmental theory of Erikson (1968) once again can support this hypothesis. According to Erikson (1968), a “normal” developmental task of early adolescence is the formation of friendships. In fact, the most important process during this stage is group identity. He postulated that those children who did not achieve group identity faced the very real reality of group alienation. He goes further, stating that only when a developmental task has been achieved is one able to move on to the next developmental task. Therefore, since children from a mainstream school could not complete the developmental task of forming friendships, they were “stuck” at this stage, not being able to form friendships during later adolescence.

6.3.3 Academic influences of previous education

Although it was not clear whether type of schooling had an influence on academic achievement, it seemed to have played a role in disclosure and requesting accommodations (see also Chapter 7 for a more in-depth discussion on disclosure and visibility). As seen from the students’ responses, those from a special school were more likely to ask for accommodations than those from a mainstream school. This could in part be explained in terms of disabled identity. Evans (2013), Jacklin (2010), Wagner et al. (2005) and Waters et al. (2012) stipulated that, if students perceived themselves as disabled, they would be more likely to disclose their disability. Similarly, this study also showed this tendency. It seems that students from a special school often had a disabled identity, while those from a mainstream school generally did not see themselves as being disabled.

Unlike the findings by Fuller et al. (2004), the visibility of the disability did not seem to have played a role in whether they required specialised accommodations. Even those students with partial sight, who came from a special school, asked for special accommodations.

Since the visually impaired students did not always receive specialised support in the mainstream school, it should come as no surprise that they also did not always know what accommodations were available and how these could have improved their tertiary experience. Furthermore, Beauchamp-Pryor (2012a, 2013) also found that, since they had to fight for their rights from very early on in life, disabled students from mainstream schools were generally more self-reliant.

Lastly, this study also confirmed the findings by many studies that students feared the social consequences inherent in disclosing their disability (Elliot & Wilson, 2008; Kranke et al., 2013; Magnus & Tøssebro, 2013; Roberts et al., 2009).

It is thus evident that students from a special school, irrespective of their visual category, were far more willing to request accommodations than those from a mainstream school.

6.4 Summary

From the stories of participants, it is clearly evident that they felt they were not valued for who they were, albeit in a mainstream or special school setting. Even though barriers were removed in a special school, their unique realities were overlooked. On the other hand, in the mainstream schools, education was not inclusive, but rather “integrative”. This meant that learners were expected to fit into the mainstream setting, while the environment did not, in all regards, adapt to include them.

It is therefore not enough to simply refer to the inclusion of young people; major changes in society are required to make this successful (French & Swain, 2004). I would therefore argue for a sensitive, cautious move to inclusive education, where social inclusion is carefully monitored and nondisabled children are sensitised to children with disabilities.

The following chapter will provide a more in-depth look at the social experiences of the participants within higher education.

CHAPTER 7

RESULTS AND DISCUSSION PART II:

THE SOCIAL ENVIRONMENT

7.1 Introduction

This chapter places the social experiences of visually impaired students under a microscope. Although these experiences were discussed partly in the previous chapter, with particular reference to the pre-tertiary environment, in this chapter I elaborate on the various elements that comprised the social interactions between visually impaired and nondisabled students.

The topic of the social environment was subdivided into two broad subthemes, namely:

- The behaviours and perceptions of nondisabled people.
- Strategies for inclusion.

The first theme described the reactions of nondisabled people towards the students, while the latter highlighted the various strategies visually impaired students employed in order to be accepted within a social group.

In this theme, there was no apparent difference between the experiences of the students from CPUT and SU. In certain, instances differences were detected between partially sighted and blind students. The experiences also differed according to previous education, but this will not be discussed at length here, since it was already explained in Chapter 6.

7.2 The Behaviour and Perceptions of Nondisabled People

This theme addressed the way in which visually impaired students experienced and interpreted the reactions of nondisabled people towards them. The majority of students believed that these reactions, for example, stares or avoidance, signified that their peers treated them in a different way than they would treat fellow sighted students, T(SI39): “People will always treat you differently if you have a disability. And yes, people, it’s difficult socially, because people don’t easily accept you. As soon as they discover or realise that you can’t see, then they treat you differently.”, and, N(CI): “There are those who will treat you like you’ve got these eyes or something is wrong, you’re different from us.”

This “different treatment” was divided into five subthemes. These were:

- Low expectations.
- Helping responses.
- Avoidance.
- Stares.
- Difficulty understanding partial sight.

I shall present each of these in turn.

7.2.1 Low expectations

Many participants observed that sighted people often expected very little of them. In fact, they noticed that sighted individuals often perceived them to be helpless, incapable victims of circumstances who “suffer” in the face of a life-consuming disability, V(SI40): “There are really countless instances where people think that you would talk slower or that you wouldn’t be able to get by. [Laughs] People literally think that disabled people cannot do anything. Or that life is such a struggle for you that you . . . it must be such a battle for you to get in somewhere.”, and, N(CI): “In our communities, if you can’t walk, you are deaf, you are blind, it’s more like you’ve got to sit at home, wash, get food and everything.”

These imaginings of disabled life also sometimes included the perceived loss of additional abilities. For example, someone might believe that a visually impaired student might also be deaf, intellectually disabled, and so on, W(SF41): "They talk right into your ear, [shouts] 'can I help you to cross the road!'"

Some noticed perceptions of incapability not only in the words of others, but also in the patronising way they were spoken to, H(SI42): "I've seen it at the first years' camp, for example, people will treat you normally until they realise that you can't see. And then all of a sudden they treat you like this, 'Hey, you're cute.' I don't know what's the term for it, but they treat you completely different."

Underlying this belief of vulnerability are the subtle layers of pity for disabled people, F(SI): "And they [sighted people] shouldn't feel sorry for us. They really shouldn't. We can get by; we are all right."

In this perception of complete incapability and vulnerability, sighted people often did not expect disabled students to be able to perform minor tasks of daily living, A(SI43): And if they ask questions, it's the most ludicrous questions, like, 'Do you dress yourself?'" Therefore, the students often found that their usual being-in-the-world was blown out of proportion and was often viewed as outstanding and remarkable, P(SF44): "He [lecturer] can't seem to understand how Carla and I walk these corridors. It's just, it's too overwhelming for him. He – he can't seem to fathom the idea that if he would have been blind, he would get lost."

Since sighted people often could not believe that visually impaired students could dress themselves, walk around and so on, it should come as no surprise that they were often shocked upon learning that disabled students were studying, N(CI): "There are people who will come to me and ask me, ‘Are you going to school?’ I’ll go like, ‘Yes, I do go to school.’ You know? They will be surprised, ‘Oh, wow!’ I’ll go like, ‘Yes, I do go to school’.”

It is therefore clear that many participants believed that nondisabled individuals perceived them as incapable and helpless. They deduced these conclusions from the way nondisabled people spoke to them (patronising and loud) and the questions they were asked by them.

7.2.2 Helping responses

Perhaps as a direct result of these perceptions of helplessness, visually impaired students noticed that nondisabled people often thought that they were in need of care and assistance. Ironically, for some, these perceptions and the resulted helping responses were very unhelpful (see also 7.3.4). In a focus group interview at SU, one student commented on the way friendships with nondisabled people could be skewed because of these unreciprocated helping responses, I(SF45): “I don’t have many friends in the residence, but one of my friends, in a certain way I don’t know whether I could really call her a friend. She is very nice to me and we went for coffee before, but it feels to me like she is almost friends with me because she really wanted to take me under her wing. She doesn’t treat me completely normally like she treat her other friends.”

In direct opposition to this view, some other students felt that these helping responses signified positive, comfortable interactions between them and their nondisabled peers, T(SI46): “You get a few who really don’t mind and the moment they meet you they know exactly or they just know how to treat you normally. And if they have to help you they simply grab you and they help you and it’s no problem at all. And it’s usually nice when you meet people like that.” Mia related a similar story. During the orientation week in her residence, they went for a tour of the campus. While wondering who would be able to help her, she recalled the following, M(SI47): “And then a girl walked passed me and she just hooked her arm within mine and the next moment we walked. I didn’t even know who she was. Today we are very good friends.”

In a similar light, students sometimes suspected that sighted individuals benefit by providing assistance to students with a visual impairment. These were emotional benefits, for example, feeling valuable since they had made a seemingly worthy contribution in assisting others, H(SI48): “I think people need to feel like they are needed. It’s very important for people to feel like they’ve made a contribution to something. And that’s why I try to, even though I don’t need any help, to walk with them, because then they feel good about themselves.” Not everyone felt willing to help others to feel good about themselves, I(SI49): “I am willing to help people, but I am sorry, I am not here to kind of make others feel better about themselves.”

It is therefore clear that students viewed these “helping responses” by sighted people in varying lights. For some, it signified the start of a friendship, while for others it represented an unequal relationship. Some recognised the need in others to feel valuable, while others did not take up this responsibility. The reactions of the blind and partially sighted students to these responses will be further unpacked in 7.3.4.

7.2.3 Avoidance

From the stories of the students it was evident that sighted students did not always want to help them. To the contrary. Sometimes they were avoided outright by their sighted peers, T(SI50): “Many people simply ignore you or forget about you. But then others, they simply walk wide circles around you.” Moreover, they observed that sighted people avoid talking to them, I(SI51): “As a blind person people aren’t really going to start talking to you. People won't come and talk to you as easily as they would to a sighted person." Some nondisabled students even tiptoed around the topic of disability, V(SI52): "It shouldn't be heard if people talk about it [disability]. It's almost like they are embarrassed that they are talking about it."

Some students thought that these avoidant behaviours were due to a general lack of awareness around disability, M(SI53): "You enter the room and they don't really know how to talk to you. Sometimes they don't want to talk to you." However, the majority of students thought that people might be cautious, scared and uncomfortable around their disability, C(SI54): "Sometimes it's a bit more difficult making friends. Uhm, you know, because some people aren't comfortable with the fact that you are blind.", and, H(SF55): "They are so afraid that they might say something that will offend you.", and, I(SF56): "They [sighted people] are so scared that they might do something wrong, so they rather do nothing at all."

For some of the female students, it was especially hard when men avoided them, V(SI57): "I can't even think when last a guy approached me and asked me on a date. So you deal with it, I have to deal with it.", and, A(SI58): "There were also some instances when they [men] came to visit me, but when they hear about it [disability] then I simply never hear from them again."

In these "non-encounters" with men, some students felt uncertain of the role their disability played. Instead, they started questioning themselves and wondered about aspects of beauty and attractiveness, H(SF59): "What is particularly difficult for me is that people don't just approach me and talk to me, especially not men. Sometimes I wonder whether it's because I don't look like a Barbie doll? Understand? I don't always know whether it's because of the fact that I can't see or because of the fact that I don't have a superstar body. But I think in instances when men don't approach me it's probably because they see that I'm blind and they don't know how to handle it.", and, V(SI60): "I don't know whether they don't want to ask me out, because I'm this passive girl who don't easily go out or is it my disability? Or is it my personality?"

Here we saw that many students felt that they were avoided by their sighted peers. They had different interpretations for these behaviours, such as ignorance, discomfort and, in the situation when men avoided them, they even ascribed this to their own unattractiveness.

7.2.4 Stares

"When we do see the usually concealed sight of disability writ boldly on others, we stare in fascinated disbelief and uneasy identification" (Garland-Thomson, 2009, p. 20).

Some students reported instances where their disability attracted stares from nondisabled people, N(CI): "Sometimes I'm inside the train, I'm talking and laughing with my friends, then you just look at someone and go like, 'Why are they looking at me so strange?'", and, Q(CI): "At first when you are meeting new people they're like just looking at you like there's something funny, like you are not normal. You're not looking the same as them."

Vicky recounted that these stares contained an element of wanting to know, of wondering about her disability, V(SI61): "People stare at you; they wonder. It's always a part of your life, your life experience."

Two students, Vicky and Nandi, mentioned that stares served as a reminder of their disability. When they saw their disability reflected in the eyes of others, they recognised it and, once again, realised they had a disability, N(CI): "When I'm around people I forget that there's something with my eyes. At a later stage you'll go like, oh, someone is looking at me in a strange way. That's when I'll come to remember, oh, my eyes are different. So they are looking at me for them, they are not even listening to what I'm saying, they are just looking at my eyes as if something is wrong with them. But it's better if someone can see and listen, you know, can see me for who I am."

In all these instances, the encounter of stares were only reported by partially sighted students. The reason for this is rather self-explanatory. Blind students could not see that others were staring at them and therefore they did not report it. It could of course also be that nobody stared at the blind students. However, given the fact that people were staring at partially sighted students, this explanation seemed rather unlikely.

7.2.5 Difficulty understanding partial sight

The range of partial sight can vary tremendously (see Chapter 5). While some students had tunnel vision, some had only peripheral vision. Sometimes, the level of sight within one person also differed according to factors such as light conditions. With this variability, many of the partially sighted students reported that sighted students found it difficult understanding the parameters of their sight, Z(CI): "Even though I told them that I can't see like maybe something else, but then they expect me to see something like a different thing almost similar to that."

This sometimes led to misunderstandings in social interactions. For example, students sometimes thought that partially sighted students were rude, because they did not greet them, while, in actual fact, they did not see them, G(CI): "Sometimes I find they are greeting me by just waving their hands and they think maybe I'm ignoring them, because of the people they don't know my problem. They know that I've got eyesight problems, but they don't think maybe I can't see them.", and, N: "They'll say, 'You also didn't greet us.' And I'll go like, 'No, I wasn't even looking at you at the time, I was looking at others.' They'll go like, 'No, you looked at us.' I'll go, 'No, look at my eyes. If I'm looking at you you'll say I'm not looking at you, I'm looking the other way around.' Then when they pass they think that you are rude. It's not always easy when people think that. Yah, people when they don't know your disability."

Let us consider the story of John. Because of his partial sight, it was often difficult for people to recognise his disability. Therefore, sometimes they thought he was rude, because he did not greet them, while in actual fact he didn't recognise them, J(SI62): "Socially it can also be difficult, because I walk past people without recognising them. Uhm, so people simply think that I am rude because I didn't greet them." Compensating for this, John attempted various creative ways of recognising others, J(SI63): "But luckily now, with time, I start getting to know people and I learn to recognise them through other ways than their faces and so on. . . . Uhm, I can sometimes actually see through the way someone walks or you get to know their voices a bit better or you see what clothes they wear in the morning and for the rest of the day you remember it. But I think it happens unconsciously." However, when he was unable to recognise someone, he deliberately looked away from that person so that they would see that he did not see them, J(SI64): "So I sort of learned to look away when I walked passed someone, because if I look in their direction in an attempt to try and determine who it is, then I think they will think, 'Oh well, he directly looked at me, but he didn't greet me'."

It is therefore clear how the invisibility and undefined nature of partial sight may lead to various misperceptions and misunderstandings.

7.2.6 The impact of being treated differently

Thus far, we have seen how nondisabled individuals behaved towards and perceived students with a visual impairment and how this was conceptualised and understood by these students. It is also important to know what these behaviours did to the students.

The reactions of others towards the difference of people with disabilities sometimes elicited feelings of shame about the disability. In other words, when others tiptoed around the topic of disability, avoided and/or stared at them, the disabled person sometimes developed a sense of "I am shameful" or "my disability is harmful.", M(SI65): "I know from experience that sometimes you walk into a room and then people just fall quiet. It's the most horrible feeling. Because you don't know whether you have intruded on something private and if they have been talking about you and whether they just got a fright.", and, V(SI666): "So I don't even have a doubt that people will think that you fall short, if you are friends with them that you fall short or that you will always be the ugly duckling or something like that."

As could be expected, this shame and exclusion can lead to feelings of worthlessness, N(CI): "I KNOW the feeling. I know the feeling of being treated like an outsider. Like it feels like you're not enough. You were not created by the same person that they were created by."

Ashley movingly recounted that her shameful, unworthy difference was sharply illuminated by being placed in a hostel room with a beautiful, seemingly "perfect" student, A(SI67): "Because in my first year Miss Popular was my room mate. She was Miss Varsity Cup that year and she was Miss Varsity and she was a fashion model. So she was really popular and very pretty. So when I arrived, there were always people in our room, but it was for Este. People who became friends with me to get to Este."

It is thus clear that being treated differently, may lead to feelings of shame, inferiority and exclusion. It is no wonder, as we will see in the following theme that students with a visual impairment tried to hide their disability.

7.3 Strategies for Inclusion

Erving Goffman (1963) believed that the aim for acceptance was the central feature of the stigmatised person's situation in life, and many disabled people have stigmatise identities. Similarly, in this study, visually impaired students tried to gain acceptance from a seemingly perfectly embodied world. These strategies for acceptance and inclusion included:

- (In)visibility – hiding disability.
- Having the "right" attitude – disguising parts of a disability.
- The "right" activities.
- (In)dependence.
- Socialising with fellow blind students.

These attempts for acceptance mostly shared one common attribute – an effort to achieve sameness with their peers, M(SI68): "People just find it easier to accept you if you are like them. But, uhm, I don't know, it was kind of difficult showing people that, even though I have a cane, even though I can't see, even though I sometimes don't know where I am, I am still just like them."

However, as Mia stated in the previous quote, they often appeared different to their peers. Therefore, gaining acceptance often required very hard work, L(SI69): "I had to work hard to get their acceptance and to earn their trust and to, you know, to sort of win their preference."

I shall now outline in more detail the strategies used to gain acceptance.

7.3.1 (In)visibility – hiding disability

> I MOVE IN a solitude fueled by secrecy. O Lord, let me never be seen with the white cane. Let me roll through the heavy oceans like the beluga whale, filled with dark seeds,

> always coursing forward. Let no one find me out! This is my lacerating tune. (Kuusisto, 2013, p. 531).

Almost all the stories of the participants spoke of matters related to the visibility of their impairment. Sometimes the visibility of their impairment went hand-in-hand with their decision to disclose or not, but generally it was not as simple as this. Often, students with and without visible impairments had conflicting feelings about disclosure and sometimes weighed up the consequences of it. The topic of options was also discussed, as some visual impairments were far more visible than others.

Whether they wanted their disability to be visible or not seemed to be related to two factors, namely, pre-tertiary environment (see Chapter 6) and/or their visual category (partial sight or blindness).

7.3.1.1 Blindness and visibility

Often, blind students did not have the option of hiding their disability, because it was fairly visible. However, this did not mean that they never wished that this option was available to them. In fact, they realised that an invisible disability would have made social encounters easier, M(SI70): “Many people want to hide it [visual impairment]. And if I could, I also would’ve done it. I mean, uhm, I don’t know, people just find it easier to accept you if you are like them.” Thus, when their disability wasn’t very prominent, it was considered a small victory, I(SF71): “I feel flattered that people say I look fully sighted, because it’s probably a sign that my eyes look normal. It’s good, because many blind people have, in quotation marks, ugly eyes.”

Having said this, all blind students requested special accommodations and were thus not silent about their impairments within the academic terrain. Furthermore, despite their desire to be seen as “normal”, they mostly realised that this was not possible. In order to avoid harm related to invisibility, they wished to be seen, M(SI72): “There were instances where a student tried walking between me and my cane. . . . They try it or they kick it aside. On the one hand you sort of want to be seen so that they don’t walk over me or try to walk between me and my cane or cause my cane to fall and then it’s a big mess.”

This realisation that they needed to be seen was sometimes an evolving process, particularly if they acquired their disability later in life. For example, when Sue became blind at the age of 13, she was ashamed to use her white cane, S(SI73): “What was probably the biggest adjustment for me was walking with a white cane. The fact that I simply appeared blind with it. The fact that others could see that I couldn’t see.” In time, however, she realised the need to be seen and, today, she wants to be seen, S(SI74): “In the beginning I would’ve thought, no, I don’t want to be so visible. Now it’s like, ‘Hey! Please see me. Don’t bump into me.’” She therefore started to appreciate the visibility of her white cane, S(SI75): “Because I just think that the cane makes you more visible as a blind person. It’s a very good thing, because then nobody bumps into me or runs me over.”

Although blind students appreciated the social value of an invisible disability, they simultaneously realised the importance of others seeing and recognising their disability. For all the blind students, it was thus important to be seen as a person with a disability. Even Ilze-Marie, who previously commented on the compliment inherent in the ability to “pass as normal”, noted that she still preferred people to know about her disability, I(SI76): “So I am glad that my eyes seem normal. So I prefer people seeing right from the start that I am blind, despite the fact that they might treat me differently because I am blind.”

In other words, some blind students wanted to appear “normal”, yet they would still disclose their disability and request special accommodations.

7.3.1.2 Partial sight and visibility

“To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; in each case, to whom, how, when, and where” (Goffman, 1963, p. 42).

While blind students barely had an option regarding the disclosure of their disability, partial sight was often invisible and left students with the choice whether or not they wanted to disclose. Often they tried to “pass as normal” in an effort to fit in amongst their peers. For example, Emma, a student with partial sight who attended a mainstream school, succeeded in hiding her disability for three years during school, E(SI77): “And I always hid it, I don’t think anyone noticed anything.”

This invisibility sometimes spilled over into their academic lives as some of them did not request any accommodations, R(CI): “I never asked for any help from the lecturers. . . . I myself never make use of the unit. Because . . . it’s because . . . I don’t want to be rude, but for now I don’t need it. . . . The problem is I don’t want to be like treated differently from the other students. The help that you get in class . . . I don’t want special help. I must get the help that all the other students get.”, and, B(CI): “There are two options, to write exams or to participate with the disability centre so that it can be convenient for me. But for me to remain positive, I want to write with the normal people, to write exams with the normal people to convey to myself what they do I will do as well.”

However, the distinction between wanting to hide the disability and/or wanting to make it visible, was often not very clear cut. Sometimes it manifested as a conflict within the student – the student wanting to be similar to the peer group and blending in, while realising the academic need for visibility and disclosure, E(SI78): “So I’m always between a rock and a hard place: whether I should tell my lecturer in order to try and make my life easier, or whether I should keep quiet and try to fit in. Because sometimes you really just want to fit in." It is therefore evident that students grappled with the conflict of blending in on the one hand, which required obscuring a part or all of the self, hence being accepted more easily; and on the other hand, revealing their impairments and allowing their disability to be seen, so that they could receive much needed accommodations.

For Ashley, the decision to disclose her disability to a prospective boyfriend was rather complex. Not only did she have to decide on the "perfect" time for this revelation, but she also had to weigh the consequences of each decision, A(SI79): "And should I tell them [prospective boyfriends] or shouldn't I tell them? And when? And let's say I don't tell, then I was dishonest. But let's say I tell him, then I lose the guy before he even gets to know me."

In Chapter 6, it was clear that disclosure also went hand-in-hand with experiences in the pre-tertiary environment. So, even though partially sighted students were often reluctant to disclose their disability, none of the partially sighted students from a special school tried to hide their disability. As was described in this chapter, this could have been explained in terms of the disabled identity. Since students from a mainstream school did not enjoy a cohesive group and identity, they probably did not obtain a disabled identity and were thus reluctant to disclose their disability, N(CI): "If I paid attention to something about disability then it was not easy to accept someone seeing that there's something wrong with me so I just didn't want anything to do with it. So I didn't – I didn't care. I didn't want to know about it, because I just wanted to hide from it."

It is thus clear that, unlike in the case of blind students, the relative invisibility of partial sight left many students with the option to conceal the impairment in order to gain acceptance and inclusion into a nondisabled peer group. This might create the impression that, for partially sighted students, hiding only contained positive effects and therefore should be encouraged.

In fact, hiding can have various adverse effects for students with a visual impairment. However, although not mentioned by the students themselves, I will discuss the possible emotional effects of hiding in the discussion part of this chapter.

7.3.2 The "right" attitude – disguising parts of a disability

This theme illuminated the perceived subtle interplay between personality and disability in the students' efforts to make friends. It touched upon matters like confidence, being outgoing and being reserved. It showed how disguising parts of a disability or the self at times facilitated social inclusion.

The stories of the students suggested that for those who were confident, outgoing and spontaneous, it was fairly easy to make friends, Q(CI): "I don't have any difficulties like in meeting new friends. Yah. As I say that I am confident. So they see in me that I'm not shy.", and, P(SI): "We've got a click of friends. You know there's times when I feel okay, enough now! Just enough, because every day it's coffee with someone else and you just like, I need to work! . . . I am a very talkative person and I will introduce myself. You know I don't need an invitation. So if one of my sighted friends are talking to a random person, I just interrupt. Or not interrupt, wait until they finish their sentence, 'Hi, my name is Petro. And you are?' And I stick out my hand."

It is not surprising that this outgoing style and personal initiative was very important in making friends, given the fact that sighted persons sometimes avoided them (refer to 7.2.3), I(SI80): "Someone wouldn't just come and talk to you as a blind person. People wouldn't come and talk to you as easily as they would to another sighted person. So you simply have to know that, if you want to make friends, you will have to put in a lot of effort from your side."

Having said this, more reserved students found it very difficult to make friends, G(CI): “Yah, I do have friends, but it’s not easy to make friends, because I’m not a talkative person.”, and, T(SI81): “I wouldn’t just go up to people and start talking to them. So then I also don’t make friends very easily.”

So, if students with more reserved personalities wanted to make friends, they often had to “adapt” their style of relating to others. In other words, if they were naturally shy, they had to behave as if they felt more confident and outgoing, I(SI82): “I feel that I’m actually an introvert. But if you are blind, you sort of have to force yourself to become an extrovert. It doesn’t matter if you are by nature more antisocial, you have to force yourself to be social if you want to make friends.” So, in some instances, those students who were introverted either did not make friends, or had to adapt what would have been their usual personal style in order to make friends.

Sometimes, in an attempt to make friends, this outgoing style of engagement also entailed a component of disguise. Sometimes it meant that the students had to “accept” their disability, that the painful parts of their disability needed to be kept hidden, in an attempt to make friends, X(CI): “I taught myself that if I don’t accept myself, nobody will. And immediately when you start to accept the problems that you have, people start not to realise that, they don’t recognise that, because they don’t see it in you. You know, when you have a problem now, if it’s not something . . . if I can’t see the depression in you, I can’t say you’re depressed. So I never had a sense of depression, because I never showed people that I had a problem. I never told myself that it was a problem.”, and, C(SI80): “The way you handle your disability is going to determine how others are going to treat you with your disability or how they are going to treat your disability. And that is where I also saw that it is what you make of your disability that is going to determine how others are going to ‘cope’ with it.” In this last quote by Carla, it is evident that nondisabled people sometimes felt like they have to “cope” with a disability; as if it is a terrible affliction. She also pointed to the fact that sometimes the responsibility rested on the disabled students to help others to cope with their disability. This acceptance seemed to entail “being at peace with”, in contrast to “grappling with”, even if “being at peace” was not genuinely how the student felt. In other words, the students had to be appear to be completely comfortable with their disability and not complain about it, otherwise they might not be acceptable to the world. Therefore they had to hide painful parts of their disability in order to be accepted by sighted individuals, and they also had to manage the anxiety of sighted individuals about disability.

Of course we can safely assume that some students really accepted their disability, but the results seemed to suggest that some others felt obligated and forced to appear to accept the disability and the social consequences of impairment in order to make friends.

It is therefore evident that, if students presented an outgoing personality style, the social barrier of a disability became less of an obstacle and students made friends more easily, C(SI84): “I think it is a two-way thing. Uhm, if you have a personality that people could easily click with, then it sort of eliminates the disability. And if you have a more difficult personality, then the barriers, the disability, first has to be overcome.” However, for those who were not outgoing, it was more difficult making friends.

7.3.3 Finding the “right” activities

> Very occasionally local Brownies would join us for activities in our extensive grounds. We would be paired off with them for a treasure hunt through the woods, searching for milk-bottle tops – the speed at which they found them was really quite amazing. They seemed to know about us, though, and would be very kind and point the ‘treasure’ out,

> and even let us pick it up ourselves sometimes, but relying on their bounty spoiled the fun and we wished we could just talk to them or play a different game. (French, 2004, p. 83)

It was often difficult for the students to participate in all socialising activities. Some popular sports, in particular, were highlighted as activities that were mostly unavailable to them, X(CI): "I can't play soccer with my friends.", and, A(SI85): "We cannot do sport with the residences. And many of these things, like sports, it was, like in [residence name] it was the biggest thing; participation in sports. And I couldn't do it. And it, like I was shut out. So you have to get something that will keep you there."

It was therefore often difficult for these students to find someone who shared their interests and abilities as these also mostly centred around inaccessible socialising activities like watching rugby matches, W(SI86): "And it's difficult finding someone in the residence who had something in common with me. Very difficult. Because in my residence, for example, which is a male residence, everyone watches rugby and I struggle a lot watching rugby. . . . And it was also difficult for me to find stuff that I could talk to them about. You know, it was, it was mostly about rugby and things that happened in the quad."

Sometimes, the students felt that participating in activities would have meant holding nondisabled people back, I(SF): "So during orientation week we did this dance routine. And, well, this girl tried showing me the moves. But in the end I just said, 'It's fine, I'll sit this one out,' because I didn't wanted to hold her back. I mean, she was also behind because of me."

Some students found that as soon as they started participating in an activity that they could share with others, they started making friends. For most of these students, this was a process and only happened in their later years of study. For example, Carla and William reported that they made friends only in their third year of studying, W(SI87): “All that I can say is that I only started making friends when I joined the choir. By that I mean sighted friends. But it’s because we had something in common. Again it’s that whole thing of commonality.”

It is thus evident that students attempted to blend their taken-for-granted worlds with that of their nondisabled counterparts. Finding the right activities and something they had in common with each other was often experienced as a very effective way of making friends.

7.3.4 (In)dependence

Students had various experiences and opinions on the way in which being dependent influenced their day-to-day relationships and social interactions with nondisabled persons. As seen in 7.3.2, nondisabled people often offered their help to visually impaired students, but students differed on whether they wanted to accept or ask for this help.

Some students easily asked for help, P(SI): “If I need something, if I want something, there is nothing wrong to ask.” In contrast, others felt ashamed asking for help, since this meant that they didn’t blend in with their nondisabled peers, M(SI88): “And it was difficult for me to forget about my pride and sometimes ask for help. Because you want to get by and you want to appear like you know where you are going. And you just want to fit in.”

This decision whether to accept or reject help was generally closely tied to their belief on how it would influence friendships. On the one hand, some students related that they made friends by asking for help and depending on others from time to time, H(SF89): “One evening I needed to go to ABSA (a local bank) and I didn’t want to go alone. I randomly asked someone in my residence, ‘Excuse me, I don’t know you, but would you mind walking with me?’ And we started chatting and today we are very good friends.” Haily went on describing that, even though in the beginning someone might want to help a disabled person, it might also be a way of getting to know someone, H(SF90): “Perhaps in the beginning they will be friends with you because you are blind and they want to help you, but as you spend more time with them they will start liking you as a person.”, and, S(SF91): “Often it starts like that. Often they help you and later they realise but this is actually a nice person.”

William even spoke of the possible hindering effect too much independence might have on potential friendships, W(SF92): “If you are very independent, some people get this idea that you are on your own mission and they just shouldn’t disturb you. And I think one way of connecting with sighted people is to accept help. Not necessarily asking for help, but accepting help.”

On the other hand, as seen previously, some students believed that accepting help might create an unequal friendship, with the blind person always receiving help without the opportunity to reciprocate. In some instances, they also observed that some nondisabled persons were not as willing to help as others. For example, Liza noticed that nondisabled persons were sometimes very cautious of entrapment, L(SI93): “Sighted people are very cautious that they, uhm, don’t end up in a situation that places them in a difficult situation. That they would have to carry their own burdens as well as that of a blind person.”

Some therefore noticed that when they became more independent, more of their peers wanted to be friends with them, C(SI94): “But the day I got my dog things changed. Uhm, yes, so then I was invited to things like, uhm, for example, to go and visit someone or for coffee or whatever. Almost like they realised, okay, she can actually be independent as well, you know? So now we don’t have to do everything for her anymore.”

William remarked that dependence on behalf of blind people was acceptable for nondisabled people, as long as they knew that the blind person could do things for themselves. For example, the sighted student would be less cautious if they did not feel obliged to provide help, W(SF95): “I know many people in the choir. They know I can walk by myself. When I walked to the choir with my cane, many people came up to me and said, ‘Hallo, do you want to walk with me?’ But he knows and I know that I could walk there by myself.”

Some students also acknowledged that relying on others left them somewhat vulnerable, C(SI96): “I often missed classes, because of other people who forgot to come and fetch me.”, and, A(SI97): “And I can’t go out with them at night. They don’t understand that I can’t see. And it’s easy to say, we’ll walk with you, but then they get drunk. They get terribly drunk and then I have to get by on my own.”

In summary, it is clear that students differed on how they viewed the effect of dependence on relationships with nondisabled people. On the one hand students saw dependence as a platform for friendships and a way of making others feel valuable. On the other hand, some students saw dependence as creating a power-imbalance in a potential friendship and containing negative consequences for both the helper and themselves.

7.3.5 Socialising with disabled students

In the light of the lived reality that visually impaired students often could not show their full selves to their fellow sighted counterparts, it is not surprising that they often socialised more with their visually impaired friends. With each other they could “let their guard down”, relax and just be themselves. They did not have to be invisible, manage the discomforts of others, adapt their personalities or thought of finding the “right” activities. The struggles they shared with each other created a sense of cohesion and comfort in a world where they often felt alienated, P(SI98): “I have a blind friend here. If she’s not here, then I’m, you know, you just feel so lost. Not for anything, but because blind people understand. They understand what you’re going through. So it’s like a support group on its own.” Interestingly, for Emma this cohesion extended visual category, since she also felt accepted by fellow deaf students.

Of particular value for them was the fact that they could share the painful and challenging parts of their disability experience with their disabled counterparts, W(SI99): “Well, I have a friend who is also blind who studies exactly the same course as myself and started studying at the same time I did. . . . So another blind person who suffers like me. . . . It sort of helps telling someone how bad life is. And then if he also agrees with it, then it’s even better.”

Similarly, Emma who transitioned from a mainstream school, found great support in fellow disabled friends, E(SI100): “So here I sort of fell in with the blind circle of friends. And it’s a great support in that way to have people to drink coffee with and you bitch together about whose lecturer is the worst and whose work is the most behind, that sort of stuff. It makes it easier. Then you don’t feel so alone and caught up in everything.”

Furthermore, apart from being supportive, blind friends were also viewed as a source of information and advice, M(SI101): “Sometimes you just want to talk to someone who shares your problems. Who could, sort of, give advice and, sort of, share experiences. And maybe you could learn something from it. And actually we are currently doing it.”

The students who did not have friends with a visual impairment often expressed isolation and the desire to have such friends. These students often came from a mainstream school environment and therefore did not have to opportunity to build friendships with fellow visually impaired people from school. For Nandi, making use of the disability unit, where staff members understood her disability, also made her feel “normal”. Here she could also relax in unconditional acceptance. It must be noted that Nandi, at the time of the interviews, did not have any blind friends; therefore the disability unit was her only contact with people that worked with and that had disabilities, “I will go like, let me go to the disability unit if it’s not busy. I just want to go and spend time there. It’s not that I’m trying to avoid the outside, but I felt normal when I went there. . . . I feel like the people who are here are dealing with different situations – are dealing with people like me. So. And they won’t look at me and go like, oh, something is different. They won’t judge me. Yah, I felt so encouraged. . . . Being here, being part of the disability unit is like knowing that I have a place; I have people who care.”

7.4 Discussion

It is clear from the previous sections that visually impaired students dearly wanted to be accepted in their social group. However, this acceptance rarely came “naturally”. To the contrary, the experience of behaviours of sighted people, along with the reactions by visually impaired students, often complicated the social interactions between them.

The following sections will shed light on and lend further depth to the understanding of these social interactions between visually impaired and nondisabled persons. The first part of this discussion will look at the visually impaired students’ experiences of being seen or not. In other words, did they feel affirmed and acknowledged; did they feel truly “seen” in the gaze or averted gaze of nondisabled persons? Moreover, how did they respond to being seen or not? After this discussion of being seen, a deeper look into the phenomenon of helping, as it manifested within the relationship between visually impaired and nondisabled persons, will follow. This section will offer an overview of the way in which visually impaired students experienced help from their nondisabled peers, as well as their reactions to it.

7.4.1 Being seen or not

“Why fear the visibility without which we cannot truly live?” (Lorde, 1984, p. 42).

"Perhaps most destructive to the potential for continuing relations is the normate's frequent assumption that a disability cancels out other qualities, reducing the complex person to a single attribute" (Garland-Thomson, 2009b, p. 68).

According to psychoanalyst, Winnicott (1960), being seen is central to the development of the self. Within the visual gaze of another, human beings come to the precious understanding that they matter to someone else. Reflected in the eyes directed to them, they find validation and, hereby, they are able to see themselves more clearly (Garland-Thomson, 2009a; Watermeyer, 2013; Watermeyer & Swartz, 2008). The words of Sartre illustrated this beautifully when he wrote, "I do not see my own face. I carry [my face] in front of me like a secret which I have not fathomed. And it is the faces of others, instead, which teach me what mine is like" (Sartre, 1956, p. 159). Thus, since being seen is like a mirror reflecting one's worth, its absence will impede individuals' ability to see and know themselves completely.

The participants in this study experienced that nondisabled persons sometimes looked at them or looked away from them. On the one hand, some recalled that the nondisabled gaze was sometimes directed to them in a stare, while, in other instances nondisabled eyes avoided and overlooked them. The real issue here is not whether nondisabled people saw them, but whether the visually impaired students felt truly seen and validated in the grasp of these looks or averted gazes.

Turning our attention to stares, the participants did not necessarily feel "seen" when someone stared at them. Even though stares meant that someone looked at them and that their presence was physically recognised, these stares often did not make them feel truly seen. Within the stare, they did not see an acknowledgement of their entire personhood, but rather the recognition of their differentness. Hence, they felt that they were seen only in part and not in the full variety and complexity of their being. This was movingly reflected by these words of

Nandi, N(CI): "When I'm around people I forget that there's something with my eyes. At a later stage you'll go like, oh, someone is looking at me in a strange way. That's when I'll come to remember, oh, my eyes are different. So they are looking at me for them, they are not even listening to what I'm saying, they are just looking at my eyes as if something is wrong with them. But it's better if someone can see and listen, you know, can see me for who I am."

From this quote, it is clear that Nandi felt that parts of herself were not validated and affirmed through the stares of others. On the contrary, only her disability was affirmed and, through the eyes of others, she was once again reminded of the differentness of her body – she was reduced to an example of a disabled body. She felt that nondisabled persons were not interested in what she had to say or who she was, since the focus of the stares fell on her disability. In this way, the stare, in some way, invalidated the nondisabled parts of herself and made her into a signifier for their own concerns and anxieties about disability. Her personhood was not recognised (Reeve, 2012).

Although stares were therefore commonly experienced as an invalidation of parts of the self, the stories of some participants showed that stares, paradoxically enough, sometimes served as an opportunity to become fully known. For example, Vicky recalled an incident during her school-going years. In her school, one learner stared at her and thought she was a monster. In response, Vicky used this opportunity to put the learner at ease and to educate her around her disability. Similarly, in her book, *Don't call me inspirational*, dealing with her life with cerebral palsy, the feminist disability activist and scholar Harilyn Rousso (2013) recalled a staring encounter in a coffee shop. While drinking coffee, Rousso noticed that a new customer was staring at her. In this stare, she recognised elements of fear and disgust. Rousso then started talking to the staring woman, finding commonalities between them. In this discussion, she recalled, she was transformed from "freak to friend" (p. 22). As Garland-Thomson

(2009a) wrote, “Staring becomes a starer’s quest to know and a staree’s opportunity to be known” (p. 14). This educational aspect of the stare should not be under-estimated, since it was clear from the literature review that nondisabled people often were not properly informed regarding disability (Erten, 2011; Mullins & Preyde, 2013; Shevelin et al., 2004).

It is therefore clear from the stories of the participants that they did not feel fully validated and affirmed in the staring gaze of nondisabled persons, these stares nevertheless on occasion presented them with the opportunity to become known. Garland-Thomson (2009a) summarised this neatly when she wrote, “Staring, then, has the power to sustain or demolish us” (p. 58).

On the opposite end of stares, students also experienced that some nondisabled people did not look at them at all. In many instances, they were ignored, forgotten and avoided by their nondisabled peers. The students mostly believed that these avoidant behaviours stemmed from fear and discomfort regarding disability within the minds of nondisabled persons. For example, they speculated that nondisabled persons were so scared of doing the wrong thing when approaching disabled persons that they rather did nothing at all. In this understanding, it seemed like the participants recognised that some nondisabled persons wanted to approach them, but they really did not know how to do so.

Of course, as could be expected, these avoidant behaviours did not lead to a feeling of “being seen” for the visually impaired students. To the contrary, it often elicited feelings of self-doubt and being overlooked. For example, many female participants mentioned that men avoided them. In instances like these, they often wondered which part of them was not okay: was it their appearance, their disability, their personality?

On the whole, it is therefore evident that the looks or averted eyes of sighted individuals did not contribute to a feeling of being seen. Instead, where the students experienced the looks of nondisabled persons, they mostly felt that their only disability, which was only a part of their identity, was seen. Their lives were much more, and much more complex, than just the experience of impairment, and it is this complexity and multifaceted nature of their lives (and all lives are complex and multi-faceted) that they felt sighted students could not understand. They felt that only their impairment was seen.

The results clearly showed that the participants put in a lot of effort to manage the way they were seen by nondisabled persons. Paradoxically, many of them tried to obscure their disability; the only part of them that was generally “seen” by nondisabled persons. They thus kept quiet about their disability and did not request special accommodations. They feared that should others discover their impairment, that they would be excluded from social groups (see also Elliot & Wilson, 2008; Kranke et al., 2013; Low, 2009; Magnus & Tøssebro, 2013; Roberts et al., 2009). Part of this fear of social exclusion seems to have centred on the worry about seeming too much, too difficult, for others to handle. Some other students did not view themselves as disabled and therefore they did not want to be seen as something they thought they were not (See Chapter 6). However, Reeve (2012) warns that trying to pass as normal (Goffman, 1963) might have emotional consequences for disabled persons as they have to live with the ever-present reality that their disability might be discovered. In some respects this is similar to “passing for white” (Nerad, 2014) in the context of racial oppression – it means living with the constant anxiety of being unmasked as dishonest. A further consequence, French (2004) and Garland-Thomson (2009b) pointed out, was that disabled persons, in their pursuit to spare nondisabled persons the discomfort of their impairment, might deny their limitations and needs and, hereby, betray themselves.

Not all the students tried to obscure their entire disability. In fact, some students, particularly those with a visible impairment, hoped that their impairment was visible to others so that they could escape physical harm. Having said this, most of them tried obscuring their experience of impairment in a different way. Although they did not hide their disability completely, they generally brushed over the difficult parts of having an impairment. Similar to those students who tried to "pass as normal", these students also considered the possible discomfort and anxiety their disability might have elicited for nondisabled persons. They learned that the painful parts of their disability, those parts that they perhaps could not make peace with, were anxiety-provoking for nondisabled persons. For example, Carla recounted that others – meaning nondisabled persons – would only be able to "cope" with her disability if she appeared to accept it with equanimity. Therefore, in order to make others feel comfortable about their disability and to fit in, they had to "accept" their disability. Generally they felt that only when they accepted their disability in a manner which did not cause anxiety to others, others would be able to accept it, too. So, despite limitations, despite the fact that, once in a while, everyone experiences difficulties and hardship, these students had to fabricate bravery (Carel, 2013a; Watermeyer, 2013).

The language of "acceptance" has a clear basis in the popularization of psychoanalysis (the opposite of acceptance, presumably, is the stigmatised and pathologised state of "denial"). Applying popularised psychoanalysis in this way is predicated on the idea that disabled people must have psychological trauma or pathology requiring a prescribed set of thoughts, feelings, and behaviours as a form of treatment or palliation. Sadly, however, the fact is that no amount of thoughts can really "treat" a disability or cure it. Sally French (2004), a disability writer who grew up with partial sight, wrote about the roots of denying an impairment. From early on, she learned that her close family members became anxious around the "truth" of her disability. So, in order to "calm" their fears, she started minimizing any talk about difficulties she experienced – in effect, she learned that in order to manage the anxiety of others she had to be inauthentic and to lie about certain key parts of her experience. As an adult, this concealment continued. She noted how disabled persons would frequently assure nondisabled individuals that they were okay, despite difficult circumstances.

However, as stated before, “being seen”, and this means being seen in all our complexity, is an invaluable part of understanding ourselves and knowing that we matter to another. If we thus do not show all of ourselves – our ugly, unlikable, shameful parts, as well as our desirable and attractive qualities – we are stripped of the ability to be fully seen by others and by ourselves (Watermeyer, 2013; Watermeyer & Swartz, 2008). If one hides parts of one’s self, the consequence may be that the precious and invaluable sensation of being accepted for who you one is, with all one’s strengths, weaknesses and challenges, is lost. In the words of Gill (2001, p. 364), “how can they be accepted for who they are unless they are knowable as they are?”

It is therefore clear, as Watermeyer (2013) noted, that disabled persons commonly find themselves between a rock and a hard place – when they show their full selves, this may raise anxieties for nondisabled persons and therefore only their impairment becomes visible. On the other hand, if they obscure their disability or parts thereof, they also live with not being fully seen. At worst, being fully seen becomes an elusive possibility regardless of what disabled people may or may not do.

It is therefore not surprising that visually impaired students generally found comfort in friendships with their fellow disabled peers. Goffman (1963) referred to people who shared one’s stigma, as “sympathetic others”. He rightfully argued that, amongst sympathetic others, a person could drop the mask of accommodative adjustment and relax in the comfort of feeling at home, feeling accepted and feeling like a whole normal human being. If they could just "be" rather than "become" (Kierkegaard, 1974), they could be their entire, complete selves. Amongst their fellow blind students, the participants experienced the value of being seen and accepted in their entirety. Nandi thus referred to the Disability Unit as "a home", where she felt "normal", while Emma said that only visually impaired students could truly understand her. Similarly, William appreciated the fact that he could share his academic struggles with another blind person, "I have a friend who is also blind who studies exactly the same course as myself and started studying at the same time I did. . . . So another blind person who suffers like me. . . . It sort of helps telling someone how bad life is. And then if he also agrees with it, then it's even better." From this it seems that they did not have to hide parts of themselves when they were with their blind friends; here they were free to talk about the painful, difficult parts of their impairment.

Having said this, although it was understandable that these students were somewhat relieved being able to talk about their painful experiences, caution is also warranted. It is somewhat worrying that not one person mentioned, for example, they felt irritated by other blind students. Surely, not all persons with a visual impairment are alike. In all groups of people, we might find people who we get along with and others who we do not. Why then did it seem that the blind students of this study only had good things to say about their nondisabled counterparts? Of course, it could be that they only chose visually impaired friends with whom they felt comfortable with and with whom they shared commonalities; on the other hand, it could also imply that they once again denied parts of themselves in order to be accepted by their fellow visually impaired counterparts. For example, even though they might have felt that they did not like some of the blind students in higher education, they might have become friends with them because it is perhaps too hard denying that, someone who shared their exclusion, was not someone they could relate to. In this way, “feeling comfortable and seen” by visually impaired students might have led to another form of misrecognition altogether.

In summary, this section showed that the participants rarely felt seen by their sighted counterparts. They therefore employed various strategies to manage how they were being seen. Ironically, these strategies could, in theory, lead to further invisibility.

7.4.2 Being helped or not

Everyone needs help. We all need to ask for assistance from time to time, whether it is with a difficult emotional problem, a physical ailment or with a practical task. Not one person possesses all the skills necessary to tackle all life’s difficulties and requirements, and this is where we sometimes lean on others for support. Help, therefore, could be said to be indispensable for survival. All people need care, all people need help (Tronto, 1995).

Having said this, for the visually impaired students of this study, asking for, receiving or refusing help was much more complex than a mere consideration of whether they needed it or not. For them, just as with being seen or not, help influenced their relationships with sighted persons. In managing their relationships, they sometimes had to be untrue to their needs, which meant that they did not necessarily accept help when they needed it or refused it when they did not need it.

Clearly, there were two divergent opinions on the way in which help influenced relationships. On the one hand, some students explained that receiving and/or accepting help was beneficial in the formation of friendships with sighted individuals. They acknowledged that, at first, nondisabled persons probably only saw their impairment. However, they believed that accepting help presented them with the opportunity to become fully known. For example, Haily recalled that she once asked someone to accompany her to the bank, “and today we are very good friends."

Some students also noted that they accepted help even in instances where they did not really need it. They did this because they presumed that sighted persons wanted to help in order to feel needed and valuable. This referred to the psycho-analytic phenomenon of psychic pay-off (Marks 1999a; Watermeyer, 2013), where nondisabled persons benefit in a psychological way from providing help to disabled individuals. However, as social model writers would warn, in their effort to make others feel needed, the visually impaired students might have run the risk of becoming the "needy" objects of charity (see Hughes, 2012; Loja et al., 2012; Oliver, 1990; 2009a).

Probably because of the afore-mentioned reason – the unequal give-and-take between a person with and without a disability, Ilse-Marie pointed out, I(SF102): "The dependence helps you in meeting people, but you meet them and they are sort of your friends, but they are not really your friends. They will help you, but they won't open up to you or allow you to help them in any way." This unreciprocated, unequal give-and-take that sometimes exists in the relationship between disabled and nondisabled persons, signifies a clear power imbalance, however good the motives of the nondisabled persons may be. A further reason why students tried not to ask for help, was because they thought that their nondisabled peers did not like being obligated to provide help. For example, Carla and Liza reported that, once they had a guide dog and had become less dependent on others, their nondisabled counterparts seemed more willing to be friends with them. Some also mentioned their own vulnerability in depending on others. As we saw, Ashley mentioned that she could not see at night. She thus avoided going out at night, because if she did, she was dependent on her friends. She went on explaining that sometimes her friends got so inebriated that they forgot to take her home. Similarly, Carla recalled that, before she knew the routes on campus, her peers often forgot to take her to her class. This is reflected in the literature. French (2004), for example, also spoke of the denial of needs to spare others the discomfort of dealing with the truth of a disability.

Perhaps in an attempt to restore equal balance to the relationships they had with nondisabled persons, some students found that the middle ground lay in accepting help, but with the knowledge that they could still do things for themselves. For example, William mentioned that people sometimes offered to accompany him to the choir building, in the knowledge that he knew how to get there on his own. Even those students who found help beneficial for the formation of relationships, stated that it was only beneficial if they knew how to perform tasks independently and were thus not helplessly dependent on a sighted person’s help for everything. This restoration of the power balance brought with it two important benefits. Firstly, the students did not feel as vulnerable in their dependence on sighted persons. Secondly, knowing that visually impaired students could, for example, get to their classes also relieved sighted students from the obligation of “having” to help.

From this section it was clear that students differed in the way they perceived the influence of help in their interactions with nondisabled persons. However, the main issue here is not whether they preferred to receive, ask for or refuse help from their nondisabled peers – even though this might also be important. What is problematic here is the fact that the students sometimes did not act according to their needs – it seems that some denied help when they needed it, while some accepted help when they were perfectly able to cope without it. For them, this decision seemed to have centred on the consideration of friendships versus unequal relationships. However, everyone agreed that accepting help was not an excuse or a reason not to learn how to do things for themselves. As Haily stated, “Someone will tell me, ‘Come, let me make you some coffee.’ Then I say, ‘Okay, but please show me where everything is so that I can also do it myself. Because I want to be able to do it myself. So that I will be able to make myself a cup of coffee even if you are not here.'"

7.5 Summary

It is clear from the previous sections that the visually impaired students often had to manage their relationships and interactions with nondisabled persons. Often, in order to establish or maintain a relationship, they obscured their disability, or parts thereof, so that others would not feel uncomfortable in the face of their differentness. This, however, meant that they were not truly seen in their entirety. Having said this, electing to show their disability with all its uncomfortable parts also sometimes left them invisible, as only their disability was seen. For example, typical reactions in the sight of disability was people who stared (seeing only their disability) and people who averted their gazes (from the sight of disability).

A further facet that possibly had an effect on the participants' relationships with nondisabled persons was the aspect of being helped or not. The visually impaired students, particularly those whose impairment was visible, generally had two different opinions on the way in which the receipt of help influenced their relationships and friendships with sighted peers. Some believed that accepting and asking for help, even in instances where they did not need it, was beneficial for the formation of friendships. They believed it served as a gateway for sighted peers to get to know them and that nondisabled persons also obtain psychological gain from helping them. On the other end of the spectrum, students did not want to ask for help. They believed it signified a power-imbalance, where the sighted person is the giver and the visually impaired person is always the receiver of help without any room for reciprocity. They furthermore pointed to the fact that sighted persons were sometimes cautious of being "trapped"; always having to help a blind person. Lastly, it was mentioned that total independence also left them vulnerable, since fellow students sometimes forgot to help them.

Clearly, the relationships and interactions between students with and without visual impairment were rather complex and contained elements of invisibility and (in)dependence. Often the visually impaired students had to manage these facets of interactions in such a way that they could still establish and maintain meaningful relationships with sighted persons, even if it meant that they had to betray themselves.

In the following chapter it will become clear that, not only did the participants often manage their relationships with sighted persons, but they also took a lot of responsibility in ensuring that they could meet academic requirements successfully.

CHAPTER EIGHT

RESULTS AND DISCUSSION PART III:

THE LEARNING ENVIRONMENT

8.1 Introduction

I have briefly touched on the academic experiences of the students in Chapters 6 and Chapter 7. Chapter 6 looked at the pre-tertiary environment and its possible influence on requests for accommodations, while Chapter 7 illuminated the need for social acceptance, the visibility of the impairment and requests for accommodations. This chapter will unpack specific difficulties and successes visually impaired students encountered within the academic milieu. More specifically, this theme will give an overview of:

- Accessing course material.
- The embodied experience of reading.
- Assessments.
- Sense of accomplishment and pride.

In some of these themes, there were some differences between the experiences of CPUT and SU students. This was partly related to the differing structure of the disability support of these institutions as well as the level of eyesight. Probably the greatest difference was with regard to economic background. It will become clear that, in instances where students came from an impoverished background, they found it especially difficult to master essential technological equipment. Where applicable, these differences between CPUT and SU students will be highlighted.

8.2 Accessing Course Material

In Chapter 3 and Chapter 4, it was clear that there were not many differences between the experiences of visually impaired students and those with other impairments with respect to their social encounters and their transition to university. However, probably the biggest difference was visually impaired students' difficulties with the written word. It is therefore no surprise that the students in this study spoke in length about matters related to the accessibility of course material.

The majority of the students in this study were unable to read the usual text size of lecture notes and textbooks, and none of them could see class notes on the board or projectors, A(SI103): "When they are using the projectors and stuff they switch the lights on then they switch the lights off then they dim it. So I said, 'My eyes can't handle it.'", and, B(CI): "It's difficult for me to see in front on the board where lecturers are working.", and, R(CI): "When you do powerpoint presentations you have the slides. So it is difficult for me, because it's bright." Therefore, in order to learn, students had to get their material in an accessible format. In this subtheme, two aspects of accessing course material will be described. These are:

- Various role-players in accessing course material.
- The initiative and responsibility of the students.

In the discussion that follows, the various role-players and their approach to access to course material will be highlighted.

8.2.1 Role-players

For the disclosing students at both SU and CPUT, lecturers played a prominent role in making course material available. Sometimes this meant providing students with class notes, while in other instances it meant providing the textbook to the Braille Office for conversion into an accessible format. The SU students also cited the Braille office (discussed in 8.2.1.2) as an important role-player in making course material accessible in a timely manner. The CPUT students mentioned the Disability Unit as an important place where they could learn and use technology and assistive devices.

8.2.1.1 Lecturers

From the stories of the students it was clear that lecturers differed in their willingness to make course material available to them. Most lecturers were accommodating and willing to assist the students, S(SF104): “Many lecturers e-mail things directly. As soon as they have something in an electronic format, they e-mail it to the Braille department. I tell them and then they are like, ‘Okay, yes, we will do it.’”, and, X(CI): “I was one of the most fortunate people. Everything was done for me. I could just tell them, ‘Please, when you print notes just print me a A3.’ And I never had a problem. I was never ashamed in class. They knew that the A3 paper was mine.”

For some students, this willingness of lecturers was a tremendous relief and helped them to fare well in their academic studies. For example, Mia said that timely accessible course material placed her on an equal footing with her sighted peers, M(SI105): “So they [French Department] really go out of their way to, I almost want to say, to make it just as possible for me to do well as it is for other students. To sort of get me on the same level as the other students.” Mia was thus able to get a certificate for academic excellence for French at the end of her first year.

Despite the willingness of most lecturers, some simply forgot about the needs of the visually impaired students in their classes, Z(CI): “Like for instance in class like the lecturers they do at times forget about me. They give out fine print and then I constantly have to remind them. . . . They just say, ‘Oh, I forgot.’ And then they will tell me to come afterwards.”, and, W(SI106): “I still remember the first test we wrote the professor forgot to get the question paper in a format that we could read. So the tutor first had to read the test to us before we could write. And that took an hour.” In instances like these, it often took a lot of energy from the students reminding lecturers of their accommodation needs.

In rare circumstances, lecturers were outright unwilling to make course material available to the students, A(SI107): “One lecturer told me that I couldn’t get the notes beforehand, I had to come to class. So, I go to class, but I can’t see on the board.”, and, M(SF108): “And the lecturer simply said that she was sorry, she was not going to give the book to us, because there are plenty of books in the book shops, I must buy me one. And when she came to class she told us that she didn’t give out slides. Nothing. You have to take notes, otherwise you will fail. So we went to her and we said, ‘I am in class every day’. I just wanted to know whether she had something on paper that I could use, because the others could take notes. She said, ‘No’. She simply said, ‘No.”

Emma’s situation clearly illustrated the implications and emotional turmoil of unwilling lecturers. At the time of the interview, Emma took a subject with no prescribed books. The only available course material was in the form of notes that the lecturer displayed on a projector during class time. Since Emma could not read the notes on the projector, she asked her lecturer to e-mail his notes to her. He refused to give his notes to her, since he did not believe that she had a disability, E(SI109): “I’ve got a letter from the eye specialist and he [lecturer] still thinks there something wrong with my IQ. He is like, ‘Yes, if I give you my notes, you will still not be able to do well.’” From this account, it seemed like this lecturer possibly conflated the need for special – and reasonable – accommodations with lazy students who did not want to work.

This was a big concern for Emma, since this was her major subject, E(SI110): "This is the subject I'm majoring in. If I fail this subject, I can't go on to honours. You can go nowhere if you don't pass this subject. It's like you're stuck in this worm hole, you know? So eventually I'll have to pass it."

In sheer desperation, Emma went to the Office for Students with Disabilities to ask for assistance. Here, she reports, she was advised to go back to the lecturer, taking her mother with her, to ask for accommodations. Emma felt that this was patronising and humiliating and she wished that the office would have been more proactive in their approach, E(SI111): "She [person at disability unit] told me that I had to go talk to the lecturer and take my mother with me. And then, if he still doesn't want to do anything, she will talk to him. But I don't think anyone understand that you don't want to cause that type of trouble. It kind of feels like school, you know, you take your mother somewhere. And it's kind of humiliating to complain about something like this all the time, you know? I mean, it was already bad enough the first time I went to talk to him and told him, 'Look, I can't see.' And then he treats me like I can't think. I feel if I have talked to him once, then they [disability unit] kind of have to sort it out in a nice diplomatic way, without me even knowing about it, you know? So that when I go to class again it's already been taken care of."

Consequently, at the time of the interviews, Emma was considering dropping out of SU and going to another tertiary institution, E(SI112): "I've actually considered checking whether the university would refund me for this year so that I could go and study elsewhere."

Interestingly, in one of the focus group interviews at SU, the students observed that it was sometimes better if lecturers did not have prior experience with visually impaired students. They felt that, as soon as lecturers were familiar with other blind students, their unique circumstances and range of vision were overlooked, W(SF113): “What I enjoyed about the Geology department is the fact that they didn’t have blind students before, so everything is new to them, you know?”, and, W(SF114): “We were the first blind people in that poor lady’s class. She really made a lot of effort. You walk in, she gives notes to the sighted person and she gives notes to me, as well.”, and, H(SF115): “It is difficult with the Sociology department, because they had so many blind students already. So when I ask for an extension, they are like, ‘But no-one ever asked for an extension before.’ ‘Hallo! But you don’t know Jonathan (staff member at Braille office) broke his foot last week!’”

In effect, they felt like lecturers saw them like “one undiscernable” unit – if one visually impaired person achieved academically, they expected the same from everyone with a visual impairment. W(SF116): “They perceive you [disabled people] as a unit”, and, H(SF117): “Then they’d tell you, let’s say, ‘But Amy got 85 % for her psychology test.’ Then I’m like, ‘But I’m not Amy’.”, and, I(SF118): “Everybody’s situation differs. Everybody’s field of vision differs. Everybody’s abilities differs.”

It is thus clear that the willingness of lecturers in making course material available to the students differed in rather significant ways. Interestingly, this willingness of lecturers did not necessarily go hand-in-hand with their prior experience with visually impaired students. To the contrary, students sometimes had more positive responses from lecturers who never had blind students in their classes, than with those who were quite familiar with disability. Having said this, it should be noted that this was not always true for everyone.

8.2.1.2 The Braille office at SU

The Braille office is a division of the Office for Students with Special Learning Needs (Disabilities) at SU. They – the Braille office – are responsible for converting printed text into an accessible format for students with a visual impairment. In other words, the staff at the Braille office scan printed textbooks, notes and other visual material and thereby convert this material into an electronic format or into Braille. The narratives of the students strongly suggested the importance of the Braille office in timely access to course content.

Similar to their accounts of lecturers, not all the students had the same experience with the Braille office. Some found the staff at the Braille office very effective and helpful. Some even noted that these staff members went out of their way and did more than was required of them, H(SF119): "And what's nice about the Braille office is that you could go and talk to them about things and it doesn't need to be about academics. Also, if I'm ill, I could e-mail them and tell them, 'listen here'. . . . For instance, last week I could e-mail them and tell them, 'I'm ill, things are going to be sent to you that must be done and so'."

Some others recognised that the office sometimes did not process their material in time, yet they were tolerant and contented with their efforts. They also showed some empathy towards the heavy workload of this office, A(SI120): "I must say I never could complain about them. Considering the amount of work they have to do I think they are doing quite okay.", and, E(SF121): "There are times when things aren't there, but it's really not their [Braille office] fault. They do what they can." On the other hand, some students felt it was unacceptable that they had to wait for course material, P(SF): "We are missing out on work. Why should we always wait?"

However, no matter how the students felt about the work of the Braille office, when they did not receive their material on time it had some implications for them. Firstly, they were unable to participate fully in class, P(SF): “I feel that that is the hugest disability that we have is to wait for documentation or work. For me, it breaks my morale. I go to class and I sit like a puppet.” Secondly, they sometimes fell behind, T(SI122): “And then sometimes you also fall behind if you . . . if they [braille office] takes too long to convert things. And then you don’t get it in time like when others get it. You only get it a week later while the sighted students already got their notes.”

When the students did not have their material on time, they were sometimes ill-prepared for tests and assignments. Therefore they sometimes had to ask for extensions. They were consequently very concerned about the impression their lecturers might have of them, perhaps thinking them to be lazy, L(SI123): “I usually handed my assignments in late and that wasn’t good for my morale. [Laughs shyly] Because it’s humiliating asking for extensions all the time and you’re scared that the lecturers might think you are lazy.”, and, M(SF124): “Do you know how far I am behind? I still can’t read any of the documents and we are already in week four. Because why? Because all the pdf’s I’ve sent them [Braille office] are bad quality, it’s so bad that they cannot process it. My point is, do you know how humiliating it is to go and sit there and she asks, ‘Have you read the assignment’ and you have to say no and you know it isn’t even your fault. You know? If I haven’t read it because I was lazy or because I wanted to go to bed early, then it would’ve been another story. But I’m so frustrated”

It is clear from this section that the Braille office played an important role in making texts accessible for visually impaired students in a timely manner. If the students did not receive their converted materials in time, they were unable to participate fully in class, they fell behind, and they were thus often ill-prepared for assessments. However, the consequences of late materials stretched further than mere practical difficulties. These students also experienced emotions such as humiliation and frustration. It is therefore clear that late materials could impact on the students' emotional well-being.

8.2.1.3 The disability unit at CPUT

As was evident from the literature review, technology such as computers and assistive devices is very important in accessing course material for visually impaired students (Cooper, 2003; Mokiwa & Phasha, 2012; Ngubane-Mokiwa, 2013). For partially sighted students, it meant that they could enlarge texts on the computer, while blind students could use a screen reader to read electronic texts. Not only did this entail being able to read books, but it also opened up possibilities to browse the World Wide Web and to read and write e-mails. Unfortunately, from this study it was clear that, due to their economic background, some students did not have prior experience with computers. This was especially true for three Black students at CPUT, R(CI): "I was struggling with computers, but not because I couldn't see. The problem was it was my first time that I had to use a computer."

In this regard, the CPUT students pointed to the disability unit as being very effective. Here they had access to computers and the accompanying assistive technology, N(CI): "This guy here told me that there are computers. Sometimes you can come here, you know use the computers. I was like, 'Okay.' 'Yes sister, yes, get yourself used to computers. You know like the picture is more bigger.' You know, I was like, 'Oh.' He was like, 'Yes, you can come here.' I was like, 'Wow!'", and, G(CI): "Because right now I came to the disability unit and they are helping me with like they come here at the computer there are zoomtext that I can zoom there and there. The computers are like that I can see what is written there", and, Z(CI): "And then there's the disability unit. Like Phelicia is the one that helps us there. We can have, if we want to print stuff or if you want to type, like they have the computers that have the zoomtext that enlarge fonts. And the keyboard is much easier to read because it's in yellow and in black and it's bigger like the letters."

It is clear that the disability unit of CPUT took the social context of the students into account, since they realised and acted upon the lack of technological knowledge amongst their students. Filling this gap, in 2011 the university employed someone who could assist students with disabilities in adjusting to technology. For the first two weeks of a disabled student's arrival at CPUT, orientation to computers and assistive technology is compulsory (personal communication, du Toit, April 25, 2012).

Unfortunately, the students still didn't have their own computers. Therefore they could not practise their newly acquired computer literacy skills at home, R(CI): "I wasn't sure about the computer. If I had my own laptop, if I were at home I would practise everything we did in class also." They were therefore also dependent on the office hours of the disability unit to finish their assignments. After office hours, some students couldn't work on their assignments, G(CI): "It's just that they are open for a few hours, because five o'clock they close."

It is therefore evident that the disability unit at CPUT played a prominent part in making technology available to visually impaired students. Through this technology, these students were able to access the written word.

8.2.2 The initiative and responsibility of the student

From the interviews it became clear that the students often took a lot of responsibility upon themselves in accessing course material. If they didn't take this initiative, they faced the grim implications of falling behind, asking for extensions, not following in class and even failing, W(SF125): "In an ideal world you probably could've argued that it isn't supposed to be your responsibility. But the point is, if you do not do it, you will struggle so much more.", and, C(SI126): "And here it is also your duty to see to it that the people who need to convert your stuff gets it in time.", and, I(SF127): "It feels like a first year blind student has so much more responsibilities than a first year student who isn't blind. I mean we constantly have to ensure that we have our notes. You can't just go to class and check whether you have your notes, because of course you don't. So you constantly have to remember and check-up. And every now and again you slip up and then you get into trouble.", and, T(SI128): "And then you will tell them [Braille office] that these things are important and that you need it before that date. You try to constantly remind them that you gave it to them and that it is very important and that they have to try and give it to you before a certain date. The others already got theirs and you are writing a test or so. You just have to keep up and go and talk to, or introduce yourself to the lecturers so that they know about you and see to it that you tell them that they have to forward stuff to you. You have to remind them on a regular basis, because they tend to forget."

In the previous extract, the heaviness of the responsibility on the students was evident. In the following quote, Carla found that this responsibility became more overwhelming when communication amongst the important role-players was lacking, C(SF129): "We won't always know what's happening between the Braille office and the lecturer and the Braille office don't know what's happening between us and the lecturer or whatever. So that triangular communication must always sort of be tiptop. And you always have to be the link between what's going on. But they don't pick up the phone and say, 'Listen' or whatever. You run up and down stairs and attend classes and please explain to this one for this and for that one for that."

The non-disclosing, as well as the disclosing partially sighted students, took a lot of responsibility upon themselves in accessing course material. For them, this often involved copying class notes, X(CI): “On the black board, I will have to sit in front of the classroom to see. And sometimes I don’t even see. I listen and write down and have to go back to class write down whatever I hear. So I need to be attentive in class.” Some also tried copying notes from their sighted classmates, G(CI): “I copy from the other students what they’re written down. Sometimes I find they don’t understand what was written down. And if you ask them, you find that they don’t really understand what’s going on on that problem that was taught.” Like Ginny in the previous quote, Nandi also recounted that copying notes meant getting second-hand information, N(CI): “But sometimes you find it’s so hard to copy from another student. Because maybe she’s writing it in her own words; her own way of understanding it. Then you will say, ‘I don’t understand what is going on.’ She’ll tell you, ‘No, I didn’t write that sentence that and that.’ And then you go like, ‘Okay, what’s the use?’ . . . That’s why it’s always better to get it from the lecturers.” This echoes the findings of Newland et al. (2006) that copying notes from peers means second-hand information, since the notes have already been subject to one level of interpretation.

Another hurdle in copying notes from sighted students was their infrequent unwillingness to share their work, G(CI): “Sometimes I feel like they they, uhm, they think maybe I’m lazy. Yah. Because I find if I ask them, they will first make excuses and say, ‘I haven’t got my book.’ So yah, I find maybe they think I’m lazy to do something in class.”

The hard work of taking the initiative and the effort it required was evident in Nandi’s words, N(CI): “To come early in the classroom, to finish all the lectures, the periods and everything. And to always listen and to always have that guidance. To ask ‘What?’ Even if I ask one of my classmates, ‘What is that and that?’ They’ll say, ‘Okay, it is this and this.’ So that if I go to the lecturer and say, ‘Sir, there was something that was saying this and that that I did not understand.’ Then he will know that at least she’s asking with some bit of knowledge. She was there. She was concentrating at least.’”

Some students felt very willing and almost obligated to take the initiative, M(SI130): “Perhaps there are things that departments can do from their side, but you can also walk the extra mile, understand? If you can, yes. I had my computer and my Braille machine and paper and then also a voice recorder. So I sat in class every day. I had no notes. I had to record everything and then I summarised everything at home and studied. So there I’ve learned to work with what I had. You rely on your memory and your hearing and what was available to you. And in the end you make it work.” While others felt the weight of the responsibility was unfair, P(SF131): “Their main thing is, as student you have to see to it that things get to them Braille office. My motto is, I have to attend class. I don’t have time for this nonsense. Just get the stuff!”

It is therefore clear that a lot of responsibility still rested on the shoulders of the visually impaired students. They sometimes had to mediate communication between various role-players and some also had to access course material by copying the notes of others.

8.3 The Embodied Experience of Reading

When the students received their course material in an accessible format, it seemed that they nevertheless sometimes experienced difficulties with reading. For the blind students who used Braille, reading was often time-consuming, since they were unable to visually scan through an article or book, P(SI): “We have to read the entire article that is 60 pages, whereas sighted people they use highlighters, they use rulers, they use pencils and they underline the most important things. . . . And when they study they study the highlighted work. . . . We have to concentrate more than sighted people and we cannot scan through our work; we have to read everything."

For many of the partially sighted students, reading was a marked embodied experience. After long sessions of reading, they commonly experienced strain on their eyes, A(SI132): "We have these four hour lectures and my eyes get terribly tired so that I start seeing spots when I concentrate for too long.", and, B(CI): "In terms of reading and whatever and preparing for examination, compromising the one eye. And of course you are going to experience pressure on that one eye."

At times, this physical strain was not restricted to their eyes. For example, Emma commonly experienced migraines after long hours of reading, E(SI133): "Then you have to lie in a dark room for a few hours and you've got a migraine. It's eye drops, cortisone drops, infections and so forth." John experienced pain in his back from the way he had to read, J(SI134): "Not only the stress on my eyes, but the stress on my body that I experienced due to my eye problem. How I had to sit or learn in school with my head almost on top of the desk and my back arched. And the back problems I developed from that; the bad posture. And then I had to go and write exams for three hours with my nose against the paper."

These bodily manifestations of reading often had real consequences for the students. It generally meant that they could not concentrate and focus on their reading for too long, J(SI135): "I avoid reading, because my eyes get tired and then I get sleepy and then I am unable to concentrate.", and, N(CI): "Every time when I read for long hours, my eyes will turn out to be, I can't see exactly what I'm reading. Then I'll go like, okay, I'm taking too much time, maybe I should take a break.", and, E(SI136): "Later on your eyes are so tired that they cannot focus any longer."

Consequently, it was often difficult for the students to set their own pace, B(CI): “You want to achieve a certain target, you want to reach a certain level of page, but it’s difficult for you to reach that page because you experience pressure of the eye and you need to stop for a while.”

Exactly for this reason, John appreciated the flexible nature of his current dissertation-based post-graduate programme, which was in direct contrast to the frequent deadlines of an undergraduate course, J(SI137): “For example, the product I was able to deliver with my research was good. And if I had only a short period of time to squash everything in and if I had to read a lot within a short period of time, well, then I don’t think it would’ve been this easy doing it.” This is contrary to the findings of Farrar (2006) who found that the reading required at post-graduate level is more difficult than during the under-graduate years.

It is thus evident that reading was often difficult for the partially sighted students in particular. Their eyes quickly grew tired, their bodies ached and therefore they were unable to concentrate and focus for long periods of time.

8.4 Assessments

In the light of difficulties with reading and course material, it should come as no surprise that many of the participants required special accommodations at the time of assessments. Firstly, exam papers needed to be converted into an accessible format, W(SI138): “All these obstacles you have to overcome. It’s not only . . . the professor can’t simply give you a stack of papers and tell you, ‘write the test’ and there you go.”

However, the conversion of the question paper into Braille or an electronic format sometimes did not solve all the problems during an assessment. Carla and William spoke about subjects that contained very visual material which was impossible to process into an accessible format.

Carla, for example, took a linguistic subject which involved a lot of pictures while William sometimes encountered very visual mathematical graphs. In both instances, it was clear that lecturers made alternative arrangements to accommodate them. This is what they said, C(SI139): “Look, learning a language is actually a very visual thing, because they show pictures. Then it’s a person who walks and underneath it, in German, they write, ‘the person is walking’. So basically your brain learns through pictures. So if it should happen in a test, then they describe it or the lecturer would say, ‘Okay, if you get to that question, just tell me.’ Because with me, especially with the language question paper, the language lecturer preferred to invigilate herself. You know, so that if there should be a problem she could sort it out herself.”, and, W(SI140): “Well, at some questions they simply asked us to describe what the graph looked like [instead of drawing it]. . . . I remember in a few tests they asked a question and the entire question just required drawing a graph. In instances like those they simply took the question out of the test and reduced the marks it counted out of.” This concurs with the South African studies by Mokiwa and& Phasha (2012) and Ngubane-Mokiwa (2013) who found that some visual material, like mathematical signs and graphic materials, were not accessible through screen reading programmes.

In addition to the visual nature of material, the majority of students also needed other accommodations like extra time for examinations and assignments, R(CI): “I do get extra time for exams.” Since extra time to complete assignments was often not included in a formal way like extra time for examinations, students had to make individual arrangements each time they needed it. From the accounts it seemed like lecturers were very accommodating in granting extensions for assignments, or, alternatively, diminishing the workload, P(SI): “The lecturers have much more you know they’re much more accommodating with us blind students . . . the lecturer will maybe have ten essays that you have to work out for the exams. So the lecturer will say, ‘Okay, please look at this; look at these three articles. And one of them is going to come in the exam.' You know? I normally go to the lecturer and say, 'You know, it's gonna take me at least ten months to do ten articles or ten essays.' so the lecturer will say to us, 'Okay, now just concentrate on this, that and the other and not ten.' You see? So they'll sort of limit the workload for you.", and, C(SI141): "They [lecturers] would tell you, for example, 'Just see to it that you hand it in. Don't worry about the date, just see to it that you hand it in.'. . . . Because they know it takes longer to search for an article for example and if the article is in PDF then it first needs to be processed."

In few other instances, lecturers weren't as understanding and willing to allow extended time for assignments, I(SI143): "Sometimes I get things a bit late, because it first needs to be processed and so on. Sometimes they [lecturers] allow extensions. Sometimes they are a bit mean and they don't."

However, it was clear from the section on course material that asking for extensions was not always beneficial for the emotional well-being of the students, L(SI142): "I usually handed my assignments in late and that wasn't good for my morale. [Laughs shyly] Because it's humiliating asking for extensions all the time and you're scared that the lecturers might think you are lazy."

It is therefore clear that most students needed reasonable accommodations for assessments, albeit through extra time, adapted question papers or both. Of course, as seen in Chapter 6 and Chapter 7, not all students made use of special accommodations, even though they sometimes needed it.

It seemed from the data that students were generally contented with the special accommodations for assessments.

8.5 Gaining Confidence, a Sense of Accomplishment and Pride

Many of the students felt proud that they were studying at a tertiary institution. Here, they gained confidence in their ability to overcome difficult obstacles (see also Chapter 6), L(SF144): “Look, it would’ve been nice if it wasn’t so much effort, but I think you can really feel good about yourself if you’ve overcome the challenges.”

For Nandi, her pride lay in the fact that, unlike other people in her community, she was making a better future for herself, N(CI): “Back in our communities there’s people who go like, ‘You’re going to school, you’re wasting your time.’ But I go like, ‘Wow, I am at university.’ Some of the people that I use to go with to school, they’ve dropped out at grade 10, they didn’t even finish grade 12. But wow, I am, I am a hero to myself. Because through all these years, up to now, I’ve come out, I’m still doing the right thing that I want, something I can use as a tool for my future.”

William was one of the first two blind students doing a certain academic course at SU. Although this meant that he had to face various challenges and bear the brunt of being in an unknown field, the fact that he was the first person taking on these specific challenges elicited tremendous pride in himself.

It is thus clear that, within a tertiary institution, some students gained confidence in their abilities to overcome difficult challenges. Some also felt proud of this accomplishment, since it was a pathway to a better future.

8.6 Discussion

The experiences of the participants painted neither a rosy nor a bleak picture of the learning environment. Instead, their stories told of their own resilience, resourcefulness and initiative, while also reflecting their humiliations, frustrations and fatigue. Their stories told of the helpfulness of lecturers and disability support staff, while it also pinpointed the lack of provisions that still exist within these tertiary institutions. In the rest of this chapter, I will discuss the steps towards inclusion, followed by the gaps in provision and what these meant for, and required of, the students.

On the one hand, the participants tasted the fruits of the progression towards inclusion within higher education. Their course materials were scanned into an accessible format, they had access to technological equipment and assistive devices and most lecturers were willing to accommodate them. In some regards, staff members even walked the extra mile for these students. For example, some students mentioned that the staff members at the Braille office at SU, in addition to their work, were also willing to talk to them about anything. Furthermore, lecturers also found creative ways of dealing with visual assessments, for example asking a student to describe a graph instead of drawing it. Interestingly, unlike the findings by previous studies (Crous 2004a, 2004b; Erten, 2011; Hurst, 2009; Lehmann et al., 2000; Matshedisho, 2010; Swart & Greyling, 2011), some students experienced that, in a number of instances where lecturers had no prior experience with disabled students, they were more open to take the unique circumstances and abilities of each student into account. It seemed like some lecturers, who had previous contact with visually impaired students, generalised across these students as if they all had the same abilities. And, as Ilse-Marie so insightfully noted earlier in this chapter, everybody has different abilities, eye sight and circumstances.

Unfortunately, this homogenising of visually impaired students and the influence this had on their access to course material, clearly illustrate the power that still rest with individual lecturers. As discussed in chapter 4, Matshedisho (2007b, 2010) ascribed this power imbalance to the distance between formal and real rights for disabled students. In other words, despite policies that outline the rights of disabled students, it seems from the voices of students that these rights were not always enforced. These aspects would need serious consideration in the transformation of higher education.

It is clear that the disability unit at CPUT also responded to the specific needs of their students. Similar to the finding by Sukhraj-Ely (2008), some students at CPUT did not know how to use assistive technology. This was partly due to their financial background, but the FOTIM (2011) report also suggested that this lack of knowledge regarding assistive devices was also prominent amongst students from mainstream schools. Taking this into account, the disability unit at CPUT currently offers a compulsory training programme on the use of technological equipment and assistive devices to first year visually impaired students.

Despite these positive experiences at SU and CPUT, the participants unfortunately also experienced barriers that hindered their full participation on these campuses. These barriers included physical reading difficulties (see also Reed & Curtis, 2012; Reed, Kraft & Buncic, 2004), unwilling or forgetful lecturers and delayed course material. The latter, in particular, was problematic for visually impaired students (see also Bishop & Rhind, 2011; Brandt, 2011; Newland et al., 2006; Ngubane-Mokiwa, 2013; Reed & Curtis, 2012; Roberts, 2009; Seyama, 2009). It is clear that these difficulties were rather practical in nature, which meant that they could be solved by making appropriate adjustments. In other words, the limitations the students experienced within the academic environment were mostly not inherent to their disability. Instead, these struggles could directly be ascribed to environmental barriers (social model). For example, reading difficulties could perhaps be less stressful if sighted individuals were employed to read for partially sighted students. Furthermore, more staff at the Braille office could also ensure that students get their course material on time. These simple reasonable adjustments could help the students to pay more attention in class, could enhance their confidence, independence and motivation and give them an equal starting point to their nondisabled peers (Newland et al., 2006; Roy, 2003). Unfortunately, particularly in South Africa, there are the very real limitation of financial constraints (FOTIM, 2011; Naidoo, 2010). Employing more staff members and/or paying someone to read to visually impaired students will be costly and there might not be the funding to do so.

The underlying thread that ran through the stories about academic experience was the undefined, fragmented way in which academic support were still delivered to visually impaired students. Instead of a unified approach, lecturers still differed in their approach to these students, which left students dependent on their “good graces” (see also Borland & James, 1999; Brandt, 2011; Elliot & Wilson, 2008; FOTIM, 2011; Fuller et al., 2004; Hadjikakou & Hartas, 2008; Hanafin et al., 2007; Holloway, 2001; Hopkins, 2011; Jacklin et al., 2006; Madriaga, 2007; Magnus & Tøssebro, 2013; Mullins & Preyde, 2013; Riddell et al., 2005; Roberts, 2009; Shevlin et al., 2004; Swart & Greyling, 2011; Taylor, 2004; Tinklin & Hall, 1999). This power that was still in the hands of individual lecturers should not be taken lightly. Afterall, in the first part of this chapter it was clear that Emma considered dropping out of SU due to the unwillingness of one lecturer to accommodate her.

We could therefore safely assume that the students were uncertain as to who would be willing to make special accommodations and when they would receive their course material. Given these gaps in provision, students commonly took up a tremendous amount of responsibility in order to ensure that they met all academic requirements. These responsibilities ranged from mediating between the Braille office and lecturers, copying notes and making individual arrangements for extensions on assignments. In other words, they had to self-advocate for their needs (Swart & Greyling, 2011). We saw that, in the face of these challenges, the students adapted and found ways to ameliorate the challenges (Carel, 2007, 2013a, 2013b).

In recent years there has been much talk around the topic of self-determination and self-advocacy of disabled students in higher education (Crews & Keil, 2005; Getzel, 2008; Getzel & Briel, 2006; Halpern, 1994; Naidoo, 2010; Roberts et al., 2014; Stodden, Galloway, & Stodden, 2003; Swart & Greyling, 2011; Thoma & Wehmeyer, 2005; Wehman, 2006). Self-determination encompasses a set of skills that include acceptance of a disability and the knowledge of how it will affect learning, understanding which support services are required, knowing how to describe one's disability and the need for certain supports to service providers; and having the determination to overcome obstacles that may be presented (deFur, Getzel, & Trossi, 1996; Eaton & Coull, 1999; Getzel et al., 2000; Getzel, McManus, & Briel, 2004). It means that a person acts autonomously, self-regulates their behaviour, reacts to an event in a psychologically empowered manner and acts in a self-realising way. Self-advocacy has much the same components of self-determination. Test, Fowler, Wood, Brewer, and Eddy (2005) defined self-advocacy as an act that a person with a disability engages in to demand support. This conceptualisation involves four major components: (a) knowledge of self, (b) knowledge of rights, (c) communication, and (d) leadership. Self-advocacy and self-determination thus require from a student to be an expert on their condition and on what they need (Powell, 2003).

Having said this, it should not be forgotten that, on top of the challenges related to their impairment, the visually impaired students still had to deal with the typical day-to-day challenges of being a student. It is therefore no wonder that, in the face of structural barriers and having to carry a large amount of responsibility, the students experienced emotions such as humiliation, frustration and fatigue. Copying notes, explaining to fellow students why they wanted to copy notes, running up and down stairs as they tried to mediate between lecturers and the Braille office and explaining to lecturers why they needed extensions, all contributed to the heaviness of the responsibility and its accompanying emotions. Hence, it could be a positive factor that the students were resourceful and resilient, but the question is, “Is it really fair on them?” Also, Roberts (2009) warns, it could mean that students who were less assertive might have fallen through the cracks since they felt unable to “battle”.

These findings concur with the study by Goode (2007). She found that “having to battle” all the time left students emotionally drained and impeded their ability to continue to “battle”. Other studies also found that having to repeat one’s needs continually also elicited negative emotions such as frustration and anxiety (Holloway, 2001; Hopkins, 2011; Madriaga, 2007). In the current study, for example, Emma had to continually ask for course materials, since one lecturer did not believe that she really had a disability. Since Emma was considering dropping out, we can safely assume that she felt unable to further advocate for herself. Instead of finding support from disability support staff, she was advised to take her mother along to the lecturers so as to explain her situation. Since she is an adult and this suggestion clearly illustrated infantilisation and patronisation, it is no wonder that she felt humiliated and that the presence of her mother would add to these feelings of embarrassment. Like a child in school, and not like the adult she was, she was expected to ask her mother to advocate on her behalf.

It is therefore very important that self-advocacy should not be used as an excuse not to make reasonable accommodations for students. Furthermore, it seems that there is a need for more enforceable guidelines to lecturers in terms of reasonable accommodations. In other words, do lecturers know what visually impaired students need in terms of accommodations?

8.7 Summary

It was clear from this chapter that, despite great moves towards inclusion, there are still some gaps in provision. For example, access to course material is still sometimes delayed, some lecturers are still unwilling to accommodate them and some experienced physical strain from reading. Filling these gaps in provision, the students sometimes took the initiative and responsibility upon themselves in order to ensure that they get everything they need.

In some of the case studies in the following chapter, the emotional toll of taking the initiative will become clear. Having said this, the resilience and ability of these students to cope with difficult circumstances, will also be evident.

CHAPTER 9

CASE STUDIES

9.1 Introduction

In this chapter, four individual case studies will lend further depth and detail to the data analysis. As far as possible, cases were selected that represent the widest range of biographical areas amongst participants. For example, both universities were represented, since two case studies from each tertiary institution were included. Cases also include different visual category, race and language. Apart from biographical consideration, I also chose stories for their interest value and according to the extent of detail and depth of each narrative.

For additional information on each participant, refer to Table 5.1 and Table 5.2 in Chapter 5. For Afrikaans speaking participants, quotes are preceded in each case by the number corresponding to the original Afrikaans transcript in Appendix F.

9.2 Case Study 1: Vicky

9.2.1 Background information

Vicky is an Afrikaans speaking, Coloured student at Stellenbosch University. At the time of the interviews, she was 27 years old and in her first year of studies (BA Humanities). She worked prior to her studies, but, following retrenchment, she decided to enrol for an academic programme.

Vicky has been partially sighted since age two with no vision in her left eye and 100 % sight in her right eye. She needs no mobility assistance and reads normal print. Despite her disability, she attended a mainstream school.

Vicky took part in all the research activities of this study. In other words, she participated in one focus group and two individual interviews.

9.2.2 The space between – Vicky's story

Vicky occupied the difficult, uncertain "in-between" space of partial sight. On the one hand, she could still see enough to "pass as normal", yet she still experienced difficulties that inextricably cleave to a body that is disabled, (145): "I literally sort of stand with one foot in a blind world and with another in a normal world. You see? That's how I feel. I also have to grope around and determine am I, uhm, am I . . . do they accept me here? Am I at the right place? Uhm, would I be able to fit in around here? Should I ask for help? How do people see me? Or, where am I going?" In this quote Vicky fleetingly mentioned the "normal" part of herself, while elaborating quite extensively on the difficulties attached to her disability. It thus seemed like the painful parts of her very real disability, and her feelings of being different, overshadowed what she would term the "normal" nondisabled part of herself. In this case study, we will look at each one of these parts of herself in turn.

From a very young age, Vicky was encouraged to see herself as someone who was "normal". Any reference to her disability as "something different" or "something needing accommodation", was strongly opposed by her mother. It seems that her mother feared that an acknowledgement of Vicky's disability and its painful parts would have left Vicky vulnerable and defenceless in the grip of self-pity. It therefore seems that her mother denied the difficulty of Vicky's disability in an effort to strengthen and equip her for the "battles of life", (146): "Since she worked, my mother knew that she couldn't be at the school all the time. So she wanted me to fight my own battles so that I could get stronger." For this purpose, she was expected to fit the mould of "normal living", without the acknowledgement that this world was created for nondisabled people, (147): "Since I was young . . . I can precisely recall the day I asked my mother, 'Mommy, I'll probably have to go to a disabled school?' And she told me, 'No, my child! You are normal. You are all right, you just have to go to school.' And she told me that I simply needed to learn how to be able to adjust and how to function normally."

However, contrary to her mother's message of normalcy, Vicky soon realised that the world did not necessarily share this view. In fact, social encounters frequently reminded, and still remind her, of her body as a strange foreigner in this world. In the mainstream school, children were frightened of her appearance, (148): "For example, there was this little girl who was terribly scared of me. She didn't want to play with me. She didn't want to touch me. To her I was like a monster." In her practical work as a psychology student, she also didn't escape the hesitancy of children, (149): "To whom do the children go first? See? Of course they wonder, uhm, that teacher doesn't seem all right, her eye is like that. You're not approachable. Then the children shy away from me."

Walking the university campus, she met the open-mouthed stares of her peers. On a daily basis she was confronted with fear, discomfort and even disgust. Even the topic of her disability was treated as "taboo"; something not to be discussed, (150): "It shouldn't be heard if people talk about it [disability]. It's almost like they are embarrassed that they are talking about it." She longed to know what people thought of her; longing to know that she did fit in, that she was worthy and "normal". However, she only faced confirmation that her body was alien-in-the-world. Particularly painful for her, was the absence of attention from men, (151): "It's like a roller coaster for me. I can't even remember when last a guy approached me and asked me on a date. So you deal with it, I have to deal with it."

In the face of this direct psycho-emotional disablism, Vicky felt lonely and isolated on the university campus, (152): "I don't have a close close friendship so that I can say, 'That is my friend, we share good and bad times'. They are only acquaintances. We only say hallo and goodbye to each other. There’s not a close friendship. I’ve tried throughout the entire year making friends, but I don’t have a close friend.” As a consequence of the social dys-appearance of her body, indirect psycho-emotional disablism manifested in the view of herself as shameful, unattractive, unsettling and even disgusting, (153):”If you are close friends with someone then you will fall short or you will always be the ugly duckling.”, and, (154): “Well, people are quite shocked by my visual impairment. Because, how can I put it? My left side is lower than my right side. And, I don’t know, it probably seems a bit harsh to people.”

Even though Vicky said that she was standing half way in a normal world, it was evident that, for her this world was, and still is, chronically crumbling under the weight of her dys-appearing “abnormal” body. Despite her body disappearing in the depths of unconsciousness, she was frequently reminded of her body’s differentness through direct psycho-emotional disablism, (155): “And sometimes I even forget that I can’t see that well. Then children are hesitant towards me and then I remember, oh yes, it’s about my eyes again.”

This dys-appearance, of course, may have created a distancing effect, since there existed a rift between what her body wanted (acceptance from able-bodied people) and what her body elicited from others (disgust, fear, curiosity, discomfort). A further distance exists between the ideal able body as perfectly beautiful and Vicky’s body which fails to adhere to these standards. Guthrie (1999) and Loja et al. (2012) argued that, when such a wide gap exists between one’s body and the cultural ideal, the acquisition of positive self-identity may be hindered.

When her body dys-appeared, when she recognised its foreign nature in this world, Vicky seemed to have one of two responses. On the one hand, the discomfort for others and the subsequent feelings of shame this stirred within her, caused her to hide her disability. Once again she tried to pass as normal, (156): “If I put on my glasses, people are less uncomfortable around me. . . . But if I don’t have my glasses on, then they can see, ‘No, she is quite partially sighted.’ Because one day I was at the market and I didn’t have my glasses on. And then the one guy told me, ‘Your one eye is not moving at all.’ I said, ‘Yes, because it cannot see.’ He only replied by saying, ‘Oh.’ But he probably wondered how I get by, because my one eye is standing still and the other one moves and is quite all right, so what’s the matter? So I don’t know, but if I don’t have my glasses on people treat me differently. So I rather put my glasses on. It makes the next person more comfortable and then they accept me more easily, because, yes, my glasses are sort of like my shield.” From this quote it is clear that her glasses, being her shield, had to protect her from others, and, on the flipside, had to protect others against her. Behind the glasses lay the vulnerable truth about her disability. That truth which makes others uncomfortable and makes her body dys-appeared. The truth from which she had to “shield” herself.

However, her story did not tell only of vulnerability, but also of resilience. At times, she actively resisted internalised oppression. When she was not hiding and she met social awkwardness head on, she used these opportunities to educate others about her disability, (157): “In her eyes I was like a monster. Until I explained to her where it [disability] came from and why it was like that. Only then she understood.”, and, (158): “Then children are hesitant towards me. . . . Then I once again have to find ways to adapt and to win their trust and so on. So for me it’s always about, can I win that person’s trust?”, and, (159):“And things that are difficult on campus, uhm, integration is difficult for me. I sometimes have to reach out to, how can I put it, to be accepted. Because people are rather reluctant to talk to you.”

Vicky wanted disabled friends. She felt that, amongst people who also had a disability, her body would find a welcoming “home”. With disabled friends, she believed, she would have felt “normal” without hiding her disability. Like nondisabled people, she would be able to “forget” about her body, secure in the knowledge that her body found a place where it would not dys-appear. The body, in this wished for scenario, and its goals will meet in mutual recognition and agreement – that which it wants (acceptance) directly aligned with what it gets (acceptance), (160): “It would mean a lot to me to be able to hear how others handle it, how they experience it and what they do to carry on every day. So then I wouldn’t feel like I am abnormal.”

And so, at the time of the focus group interview, Vicky told me that she had moved into a university residence and had made disabled friends. She related that she was much happier having made friends.

9.2.3 Conclusion

Vicky’s story showed how direct psycho-emotional disablism – in the form of negative social reactions – may lead to the disabled body’s dys-appearance. Reflected in the gaze of others, she saw her body as unattractive and shameful. In the eyes of others, her hope for normality dissipated and was replaced by feelings of inferiority (indirect psycho-emotional disablism). She therefore, at times, chose to escape her dys-appearing body by hiding her disability. Yet, in other accounts, she used the dys-appearance of her body to raise awareness around disability. But, at the time of the individual interviews, her ultimate goal was to find comfort and a sense of normality amongst students with visual impairments.

Interestingly, Vicky barely mentioned her academic experiences at Stellenbosch University. Instead, she spoke about those experiences most central to her lifeworld, namely, the interwoven phenomena of (a) her desire for normalcy, and (b) her social encounters.

Congruent to her narrative, I therefore gave an account of these experiences that mostly reflected her lifeworld.

In my opinion, she did not refer to her academic life because it did not make her body dys-appear. Those aspects of her life she chose to share thus went hand-in-hand with that which brought her body to the forefront of her awareness.

9.3 Case Study 2: Yolandie

9.3.1 Background information

Yolandie is an Afrikaans speaking, White female. When I conducted the interview with her, she was a 23 year old, final year fine arts student at CPUT.

Yolandie has been partially sighted since birth. She attended a mainstream school. She uses no mobility assistance and reads enlarged text. She has 10 % sight, however her vision fluctuates tremendously, (161): “My eyes get better and worse. Not like I am losing sight or gaining any, but because of the complexity of my eyes, of my sight, because apparently there are so many facets of my sight. So that’s what’s changing all the time. So I can’t go for new reading glasses all the time. So I have to stick to what I have.” [Sighs]

For this study, Yolandie participated in one research activity, namely one individual interview. When I invited her to participate in the study, she informed me that I was just in time, since she would graduate shortly, whereafter she would leave for Johannesburg (she graduated in April, 2012). The day after our interview she graduated and also left Cape Town.

9.3.2 The melting ice-cream – Yolandie's story

This case study will illuminate the intercorporeal (interrelational and intersubjective) and the intracorporeal dys-appearance of Yolandie's body in the face of direct and indirect psycho-emotional disablism. It will also highlight her efforts to escape this disablism and its subsequent dys-appearing effect and, paradoxically, how these efforts only led her further into the entangled maze of bodily alienation and threatened to engulf her sense of self.

From very early in her life, Yolandie discovered that she was not considered "good enough". Attending a mainstream school, she was often exposed to belittling remarks from her peers, (162): "At school people incessantly teased me about my glasses. My glasses were so thick that I had huge eyes and I was overweight and my teeth were crooked. And so I developed this complex. I just felt people are nauseating and cruel." Through the eyes of others, she thus saw herself as inferior and, perhaps even shameful; an unwelcome guest in the world (direct psycho-emotional disablism), (163): "My eyes were always one of the main factors that made it difficult for me, because you sort of feel like you are lacking." In response to the intercorporeal dys-appearance of her body and the consistent failure of others to affirm her, Yolandie partly withdrew from the social world, (164): "I only had two best friends throughout my entire life, but I just feel that people can be very cruel, so it's better to keep your emotions to yourself."

As Yolandie stepped out of the world of friendships, she threw herself into her work, (165): "Weekends I stayed at home and continued with my work; I did my work. . . . I find work to be easier than a social life." Whereas her peers presented a distancing effect from her body ("I want acceptance, but my disabled body doesn't allow it"), her work was an attempt to bridge this gap through aligning her body to her abilities. And, through aligning her body to her abilities, she could gain the acceptance of others. In the face of others, she often felt inferior, but work created an opportunity to enhance her feeling of self. In the reflection of others she saw ridicule, but work served as a mirror reflecting her abilities. She therefore saw her work as a means of recovering her image; of foregrounding it as a competent, able working body. Through this, she hoped that her disabled body would disappear into the depths of the unconsciousness of herself and others. And at CPUT, to a certain extent, she did get the acceptance of others through her work, (166): “Like there are many emotional things where my self-esteem was broken down, but in terms of my work I know that I am one of the top students and I will always be, because it is my life.” From the previous quote, it is evident that work was so important to her that it became an integral part of her identity; inseparable and almost indistinguishable from her sense of self, (167): “So it wasn’t like it was work, it always was like it was part of me. . . . It [work] is literally my life.”

When someone thus accepted her work, she felt that they accepted her, (168): “It [CPUT] was the first place where I was accepted for who I am. Every time I entered the building, I felt like people were looking at me for my work; that they were looking at the quality of my work and not at my appearance.” Therefore, since her school-going years, Yolandie placed an unbearable amount of pressure on herself to perform academically. Doing the bare minimum was not good enough for her, she had to excel and do more than what was required of her. She did more, in spite of many challenges, (169): “I was always very fond of my work. So I achieved academically. I was a prefect in primary school and head girl in primary school. And then I went to high school. . . . I was head girl once again in grade 12. I kept an A plus average and I did voluntary work. . . . But you have to do more, because you don’t only do it for your lecturers, you are also doing it for yourself.” Interestingly, being head girl seemed inconsistent with her accounts of social exclusion.

Yet, the alignment between her body and its goals was not always possible at CPUT. This could be ascribed to structural barriers (physical inaccessibility) and/or the pressure she placed on herself (as described in the previous paragraph). Structural barriers included, amongst others, inherent course requirements such as painting, (170): "It was like a nightmare walking into the art room. . . . The first year was the most difficult, so I dropped out because I couldn't take it anymore, just the paintbrushes. I came back and finished my year." The inaccessibility, combined with the amount of time she poured into her work, led to the intracorporeal dys-appearance of her body. The emotional stress of academic work was felt in her flesh, (171): "And then, to squint all the time, you get unbelievably terrible headaches, unbelievably terrible! . . . My shoulders, these muscles in my neck, sometimes it . . . it was like a burn and sting. It was . . . sometimes while sitting in front of the PC I was so stressed that I couldn't pull my shoulders away. Like my shoulders were here at my ears and I couldn't pull it away." She came face-to-face with her body as limit case, with all its limitations. Needles, intended for art work, became dangerous objects and almost useless in her hands, (172): "It was almost like my eyes sometimes decided not to work with my hands. There were always needles in my fingers. So always plasters. The secretary always kept some plasters for me."

Because her work was such an integral part of her identity, we can safely assume that when she could not achieve academically, she saw it as a failure of her entire being. And as her "self" slipped from her grasp, she felt like she was slowly melting into nothingness. In a sense, we could assume that she felt, "If I am not work, then who am I?" Her tattoo of a melting ice-cream was symbolic of this, (173): "In my first year I got a tattoo of a melting ice-cream, because it's my life – like a melting ice-cream." Like an ice-cream in the sun, she felt like she was slowly melting away; becoming less significant with each academic "failure". And so, once again, she felt like she became removed from her body, as it refused to yield to her desires, (174): “Since artistic design is so important to me and since it is part of who I am, it’s very intimate and personal to me. And the fact that people don’t understand that part of art, is so frustrating to me. And it feels like they are breaking down what I stand for and what I do instead of trying to help. And so I first need to grow a thicker skin and stop crying before I can stand for what I believe in.”

And so, under the weight of her efforts to perform academically, direct psycho-emotional disablism erupted in her flesh and bones. As she became aware of her body’s difficulty adhering to her wishes, as her body dys-appeared, she started tearing her skin. And in this, “*korper*” and “*lieb*” collided, as the painful parts of her disability manifested in her body. This concurs with Reeve (2012) who stated that psycho-emotional disablism may have an adverse effect on psychological well-being and self-esteem, (175): “In my second year I started pulling my hair and I pulled it out all the time. I simply couldn’t take the pressure any longer. I didn’t know whether it was all my fault since I’m too finicky or whether I really couldn’t cope with everything. So every time I stressed I went for my hair. It’s probably the most horrific thing I’ve ever done. It’s that moment where it made me feel better. It’s kind of damaging for my self-esteem; the marks on my skin.”

So it seemed like Yolandie tried to avoid direct psycho-emotional disablism, only to come face-to-face with indirect psycho-emotional disablism, (176): “You are never done searching to find out who you are and what you want. And you are never satisfied with who you are. Due to systems there are always things making you feel inferior.”

Yolandie had conflicting feelings about special accommodations/reasonable adjustments, (177): “I didn’t know whether it was all my fault since I’m too finicky or whether I really couldn’t cope with everything.” On the one hand, she felt that she was not entitled to any special assistance and she was uncertain to what extent her disability impacted on her academic work, (178): “My lecturers told me that they couldn’t make exceptions for me. And they are right, it’s not fair. And regarding pressure in general, well, everyone struggle with fine arts; generally everyone.” She therefore did not believe that accommodations would have improved her academic performance, (179): “And I also always thought to myself, what support could they actually give me anyway? It’s not like they could make my work any easier. It’s not right.” In this sense, she believed that she should solely rely on herself, “So I always had this mind set of, just do it yourself.”

On the other hand, she acknowledged that her disability placed her at an ongoing disadvantage relative to her peers, (181): “It’s difficult. Everything is ten times more difficult for me.” In this regard, she strongly desired the empathy and understanding from able-bodied individuals, (182): “I never wanted to be singled out and I never wanted special treatment. All I asked was, if they just suddenly had an eye patch over their one eye and they were being told, ‘You’ve got half an hour to do this.’ And then they do it. And then they remove the eye patch and they let them do exactly the same thing and they check afterwards, then they will see what it’s like to literally have half of your capabilities. Half your skills, uhm, were taken away.” In this sense, she acknowledged the pain and loss entrenched in having a disability, (183): “Your sight is taken away. It’s not something you could make better through anything, it’s just gone. It’s not something that will get better if you give me this or this or this; it’s gone! It cannot be replaced. And that’s, that’s a terrible thing to deal with.”

And in these times of bodily recognition, she wished that the disability unit would approach her, providing assistance where she needed it. She was afraid of asking for their help, as well as the help of peers and lecturers, since she believed she did not qualify for any assistance, (184): “Because you are too afraid to say that it’s ten times more difficult for you to see on the board and that you have to ask everyone what’s written there. So you feel you’re too afraid to ask, because you are going to be told ‘No’.” From the previous quote, it is evident that Yolandie was also afraid of asking for help, since she feared that people would not want to help her. Since she filled out the form disclosing her disability, she felt the responsibility rested upon them contacting her, (185): “I applied. I filled out the paper. No-one ever mentioned anything about it. And I also didn’t know what I was entitled to. That’s why I was so shocked when you told me that I was on the database, because I thought that they never even considered it. Because I never heard from them. I thought I didn’t qualify or something like that. So I never knew that I could get the assistance or the support.”

Yolandie mentioned that her lecturers were “always” willing to accommodate her, but that this never really helped her, (186): “And I know these lecturers try their best. And these lecturers have so much knowledge and so much experience. They really helped me a lot, but sometimes it was just very difficult. At a stage it was really very bad and then they said, okay, they would give me fifteen minutes extra for paintwork. It doesn’t help. After spending an hour looking at that picture I am unable to see anything at all. Especially with those lights they have there.”

So, in asking for and accepting special accommodations, we see that Yolandie moved between two modes of internalised oppression, namely, false consciousness and double consciousness. Reeve (2012) contended that it is possible for one person to experience both these forms of internalised oppression. In instances of “false consciousness”, Yolandie believed that it was right for her lecturers not to help her, since her disability “wasn’t that bad”. According to Reeve (2012) this false consciousness means that the body does not dys-appear, because it feels that its oppression is right and “normal” in this world. On the other hand, Yolandie felt double consciousness as she chronically realised her disadvantage in comparison to other students.

9.3.3 Conclusion

Yolandie's life world told the story of intra- and intercorporeal dys-appearance. It exposed the deeply painful reality of social rejection and how it physically manifested on and within her body. Subsequently, it showed her efforts to diverge attention away from her corporeal body through her work. Yet, despite these attempts, she still could not escape the ever-present reflection of her body as alien in this world.

9.4 Case Study 3: Xavier

9.4.1 Background information

Xavier is a Xhosa speaking, black man, studying at CPUT. At the time of the interview, he was 24 years old, in his final year of studying marketing and staying on campus in a university residence. In terms of his sight, Xavier has been partially sighted since birth and he attended a special school. He uses no mobility assistance and reads enlarged text.

He participated in one individual interview for this study. It was difficult scheduling this interview, since he informed me that he was very busy with disability awareness duties. He therefore said that he could only attend one interview. Although he indicated that he would attend the focus group interview, he did not attend this meeting. In my interview with Xavier, his busy schedule was evident through the frequent phone calls he received during which he scheduled other meetings.

9.4.2 The advocate – Xavier's story

Xavier regarded his disability as an integral, central and even welcomed part of his identity, "It's [disability] what defines whatever I see and think. That's just who I am. That's all. . . . So I don't have a problem. I think it has made me into who I am. . . . I can't define it as something that is a disadvantage. For me it’s just a complement to a wonderful life I think I have.”

Xavier’s statement, “it has made me into who I am” suggests a process of becoming; an identity that developed over time. For example, he did not agree with the way he was defined in the special school where he grew up. Here, under the specialist care of professionals, he reported that his voice was silenced and personal growth stifled, “They are more people with extraordinary care, than people who would just like you to go out there, grow, learn to live.” This last phrase, “learn to live”, encapsulated a subtle suggestion that, in school, he was not equipped to live fully. It also suggests that the school did not prepare him to live outside their boundaries. However, what is clear is that the school, from his perspective, was disabling in its own way, not encouraging him to explore his entire self. Paulo Freire (1978) contends that a person who is deprived of participating in dialogue is oppressed.

However, his transition to CPUT and the inevitable break from specialist care, introduced an important shift in his way of being and significantly changed his position in the world. Initially, he had to learn to live outside the school, “At CPUT I really just basically learned the life beyond the borders that I was used to live. . . . So that became my experience here.” He soon realised that CPUT’s focus was on the restructuring of the environment, rather than on his disability, “So when I was in school, the problem was disability, when I was in the institution, the problem was access, success and redress.” And so, in his move from a charity-based, medicalised school to an environment that embraced the social understanding of disability, he had more freedom to add his voice to discussions affecting his life. Therefore, it was not long before he exchanged the passive, voiceless role of the past, for an active, emancipatory involvement in disability matters. A clear example of this, is the proactive part he played in establishing the Disability Unit at CPUT, “I arrived in 2008 and when I arrived fortunately the person who was developing this idea of a disability unit was a person that was my lecturer. So she had this passion about it. And then I joined hands with her. Uhm, we started working on the issue of the disability unit. . . . So you sit in meetings the whole day. So it's quite a lot of responsibility. But I don't regret any of it, because it's quite an experience that I could've never get anywhere else." His activism quickly extended the borders of CPUT, as he is currently actively involved in disability awareness initiatives nationwide, "I'm provincially known. I've never been secretive about my disability. I speak on national television every day."

In such participation in dialogue, the oppressed is liberated (Freire, 1978). In addition to the influence of the educational milieu, Xavier also acknowledged the major role played by political changes in his liberation as a Black South African man, "The educational component has assisted me, yes, but the political has played a significant part in my life. . . . Because if it was not for democracy, I don't see myself having to even sit with you like this today."

Of course, this liberating experience at CPUT did not mean that Xavier never encountered any challenges. For example, he was unable to follow text on the blackboard and overhead projectors in class. However, he had strong faith in his ability to overcome barriers, "Any challenge I had I saw it as an opportunity to fight and to make sure I overcome it." So, when he could not follow in class, he used alternate techniques, "On the black board, I will have to sit in front of the classroom to see. And sometimes I don't even see. I listen and write down and have to go back to class to write down whatever I hear. So I need to be attentive in class. Sometimes I don't even see, because sometimes they use projectors. Projectors are not really that accommodating. Cause remember, a projector can only be zoned in to a certain extent and that's the fonts that you can get out of it. So you get to a projector and you realise, aah, I can't see. Now, what I did because I've got a laptop, so I took all the slides that the lecturers use and I put them into my laptop. So when he's using a projector there I'm using a projector here to follow, then I write it down. So I can see that way." In addition to his own initiatives, he also found the lecturers to be very willing to make accommodations, "I was one of the most fortunate people. Everything was done for me. I could just tell them, please, when you print notes just print me a A3." So, even though Xavier encountered some challenges, it moved him to take action.

Despite his strong sense of agency in confronting challenges, he also expressed the ability to accept those things he could not change, "I've always seen myself as being a person who is fortunate to be given the ability to accept things and to change whatever I can. . . . You have to be real to yourself and accept that there are things that you cannot do. There are things you would've wished to do, there are things you would've wished to do, but unfortunately you can't. So there are things that you needed to accept. That is just how I managed to overcome a number of issues." One of these "number of issues" is his social life. He believed that, if he accepted his disability with its accompanying difficult parts, others would not notice it in him. So, he might not be able to change certain aspects of his life, but he felt that he could still have agency in how others perceive him, "I taught myself that if I don't accept myself, nobody will. And immediately when you start to accept the problems that you have, people start not to realise that, they don't recognise that, because they don't see it in you. . . . I never showed people that I had a problem. I never told myself that it was a problem." So even though Xavier was not ashamed of his disability, he did not want to be seen as vulnerable. In this sense, he did not mind people noticing his disability and his needs, "I was never ashamed in class, they knew that the A3 paper was mine", as long as he was not seen as vulnerable, "if I can't see the depression in you, I can't say you're depressed. So I never had a sense of depression." Of course it might be that Xavier was hiding an underlying sense of vulnerability, because he did not want people to see him as struggling. However, from the interview this did not seem to be so. I perceived him as very confident and this observation was confirmed by his words, “I’ve never been opposed in life. I don’t know what it means to be a loser; to be understated; it’s not in me. . . . I have so many followers. I have won elections. For the first time I had the highest number of voting participants for the SRC presidency. So I don’t have an experience of being understated.” Donna Reeve (2012), stipulates that it takes a certain amount of energy and self-worth to resist psycho-emotional disablism. This clear sense of self-worth, coupled with his active involvement in disability-related matters, could explain Xavier’s ability to resist emotional responses to disabling environments. He confirmed this hypothesis when he said, “Immediately if you have the psychological strain to confront your own challenges, you don’t have a problem.”

There is thus little indication that Xavier experienced his body as a foreigner in the mainstream environment of CPUT. When he encountered challenges, it moved him to overcome them or, if not possible, he accepted them. It seems that the tertiary environment was a tremendously empowering experience for him; liberating him from the limitations of the special school environment. Since he was actively involved in disability-related matters, we can safely assume that his disability was frequently in the forefront of his awareness, but evidently not in a “dys” way. Instead, it seemed that he regarded the world as limit case; having to change in order to fit him, “I still want a meeting with the CEO of NSFAS [an institution that provides funding for students]; their funding is not consistent with the technological development.” We can almost say that for Xavier, the world dys-appeared, as he recognised its limitations. Yet, he played an active role in “equipping” the world, through his active involvement in the establishment of the disability unit and his talks nationwide.

9.4.3 Conclusion

Xavier’s story told of confidence, resilience and a strong sense of agency over his own life. For him, the transition from a special school to a tertiary environment was a liberating experience whereupon he discovered many facets of himself. In this environment, where his voice was heard, he could confidently say, “For me it’s [disability] just a complement to a wonderful life I think I have.”

9.5 Case Study 4: Liza

9.5.1 Background information

At the time of the interview, Liza was a 25 year old drama student, at the beginning of her master’s year, living in a university residence at SU. She is a White, Afrikaans speaking student. Liza has been blind since birth and attended a special school. She uses a guide dog for mobility and reads Braille and electronic texts through a screenreader. She participated in all the research activities of this work.

9.5.2 The caged bird – Liza’s story

I know why the caged bird sings

By Maya Angelou (Angelou, 1978)

The free bird leaps
on the back of the wind
and floats downstream
till the current ends
and dips his wings
in the orange sun rays

and dares to claim the sky.

But a bird that stalks
down his narrow cage
can seldom see through
his bars of rage
his wings are clipped and
his feet are tied
so he opens his throat to sing.

The caged bird sings
with fearful trill
of the things unknown
but longed for still
and his tune is heard
on the distant hill
for the caged bird
sings of freedom

The free bird thinks of another breeze
and the trade winds soft through the sighing trees
and the fat worms waiting on a dawn-bright lawn
and he names the sky his own.

But a caged bird stands on the grave of dreams
his shadow shouts on a nightmare scream
his wings are clipped and his feet are tied
so he opens his throat to sing

The caged bird sings
with a fearful trill
of things unknown
but longed for still
and his tune is heard
on the distant hill
for the caged bird
sings of freedom.

From her early childhood years [aged 6], Liza went to a special school. Here the environment was conveniently tailored to her needs, with seemingly very few physical and social obstacles. She could read textbooks because they were Brailled and she could find her way due to carefully designed routes, (187): “It’s a very protected environment and there are paths from one place to the next. It’s absolutely designed for blind people.” It can therefore be said that, for Liza, the objects and features of this environment did not lose their innate possibilities as they so often do for disabled persons (Carel, 2013a, 2013b). Because she could, for example, use a book for its innate purpose (reading), the book stayed a ready-to-hand entity in her hands (Carel, 2013a 2013b), (188): “. . . and textbooks and notes are always converted.”

Even though this environment may therefore seem ideal for blind learners, Liza recalled it to be very limiting. The physical and social environment might have been accessible, but this access did not extend beyond the borders of the school. This lack of exposure limited her in various ways. For example, she missed out on social experiences, (189): "Particularly on a social level I couldn't experience a lot of things, because your peers are basically blind people who are as limited as you are. So, you know, you develop according to other terms. I mean, because we are not necessarily interested in things like fashion or MTV's latest music video, there are many aspects we are not aware of, that we don't understand, that we are not interested in." She speculated that a regular school, with its accompanying barriers, would have prepared her more for the challenges of a tertiary environment, and, (190): "I would've learned how to fend for myself and the various ways of doing so. Academically, to be able to tell the teacher, 'Listen, regarding these and these aspects,' like visual material for example, you know, uhm, 'could I rather do this assignment', or you know, so that I still get marks for the work I do. So that I'm not just exempted from it, like so often happened at university." It seems that she believes that the early recognition of her disability, and the limitations of the environment, would have strengthened and equipped her in advance for the challenges of higher education. In this sense we can theorise that, for Liza, an environment designed to ensure no dys-appearance, was not ideal in the light of the reality of mainstream life.

In the light of this limited exposure outside the school, Liza called it a "closed" environment, in direct contrast to the mainstream "outside world". In her transition to SU, away from the boundaries of the "inside" world – from designed pathways and equally disabled peers – Liza enjoyed her newly acquired freedom, "I enjoy the freedom so much." Yet, in the midst of this new world of possibilities, she also became aware of the inevitable limits to her freedom. Reflected in the seemingly boundlessness of her sighted counterparts, her freedom appeared insufficient, (191): "The fact that I'm still a bit limited in things I do. I've got this thing about that I might never have enough freedom. And that is something I've particularly discovered at university – how much freedom one can have and how much I do not have. . . You [sighted person] have all this freedom. You know exactly what's going on around you, so you can base your choices on that." Within the wide-open spaces of university, Liza was therefore confronted with the narrowing of possibilities attached to having a disability (Carel, 2013a, 2013b). She believed that she always had to approach her freedom with caution and responsibility, which, of course, is limiting in itself, (192): "More freedom for blind persons, but also the responsibility attached to it. For example, you can't go out with just any group of people. You have to think, listen here, do they know how to handle me? Will they just leave me somewhere? So one needs to be extremely responsible. . . . For example, you have to plan if you want to go to the movies or if you want to go to town. When is it more quiet? At what times is the traffic not that bad?" Exacerbating the limits on her freedom imposed by the tertiary environment, was the overprotection of her parents, (193): "And then there were my parents in the background who also tried to dictate everything and basically didn't allow me my freedom. And that's difficult, because it denied me, it stripped me from a lot of things – uhm, like your identity that you are entitled to; to develop a new identity. You don't want to be known as the blind girl whose mother brings her rusks every day." Liza thus expressed the fear that she would never have enough freedom.

In differing ways, the limits to her freedom influenced her social and academic life. Socially, she noticed that people seem to be afraid of entrapment, of losing their own freedom to her dependence; of being bound to her, (194): "Persons who can see are very cautious of landing up in a situation which can place them in a difficult position. That they would have to carry their own burdens, but also that of the blind person. I don't think people like being tied down. I don't think anyone likes being tied down." This belief was confirmed when she got her guide dog; which enhanced her independence considerably, (195): "I firmly believe that people view you in a more positive light when you are independent. I especially saw a significant difference when I got my guide dog. Because then, all of a sudden, people saw, oh, but she likes going to town and she's not just this clingy girl; she also missions on her own."

Academically, she did not have the freedom of various options. Firstly, coming to university reflects this world of limited choice, (196): "And I know for people in my position, blind people, university is pretty much one of the best options, because you can't scrub ship decks or that type of thing." Of course this is not to say that she would not have chosen university as a sighted person. The point here is that she could not choose from many available options. These limitations continued during her university years. She decided on specialising in a certain field. In her second year, she asked her lecturers whether this would be a viable specialisation field for her. When they told her that she would be able to follow this career, she chose her subjects according to this goal. However, when the time came to further her studies, they told her that she would not be able to follow this course, (197): "For example, in my second year I was in a position where I chose which master's I wanted to do. Uhm, it was in a practical field. In other words, a lot of acting, a lot of learning lines, you know, like that. Uhm, and uhm, I went and spoke to my lecturers and they said, 'No, it's all right', I can do this M. So consequently I chose my honours so that it could correspond with my M. Yes. And then when I was in third year, I already chose my honours at the time, then they turned around and said, 'No, you learn your stuff too slowly, you can't do it anymore.'"

Hass (2008) stated that the narrowing down of possibilities changes one's whole being-in-the-world. Although Liza was blind since birth, the nature of her narrowed possibilities only became evident at Stellenbosch, where she could see the wide range of possibilities available to her sighted counterparts. She started realising that she could not study anything she chose, that social encounters were difficult and that her freedom would forever be limited.

However, this did not mean that Liza quietly accepted these limitations. Her story also tells of hard work in trying to counter various challenges and limitations. Her social encounters provide a clear example of this determination. She believed that her social difficulty could be ascribed to (a) her background of limited exposure to sighted people, and (b) the lack of exposure of sighted peers to disabled people, (198): “I think socially both the other students and myself were to blame. Because, like a friend told me later on, he simply didn’t know what to do with me. And it worked both ways. There were so many new codes that simply didn’t exist in my school. I mean, it was a completely different world to me. So it was a big adjustment for me.” Yet, Liza worked hard to gain acceptance and to make friends, (199): “I had to work hard to get their acceptance and to earn their trust and to almost win their preference. So I really had to go out of my way to prove to them that, ‘Listen here, we come from different backgrounds, but hey, I can learn.’ Uhm, and also that, apart from the course we are studying, that we have things in common. You know, we are all young, we all have fears and things that make us happy, likes and dislikes. And you know, we are all human beings. I am just one that cannot see while you are. . . . Uhm, so yes, I had to, I had to work hard.” Her academic work also required hard work; seemingly more so than for sighted students, (200): “You have to plan. If you have to do assignments, okay, I actually have to start a month beforehand. So I have to get my assistant so that we can start looking for sources. Uhm, you know, so you have to be on your toes all the time.”

Working this hard often felt like a battle for Liza. Her narrative was drenched with battle-related words such as, “fighting spirit”, “battle-axe”, battle”, die”, and “struggle”. In thinking about war, enemies spring to mind. For Liza, this “enemy” was the entrapment and prescriptions of the special school. Her hard work, in essence, could be seen as rebellion against that world; a determined effort to never go back to such an environment, (201): “The fighting spirit. You know I never want to return to where I came from. Whatever it takes.

Really whatever it takes. Uhm, so you absolutely have to tell yourself, come hell or high water, I will do it. . . . So you need to have this resilience and a determination to, uhm, reach your goals. You absolutely have to be hard on yourself and pressure yourself a lot. . . . You shouldn't throw down your battle-axe. I think we, uhm, you must die trying to some extent. You know, you should always always go higher, always better. You know, you must strive for something."

So even though the special school felt protected and the university presented her with numerous barriers, Liza, at all costs, did not want to return to the school. For her, it was exactly the limitations of the outside world that unlocked those abilities that were hidden during her school days, (202): "Once you obtained your first degree and everyone applauds you, then you realise, sjoe, it was actually all worth it. And I think the self-confidence you develop – it's extremely nice to realise, yo, I've made it and I'm making it. You know?" At university, she had the opportunity of developing herself and of understanding her own abilities, (203): "So the challenges are more difficult, but in the end the reward is bigger."

Moving to this environment unhinged her taken-for-granted world and forced her to self-reflect (Carel, 2013b), (204): "Phew, university is such an overwhelming experience for a blind person, because in university a lot of self-examination takes place and so on. And it's a time when you really discover a lot." Immediately we see that the protected environment of the school did not enhance self-discovery – she never needed to examine herself, because her abilities were never challenged. Despite the limitations, she also discovered new aspects about herself; aspects that are in direct contrast to the prescribed identity of the school, (205): "And also the realisation that, listen here, I don't need a special path from the bathroom to the lounge to the dining room, I can survive. . . . And the fact that you can only relate with blind people, it's not true. Or you only have things in common with blind people. Socially I learned that, hey, I can actually make friends with sighted people, you know, we do have things in common.” So Liza discovered her strengths and her capabilities; that she can make friends and that, without the walls keeping her safe, she can survive. Instead of the “I can’t”, she learned that, in many instances, she could. Based on these new aspects she discovered about herself, she started rebuilding a new identity, (206): “You really learn so much about yourself which, in the end, causes you to rebuild your identity. That which people always said about you, you choose for example not to believe it.”

9.5.3 Conclusion

Liza’s story told of the transition from an enclosed environment towards a mainstream setting open to all. Even though it was more comfortable in the accessible school, Liza perceived it to be limiting, stifling her freedom and independence. At SU, she learned the limitations to her freedom, but she also discovered her ability to work hard towards her goals.

9.6 Summary

The case studies that were discussed in this chapter illuminated the varying experiences of visually impaired students within higher education. It highlighted issues around normalcy and difference, social acceptance and rejection, academic struggles and triumphs, identity and the body, freedom and limitations, and resilience and liberation. From this chapter it became clear that, although visually impaired students might share similar experiences, the lived reality of their disability, coupled with their personal circumstances, makes each life story unique.

CHAPTER 10

CONCLUSION

10.1 Introduction

This final chapter presents the main aims of this study and a short summary of the findings. Recommendations for future research are made. The chapter concludes with a personal reflection.

With this dissertation I aimed to capture the lived experiences of visually impaired students at two historically different universities. In contrast to the initial expectation, there were very few differences in the experiential accounts of students from the respective universities. Where differences between students were evident, this seemed to be related mostly to their experiences of secondary education (Chapter 6) and/or their visual category (Chapter 7).

10.2 Tying All Threads Together

Critiques hold that disability studies' analyses have too often lacked insight into the personal and psychological ramifications of exclusion (Watermeyer, 2014). Listening to the voices of these students illuminated both their felt worlds and their experiences of environments they were living in. We heard their vulnerabilities and triumphs, their resilience and frustrations, as these simultaneously shed light on the enabling and disabling aspects of secondary and tertiary education. Thus, as predicted in Chapter 2, listening to the experiences of visually impaired students told their personal lived stories, whilst also illuminating the gaps in provision on societal level. For example, some students recalled that finding their way around the university campus was initially anxiety-provoking. Although this experience was clearly an emotional one, it simultaneously highlighted a lack of mobility and orientation training for visually impaired students entering higher education. It thus became clear how an exploration of the personal and psychological aspects of disability can serve to bring about change at the level of social action (Watermeyer, 2006, 2009, 2012a, 2012b, 2013, 2014). In this study, the students spoke of their experiences in three environments, namely, the pre-tertiary, the social and the learning environment. The paragraphs that follow will give a short overview of these environments and the experiences as recounted by the participants.

10.2.1 A brief overview

The lived experiences of the pre-tertiary environment brought interesting and important findings to the fore. It was clear that an essentially disablist ideology of low expectations and exclusion, probably associated with aspects of medical model views on disability, still prevailed in special schools at the time participants were there. Learners reportedly were not encouraged to utilise their full academic potential in school and to leave the borders of the "special" environment to further their studies. Importantly, the participants of this study decided to pursue a tertiary qualification despite these prescriptions of the special school. Whether this was due to their personal determination and resilience, or the support of family, friends and/or encouraging teachers, was not clear from this study. However, it is essential that an appreciation of the resilience and/or support of these learners should not be used to obscure an understanding of the limitations of their reported school experiences. A limitation of this study is that it focussed only on the experiences of students who had reached higher education. Some who were not as resilient, determined and/or supported as these participants, but just as academically capable, may well not have reached tertiary education.

On the other hand, the results also showed that the special school environment contained some valuable attributes. Coming from what they describe as a cohesive community of friends with similar experiences, it seemed that students from a special school made friends more easily in university than those who were reportedly more isolated in a mainstream school. Furthermore, those students from a special school appear to have been more likely to ask for special accommodations than mainstream learners. There are a number of possible reasons for this. Mainstream learners may have had to be self-reliant from a young age; they may have been less familiar with special accommodations; and/or they may have not wished to act in such a way as to mark themselves as different and disabled within the mainstream environment. On the other hand, for the learners from special schools, their sense of self was so entangled with the cohesive group they left behind, that they commonly reported having to renegotiate a new identity in the wide-open spaces of higher education. It thus seemed that special schooling, as well as mainstream education, shaped the transition of visually impaired students to university to some extent.

This study also shed light on the experience of social interactions between the participants and their nondisabled counterparts. Particularly important from this section (Chapter 7), were the accounts of participants that they sometimes felt the need to obscure their impairment or the difficult parts of it in an effort to feel fully seen and to spare others any discomfort. This sometimes meant that they also did not seek or accept help even when they needed it. On the other hand, some accepted help and even used stares from nondisabled peers as an opportunity to become known. Whether this “becoming known” included allowing others to appreciate the extent of their vulnerabilities was not clear from the data. Here once again, the resilience of the students was clear, but also their vulnerabilities and uncertainties in their interaction with students without disabilities.

In terms of their academic studies (Chapter 8), it was clear that the students in general found comfort and support through the work and help of lecturers and disability units. For some, adequate support meant that they could be on an equal footing with their sighted peers. Having said this, it was clear that much responsibility still rested on the participants to access course material. Often, they had to self-advocate and mediate amongst important role-players to get their accessible course material on time. Commonly this responsibility left them frustrated, while late course material and the consequent extensions for assignments was an humiliating experience. For Yolandie, not being able to perform all the requirements of her academic course was a corporeal experience, since she experienced muscle tension and tore at her skin. For partially sighted students, reading difficulties were also a corporeal experience as they frequently had headaches and muscle tension from the effort it took to read with limited sight.

10.2.2 Concluding remarks

Overall, having a visual impairment in higher education was an embodied experience. It was often hard to study in a world that was essentially not designed for their bodies; in a world that was not their home. For some, this elicited anxiety in their bodies. Walking amongst thousands of students, trying to find their way to class with a white cane, was often anxiety-provoking. Some also had a lonely body, since they felt anonymous, orphaned and lost amongst large crowds of people. Their stories told of invisible and shameful bodies. The gaze or nongaze of nondisabled persons contributed to a feeling of shame and invisibility, which they at times tried to ameliorate through denial and silence around their disability. In the academic environment, the students often felt frustrated and humiliated when special accommodations were refused or were not delivered on time. Partial sight, for some, also meant a tired body. As they tried to read with limited sight, their disability erupted in their bodies as muscle tension, tired eyes, headaches and back pain.

These students clearly worked hard to manage their environments. They had to learn new routes, manage the way they were perceived by nondisabled persons, and self-advocate to get the accommodations they needed to complete their studies. Although they sometimes coped well and employed strategies to meet these challenges, universities should ideally not count on these students to be resilient. It should be kept in mind that these students are faced with all the typical demands of being a student, and the extra efforts required for disability-related matters may drain their energy and have negative emotional consequences for them.

From the previous paragraphs it might seem that it was primarily an emotional struggle for the visually impaired students to study within higher education. Such an impression would not be accurate, since there were many positive accounts from the participants. Many made friends, participated in social activities and received valuable and indispensable support from lecturers and disability support staff.

In conclusion, the data collected in this study provide some corroboration for the usefulness of steps taken since 1994 to include disabled students in South African universities. In Chapter 1, for example, the services provided by CPUT and SU were described and some of these services were appreciatively discussed in the voices of the participants' stories. Welcoming and supportive disability units, the conversion of printed texts into Braille and enlarged texts and enthusiastic and supportive lecturers clearly played a major role in making students feel welcome and included. However, despite major positive steps towards inclusion, I have to concur with previous literature that visually impaired students are still not fully included within South African universities.

10.3 Recommendations

> Then listen to the people you want to help. Learn to be still and listen. Put aside the rush to find answers and listen. Listen for the voice in the wind. Do not force solutions. Let them emerge. Let the problems speak. (Leibrich, 1997, p. 277)

After completing a project of this nature, one may be lured into the temptation to suggest immediate solutions and interventions. Having listened to some struggles and barriers faced by these students, there exists a feeling of urgency to bring about change. The danger thus exists that one might act too hastily, resulting in ineffective or even unnecessary interventions. Safeguarding against these possible dangers, the research-based, evaluative steps towards intervention through the process of action research is recommended.

Armstrong and Moore (2004) defined action research as, “the cyclical nature of collaborative planning, carrying out the evaluation of a particular intervention which has an identifiable focus and purpose, but which does not predetermine outcomes, or discard those that are unexpected” (p. 2). This definition indicates that there are two processes involved in action research, namely, (a) collaborative planning and, (b) execution combined with ongoing evaluation and monitoring. Recommendations for both these processes are made in the following sections.

10.3.1 Collaborative planning

This study aimed to capture the lived experiences of visually impaired students through their self-reports. In this way, only a part of the picture of their worlds emerged. We heard stories about their school days and university life, but the experiences of school educators and disability support staff were missing from this research. Of course the personal accounts of the participants were accepted to be true, but it is never possible to get a full and clear picture of service delivery only through the self-reports of those who received it. For example, the students recalled that they did not receive career guidance at school. It could have been that this service was available, but that it was simply not effective or properly administered. Similarly, when students said that they did not receive their course material on time, it is not clear what the reasons for this were. It could have been due to financial constraints or understaffed Braille office. The students experienced these delays viscerally, but there may be a range of different ways of dealing with the problem and of preventing it in the future, depending on the reasons for the problem, which may vary.

The first recommendation therefore involves building on this research study by consulting with important role-players in the academic lives of visually impaired students. Dialogue with and listening to school educators and disability support staff may broaden the knowledge gathered through this research and further pinpoint effective practices and gaps in provision for these students. The data gathered through this research, combined with suggestions and guidance from important stakeholders, might then adequately inform tentative steps towards intervention. My hope is to run workshops with staff and students, using my feedback from this study as a basis but listening carefully to their views. As Armstrong and Moore (2004) so eloquently write, “We are keen that action research in and for inclusive education should bridge the gulf between the academic world of research on inclusion and the actuality of people’s everyday lives by emphasising that it is those living and working with, and within, the structures, values, practices and political states of play which produce or reduce exclusion in particular settings who best know the questions and issues with which researchers should be concerned and who will have the most productive ideas about how the research process can best be managed” (p. 14).

10.3.2 Intervention and evaluation

Of course, action research is not only about contributing to the body of knowledge, but also about creating about change (Armstrong & Moore, 2004). Based on the current research and ongoing consultation with important role-players and visually impaired students themselves, interventions could be executed. These interventions should be evaluated and monitored closely to ensure that it is effective and to adjust it according to the suggestions by students and staff members. This would require following visually impaired students over the course of a few years (longitudinally) in order to assess what works and which intervention strategies should be discarded.

The current research tentatively showed that, in special schools, interventions would possibly be directed to career guidance for learners as well as facilitating their interaction with nondisabled peers.

At universities, interventions would probably take the form of academic and social support, as well as a more active role for students with visual impairment to design and implement services. This might include developing new strategies of support and/or evaluating old strategies. Based on this research alone, it would be feasible to implement an orientation programme specifically for visually impaired students. Ideally, such a programme would take place after they have been accepted for an academic programme, but before their classes start. Tentative suggestions for such a programme include:

- Orientating them to the physical environment, including teaching them the routes to their classes and residences.
- Introducing them to important role-players such as disability support staff.
- Workshops on their rights and responsibilities and the scope of each role-player in providing special accommodations.
- Introducing them to accessible social activities, such as the church choir and chess clubs, where they could also meet new friends.
- Introducing them to other and older visually impaired students who would be willing to provide mentorship, in the form of guidance and support, to their younger counterparts.

Of course, consultation with disability support staff may indicate further suggestions or alternative plans of action to include visually impaired students on tertiary campuses. There will be great value in the action research cycle of holding dialogue meetings in mixed groups with disabled students, lecturers, and disability units. Given the sensitivities involved, these groups will have to be managed carefully as both deeply personal and intergroup events, but facilitated and supportive dialogue may lead to a broader understanding of issues. It is in the nature of services for a minority group in an institution that, without support and safety, members of that group may struggle to criticise services for fear of losing the little they have. Similarly, staff who, in an environment not uniformly open to the challenges and opportunities of diversity, may feel defensive about their own position and may need support, acknowledgement and help to be co-designers of better practices. My hope is that, as part of my feedback to both institutions, I may play a role in this facilitation and support process in service of constructive changes.

10.4 A Last Word

Writing this dissertation and collecting the data was not only an intellectual process for me, but it was also an emotional one. Of course, I knew from the start that listening to stories somewhat similar to my own would be difficult at times. However, I never could have imagined the extent of this difficulty. On a day-to-day basis I was constantly reminded and aware of my disability as I read through transcripts and engaged with the dialogue of the participants.

Yet, this process not only touched on old familiar truths of living with an impairment, it also revealed new lived worlds previously unknown to me. As I learned more and became familiar with the stories of the participants, I got a glimpse into their lives – their vulnerabilities and strengths, their resilience and accomplishments. I was driven forward by the hope that, through this work, others would be able to see them in a world where a core challenge for them is not just that they are unable to see as others see, but that they experience not being seen, as others are seen.

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APPENDICES

APPENDIX A

INVITATION LETTER TO PARTICIPANTS

Dear Student

INVITATION TO PARTICIPATE IN RESEARCH PROJECT

You are hereby invited to participate in the research project of Heidi Lourens under supervision of Prof L. Swartz. I am undertaking this study as part of a doctoral programme in psychology (PhD) at Stellenbosch University.

You were selected as a potential participant for this study, since this research aims to investigate the experiences of university students with a visual impairment. It is hoped that this research will facilitate a deeper understanding into the experiences of students with visual impairment and lay the foundation for positive experiences for these students at tertiary level.

Should you be willing to participate in this process, the following will be required of you: (1) completion of one short biographical questionnaire, (2) participation in two individual, approximately one-hour interviews, (3) participation in one focus group interview, and (4) attending one workshop where the results of the study will be discussed and confirmed. I will conduct the interview at a time that best suits you to minimise inconvenience.

All results will be treated confidentially. Only the promoter of the study and I will have access to these results. For the purpose of the research project, pseudonyms will be used at all times and your privacy will be protected. The interviews will be audio-recorded, but will be treated with the utmost confidentiality.

Please keep in mind that you may withdraw from the study at any time without providing the reason for your withdrawal. Should you decide not to participate or withdraw from the study, there will be no adverse consequences for you, for Stellenbosch University or CPUT.

If you want to participate in this study or for further enquiries, please contact

Heidi Lourens at 082 842 1724; e-mail: hlourens.psych@gmail.com or

Prof L. Swartz (promoter) at lswartz@sun.ac.za

APPENDIX B

INFORMED CONSENT FORM

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: The lived experiences of higher education for students with a visual impairment: A phenomenological study at two universities in the Western Cape, South Africa

PRINCIPAL INVESTIGATOR: Heidi Lourens

ADDRESS: University of Stellenbosch, Department of Psychology, MATIELAND, 7602

CONTACT NUMBER: 082 842 1724

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 the study staff or doctor 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.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** 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?

This study is conducted at Stellenbosch University and the Cape Peninsula University of Technology. Fifteen participants were randomly recruited from both these institutions respectively. In total, thirty participants will, therefore, take part in the study. However, if new information still emerges after the individual interviews, more participants will be contacted to participate in the study.

This study aims to explore the lived experiences of students with a visual impairment at the above-mentioned two institutions. Through this study, it is hoped that a fuller understanding will be gained regarding: (1) factors that facilitate positive experiences at tertiary level, and (2) issues that still need to be addressed.

If you volunteer to participate in this study, the following will be requested of you:

(A) To complete a biographical questionnaire that will take approximately 10 to 20 minutes of your time. This questionnaire will be available in your medium (Braille, large print or orally).

(B) Take part in two individual semi-structured interviews of approximately 60 to 90 minutes respectively.

(C) Take part in one focus group interview of approximately 90 to 120 minutes. All the participants from your research site will probably take part in this focus group interview.

(D) Attend one workshop where the results of the study will be revealed. This workshop will provide you with the opportunity to confirm whether the results reflect your actual experiences at tertiary level.

Why have you been invited to participate?

You have been invited to participate in this study because you are a student with a visual impairment studying at either Stellenbosch University or the Cape Peninsula University of Technology.

What will your responsibilities be?

When you participate in the focus group interview with other participants, it will be your responsibility to respect the privacy of your co-participants and to treat all information as confidential.

Will you benefit from taking part in this research?

You will probably not benefit from this research directly. However, this research may inform decision-makers, important role-players at tertiary level and even future students of the actual experiences of students with a visual impairment and alert them to the essential factors that are needed to cope at tertiary level.

Are there in risks involved in your taking part in this research?

The research may possibly cause some emotional discomfort. To safeguard against this discomfort, you may withdraw from the study at any time without an explanation to the researcher.

Who will have access to your records?

Your identity will be protected at all times and will be kept confidential. Only the research promoter, Prof L. Swartz, and I, Heidi Lourens, will have access to the data. Confidentiality will be maintained by keeping questionnaires and transcripts in a locked cabinet. The data will also be in electronic format on a computer. A password is needed to gain access to this electronic material and only I will have access to this password.

Audio recordings of the interviews will be erased immediately after transcription. You may request to listen to your audio recording before it is erased.

This research will contribute to a research dissertation and will probably be published in a peer reviewed journal. In these instances, your identity will be protected by the use of pseudonyms. As far as possible, the researchers will take precautions that no information be divulged that may threaten your confidentiality.

What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research study?

Should you feel any emotional discomfort during the study, you will be referred to The Centre for Student Counselling and Development at Stellenbosch University or to the Centre for Student Counselling at the Cape Peninsula University of Technology. Your permission will first be sought prior to this referral.

Will you be paid to take part in this study and are there any costs involved?

You will not be paid to take part in the study but your transport costs will be covered for each study visit. There will be no costs involved for you, if you do take part.

Is there any thing else that you should know or do?

You can contact Prof L. Swartz (promoter) at Tel. 021 808 9111 if you have any further queries or encounter any problems.

You can contact the Health Research Ethics Committee at Tel. 021 938 9207 if you have any concerns or complaints that have not been addressed adequately by your study investigator.

You will receive a copy of this information and a consent form for your own records.

DECLARATION BY PARTICIPANT

By signing below, I ………………………………..………… agree to take part in a research study entitled “The lived experiences of higher education for students with visual impairment: A phenomenological study at two universities in the Western Cape, South Africa”.

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 study doctor or researcher feels it is in my best interest, or if I do not follow the study plan as agreed to.

Signed at (*place*) ....…........……………….. on (*date*) …………....……….. 2005.

....

Signature of participant   **Signature of witness**

DECLARATION BY INVESTIGATOR

I ……………………………………………..……… 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.
- ☐ I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below*.)

Signed at (*place*) ....…........……………….. on (*date*) …………....……….. 2005.

....

Signature of investigator **Signature of witness**

APPENDIX C

AFRIKAANS VERSION OF INFORMED CONSENT FORM

DEELNEMERINLIGTINGSBLAD EN -TOESTEMMINGSVORM

TITEL VAN DIE NAVORSINGSPROJEK: Die leefervaringe van studente met visuele gestremdheid in hoër onderwys: 'n fenomenologiese studie aan twee universiteite in die Wes-Kaap, Suid-Afrika

HOOFNAVORSER: Heidi Lourens

ADRES: Stellenbosch Universiteit, Sielkunde Departement, Privaatsak X1,
MATIELAND, 7602

KONTAKNOMMER: 082 842 1724

U word genooi om deel te neem aan 'n navorsingsprojek. Lees asseblief hierdie inligtingsblad op u tyd deur aangesien die detail van die navorsingsprojek daarin verduidelik word. Indien daar enige deel van die navorsingsprojek is wat u nie ten volle verstaan nie, is u welkom om die navorsingspersoneel of dokter daaroor uit te vra. Dit is baie belangrik dat u ten volle moet verstaan wat die navorsingsprojek behels en hoe u daarby betrokke kan wees. U deelname is ook **volkome vrywillig** en dit staan u vry om deelname te weier. U sal op geen wyse hoegenaamd negatief beïnvloed word indien u sou weier om deel te neem nie. U mag ook te eniger tyd aan die navorsingsprojek onttrek, selfs al het u ingestem om deel te neem.

Hierdie navorsingsprojek is deur die Etiek Komitee oor Gesondheidsnavorsing van die Universiteit Stellenbosch goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

Wat behels hierdie navorsingsprojek?

Hierdie studie word by Stellenbosch universiteit en Kaapse Skiereilandse Universiteit van Tegnologie uitgevoer. Vyftien deelnemers vanuit elkeen van bogenoemde instansies is op 'n ewekansige wyse gewerf. In totaal sal daar dus dertig deelnemers aan hierdie studie deelneem. Indien daar egter na afloop van die individuele onderhoude steeds nuwe inligting navore kom, sal verdere deelnemers vanuit elke instansie gewerf word.

Hierdie studie poog om die leefervaringe van studente met visuele gestremdheid aan die bogenoemde twee hoër onderwys instansies te ondersoek. Hierdie navorsing word onderneem ten einde lig te werp op: (1) die faktore wat positiewe ervaringe op tersiêre vlak bevorder, en (2) die kwessies wat steeds aangespreek moet word.

Indien u instem om deel te neem aan die studie, sal die volgende van u versoek word:

(A) Voltooiing van 'n kort biografiese vraelys wat ongeveer tien tot twintig minute van u tyd in beslag sal neem. Hierdie vraelys sal in u gekose medium beskikbaar wees (braille, grootdruk, mondeling);

(B) Deelname aan twee semi-gestruktureerde individuele onderhoude van ongeveer 60 tot 90 minute onderskeidelik;

(C) Deelname aan een fokusgroep onderhoud van ongeveer 90 tot 120 minute. Al die deelnemers van u betrokke universiteit sal waarskynlik hierdie groepsonderhoud bywoon;

(D) Bywoning van 'n Werkswinkel waartydens die resultate van die navorsing bekend gemaak sal word. Hierdie byeenkomste sal ook aan u die geleentheid bied om te bevestig of die resultate in werklikheid u ervaringe op tersiêre vlak weerspieël.

Waarom is u genooi om deel te neem?

U is uitgenooi om deel te neem aan hierdie studie, aangesien u 'n student met 'n visuele gestremdheid is wat tans aan Stellenbosch universiteit of Kaapse Skiereiland Universiteit van Tegnologie studeer.

Wat sal u verantwoordelikhede wees?

Die verantwoordelikheid sal by u berus om die privaatheid van u mede-deelnemers te beskerm en om alle inligting as vertroulik te beskou, veral ten opsigte van die fokusgroep onderhoud.

Sal u voordeel trek deur deel te neem aan hierdie navorsingsprojek?

U sal na alle waarskynlikheid nie direk voordeel trek uit hierdie studie nie. Die studie mag egter toekomstige studente en belangrike rolspelers op tersiêre vlak bewus maak van die ervaringe van studente met visuele gestremdheid. Die noodsaaklike faktore vir die voortgesette studering van hierdie studente mag dus deur middel van hierdie studie onder besluitnemers, rolspelers en selfs voornemende studente se aandag gebring word.

Is daar enige risiko's verbonde aan u deelname aan hierdie navorsingsprojek?

Die navorsing mag moontlik emosionele ongemak veroorsaak. U mag egter ter enigertyd van hierdie studie onttrek sonder om u redes aan die navorser te verklaar.

Wie sal toegang hê tot u rekords?

U identiteit sal te alle tye konfidensieel gehou word. Slegs ek, Heidi Lourens, en die navorsingspromotor, Prof L. Swartz sal toegang tot die data hê. Vraelyste en getranskribeerde onderhoude sal in 'n geslote kabinet gestoor word. Elektroniese rekords sal op 'n rekenaar gestoor word waarvan slegs ek oor die wagwoord beskik.

Klankopnames van die onderhoude sal direk na afloop van transkribering uitgewis word. U mag versoek om na die klankopname van u onderhoude te luister voor uitwissing.

Hierdie studie vorm deel van 'n navorsingstesis en sal na alle waarskynlikheid in 'n vaktydskrif gepubliseer word. In so 'n geval, sal u identiteit beskerm word deur die gebruik van skuilname. So ver moontlik, sal Geen inligting wat u identiteit mag bedreig uitgegee word nie.

Wat sal gebeur in die onwaarskynlike geval van 'n besering wat mag voorkom as gevolg van u deelname aan hierdie navorsingsprojek?

Indien u enige emosionele ongemak ten tye van die studie ervaar, sal u met u toestemming verwys word na sielkundige dienste by die Sentrum vir Studente Voorligting en Ontwikkeling aan Stellenbosch universiteit of na die Sentrum vir Studente Voorligting aan Die Kaapse Skiereilandse universiteit van Tegnologie.

Sal u betaal word vir deelname aan die navorsingsprojek en is daar enige koste verbonde aan deelname?

U sal nie betaal word vir deelname aan die navorsingsprojek nie, maar u vervoer ten opsigte van elke besoek vir die navorsingsprojek sal betaal word. Deelname aan die navorsingsprojek sal u niks kos nie.

Is daar enigiets anders wat u moet weet of doen?

U kan Prof L. Swartz kontak by Tel. 021 808 9111 indien u enige verdere vrae het of enige probleme ondervind.

U kan die **Etiek Komitee oor Gesondheidsnavorsing** kontak by 021 938 9207 indien u enige bekommernis of klagte het wat nie bevredigend deur u studiedokter hanteer is nie.

U sal 'n afskrif van hierdie inligtings- en toestemmingsvorm ontvang vir u eie rekords.

VERKLARING DEUR DEELNEMER

Met die ondertekening van hierdie dokument onderneem ek,

……....................…………....……...………., om deel te neem aan 'n navorsingsprojek getiteld Die leefervaringe van studente met visuele gestremdheid aan hoër onderwys: 'n fenomenologiese studie aan twee universiteite in die Wes-Kaap, Suid-Afrika.

Ek verklaar dat:

- ☐ Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in 'n taal geskryf is waarin ek vaardig en gemaklik mee is.
- ☐ Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- ☐ Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- ☐ Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- ☐ Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die studiedokter of navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te *(plek)* ....……………….. op *(datum)* ……………...……….. 2005.

....

Handtekening van deelnemer   **Handtekening van getuie**

VERKLARING DEUR NAVORSER

Ek …………………………………...………………… verklaar dat:

☐ Ek die inligting in hierdie dokument verduidelik het aan

……………………….......................................……….

☐ Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.

☐ Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.

☐ Ek 'n tolk gebruik het/nie 'n tolk gebruik het nie.

Geteken te *(plek)* ....……………….. op *(datum)* …………...……….. 2005.

....

Handtekening van navorser **Handtekening van getuie**

APPENDIX D

BIOGRAPHICAL QUESTIONNAIRE

Thank you for your willingness to complete this questionnaire. Your participation is greatly appreciated.

Please specify the following details:

1. Name and surname/Naam en van:
2. Age/Ouderdom:
3. Gender/gender:
4. Home language/Huistaal:
5. Second language/Tweede taal:
6. Current university/Huidige universiteit:
7. Academic course and year/Akademicese kursus en jaar:
8. Currently, where do you live?/Waar bly jy tans?
9. What did you do prior to coming to university?/Wat het u gedoen voordat u universiteit toe gekom het?
10. Where did you live prior to your tertiary education?/Waar het jy gewoon voor jou tersiêre opleiding?
11. Preferred medium for writing and/or reading/Voorkeur van medium vir skryf en/of lees:
12. When did you acquire your visual impairment?/Wanneer het u u visuele gestremdheid opgedoen?
13. Did you attend a mainstream or special school?/Was U in ‘n hoofstroom of spesiale skool?

APPENDIX E

INTERVIEW QUESTIONS

The interview took the form of a conversation and was semi-structured in nature. Although the questions therefore did not necessarily flow as indicated below, all the following questions were covered in the interviews:

1. What made you decide to come to university?/Wat het jou laat besluit om universiteit toe te kom?
2. How do you experience being at university?/Hoe ervaar jy dit om op universiteit te wees?
3. What does it mean for you to be at university?/Wat beteken dit vir jou om op universiteit te wees?
4. How do you feel about being a student with a visual impairment at university?/Hoe voel jy daaroor om 'n student met 'n visiuele gestremdheid op universiteit te wees?
5. If any, what were the difficulties you encountered at university?/Wat was vir jou moeilik op universiteit?

Possible prompts:

Is this still difficult?/Is dit steeds moeilik?

How did you approach these difficulties?/Wat was jou benadering tot hierdie moeilike aspekte?

Are there things that you think could have made it easier for you?/Is daar dinge wat dit vir jou moontlik makliker kon gemaak het?

Please name these things?/Noem asseblief hierdie dinge.

6. If any, what are the benefits for you and what are the aspects you enjoy about university?/Indien enige, wat is die voordele en daardie aspekte wat jy geniet van universiteitslewe?
7. What helped you through your university experience?/Wat het jou gehelp deur jou universiteitservaring?

Possible prompts:

What personal strategies helped you?/Watter persoonlike strategieë het jou gehelp?

What in the environment helped you?/Wat in die omgewing het jou gehelp?

8. Is there anything else you would like to add?/Is daar enigiets anders wat jy wil byvoeg?

Probe questions (if it did not naturally occur in discussion):

1. How do you feel about disclosure of your disability?/Hoe voel jy daaroor om jou gestremdheid bekend te maak?
2. How is it academically at university?/Hoe is dit academies op universiteit?
3. What are your social experiences like at university?Hoe is jou sosiale ervaringe op universiteit?
4. In what way(s) if at all do your experiences differ from those students who do not have visual impairments e.g. students with other impairments and those who are able-bodied?/In watter opsig(te) indien enigsins verskil jou ervaringe van studente sonder visiuele gestremdhede, insluitend studente met ander gestremdhede en nie-gestremde persone?

Questions in the focus group interview were guided by findings from the individual interviews.

How do you feel about those experiences you discussed during the individual interviews?/Hoe voel jy oor die ervaringe wat jy bespreek het in die twee individuele onderhoude?

What is it like being a student with a visual impairment at university?/Hoe is dit vir jou om 'n student met 'n visiuele gestremdheid op universiteit te wees?

APPENDIX F

ORIGINAL AFRIKAANS QUOTES

Chapter 6

1: Jy het nooit regtig tussen ander mense gekom wat 'n groot groep mense wat almal normal kan sien of wat ookal nie.

2: In skool het jy te doen gehad met net 'n sekere groep mense. Dit was byvoorbeeld in die laerskool net kan ek amper sê gesiggestremdes. En in die hoërskool ook maar net met dieselfde tipe mense elke dag.

3: Ons was letterlik hierdie blinde gemeenskap, want jy het nooit met iemand anders te doen gehad nie.

4: Want jou "peers" is basies blinde persone wat ewe beperk is. So julle ontwikkel maar jy weet volgens ander terme. Ek bedoel omdat ons nie belangstel noodwendig in mode of MTV se nuutste music video, jy weet sulke goed nie, is daar baie aspekte wat ons nie van weet nie, nie verstaan nie, nie in belangstel nie. Jy weet, so. So mens basies kultiveer die omgewing jy weet bepaalde sosiale konvensies wat in die buitewêreld net nie bestaan nie.

5: Ek dink dit is goed vir tot 'n mate om so groot te word, alhoewel uhm jy moet tog blootstelling hê aan ander mense, ander dinge, uhm anders gaan jy baie meer sukkel om aan te pas.

6: As jy in hierdie "community" is dan kry jy half nie jou eie persoonlikheid nie, mense skeer half almal oor dieselfde kam.

7: Op skool is jy so half veilig en dis ‘n klein omgewinkie waarin jy moet beweeg en daar’s altyd iemand wat jou kon gehelp het.

8: Vir van ons was dit seker lekker om so in ‘n beskermende omgewing te wees. Vir my en van my vriendinne was dit weer frustrerend. Ons het nie daarvan gehou om heeltyd ge”nanny” te word nie. Verstaan? Uhm ons het nie gehou daarvan dat dat ons die heeltyd amper onder streng beheer moes wees. . . . En nie dat jy op skool al volwasse is nie, maar toe al was dit vir ons inperkend en dit het ons nie rêrig toegelaat om ons horisonne uit te brei nie.

9: Toe ek gegaan het vir “career counseling”, het hulle my ontmoedig om moeilike vakke te vat soos Wiskunde en Skeinat. Uhm en met ander vriende van my Uhm vriende van my wat eintlik die vermoë gehad het om sewe vakke te neem is aangemoedig om ses vakke te neem.

10: Die probleem is hulle verwag nie dat mense met visiuele gestremdhede gaan studeer nie. Hulle verwag dit nie. En ongelukkig moet hulle dit begin agterkom dat mense uhm, mense wil . . . mense is ambisieus. Hulle gaan nie net rondsit, omdat hulle gestremd is nie.

11: Jy kom daar as jy vyf is, jy gaan daar preprimêr, jy spandeer jou hele skooloopbaan daar. As jy klaar is word jy aangemoedig om afdeling vir loopbaanontwikkeling toe te gaan – ook ‘n skool inisiatief van die instituut. Dan gaan werk jy by die instituut. Dan gaan jy Huis Brevis toe, die ouetehuis vir gestremdes en dan gaan jy dood.

12: Ek het glad nie ingepas nie. . . . Ek et letterlike net soos in ‘n “foreign” wêreld daar ingeval en glad nie ingepas nie. Ek kon net nie vriende maak nie.

13: ek was baie gespot op skool oor my bril. My bril was so dik dat ek het huge oë gehad en ek was oorgewig en my tande was skeef.

14: Skooldae is mos nou koggel en daai. Die kinders koggel jou regtig letterlik.

15: En soos ek het hierdie kompleks ontwikkel. So ek het net gevoel dat mense is naar.

16: In “all honesty” ek wou nie agter ‘n skakelbord gaan sit het na skool nie. . . . Ek wil net ‘n graad agter my naam kan hê en ek wil gaan sit in ‘n werk en kan sê okay, ek het regtig geswot hiervoor, hard gewerk hiervoor en ek is hierso.

17: ek het nie geweet wat anders om te doen nie, want watse werk kan jy nou eintlik doen as jy nie goed kan sien nie?

18: En ek weet dat vir mense in my posisie, blinde persone, is universiteit “pretty much” maar een van die beste opsies, want jy kan nie gaan skeepsdekke skrop of jy weet sulke tipe van goed doen nie.

19: Ek het gesukkel om werk te kry. ek het eintlik net half gesê die swot is my plan B uhm en werk is my plan A.

20: Ek het hiernatoe gekom om te kyk hoe lyk dit, nie op ‘n opedag maar sommer op ‘n gewone dag. Maar dit is nogsteeds nie dieselfde as om soos duisende student om jou te hê nie. Dis ‘n bietjie van ‘n ander ervaring.

21: Of ek is nou die dag by ‘n voetoorgang, toe sien ek die kar en hy’t vir my ver gelyk, maar hy’t duidelik vinnig gery. En hy’t net gekom. Hy’t nie gestop nie. Hy was soos ek dink ‘n sentimeter verder dan was hy oor my voete.

22: Dit vat ‘n bietjie van my energie om om my pad te kry plekke heen. Die heeltyd is dit vir my, okay, ons skraap nou die moed bymekaar, hier gaan ons. . . . Uhm so ek kom ek kom reg, maar elke keer is dit ‘n bietjie van ‘n emosionele uhm ervaring.

23: Dit klink nou baie baie “lame” en miskien kinderagtig, maar weet jy vir die eerste twee weke van my akademiese jaar was dit my grootste bekommernis. Nie hoe ek in die klasse gaan regkom nie, maar hoe gaan ek kom waar ek wil wees en hoe gaan ek kom van klas tot klas.

24: Dit was vir my ontsettend moeilik om…ek het later nie eens meer teruggegaan koshuis toe om te gaan eet nie, want weet jy dit was ontsettend vir my om met my kierie . . . ek ken nog nie eens behoorlik die pad hiernatoe nie, nou moet ek nou oor middagete met al daai hordes studente my pad probeer terugvind koshuis toe.

25: Dit was moeilik, maar later . . . een oggend dan staan jy net op, dan besef jy maar hoor hier, ek doen dit nou al sonder om daaraan te dink.

26: En toe jy nou hier kom, toe’s dit nou ‘n uit jou beskermende omgewing uit en alles is so groot en so baie mense en jy ken niemand nie. . . . Jy moet tussen duisende mense loop in strate om by verskillende klasse te kom. Groot geboue. En dis groot klasse met baie mense. Die dosent ken jou nie en niemand anders ken jou nie.

27: En dit was op ‘n stadium vir my erg, want ek het heeltemal onveilig en half wees as ek dit so kan stel gevoel, want niemand niemand weet nie en niemand “worry” nie.

28: Ons was letterlik hierdie blinde gemeenskap, want jy het nooit met iemand anders te doen gehad nie. En skielik is dit asof mens nie weet hoe jy is nie.

29: Vir ‘n blinde person is universiteit so ‘n oorweldigende ervaring, want in universiteit gebeur daar mos maar baie selfondersoek en en so aan. En dis ‘n tyd wanneer jy regtig tot ‘n klomp ontdekkings kom. So jy leer verskriklik baie van jouself. . . . So jy leer verskriklik baie van jouself wat op die ou end tweeg bring dat jy uhm jy herbou jou identiteit. Dit wat mense altyd van jou gesê het, jy kies byvoorbeeld om dit nie te glo nie.

30: Sosiaal om te leer maar hey, ek kan actually vriende maak wat kan sien. Jy weet, ons ons het tog goed in gemeen.

31: My twee beste vriendinne is altwee jy weet “visually impaired”. So. Jy raak gewoond aan vriende maak met mense wat jou verstaan, “therefore” mik jy altyd vir mense wat dieselfde probleme as jy ervaar.

32: Daar is nou nie een persoon wat ek my vriend kan noem nie.

33: Ek het nog net twee beste vriende in my hele lewe gehad. But ek voel net dat mense kan baie wreed wees, so dis beter om jou emosies vir jouself te hou.

34: ek wou nie vir vergunnings vra nie. . . . Kyk, ek dink ek ek wou nie ‘n las wees nie. En ek ek was miskien bang dat mense sou dink ek gebruik dit net as ‘n verskoning.

35: So ek het nooit geweet dat ek die “assistance” of dat ek die ondersteuning kan kry nie. En ek het ook altyd gedink, watter ondersteuning kan hulle my regtig gee? Dis nie asof hulle my werk kan makliker maak nie. Dis nie reg nie.

36: Partykeer wil jy regtig net inpas.

37: Dit was soos letterlik twee wêrelde. Van skool waar jy alles gehad het. . . . en ewe skielik is jy hier in ‘n “selfcatering” wêreld. Ja, so ek dink die sprong was nogal groot. Maar wat ook ‘n goeie ding was. Ek dink dit was ‘n goeie leerskool uhm vir vir my as mens om uhm ek dink jou net meer selfvertroue te gee en sien maar jy kan dit eintlik doen.

38: Dit vat baie om aan te pas en so, maar tog het jy daai “feeling of accomplishment.” Jy weet as jy jou eerste jaar deurkom en jy maak vriende en sulke dinge.

Chapter 7

39: Mense sal jou altyd anders hanteer as jy ‘n gestremdheid het. . . . En ja die mense . . . dis moeilik sosiaal sê nou maar, want mense aanvaar jou nie so maklik nie. Sodra hulle uitvind of agterkom dat jy nie kan sien nie, dan hanteer hulle jou anders.

40: Daar is regtigwaar hordes tye wat mense dink jy jy jy sal stadiger praat of jy sal nie kan die mas opkom nie. [lag] Mense dink letterlik gestremde mense kan niks doen nie. Of jy jy’t dit so swaar in die lewe dat jy sal . . . dit moet alles net vir jou ‘n “battle” wees om iewers in te kom.

41: Hulle praat so hier by jou oor. [skree] “Kan ek jou oor die straat help!”

42): Ek het gesien op die eerstejaarskamp byvoorbeeld, mense behandel jou normaal totdat hulle agterkom jy kan nie sien nie. En dan ewe skielik behandel hulle jou so: “Haii, jy’s oulik!” Ek weet nie wat die term daarvoor is nie, maar hulle behandel jou heeltemal anders.

43: En as hulle vrae vra is dit die belaglikste vrae, soos “trek jy jouself aan?”

44: Hy kan nie verstaan dat hoe stap ek en Carla in hierdie gange nie. “It’s just, it’s too overwhelming for him. He he can’t seem to fathom the idea that if he would have been blind, he would get lost.”

45: Ek het nie baie vriendinne in die koshuis nie, maar een van die vriendinne wat ek het, op ‘n manier weet ek nie of ek haar rêrig ‘n vriendin kan noem nie. Sy’s baie nice met my en ons het al koffie saam gedrink, maar dit voel amper vir my asof sy vriende is met my omdat sy graag vir my onder haar vlerk wou neem. Sy tree nie heeltemal normaal op teenoor my soos teenoor haar ander vriende nie.

46: Jy kry ‘n paar wat glad nie omgee nie wat die oomblik wat hulle jou ontmoet dan weet hulle net presies of hulle weet net om jou normaal te hanteer. En as hulle jou moet help dan gryp hulle jou net en hulle help jou en dis nie ‘n probleem nie. En dis gewoonlik lekker as jy sulke mense ontmoet.

47: En toe kom daar ‘n meisie verby my maar sy druk sommer net haar arm hier by my in en die volgende oomblik, daar loop ons. Ek het nie eens geweet wie sy was nie. Vandag is ons baie goeie vriende.

48: ek dink mense het nodig om te voel mense het hulle nodig. Dis baie belangrik vir mense om te voel hulle het ‘n bydrae gelewer tot iets. En dis hoekom ek probeer om, al het ek nie hulle hulp nodig nie, ek sal partykeer sommer net saam met hulle stap. Net sodat jy weet dan voel hulle ook goed oor hulle self.

49: Ek is bereid om mense te help, maar ek is jammer, ek is kind of nie hier om mense te laat beter voel oor hulself nie.

50: baie mense ignorer jou maar net of hulle vergeet jou maar net. . . . Maar dan die ander, hulle loop nou maar net wye draaie om my.

51: Iemand gaan nie sommer met jou as blinde begin praat nie. . . . mense gaan nie so maklik met jou kom praat soos wat hulle met ‘n ander siende student gaan praat nie.

52: dit mag nie gehoor word nie of die mense daaroor praat nie. Dis amper soos hulle kry skaam oordat hulle nou daarvan praat.

53: Jy stap daar in en hulle weet nie regtig hoe om met jou te praat nie. Partykeer wil hulle nie met jou praat nie.

54: dit is soms ‘n bietjie moeiliker om vriende te maak. Uhm jy weet want sommige van hulle is nie altyd gemaklik met die feit dat jy blind is nie.

55: Hulle is so bang hulle sê iets wat jou gaan “offend”.

56: Hulle is so bang hulle doen iets verkeerd dat hulle eerder niks doen nie.

57: Ek kan nie eens dink wanneer het ‘n seun my “approach” en vir my vir ‘n “date” gevra nie. So jy “deal” daarmee; ek moet met dit “deal”.

58: Ek het ook al die geval gehad dat hulle kom kuier, maar as hulle uitvind dan hoor ek net nooit weer van hulle nie.

59: Wat dit vir my baie moeilik maak is mense kom nie net na my toe en begin met my te praat nie, veral nie ouens nie. Dan wonder ek partykeer is dit omdat ek nie soos ‘n “Barbie doll” lyk nie? Verstaan? Ek weet nie altyd of dit die feit is dat ek nie kan sien nie of is dit die feit dat ek nie hierdie “superstar body” het nie. . . . Maar ek dink in ‘n geval waar ‘n ou nie na jou toe kom nie gaan dit “probably” oor hulle kan sien jy’s blind en hulle weet nie hoe om dit te hanteer nie.

60: Ek weet nie of wil hulle jou maar nie uitvra nie want jy’s nou die passiewe meisie wat nie maklik uitgaan nie of dit jou “disability” is nie. Of is dit die persoonlikheid?

61: mense staar jou aan; hulle wonder. dit bly maar altyd n deel van jou lewe, lewenservaring.

62: sosiaal kan dit ook moeilik wees, want ek stap verby mense en ek kan nie sien wie dit is nie. Uhm so mense dink net ek is onvriendelik as ek hulle nie groet nie.

63: Maar gelukkig nou met tyd uhm leer ek die mense ken en ek leer maar nou om hulle op ander maniere te herken eerder as net gesigte en so aan. . . . Uhm ‘n mens kan nogal soms sien aan die manier waarop iemand loop of as jy hulle stemme beter leer ken of jy sien in die oggend watter klere hulle aantrek en dan die res van die dag onthou jy dit. . . . Maar ek dink dit gebeur onbewustelik.

64: So ek ek het half geleer as ek verby iemand stap om maar net net weg te kyk, want as ek in die persoon se rigting kyk om te sien of om te probeer sien wie dit is, dan dink ek gaan hulle dink, “oe, wel hy kyk reg in my vas maar hy groet my nie.”

65: Ek weet uit ondervinding dat mens byvoorbeeld soms in ‘n groep mense instap en dan raak hulle almal so stil. Dis die verskriklikste gevoel, want jy weet nie jy weet nie of jy “intrude” het op iets privaats en of hulle besig was om oor jou te praat en of hulle nou net skrik gevang het nie.

66: So ek het nie eens ‘n “doubt” dat jy weet mense altyd dink maar jy sal afsteek as jy met hulle vriende soos in goeie vriende is dan sal jy nou afsteek of jy sal altyd die lelike eendjie wees of so.

67: Want ek het ook in my eerstejaar “miss popular” as kamermaat gehad. Sy was mejuffrou “varsity cup” daai jaar en sy was mejuffrou “varsity” en sy was ‘n “fashion” model. So sy was rêrig popular en bitter mooi gewees. So toe ek ingekom het, daar was altyd mense in ons kamer gewees, maar dit was vir Este. Mense wat met my vriende geraak het om by Este te kom.

68: Mense aanvaar jou net makliker as jy soos hulle is. . . . Maar uhm ek weet nie dit was half moeilik om vir mense te wys dat, al het ek ‘n kierie, al kan ek nie sien nie, al weet ek soms nie waar ek is nie, dat ek net soos hulle is.

69: Ek moes hard werk om hul Aanvaarding te kry en en om hulle vertroue te wen en om hulle uhm jy weet soos amper voorkeur te wen.

70: Baie mense wil dit [blindheid] so wegsteek. En as ek kon sou ek ook. Ek meen, uhm ek weet nie, mense aanvaar jou net makliker as hulle dink jy is soos hulle.

71: Ek voel gevlei dat mense sê ek lyk siende, want dis seker 'n teken dat my oë normaal lyk. Wat vir my goed is, want daar's baie blinde mense wat in "quotation marks" lelike oë het.

72: Ek het al kere gehad wat 'n student tussen my en my kierie probeer deurloop. Hulle probeer dit of hulle skop dit eenkant toe. Dis so half aan die eenkatn wil jy raakgesien word sodat hulle nie bo-oor my loop of tussen my en my kierie prober loop of die oorsaak daarvan is dat ek hom nou laat val en dat is dit nou 'n hele gemors.

73: Wat vir my seker die grootste aanpassing was was om met 'n kierie te loop. . . . die feit dat ek net blind gelyk het met hom. Die feit dat ander mense kon sien dat ek nie dat ek nie kon sien nie.

74: Aan die begin sou ek gedink het nee, ek wil nie so sigbaar wees nie. Nou is dit soos, "jy! Sien my raak asseblief. Moenie in my vas loop nie."

75: Want ek dink maar net die kierie maak jou meer sigbaar as 'n blinde. . . . Dis 'n baie goeie ding, want dan loop niemand in my vas nie of niemand ry my om nie.

76: So ek is bly dat my oë normaal lyk. Maar ek verkies dat mense van die begin af weet ek is blind, al behandel hulle my nou vreemde omdat hulle nou weet ek is blind.

77: En ek het dit altyd so mooi weggesteek dat ek dink nie iemand het dit ooit agtergekom nie.

78: So ek's altyd so half tussen 'n klip en 'n harde plek – of ek nou die dosent gaan sê om my lewe te probeer makliker maak en of ek net gaan stilbly en jy weet probeer inpas. Want partykeer wil jy regtig net inpas.

79: En moet ek nou vir hulle [moontlike kêrels sê, moet ek nou nie vir hulle sê nie? En wanneer? En sê ek nou nie, dan was ek nou oneerlik, en sê ek nou, dan verloor ek die ou nog voor hy my ken.

80: Iemand gaan nie sommer met jou as blinde begin praat nie. . . . mense gaan nie so maklik met jou kom praat soos wat hulle met 'n ander siende student gaan praat nie. . . . So jy moet maar net weet as jy wil vriende maak moet jy van jou kant af moeite doen.

81: Ek sal nie sommer na iemand toe gaan en net begin praat met hulle nie. So dan, ek maak ook nie so maklik vriende nie.

82: Ek is eintlik voel ek n introvert. Maar as jy blind is moet jy jouself half dwing om 'n ekstrovert te word. Maak nie saak of jy of jou natuur antisosiaal is nie, jy moet jouself dwing om sosiaal te wees as jy wil vriende maak.

83: hoe jy jou gestremdheid hanteer gaan maak hoe ander mense jou gaan hanteer met jou gestremdheid of dan nou ook jou gestremdheid hanteer. . . . en dit is waar ek ook gesien het dit is wat jy van jou gestremdheid gaan maak hoe ander mense daarmee gaan "cope".

84: ek dink dit is 'n "two way" uhm ding. Uhm as jy 'n persoonlikheid het wat mense maklik mee kan "click" dan skakel dit half die gestremdheid uit. En as jy nou weer 'n moeiliker persoonlikheid het dan moet die gestremdheid half eers die "barrier" eers bietjie oorkom word.

85: ons kan nie sport doen saam met die koshuise nie. En baie van die goed soos sport, dis soos in in [koshuisnaam] was dit die grootste ding was sport deelname. En ek kon dit nie doen nie. En dit was half mens word uitgeskakel. So mens moet iets kry wat jou nogsteeds daar hou.

86: En dis moeilik om iemand in jou koshuis te kry wat iets in gemeen het met jou. Baie moeilik. Want byvoorbeeld in my koshuis, manskoshuis, hulle kyk maar almal rugby en ek sukkel my dood om rugby te kyk. . . . Enne ook ek het dit ‘n bietjie moeilik gevind om goed te vind om met hulle mee te praat. Ag jy weet mos nou, dit was meer oor rugby en die goed wat in die “quad” gebeur.

87: Al wat ek kan sê is ek het eers rêrig begin vriende maak toe ek by my koor ingeskakel het. Siende vriende bedoel ek nou. Maar dis omdat hulle het iets in gemeen met my. Dis weer daai hele ding van daar’s iets in common.

88: En dit was vir my moeilik om my trots in my sak te steek en soms vir iemand te vra vir hulp, want mens wil regkom en jy wil jy wil lyk asof jy weet waentoe jy gaan. En jy wil net inpas.

89: Ek het een aand nodig gehad om ABSA toe te stap en ek wou nie alleen nie. Ek vra toe vir haar “randomly”, sy’s saam met my in die koshuis, “ekskuus, ek ken jou nie, maar sal jy saam met my stap?” En ons het begin chat en vandag is ons baie goeie vriendinne.

90: Hulle gaan dalk aan die begin met jou vriende wees omdat jy blind is en hulle jou wil help, maar as jy meer tyd met hulle spandeer gaan hulle van jou as mens begin hou.

91: Baiekeer begin dit net so. Baiekeer help hulle jou en dan later besef hulle maar hierdie is eintlik ‘n “nice” persoon.

92: As jy baie onafhanklik is, party mense kry hierdie idee jy is op jou eie “mission” en hulle moet jou tog net nie pla nie. En ek dink baiekeer een manier om te “connect” is deur met siende mense, is om hulp te aanvaar. Nie hulp noodwendig te vra nie, maar hulp te aanvaar.

93: persone wat kan sien is maar baie katvoet dat hulle uhm nie in ‘n situasie kan beland wat wat hulle in ‘n moeilike posisie stel nie. Wat hulle miskien hulle eie laste moet dra, maar ook die van ‘n blinde persoon.

94: Maar die dag toe ek my hond gekry het toe’t dinge nogal verander. Uhm ja so toe uhm was ek genooi vir goed uhm sê nou maar om by iemand te gaan kuier of te gaan koffie drink of wat ookal. So asof hulle kon agterkom okay maar sy kan eintlik onafhanklik ook wees, jy weet? Nou hoef ons nie meer alles vir haar te doen nie.

95: Ek ken baie mense in my koor. Hulle weet ek kan self opstap. As ek met my kierie koor toe stap het baie mense al na my toe gekom en gesê, “hallo, wil jy sommer saam met my stap?” Maar hy weet en ek weet ek kan self tot daar loop.

96: Ek het baiekeer klas gemis as gevolg van van ander mense wat vergeet het om my te kom haal.

97: En ek kan nie in die aande saam met hulle uitgaan nie. Daai begrip het hulle nie – ek kan nie sien nie. En maklik om te sê maar ons sal saam met jou loop, maar dan raak hulle so dronk. Hulle raak vieslik dronk en dan moet ek op my eie regkom.

98: Ek het ‘n blinde vriendin hierso, as as sy nie hier is nie, dan is ek half jy weet “you just feel so lost. Not for anything, but because blind people understand. They understand what you’re going through. So it’s like a support group on its own.”

99: wel, ek het ‘n vriend wat ook blind is wat presies dieselfde as ek swot en dieselfde tyd as ek begin swot het. . . . So nog ‘n blinde wat saam met my “suffer”. . . . Dit help nogal baie om vir iemand anders te vertel hoe sleg die lewe is. En dan as hy nog saamstem ook, dan is dit nog beter.

100: So ek het so half hier “mostly” ingeval by die die “totally blind” vriendekring. En dis vir my ‘n groot ondersteuning op daai manier om mense te hê wat jy mee koffie drink en julle “bitch” saam Soos wie se dosent is die ergste en wie se werk is die meeste agter of daai tipe goed. . . . Dit maak dit makliker. Dan voel jy nie so alleen en vasgevang in alles nie.

101: . . . maar mens wil soms net met mense praat wat half dieselfde probleme het as jy. Wat jou half kan raad gee en half ondervindings kan deel. En jy kan dalk iets daaruit leer. En ons doen dit tog op die stadium.

102: die afhanklikheid help jou om mense te ontmoet, maar jy ontmoet hulle en hulle word so semi-jou-vriende, maar hulle is ook nie rêrig jou vriende nie. . . . Hulle wil jou help, maar hulle sal nie hulle self oopmaak vir jou of hulle sal nie jou toelaat om hulle op enige manier te help nie.

Chapter 8

103: As hulle die projektors en goed gebruik dan sit hulle die ligte aan dan sit hulle di ligte af dan dim hulle dit. Toe sê ek, “my oë kan dit nie hanteer nie.”

104: Baie van die dosente e-mail die goed direk. Sodra hulle iets elektronies het dan e-mail hulle dit vir die Braille department. Want mens sê vir hulle, dan’s hulle soos, “okay, yes ons doen dit”.

105: So hulle [Franse Department] gaan regtig uit hulle pad uit wil ek amper sê om dit om dit vir my om dit vir my soveel moontlik te maak soos wat dit vir die ander studente is om goed te doen daarin. Om my half op dieselfde vlak te kry as die ander studente.

106: Ek onthou nog die eerste toets wat ons geskryf het het die professor vergeet om vir ons die toets te kry in ‘n formaat wat ons lees. Toe moes die tutor eers vir ons die toets lees voor ons kon skryf. En dit het klaar ‘n uur gevat.

107: Een dosent het vir my gesê ek kan dit [notes] nie voor die tyd kry nie, ek moet klas toe kom. Nou ek gaan klas toe, maar ek kan nie sien wat op die bord is nie.

108: En die dosent sê net eenvoudig, sy’s jammer, sy gaan nie die boek gee nie, die boekwinkel is vol daarvan, ek moet een gaan koop. En toe sy in die klas kom, toe sê sy sy gee nie slides nie. Niks nie. Jy moet notes maak, anders gaan jy dop. So ons gaan toe na haar toe en ons sê vir haar, “ek is elke dag in die klas. Ek wil net uitgevind het of sy nie dalk of sy nie dalk iets op papier het wat ek net kan gebruik soos wat die ander notas maak.” “Nee,” sê sy. Sy’t net eenvoudig gesê nee.

109: Ek het ‘n brief van die oogarts en hy dink nogsteeds daar’s iets fout met my I.K. Hy’s soos, “Ja, as ek vir jou notas gee gaan jy nogsteeds nie beter doen nie.”

110: Hierdie is my hoofmodule. As ek hom druip, kan ek nie aangaan honneurs toe nie. Jy kan nêrens heengaan as jy dit nie deurkom nie. “It’s like you’re stuck in this worm hole,” jy weet? So “eventually” sal ek dit moet deurkom.

111: Sy het vir my gesê ek moet saam met my ma teruggaan na die dosent toe. En dan, as hy nogsteeds niks doen nie, dan sal sy met hom praat. Maar ek dink ook nie enigiemand verstaan dat dit is dis so half jy wil nie daai tipe moeilikheid maak nie. . . . Dit voel half soos skool, jy weet? Jy vat jou ma saam êrens heen. . . . En dit is “kind of” vernederend om die heeltyd te moet, jy weet, kla oor so iets. Ek meen dit was klaar erg genoeg om die eerste keer met hom te gaan praat en vir hom te sê, “kyk hier, ek kan nie sien nie.” En dan behandel hy jou asof jy nie kan dink nie. . . . Ek voel as ek eenkeer met hom gaan praat het dan moet hulle dit so half uitsorteer op ‘n mooi diplomatiese manier wat ek nie van weet nie, jy weet? Net sodat as ek weer by die klas kom dan’s dit klaar uitgesorteer.

112: Ek het nou al ge”consider” om actually te kyk of die universiteit vir my die geld vir die jaar wil teruggee en êrens anders te gaan swot.

113: Wat vir my baie lekker was by die geologie department was hulle het nog nooit blindes voorheen daar gehad nie, so als is vir hulle nuut. Jy weet?

114: En ons was die eerste blindes in daai arme dame se klas. Sy’t rêrig moeite gedoen. Jy stap in, nè, sy gee vir die sindes notas, sy gee vir my ook notas.

115: Wat dit moeilik maak is soos met die Sosiologie department, hulle het nou al so baie blindes deur hulle gehad, nou kom vra ek vir uitstel. Dan’s hulle soos, maar niemand anders het nog vir uitstel kom vra nie. Hallo! Maar jy weet nie Jonathan het verlede week sy heup gebreek nie. Verstaan? Sulke goed.

116: Hulle sien jou soos ‘n “unit”.

117: Dan sal hulle vir jou sê, kom ons sê nou maar, “maar Amy het 85 vir haar Sielkunde opstel gekry.” Dan’s ek soos, “maar ek is nie Amy nie.”

118: Almal se situasie is anders. Almal se gesigsveld is anders. Almal se “abilities” is anders.

119: En wat vir my “nice” is van die braillekantoor is dat jy kan met hulle gaan praat oor goed, dit hoef nie net academies te wees nie. … Ook as ek nou soos siek is die dag, dan kan ek hulle e-mail en vir hulle sê, “okay, hoor hier” . . . soos verlede week kan ek vir hulle sê, “ek is siek, daar gaan goed na julle toe kom wat gedoen moet word en so.”

120: Ek moet sê ek kon nog nooit gekla het oor hulle nie. Vir die hoeveelheid werk wat hulle moet doen dink ek doen hulle dit heel okay.

121: Daar is soos tye wat goed nie daar is nie, maar dis rêrig nie hulle skuld nie. Hulle doen wat hulle kan.

122: En dan raak mens partykeer ook agter as jy nou…as hulle lank vat om die goed te verwerk. En dan kry jy dit nie betyds wanneer die ander mense dit kry nie. Jy kry dit eers ‘n week later waar die siende mense nou al hulle notas gekry het.

123: Ek het gewoonlik take laat ingehandig en dit was nie goed vir my moraal nie. [lag verleë] Want om elke keer te vra vir uitstel uhm dis vernederend en jy’s bang die dosente dink jy’s lui.

124: Weet jy hoe agter is ek? Ek kon nog nie een van daai dokumente lees nie en ons is in week 4. Want hoekom? Want al die pdfs wat ek vir hulle gestuur het is “bad quality,” dis te sleg, hulle kan dit nie verwerk nie. . . . My punt is weet jy hoe vernedered is dit om daar te gaan sit en sy vra vir jou, “het jy die taak gelees?” en jy moet sê nee en jy weet dit is nie eens jou skuld nie. Jy weet? As ek dit nie gelees het nie, omdat ek lui was of omdat ek vroeg wou gaan slaap, dan’s dit ‘n heel ander storie. Maar ek is al so gefrustreerd.

125: In ‘n ideale wêreld sal jy seker nou kon argumenteer dit is nie veronderstel om jou verantwoordelikheid te wees nie. Maar die punt is net, as jy dit nie doen nie gaan jy soveel meer sukkel.

126: En hier is dit natuurlik ook jou plig om te sorg dat dit wat jy verwerk wil hê betyds by die mense wat daarvoor verantwoordelik is kom.

127: ‘n Eerstejaar blinde student voel dit vir my het soveel meer verantwoordelikhede as iemand wat nou nie blind is nie wat eerstejaar is. Ek meen ons moet konstant seker maak ons het daai notas. Jy kan nie net na jou klas gaan en gaan kyk of jy al jou notas het nie, want natuurlik het jy nie. So jy moet konstant onthou en “check up” en hier en daar maak jy foute en dan kom jy in die moeilikheid daaroor.

128: En dan sal jy nou sê maar hierdie goed is belangrik en jy moet dit hê voor daai datum. Jy probeer hulle maar gereeld te herinner dat jy dit vir hulle gegee het en dis baie belangrik en hulle moet probeer om dit vir jou voor ‘n sekere datum te gee. Die ander mense het dit al gekry en jy skryf sê nou maar toets of so . . . jy moet net bybly en gaan praat met die of stel jouself voor aan die dosente dat hulle weet van jou en sorg dat jy vir hulle sê om die goed aan te stuur. Jy moet hulle maar gereeld daaraan herinner ook, want hulle vergeet

129: Ons gaan nie altyd weet wat tussen die dosent en die braillekantoor gebeur nie en die braillekantoor weet nie wat tussen ons en die dosent gebeur nie of wat ookal. So daai driehoekkommunikasie moet altyd eintlik half tiptop wees. . . . En jy moet heeltyd die “link” wees tussen wat aangaan. Waar hulle tel nie die foon op en sê, “luister” of wat ookal. Jy hardloop die trappe op en af en woon die klasse by en “please explain” vir die een vir dit en vir daai een vir dat.

130: Daar is miskien dinge wat departemente kan doen van hulle kant af. Maar mens kan maar ook daai “extra mile” loop. Verstaan jy? As jy kan, dan, ja. . . . “ek het maar my rekenaar gehad en my braillemasjien en papier en dan ‘n “voice recorder”. So ek het elke dag in die klas gaan sit. Ek het geen notas gehad nie. Ek moes alles opneem en dan maar by die huis gaan opsommings maak en leer. So daar het ek geleer om maar te werk met dit wat ek het. Jy gaan nou maar op jou geheue en jou gehoor en dit wat vir jou beskikbaar is. En op die ou end dan maak jy dit nogsteeds werk.

131: Hulle main ding is, jy as student is verantwoordelik om te sorg dat daai goed by ons uitkom. My motto is, ek moet klas bywoon, ek het nie tyd vir hierdie nonsense nie. Kry die goed!

132: Ons het sulke vier uur lesings en my oë raak verskriklik moeg dat ek kolle sien as ek lank konsentreer.

133: Dan moet jy eers in ‘n donker kamer lê vir ‘n paar uur en jy’t ‘n migraine. Dis oogdruppels, dis kortisoondruppels, infeksies en so.

134: Nie net die stremming op my oë nie, maar die stremming op my liggaam wat ek al moes beleef as gevolg van my oogprobleem. Hoe ek op skool moes leer of sit in die klas en werk met my kop omtrent op die lessenaar met my rug krom. En die rugprobleme as gevolg daarvan wat ek ontwikkel het, die slegte postuurgewoontes en so aan. En dan moet jy eksamen gaan skryf vir drie ure lank wat ek so sit met my neus teen die papier.

135: Ek vermy dit om te lees . . . want my oë raak moeg en dan raak ek vaak en dan kan ek nie meer konsentreer nie.

136: Jou oë raak later so moeg en dan fokus hulle net nie meer nie

137: Die produk wat ek nou kon lewer met my navorsing byvoorbeeld uhm was goed. En as ek dit in ‘n kort tydjie moes inge”squash” het uhm en verskriklik baie goeters moes gelees het in ‘n kort tydjie dan dink ek nie sou ek dit so maklik kon doen nie.

138: Al hierdie struikelblokke wat jy moet oorkom. Dis nou nie die professor kan nie nou net vir jou ‘n “stack” papier hier kom neerplak en sê, “skryf die toets,” en daar gaan jy nie.

139: Kyk, om ‘n taal aan te leer is eintlik ‘n baie visiuele ding, want hulle wys prentjies. Dan is dit nou ‘n persoon wat loop en dan sal daar nou onder in Duits staan, “die persoon loop.” So jou brein leer mos maar basies in prentjies. So as dit in ‘n toets sou gebeur dan dan omskryf hulle dit of die dosent sal sê, “goed, as jy by daai vraag kom, sê net.” Want in my geval het die, veral met die taalvraestel het die taaldosent verkies om self toesig te hou. Jy weet dat as daar ‘n probleem kom dan kan sy dit self uitsorteer of wat ookal.

140: Wel, by party vrae het hulle net gevra ons moet net beskryf hoe die grafiek lyk. . . . Ek onthou hulle het in ‘n paar toetse ‘n vraag gevra, dan het die hele vraag net daaroor gegaan dat jy moet die grafiek teken. Wat hulle dan doen is hulle haal die grafiek uit en dan tel die toets net uit minder vir jou.

141: Hulle sal byvoorbeeld vir jou sê: “sorg net dat die ding ingehandig word. Moenie worry oor die datum nie, dit moet net inkom.”. . . Omdat hulle weet dit vat langer om byvoorbeeld ‘n artikel te soek of as die artikel in PDF is dan moet hy eers verwerk word.

142: Ek het gewoonlik take laat ingehandig en dit was nie goed vir my moraal nie. [lag verleë] Want om elke keer te vra vir uitstel uhm dis vernederend en jy’s bang die dosente dink jy’s lui.

143: Soms kry ek die goed ‘n bietjie laat, want dit moet nog verwerk word en so. Soms gee hulle vir my uitstel. Soms is hulle ‘n bietjie “mean” en hulle doen nie.

144: Kyk, dit sal lekker wees as dit nie sulke “effort” was nie, maar ek dink ‘n mens kan regtig goed voel oor jouself as jy die “challenges” wat daar is oorkom.

Chapter 9

145: Ek staan letterlik half met my een been in ‘n blinde wêreld en my ander been staan ek in ‘n normale wêreld. Sien jy? Dis hoe dit vir my voel. Ek moet ook rondtas en voel is ek uhm is ek . . . word ek hier aanvaar? Is ek op die regte plek? Uhm sal ek kan inpas hier? Moet ek vra vir hulp? Hoe sien mense my? Of sien jy, waentoe is ek op pad?

146: Sy [mother] het geweet sy sal nie altyd daar kan wees by die skool nie, want sy gaan mos nou werk toe. So sy wou hê ek moet my “battles” self “fight” om sterker te word.

147: Vir my van kleins af – ek kan nog presies onthou, die dag het ek vir my ma gevra, “mamma, ek moet seker nou na ‘n gestremde skool toe gaan?” En sy sê vir my, “nee, my kind! Jy is normaal! Jy is reg, jy moet net skool toe gaan.” . . . En sy’t vir my gesê dat ek moet net leer om aan te kan pas en so normaal as moontlik te funksioneer.

148: Soos daar was een meisietjie, sy was verskriklik bang vir my. Sy wou nie met my gespeel het nie, sy wou nie aan my geraak het nie, vir haar was ek soos ‘n monster.

149: Na wie toe gaan die kinders eerste? Sien jy? Want hulle wonder mos nou uhm daardie juffrou lyk nie “all right” nie, haar oog is nou so of so. Jy is nie “approachable” nie. Dan dan is kinders nou weer scrams.

150: dit mag nie gehoor word nie of die mense daaroor praat nie. Dis amper soos hulle kry skaam oordat hulle nou daarvan praat.

151: Dit is vir my ‘n “roller-coaster”. . . . Ek kan nie eens dink wanneer het ‘n seun my “approach” en vir my vir ‘n “date” gevra nie. So jy “deal” daarmee; ek moet met dit “deal”.

152: Ek het nie ‘n vaste vaste vriendskap wat ek kan sê “die’s my maatjie, ons deel goeie en slegte tye met mekaar nie.” Vir my is dit net kennisse. Dis net hallo sê en bye. Daar’s nie ‘n vaste vriendskap nie. In die hele jaar prober ek vriende maak, maar ek het nie ek het nie ‘n vaste vriend nie.

153: as jy ment mense goeie vriende is dan sal jy nou afsteek en jy sal altyd die lelike eendjie wees of so.

154: My visiuele gestremdheid, nè, dit is maar skokkend vir mense. Want want my, hoe kan ek sê? My een my linkerkant nè, is baie laer as my regterkant. en dit lyk seker maar ‘n bietjie wreed vir mense, ek weet nie.

155: En somtyds vergeet ek self dat ek nie goed kan sien nie. . . . dan is kinders nou weer scrams. Dan is dit nou weer vir my, o ja, ek het nou weer vergeet. Is nou alweer my oog se storie.

156: As ek my bril ophet, dan reageer mense minder ongemaklik. . . . Maar as my bril af is, dan kan hulle nou sien, “nee, maar sy is nou heel swaksiende.”. . . . Want ek was eendag by die markie en ek het nie my bril opgehad nie. En die een ou sê toe nou vir my, “maar jou een oog staan stil.” Ek sê, “ja, want dit kan nie sien nie.” Maar hy sê toe nou net, “o.” Hy dink seker maar hoe kom jy dan nou oor die weg, want jou ander oog staan dan nou stil en hierdie een beweeg en alles is reg; so wat is fout. So ek weet nie, maar as ek nie my bril ophet nie, dan hanteer mense my anderste. Ek sit maar my bril aan. Dit maak dat die volgende persoon meer gemaklik is en vir my beter aanvaar, want ja, my bril is ook maar soos my skerm.

157: Vir haar was ek soos ‘n monster. Totdat ek vir haar verduidelik het waarvanaf dit kom, hoekom is dit so. Toe verstaan sy eers.

158: Dan is kinders nou weer scrams. . . . Dan moet ek maniere alweer vind om aan te pas en die kinders se vertroue te wen en so aan. So vir my gaan dit heeltyd oor kan ek die person se vertroue wen?

159: En dan nou is dit dinge wat vir my ‘n bietjie moeilik is op kampus is ook dat uhm soos integrasie is vir my moeilik. Ek moet uitreik partykeer om, hoe kan ek sê, om geaanvaar te wees. Want mense is maar bietjie skuerig omet met jou te praat.

160: Dit sal vir my baie beteken om te kan hoor hoe ander mense dit hanteer, hoe hulle dit ervaar en wat hulle doen om elke dag aan te kan gaan. So ek sal nou nie voel ek is abnormaal nie.

161: My oë raak beter en slegter. Nie in die sin dat ek meer visie verloor of meer bykry nie, maar die kompleksiteit van die oog self van my sig, want daar is blykbaar soveel fasette daarvan. So dit is wat die heeltyd verander. So ek kan nie elke keer gaan vir ‘n nuwe leesbril nie. So ek moet nou maar net bly by wat ek het. [sug]

162: Ek was baie gespot op skool oor my bril. My bril was so dik dat ek het huge oë gehad en ek was oorgewig en my tande was skeef. En soos ek het hierdie kompleks ontwikkel.

163: My oë was altyd een van die hooffaktore wat dit moeilik gemaak het. Want jy voel half asof jy “lacking” is.

164: Ek het nog net twee beste vriende in my hele lewe gehad, but ek voel net dat mense kan baie wreed wees, so dis beter om jou emosies vir jouself te hou. . . . So ek het net gevoel dat mense is naar.

165: Ek het naweke by die huis gebly en verder gewerk; my werk gedoen. . . . Werk is vir my makliker as ‘n sosiale lewe.

166: Soos daar’s baie emosionele goeters waar my selfbeeld gebreek is, maar as dit kom by my werk weet ek dat ek een van die topstudente is en sal altyd wees, want dit is my lewe.

167: so dit was nie vir my asof dit werk was nie, dit was nog altyd asof dit deel van my was. . . . Dit [werk] is letterlik my lewe.

168: Dit [CPUT] was die eerste plek [CPUT] waar ek aanvaar is vir wie ek is. . . . Maar elke keer as ek in die gebou ingestap het voel ek dat mense het na my gekyk vir my werk, na die kwaliteit van my werk en nie na hoe ek lyk nie.

169: Ek is nog altyd baie erg oor my werk. So ek het presteer. Ek was prefek in laerskool en hoofmeisie in laerskool. En toe gaan ek hoërskool toe. . . . Ek was ook weer hoofmeisie in graad 12. En “eventually” . . . ek het ‘n 1+ gemiddeld behou en ek het vrywilligheidswerk gedoen . . . maar jy moet meer doen, want jy doen dit nie net vir onderwysers nie, jy doen dit vir jouself.

170: dit was soos ‘n nagmerrie vir my om in die kunskamer in te loop . . . die eerste jaar was vir my die moeilikste, want ek het opgeskop, want ek kon dit nie meer hanteer nie soos net die verfkwaste. En ek het teruggekom en ek het my jaar kom klaarmaak.

171: En dan om die heeltyd te “squint,” ongelooflike kopsere wat jy kry! Ongelooflike Kopsere. . . . My skouers self, hierdie spiere hier in my nek, soms het dit so . . . dit het soos ‘n ‘n brand en ‘n steek. Dit was . . . ek is letterlik so gestress oor as ek by die PC sit dat ek kon my skouers soms nie wegtrek nie. Soos my skouers sal by my ore sit en dan sal dit so bly.

172: Dit was amper soos soms het my oë besluit om nie saam met my hande te werk nie. Daar was altyd naalde in my vingers. So. Altyd pleisters. Die seketaresse het altyd pleisters vir my gehou.

173: Ek het ‘n tattoo van ‘n smeltende roomys in my eerste jaar gekry, want dis my lewe – soos ‘n smeltende roomys.

174: Omdat kuns vir my so belangrik is en omdat dit deel is van wie ek is, is dit vir my ook baie intiem en persoonlik. En die feit dat mense nie daai gedeelte van kuns verstaan nie, is vir my so frustrerend. En ek voel hulle breek waarvoor ek staan en wat ek doen af, in plaas van om te probeer help. So ek moet eers ‘n sterker vel kry en ophou huil voordat ek kan staan vir waarin ek glo.

175: Ek het in tweede jaar begin trek aan my vel en soos dit oopgetrek die heeltyd. Ek kon net nie meer die druk hanteer nie. Ek het nie geweet of dit my skuld is dat ek net te vol fiemies is nie en of ek rêrig nie kon cope met die alles nie. . . . So elke keer as ek stress dan gaan ek vir my vel. Dis seker die aakligste ding wat ek ooit gedoen het. Dis daai oomblik wat ek gevoel het dit laat my beter voel . . . dit werk nogal ‘n bietjie op jou selfbeeld, die merke in my gesig.

176: jy’s nooit klaar gesoek na wie jy is nie en wat jy soek en jy’s nooit tevrede met wie jy is nie. Daar’s altyd iets as gevolg van sisteme wat jou laat minderwaardig voel.

177: Ek het nie geweet of dit my skuld is dat ek net te vol fiemies is nie en of ek rêrig nie kon cope met die alles nie.

178: My onderwysers het vir my gessê . . . hulle kan nie uitsonderings maak nie. En dis reg, dis nie regverdig nie. En met druk oor die algemeen, almal sukkel met skone kunste; almal oor die algemeen.

179: En ek het ook altyd gedink, watter ondersteuning kan hulle my regtig gee? Dis nie asof hulle my werk kan makliker maak nie. Dis nie reg nie.

180: So ek het net altyd hierdie mind set gehad van, doen dit net self.

181: dit is moeilik, vir my is alles tien keer moeiliker.

182: Ek wou nooit soos uitgesonder word en spesiaal behandel word nie. Al waarvoor ek gevra het is dat, as hulle ‘n oogklap op hulle een oog gesit word, net skielik, en vir hulle sê, “jy’t ‘n halfuur om dit te doen.” En dan doen hulle dit. En dan haal hulle die oogklap af en hulle laat hulle presies dieselfde ding doen en hulle kyk na die tyd, sal hulle sien hoe dit voel om soos letterlik die helfte van jou “capabilities” te hê. Die helfte van uhm jou “skills” word weggevat.

183: Jou sig word weggevat. Dit is nie iets wat mense kan beter maak met goeters nie, dit is net weg. Dit is nie iets wat kan beter raak as jy vir my dit gee of dit of dit nie, dis weg! Dit kan nie vervang word nie. En dit is dit is ‘n baie erge ding om mee te deal ook.

184: Want jy’s te bang om te sê dat dit tien keer moeiliker is vir jou om te sien op die bord en dat jy vir almal moet vra wat daar staan. . . . So jy voel dat jy’s te bang om te vra, want jy gaan ‘n nee antwoord kry.

185: Ek het aansoek gedoen, ek het die papiertjie ingevul. Daar’s nooit vir my iets daaroor gesê nie. En ek het ook nie geweet waarop ek geregtig is nie. . . . Want dis hoekom ek so geskook was toe jy sê ek is op die databasis, want ek het gedink dat hulle glad nie eens dit in ag geneem het nie. Want ek het nooit van hulle gehoor nie. Ek het gedink ek kwalifiseer nie of iets soos daai. So ek het nooit geweet dat ek die “assistance” of dat ek die ondersteuning kan kry nie.

186: En ek weet die onderwysers probeer hulle beste. En hierdie onderwysers het soveel kennis en soveel ervaring. Hulle het regtig baie gehelp, maar somtyds het dit net baie moeilik geraak. . . . Daar was ‘n stadium wat dit regtig erg geraak het wat hulle gesê het, okay, hulle sal vir my 15 minute ekstra tyd gee vir verfwerk. Dit help nie. As ek vir ‘n uur na daae prent gekyk het kan ek nie meer sien nie. Veral met die tipe ligte wat daar is.

187: Die omgewing is verskriklik beskermend en daar is paadjies van een plek na ‘n ander plek. Dit is absoluut uitgelê vir blinde persone.

188: En handboeke en notas is altyd verwerk.

189: veral op ‘n sosiale vlak was daar baie dinge wat ek nie kon ervaar nie, want jou “peers” is basies blinde persone wat ewe beperk is. So julle ontwikkel maar jy weet volgens ander terme. Ek bedoel omdat ons nie belangstel noodwendig in mode of MTV se nuutste music video, jy weet sulke goed nie, is daar baie aspekte wat ons nie van weet nie, nie verstaan nie, nie in belangstel nie.

190: Ek sou kon leer hoe om vir myself te “fend” en op watter wyses. . . . Om academies vir die onderwyser te kan sê, “hoor gou, as dit by hierdie en hierdie aspekte kom,” jy weet byvoorbeeld visiuele material of so, uhm kan ek eerder hierdie werkstuk doen? Of jy weet so. Dat ek nog altyd punte kry vir die werk wat ek doen. Dat dit nie net oorgeslaan word soos wat dit partykeer op universiteit gebeur het nie.

191: Die feit dat ek nou nog ‘n bietjie ge”limit” is in goed wat ek doen. Ek het hierdie ding oor dat ek nooit genoeg vryheid sal hê nie. En dit is iets wat ek veral op universiteit ontdek het - uhm opnuut hoeveel vryheid mens kan hê en hoeveel ek nie het nie. . . . Jy (siende persoon) het al hierdie vryheid. Jy weet wat om jou aangaan, so jy kan keuses dienooreenkomstig uitoefen.

192: Vir blinde persone ook meer Vryheid, maar ook die verantwoordelikheid wat daarmee saam gaan. Byvoorbeeld, jy kan nie net met enige groep mense uitgaan nie. Jy moet nou dink, hoor hierso, weet hulle hoe om my te hanteer? Gaan hulle my iewers net los? So ‘n mens moet verskriklik verantwoordelik wees. . . . Jy moet byvoorbeeld beplan as jy wil gaan fliek of as jy wil dorp toe gaan. Wanneer is tye bietjie stiller? Wanneer is die verkeer nie so erg nie.

193: En dan my ouers wat hier vanuit die agtergrond ook dinge prober dikteer het en basies net nie my Vryheid vir my gegun het nie. En dit is moeilik, want dit ontneem jou, dit stroop jou eintlik van ‘n klomp dinge. Uhm jou identiteit waartoe jy geregtig is, om ‘n nuwe identiteit te ontwikkel. Jy wil nie bekend staan as die blinde student wie se ma vir haar elke dag beskuit bring nie.

194: Persone wat kan sien is maar baie katvoet dat hulle nie in ‘n situasie kan beland wat wat hulle in ‘n moeilike posisie stel nie. Wat hulle miskien hulle eie laste moet dra, maar ook die van ‘n blinde persoon. . . . Ek dink nie mense hou daarvan om gebind te wees nie. Ek dink niemand hou daarvan om gebind te wees nie.

195: Ek glo vas dat as mense sien jy is onafhanklik dan uhm bejeën hulle jou bietjie meer op ‘n positiewe wyse. . . . Ek het veral ‘n merkbare verskil opgetel toe ek my gidshond gekry het. Want toe sien die mense skielik maar, o, jy weet, sy hou ook van dorp toe gaan en sy’s nie net die “clingy” blinde meisie nie, sy mission ook op haar eie.

196: En ek weet dat vir mense in my posisie, blinde persone, is universiteit “pretty much” maar een van die beste opsies, want jy kan nie gaan skeepsdekke skrop of jy weet sulke tipe van goed doen nie.

197: ek was byvoorbeeld in ‘n posisie waar ek in my tweede jaar al beplan eht watse meesters ek wou doen. Uhm dit was in ‘n praktiese rigting. Met ander woorde, baie toneelspel, baie aanleer van teks – jy weet, so. Uhm en uhm ek het met my dosente gaan praat en hulle’t gesê, “nee dis reg, jy kan hierdie M doen.” So gevolglik het ek my honneurs dienooreenkomstig gekies om jy weet te korrespondeer met die M. Ja. En toe ek in my derdejaar kom, klaar my honneursrigting gekies het, toe draai hulle om en sê “nee, jy leer jou goed te stadig aan, jy kan nie meer nie.”

198: sosiaal uhm ek dink daar sal ek die skuld lê by beide my asook die ander studente, want soos ‘n vriend later van tyd vir my gesê het, hy’t doodeenvoudig net nie geweet wat om met my te maak nie. En uhm andersom ook. Daar was vir my soveel nuwe sosiale kodes wat in my skool net glad nie bestaan het nie. Ek bedoel, dit was vir my ‘n totale ander wêreld. So dit was vir my ‘n groot aanpassing.

199: ek moes hard werk om hul Aanvaarding te kry en en om hulle vertroue te wen en om hulle uhm jy weet soos amper voorkeur te wen. So ek moes baie uit my pad uitgaan om vir mense te bewys, “maar hoor hier, ons kom uit verskillende agtergronde, maar hei, ‘I can learn.’” Uhm en ook dat ons, buiten die kursus wat ons swot, dat ons wel goed in gemeen het. Jy weet ons is almal jonk, ons het almal sekere vrese en dinge wat ons “happy” maak, “likes” en “dislikes.” En jy weet ons is almal mense. Ek is miskien net een wat nie kan sien nie en jy is weer. . . . Uhm so ek moes ja, ek moes hard werk.

200: Jy moet beplan. As jy take moet doen, okay, ek moet “actually” ‘n maand voor die tyd begin. So ek moet my assistent in die hande kry sodat ons vir bronne kan soek. Uhm so jy weet jy moet verskriklik op jou tone wees.

201: Die vegtersgees. Daai uhm jy weet ek wil nie teruggaan na waar ek vandaan gekom het nie, ten alle koste. Rêrig, ten alle koste. Uhm so jy moet absoluut vir jouself sê, “come hell or high water,” jy moet dit doen. . . . So dis hierdie “resilience” wat jy moet hê en en ‘n gedetermineerdheid uhm om jou doelwitte te bereik. Jy moet absoluut hard op jouself wees, jouself baie druk . . . jy moet nou nie jou strydbyle heeltemal neerlê nie. Uhm ek dink ‘n mens, you must “die trying” op ‘n manier. Jy weet jy moet altyd altyd hoer, altyd beter. Jy weet, jy moet streef na iets.

202: as jy eers jou eerste graad gekry het en almal klap vir jou hande, dan besef jy joe, dit was eintlik die moeite werd. En ek dink die selfvertroue wat ‘n mens ontwikkel – dis vreeslik lekker om te besef, jo, “I’ve made it and I’m making it.” Jy weet?

203: So die “challenges” is moeiliker, maar die “reward” is op die ou einde vir my groter.

204: Sjoe, vir ‘n blinde person is universiteit so ‘n oorweldigende ervaring, want in universiteit gebeur daar mos maar baie selfondersoek en en so aan. En dis ‘n tyd wanneer jy regtig tot ‘n klomp ontdekkings kom.

205: En ook die besef dat, hoor hier, ek het nie ‘n paadjie van die badkamer na die sitkamer na die eetkamer en so nodig nie, ek kan eintlik “survive. . . . En ook die feit dat jy kan net “relate” tot blind mense. Dit is nie waar nie. Of jy het dinge net in gemeen met blinde mense. Om te leer maar hey, ek kan actually vriende maak wat kan sien. Jy weet, ons ons het tog goed in gemeen.

206: So jy leer verskriklik baie van jouself wat op die ou end tweeg bring dat jy uhm jy herbou jou identiteit. Dit wat mense altyd van jou gesê het, jy kies byvoorbeeld om dit nie te glo nie.