BLINDNESS, REHABILITATION AND IDENTITY

A critical investigation of discourses of rehabilitation in South African non-profit organisations for visually impaired persons

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PLAGIARIASM DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

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ABSTRACT

This study explores the role of rehabilitation in shaping the subjectivity of blind persons. It considers what engaging with rehabilitation services might communicate to people with visual impairments about their status, their value and their place in the world. Rather than being concerned with the practical aspects of rehabilitation, it explores how rehabilitative practices operate at the symbolic level, and interrogates the meanings about blindness which are produced within relationships where help is given and received.

Drawing on Foucauldian concepts, this research traces the interplay between discourse, power and knowledge in rehabilitation services. The research design includes two phases. Through analysing the website copy of eight organisations located across South Africa, Phase One identified discourses employed by organisations as they represent themselves in the public realm. In Phase Two, semi-structured interviews were conducted with eight service providers and eighteen service users across four organisations operating in the Western Cape province of South Africa. This phase identified the discourses framing rehabilitative activities and relationships.

Visually impaired participants described sight loss as a significant trauma – as dislocation from society and self – revealing that service users might be particularly vulnerable to the shaping influence of rehabilitation. Data analysis found, firstly, that the discourses which frame rehabilitation services position visually impaired service users as passive recipients in relation to the work of service providers and the gifts of the public. This positioning objectifies service users and may signal to them that they are neither valued as stakeholders nor recognised as autonomous adults, while also requiring that they demonstrate gratitude towards service providers and the public. Secondly, rehabilitation is constructed as a linear journey with strictly defined outcomes. This ‘journey discourse’ relies on polarised fantasies about blindness involving, on the one hand, dependency, dislocation and struggle and, on the other, independence, integration and coping. Visually impaired service users are required to demonstrate evidence of the latter while the former shadowy figure of pre-intervention blindness must be defended against. This discourse prohibits nuance and expressions of ongoing struggle, underpinning an imperative to cope found within organisations.

Amid limiting discursive practices in rehabilitation, a key finding is that visually impaired service users are involved in complex negotiations of self and place. Investigating the discourses which frame and support rehabilitative practices sheds light on investments in promoting particular ways of being for visually impaired people, prompting us to consider what service providers, service users and, indeed, society as a whole might be colluding with. This work offers a novel perspective on blindness rehabilitation in South Africa as it explores an interplay between essential practical interventions found in rehabilitation and the influences on identity which those who experience sight loss undergo as they move into a new life with visual impairment.

Keywords: visual impairment; rehabilitation; subjectivity; belonging; power-knowledge; discourse

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LIST OF ACRONYMS

AoIR – Association of Internet Researchers

BBBEE – Broad-based Black Economic Empowerment CDA – Critical Discourse Analysis

EEA – Employment Equity Act

HPCSA – Health Professions Council of South Africa NPO – Non-profit Organisation

O&M – Orientation and Mobility OT – Occupational Therapy

SANCB – South African National Council for the Blind UNISA – University of South Africa

WHO – World Health Organisation

CONTENTS

CHAPTER 1
INTRODUCTION

[W]e have all in a general way learned the role of blind man [sic]; however, for most of us, it is a role we will never have to play (Scott, 1969: 16).

What counts as 'help' has taught me more about our society than it has about blindness. It has taught me what our society thinks blindness is and how our society tells blind persons what they are, how to act, and how to conceive of themselves (Michalko, 1998: 3).

1.1. Background

The cultural representations, beliefs and meanings which surround disability are overwhelmingly negative, involving frailty, vulnerability, dependence and mortality among other things (Garland-Thomson, 2009; Hevey, 1992; Hughes, 2019; Shakespeare, 2014; Watermeyer, 2013). In addition to these, blindness is subject to very specific and evocative cultural meanings, which pervade art, literature, philosophy and religion (Barasch, 2001; Hughes, 2019; Kleege, 2005; Paterson, 2013). Blindness is culturally connected to ideas about lack of knowledge, spiritual lostness, disconnection, divine punishment and loss of control (Michalko, 1998; Paterson, 2013). Paterson (2013) describes how out of thirteen dictionary entries under 'blindness', only one refers to the actual condition of sight loss while the others are metaphors such as 'blind fear', 'blind rage' and 'blind ignorance'. Scott (1969) suggests that in being surrounded by these meanings we all come to know "in a general way" what blindness is and what it is to be blind. Further, the experience of blindness is believed to be easily discoverable for those who can see. As Silverman (2015: 4) observes: "People often believe that they are discovering what it is like to be blind when they are briefly blindfolded". The assumption is that one need only close one's eyes in order to apprehend the 'darkened world of the blind' (Paterson, 2013; Silverman, 2015). However, it is "when the blindness belongs to ourselves" that we must begin to navigate not only the practical implications of sight loss, but also a sense of belonging and of self against the backdrop of narrow and largely negative ideas about blindness (Scott, 1969: 16).

This work is interested in the interplay between the provision of essential practical techniques, skills and tools for adjusting to blindness found in rehabilitation, and the influences on identity which those who experience sight loss undergo as they move into a new reality of life with visual impairment. This layer of experience in rehabilitation, which relates to identity, has tended to be obscured by the practical business of skills development. Through employing a discursive lens, this study considers the knowledge about blindness and blind persons which is produced and broadcast by rehabilitation organisations, and the role of rehabilitation services in shaping the subjectivity of blind persons. Michalko (1998) approaches his theorising of the experience of sight loss as a story told by a series of voices, which each take their turn to add to and shape the meaning of blindness. He describes how the voice of rehabilitation enters the story of blindness, following on from and filling the silence left by the voice of medicine. He says:

> Medicine has much to say about blindness…But suddenly, it falls silent. It has nothing more to say, and, even when asked, it refers all queries to rehabilitation…The diagnosis of incurable blindness means that it is not possible to restore sight…From a medical point of view, blindness is a physiological condition that, like any other such condition, is subject to the medical ideal of cure. It is the possibility of cure that permits medicine to remain in the conversation of blindness…The impossibility of a cure renders medicine hopeless. Where there is no hope, medicine bows out (Michalko, 1998: 54–55).

Michalko asserts that while the voice of medicine is significant in the story of blindness, there comes a time, once the permanence of impairment is established, when medicine can only fall silent and hand the story of blindness over to rehabilitation. The work presented here is primarily focused on the shaping influence of the rehabilitative voice. Through drawing on their own experiences of sight loss, several blind scholars have posed critical questions about how rehabilitation services shape the self-perceptions of visually impaired people (French, 2004; Kleege, 1998; Kuusisto, 1998; Michalko, 2002). I extend similar critical questions to the South African context, where work focused on the interplay between disability, discourse, identity and inequality remains scarce. This study also recognises the position of influence occupied by rehabilitation organisations in terms of building into societal expectations concerning the capabilities, status and behaviour of blind persons. This view suggests that disrupting the present power-knowledge dynamics in rehabilitation services might have far-reaching ramifications for visually impaired persons in terms of their ability to claim a place in society.

1.2. Context

In South Africa, rehabilitation services for visually impaired persons are found within local non-profit organisations (NPOs), where services are offered at no cost. These organisations are regulated and monitored in accordance with the Non-Profit Organisations Act of 1997 (Swilling and Russell, 2002). However, the origins of the organisations included in this study far predate this post-apartheid legislative framework. Founded by the apartheid government, the church, concerned citizens or, more rarely, visually impaired people, these organisations, which are often called “societies for the blind”, have formed part of the South African welfare landscape for many decades. Consequently, the histories of these organisations, like many organisations forming part of what we now call the non-profit sector, are bound up with South Africa’s apartheid past (Swilling and Russell, 2002). At one time, many blindness sector service organisations were racially exclusive, offering services for Whites only, or racially segregated, with separate facilities for White and Black beneficiaries. However, there were a few organisations founded in response to a lack of available services for visually impaired people of colour under apartheid. Despite South Africa’s transformed political and legislative landscape, the legacy of apartheid can still be seen in a visually impaired community which remains racially divided in many ways. As opportunities have opened up for visually impaired people to enter inclusive school education settings, tertiary education and formal employment, these have tended to be more accessible to White people, who have historically had greater access to financial and other resources. In contrast, the marginal space of public welfare has become largely occupied by people of colour, the vast majority of whom remain socio-economically disadvantaged.

South African blindness sector NPOs include a mixture of paradoxical elements as the residue of traditional institutionalised welfare mingles with a growing recognition of disability as a human rights issue. In many of these organisations, activities associated with traditional institutions ‘for the blind’ such as cane weaving and other craft work exist alongside training programmes to facilitate job placement in the open labour market, which include computer literacy, office administration, communication and work readiness courses. Sheltered employment workshops are maintained alongside programmes that advocate for the right to equal employment opportunities, and advocacy for the social inclusion of visually impaired people emanates from organisations where unequal dynamics of power have remained largely undisturbed. Visually impaired persons, especially those who are racially and/or socio-economically disadvantaged, do not generally occupy influential positions in these organisations. As noted, many of these organisations are called “societies for the blind”, a label which continues to promote a view of rehabilitation services for visually impaired persons as a charitable endeavour, strengthening the notion that a group of benevolent people are working in the interest of “the blind”.

I argue that the binding up of rehabilitation and charity poses a significant challenge in terms of transforming discursive practices surrounding the provision of rehabilitation services for people with visual impairments. In other words, this study maintains an awareness of the fact that the survival of organisations is contingent upon public approval and generosity, and that this may draw those involved in the provision of rehabilitation services into broadcasting certain discourses to do with the dependency and neediness of visually impaired people.

1.3. Research Questions

The questions posed in this study have been influenced by my experiences as both a user and a provider of rehabilitation and development services for visually impaired adults in South Africa. As a service user, I experienced the gaining of techniques for adjustment to sight loss as hugely valuable on the one hand and, on the other, as an assault on my identity. Part of this had to do with entering public welfare, which involved transgressing boundaries that would otherwise have protected my privilege (Botha and Watermeyer, 2018). Beyond this, beginning to use visible mobility aids was, for me, an experience of becoming subject to the gaze of others, and being associated with negative ideas about blindness. Wilchins (2006) considers how bodily realities, cultural meanings and the social gaze intersect in painful ways for those who transgress the bounds of acceptability. She says:

> In order to grasp our bodies, to think of them as well as to understand the cultural gaze that fixes upon them, we must construct what our bodies can be said to mean and to look like. We rely upon other members of our speech community to do this, since it is in the meanings reflected back at us through culture that we find truth. Almost everything about bodies is discovered through comparison from the collection of meanings stored in a common language…The litany traps and enfolds each body. For some of us, the meanings culture drapes upon our bodies are extremely painful and depressing (Wilchins, 2006: 5).

Although short-lived, my experience as a user of rehabilitation services began to prompt questions concerning what the impact of being drawn into the fabric of rehabilitation organisations might be for those who are experiencing the trauma of sight loss, and about the role played by rehabilitation services in relation to individuals who may be experiencing threats to their sense of self and social belonging.

As a service provider, I found myself occupying a position of influence in relation to service users who were in the process of making sense of what sight loss would mean for their capabilities, prospects and identities. However, as a visually impaired person my positioning within the organisational power dynamics was precarious (see section 3.2.1.). When required to communicate with donors and supporters of the organisation, I felt drawn into colluding with constructions of visually impaired persons as unfortunate, and into presenting rehabilitation services as a charitable endeavour. This began to shape my interest in questions concerning what we as rehabilitation practitioners might be drawn into in terms of producing and reproducing meanings about blindness.

This work seeks to address two interrelated questions: firstly, what meanings about blindness and blind persons are produced and perpetuated by organisations providing rehabilitation services for visually impaired adults in South Africa? and secondly, what might be communicated to visually impaired persons undergoing a rehabilitation process about who they are, where they belong and how they are expected to behave?

Throughout this study I draw heavily on the work of two theorists in particular. The first of these is the French philosopher, Michel Foucault (1977; 1978; 1981), as well as the Foucauldian-framed work in disability theory and research found in Tremain's (2005) edited collection, Foucault and the Government of Disability. Foucault's work is most often characterised as post-structuralist, however, it is well-known that he rejected this label (Blackmore and Hodgkins, 2012). Blackmore and Hodgkins (2012) suggest that it might be more accurate to position Foucault as a critical theorist. Ultimately, through his work, Foucault has prompted scholars from across diverse disciplines to question an uncritical acceptance of knowledge as self-evident, and to interrogate how knowledge is historically contingent and mediated through relations of power (Blackmore and Hodgkins, 2012; Tremain, 2005). In terms of disability, both The Birth of the Clinic and Madness and Civilisation are concerned with the production of the 'abnormal body', and the ways in which power and knowledge coalesce around these bodies in order to manage them (Blackmore and Hodgkins, 2012). Disability

Studies scholars making use of Foucauldian concepts often refer to the fact that he lived with HIV, however, Foucault was not politically connected to disability nor did he position himself as a disabled person (Blackmore and Hodgkins, 2012; Tremain, 2005). Nevertheless, the tools which Foucault offers for understanding oppression, control, the production of subjectivity, the operation of relationships and the ways in which the social world is structured, are viewed as useful and have been increasingly employed within disability research. The value of Foucauldian concepts for work in disability lies in their ability to "illuminate the darker aspects of social control and regulation, through which we can become aware of everyday dangers that permeate human oppression, and so make 'ethico-political' choices to resist them" (Blackmore and Hodgkins, 2012: 75).

In this study, drawing on the work of several scholars in Critical Disability Studies, I use Foucauldian concepts as a lens through which to critically interrogate the operation of rehabilitation services as a disciplinary force, which is involved in producing knowledge about blindness and shaping the subjectivity of blind persons (Blackmore and Hodgkins, 2012; Drinkwater, 2005; Friedner, 2010; Sullivan, 2005; Tremain, 2005; Yates, 2005). In particular, I trace an interplay between discourse, power and knowledge in blindness rehabilitation services in order to explore its impact at the level of meaning and identity. It is important to acknowledge that there are several strong criticisms concerning the relevance of Foucauldian-framed disability work, which I address in detail in the following chapter (see section 2.1.2.2.). The most salient of these holds that Foucauldian work is solely ideological and that, consequently, the critical perspective which it offers tends to be impractical in terms of the real world operations of, in the case of this study, rehabilitation services. While this important criticism is in part addressed through avoiding a misapplication of Foucault's concepts in this work (see Chapter 2), I also attempt to navigate some shortcomings of Foucauldian analysis through drawing several other arguments and concepts into the conceptual framework. For example, while a Foucauldian discourse analytic approach can be valuable for understanding disability inequality, as it enables a critical view of what might otherwise be accepted as self-evident (Hook, 2007; Tremain, 2017), this study recognises the limitations of discursive enquiry, as it is not able to account for oppression as deeply psychically rooted (Hook, 2012; Watermeyer, 2013). Therefore, I draw on some concepts from psychology in order to explore the interplay between discursive practices and psychic investments in the design, implementation and management of rehabilitation services (Lourens, 2018; Thomas, 2004; Watermeyer, 2016). Therefore, although Foucauldian concepts are central to the interpretation of data in this research, this study should not be viewed as an in-depth Foucauldian analysis.

Further to ensuring the relevance and applicability of this research, the second theorist whose work features extensively here is the American Sociologist, Robert Scott, specifically his 1969 critique of American blindness agencies, *The Making of Blind Men* [sic]. Scott interrogates the ways in which those who experience sight loss are socialised into the role of "blind man" [sic] through their engagement with the services offered by agencies for the blind. Scotts's work is associated with labelling theory, a sociological approach popular in the study of crime and deviance in the 1960s, although studies in education and mental health have also made use of labelling theory (Gunnar Bernburg, 2009). The theory posits that, although a variety of factors may lead to an individual being labelled, once a social label has been ascribed to an individual, once they have been defined as deviant, criminal, mentally ill or blind, "they often face new problems that stem from the reactions of self and others to negative stereotypes" (Gunna Bernburg, 2009: 187). Thus, labelling theory is closely connected to Goffman's work on stigma (Gunnar Bernburg, 2009). While there has recently been a resurgence in work drawing on labelling theory, debates around its merits and shortcomings continue. I do not engage with these debates here as, despite them, Scott's work offers a critical perspective on the personal and social impact of blindness rehabilitation which benefits the interpretation of data in this study in three important ways. Firstly, Scott provides a highly critical analysis of blindness-related services, particularly how they influence the social roles that blind individuals are expected to fulfil, while recognising and being sensitive to the real world operation of a complicated ecosystem of organisations, rehabilitation workers, donors, governance, families, blind individuals and the need for practical adjustment to sight loss. Secondly, he identifies very real consequences for blind individuals of being drawn into fulfilling the role of "blind person" in terms of their agency, citizenship, livelihoods and well-being. Thirdly, although American blindness agencies may well have changed significantly since the publication of Scott's study in the 1960s, his critique is strikingly resonant with the present situation in South African blindness rehabilitation services. As there is no equivalent critique of organisations providing services for visually impaired persons in South Africa, I often include references to Scott in order to speak into the issues arising in this work. Even though Scott's (1969) work falls outside of the bounds of either Foucauldian analysis or, indeed, Critical Disability Studies, his work is used throughout this study as a means to ground the analysis, drawing our focus to the material implications of the discourse and power-knowledge found to underpin the provision of rehabilitation interventions.

1.4. Research Aim and Objectives

This research investigates the discursive practices operating within organisations providing rehabilitation services for visually impaired adults in South Africa and critically interrogates the ways in which knowledge about blindness and blind persons is produced and reproduced within relationships where help is given and received. In order to address the above-mentioned research questions, this work has the following objectives:

1) Through reviewing a sample of organisation website copy, to investigate the discourses of blindness broadcast by organisations in the public realm.

2) Through conducting interviews with providers and users of rehabilitation services to,

- investigate discourses framing the operation of rehabilitation services and whether and to what extent public facing[1] discourses are deployed within organisation operations.

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[1] Referring to the public relations activities of organisations, investigated in this study through the analysis of organisation websites.

- explore the ways in which these discourses are deployed within relationships where help is given and received, and what rehabilitative relationships communicate to visually impaired people about their status, their value and their place in the world.

These objectives were met through a two-phase qualitative research process, where Phase One involved a discourse analytic review of the website copy of eight organisations operating across five provinces in South Africa, and Phase Two involved conducting semi-structured interviews with eight service providers and eighteen service users from four organisations operating in the Western Cape province.

1.5. Scope

At the outset, it is important to be clear about what this study is not. Firstly, it is not a review of the rehabilitation services available for visually impaired people in South Africa, nor is it intended as a critique of the practical techniques, skills and tools provided by organisations and their workers. This study is not involved in questioning the value of practical rehabilitative interventions for those who lose their sight. On the contrary, techniques for adjustment to blindness are acknowledged as essential. What I am interested in is a layer of experience in rehabilitation that tends to be overlooked amid the largely practical preoccupations of rehabilitation programmes. In other words, this work poses questions about the symbolic operation of rehabilitation.

Secondly, in light of the use of discourse analytic methods, it is important to be clear that this study does not offer a critique of the language used by rehabilitation organisations as an end in itself; that is, it is not intended as an exercise in linguistic fault-finding for the sake of political correctness. Rather, through using a discourse analytic approach I aim to trace the operation of power dynamics within rehabilitation organisations, recognising that an interplay between discourse, power and knowledge has material effects. Within this work, ‘discourse’ is defined not merely as linguistic/textual but, in line with Foucault (1981), as practice, rooted in and productive of materiality (Hook, 2007; Tremain, 2017). Therefore, ‘discourse analysis’ is understood as a method involved in “denaturalising ideologies” (Fairclough, 1995: 27), that is, interrogating how social structures are discursively constituted and, in turn, productive of discourse.

This research has focused on a relatively modest sample of organisations, service providers and service users. While the review of organisation public face material was able to include organisations from across South Africa, the interview phase was limited to the Western Cape. Therefore, the findings presented here should not be viewed as representative of the South African blindness service sector as a whole. However, through analysing a sample of organisation public face material and considering the accounts of some service providers and service users, this study is able to offer a broad view of the discursive practices framing the provision of rehabilitation services, and some sense of what being drawn into this discursive framework might signal to visually impaired people about who they are, where they belong and what society expects of them.

1.6. Significance

Disability Studies is an emerging discipline in South Africa. In particular, work concerned with issues of disability, identity, discourse and inequality is limited. I suspect that this is largely due to an unfortunate view of discursive enquiry as apolitical and, therefore, at odds with work committed to developing practical solutions to the extreme material deprivation faced by the vast majority of people with disabilities in South Africa. I hope that the present study is able to demonstrate that this is not the case and that, rather, considering the interplay of discourse, power and knowledge, as well as the ways in which disablist discrimination is deeply psychically rooted, should be viewed as essential for understanding the persistent nature of disablism in our society. Moreover, scholars who draw on Foucauldian concepts to theorise disablist discrimination suggest that understanding the discursive underpinnings of oppressive systems is vital if these are to be critiqued, resisted and dismantled (Blackmore and Hodgkins, 2012; Friedner, 2010; Tremain, 2005; Yates, 2005). As Foucault states:

> The recourse to history…takes on its import to the extent that history has for its function to show that that which exists didn't always exist, that is to say, that it is always at the confluence of encounters, accidents, through the course of a fragile, precarious history that things are formed that give us the impression of being the most obvious. What reason experiences as its necessity or rather what different forms of rationality present as their necessary condition one can perfectly well do the history of, and recover the networks of contingencies from which it has emerged; which does not mean however that these forms of rationality were irrational; it means that they rest on a base of human practice and of human history and since these things have been made, they can, provided that one knows how they were made, be unmade (Foucault, 1994: 148–149 cited in Tremain, 2017: 93).

This research aims to contribute to a growing body of knowledge in Critical Disability Studies emerging from the Global South. NPOs are the primary providers of rehabilitation services for visually impaired adults in South Africa. They are viewed as experts not only in relation to appropriate rehabilitative interventions for visually impaired persons, but with regard to blindness in general. These organisations are often approached by both the public and private sectors to consult on disability related issues concerning physical access, employment and policymaking, among other things. NPOs in South Africa are relied upon to fulfil government objectives and the vast majority of these organisations work in partnership with government, receiving large subsidies in exchange for meeting gaps in public service delivery. Blindness service sector NPOs, therefore, occupy a significant position in terms of influencing the public perception of blindness and blind persons. The fact that these organisations produce discourses that are able to be widely broadcast and deployed makes them an important focal point for work concerned with the production of meanings about blindness, as well as both the personal and social impact of these meanings.

1.7. Terminology

Terminology can be a contentious and emotionally charged issue in disability work. Some scholars advocate for the use of ‘person-first’ language, as this does not foreground disability/impairment as the sole defining feature of an individual. These scholars, in line with the language used in global disability rights instruments, use terms such as “person with a disability” or “people with disabilities”. On the other hand, there are those who feel that person-first language obscures disability as a valuable and chosen identity. These scholars, who are often connected with disability research and activism in the United Kingdom and the British Social Model of Disability, prefer the term “disabled people”. Shakespeare (2014) asserts that arguments about terminology are diversionary, detracting from efforts to promote disability rights and inclusion. This study is interested in language use to an extent, but not as an exercise in political correctness. It is not concerned with words, but with what words indicate – the power dynamics they reveal. For example, it has been suggested that ongoing disputes over appropriate terminology and ever-changing standards for acceptable disability language are indicative of society’s unease when confronting disability, and the search for comforting ways to apprehend disability difference (Watermeyer, 2013). In this work, I do not get caught up in debates about politically correct terminology, and therefore use the terms “people with disabilities”/“people with visual impairments” and “disabled people”/“visually impaired people” interchangeably. I also use the terms “visually impaired”, “blind”, “partial sight” and “residual vision”, reflecting the diverse terms employed by participants in this study.

1.8. Thesis Structure

The thesis includes eight chapters. Chapters 2 and 3 lay out the conceptual and methodological framework of the study. Chapter 2 presents a discussion of the key theoretical ideas underpinning this work and also considers some pertinent literature which has influenced the research questions. This chapter also contextualises the research, presenting a discussion of the South African disability landscape and the particular circumstances faced by visually impaired South Africans. Chapter 3 describes the methodological framework in which the study is situated, and the particular methods I have employed.

Chapters 4 to 7 present the research findings. Chapter 4 focuses on the review of public face material in Phase One, considering the ways in which rehabilitation services are represented in the public realm and the implications of these representations for visually impaired service users. Many of the discourses identified in organisation public face material were found to be enacted within rehabilitative operations and relationships. Therefore, the findings presented in this chapter can be viewed as a backdrop to the rest of the study. Chapter

5 begins the discussion of findings from the interview phase (Phase Two). This chapter explores the experiences of individuals prior to entering rehabilitation. It considers the question of who is coming through the doors of rehabilitation, what they have been through and how these experiences might impact their engagement with rehabilitation services and service providers. These considerations are essential if we are to view rehabilitation as part of a broader experience of sight loss and to grasp the influential position of rehabilitation organisations and workers in relation to individuals who may feel dislocated from society and self.

In Chapter 6, I turn to a discussion of the discourses underpinning rehabilitative activities. In particular, this chapter considers the implications of a constructed rehabilitation journey, found across both the public face material and interview data. This chapter questions what service providers, service users and society in general may be colluding with, having been exposed not only to the discourses framing the provision of rehabilitation, but also to certain fantasies[2] about life with visual impairment that may have shaped our understanding of blindness and what we perceive as appropriate assistance for those who lose their sight. Chapter 7 goes on to discuss the signalling influence of rehabilitative relationships, considering the organisational cultures into which service users are drawn and what might be imparted to visually impaired persons in these environments about their status and place in the world.

In closing, Chapter 8 provides a summary of these findings, drawing together threads from across the two research phases. This chapter offers some recommendations for how this work might be expanded and how it might contribute to a transformation in rehabilitation services for blind persons in South Africa.

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[2] ‘Fantasy’ refers to the psychic realm, specifically to assumptions about the other which are influenced by emotional and unconscious material in the observer.

CHAPTER 2
LITERATURE REVIEW

This chapter includes three sections. In the first, I outline the theoretical approach framing the work presented here. I unpack some key debates in disability theory and describe the interrelated Foucauldian concepts of discourse, power and knowledge, which are used as a lens through which to critically interrogate the operation of rehabilitation services in this work. The discussion suggests that these concepts are valuable for work in disability as they enable us to apprehend the otherwise taken-for-granted operation of disciplinary power in shaping disabled subjectivity.

In the second section I narrow the focus to visual impairment. This section considers the autobiographical accounts of a number of blind scholars who describe their experiences of sight loss and rehabilitation. Their accounts suggest that rehabilitation plays a role in shaping the self-perceptions of blind persons. This section also considers the relational nature of rehabilitation services, as well as the ways in which the public are invested in the rehabilitation process.

The final section discusses visual impairment in South Africa. I include some engagement with the broader South African disability landscape, paying particular attention to the impact of the legacy of apartheid. The chapter ends with a discussion of the circumstances faced by many visually impaired South Africans, in particular, the significant obstacles to accessing education and employment which they face.

2.1. Conceptual Framework

This section begins with a discussion of materialist conceptions of disability, notably the British Social Model. I acknowledge the significance of this historical reframing of disability as a social construct and of the activist activities it sparked in the Global North, paying particular attention to the disruption of uncritical links between disability, rehabilitation and charity. I then turn to discuss critiques of social model theorising, focusing in particular on its maintaining of problematic binaries and a hegemonic status which stifles critical engagement with disability in diverse disciplines and contexts. These critiques are important given that this work is located in the Global South and is interested in the formation of disabled subjectivity, which materialist conceptions are not able to frame satisfactorily.

I then turn to a discussion of Foucauldian concepts concerning the entanglement of discourse, power and knowledge, and of the ways in which these have been used to expand work in Disability Studies. This section also addresses a number of criticisms of the relevance and appropriateness of Foucauldian analysis for theorising disability. I suggest that Foucauldian concepts are indeed valuable as a lens through which to explore the operation of rehabilitation as a normalising force involved in the shaping of disabled subjectivity. This section also considers an interplay between discursive practices and psychic investments, which I argue is essential for understanding the potency and persistence of disablist discrimination in society.

Finally, this section includes some engagement with critiques of coloniality in order to consider not only the normalising but also the 'civilising' force of rehabilitation. The discussion draws on Fanon's work, in particular his theorising of colonial control as both an external and internal force. I show that some useful parallels can be drawn between systems of colonial and rehabilitative control. In drawing these parallels, however, I remain aware of the use of simplistic metaphors in some work, both in Disability Studies and critical race theory, which collapse race and disability and obscure the complexity of multiple strands of identity.

2.1.1. Social model critiques of welfare: disrupting links between disability, rehabilitation and charity

The British Social Model is a materialist approach to theorising disability with its roots in the political mobilisation of disabled people in the United Kingdom. It emerged in the 1970s out of a burgeoning disabled people's movement, and marked a significant and radical reframing of the concept of disability (Barnes and Mercer, 2004; Oliver, 2004). This reframing rested on a theoretical split between the concepts of 'impairment ' as biological, and 'disability 'as materially constituted by society through maintaining physical and attitudinal barriers that prevent disabled people from social, economic, political and cultural participation (Oliver, 2004). This significant causal shift to disability being socially rather than naturally produced influenced both a rising tide of political activism from disabled people's groups and the academic discipline of Disability Studies. This discipline drew disability out of the realm of medical enquiry and began to problematise the role of socially constructed systems of exclusion found in education, healthcare and social services, among other domains, in denying the agency and capability of disabled people (Barnes and Mercer, 2004; Davis, 1999; Drake, 1996; Oliver, 2004; Riddell, 1996).

Tremain (2017) draws a helpful distinction between the British Social Model, what Shakespeare (2014) refers to as the strong social model, which is inextricably historically and contextually linked to the rise of the Disabled People's Movement in the United Kingdom, and broader applications of a materialist conceptualisation of disability. Nevertheless, both of these rely on maintaining a distinction between impairment as natural and disability as a social construct. The production of a rigid dichotomy between what has become known as the medical model, a view of disability as located on the body and in need of medical or rehabilitative intervention, and the social model (in either of the above-mentioned senses) is well known in Disability Studies, and its consequences have been widely discussed (Corker, 2001; Garland-Thomson, 2011; Popplestone, 2009; Shakespeare, 2014; Watermeyer, 2013). While these discussions are important for the work that follows, the social model has been instrumental in disrupting links between disability, rehabilitation and charity in ways which shed light on a power imbalance within welfare or charitable organisations, where rehabilitation, care and other services for disabled people have traditionally been located.

Scholars influenced by social model theorising assert that the links binding disability, rehabilitation and charity are maintained by understandings of disability as a problem of the individual body and as a personal tragedy (Drake, 1996; hevey, 1992; Oliver, 2004). In charitable or welfare organisations, strict boundaries of control tend to exist between ‘the helpers’, that is, health professionals, social workers and other rehabilitation professionals, who are likely to be able-bodied, and ‘the helped’, that is, disabled people receiving services and/or care (Barnes and Mercer, 2004; Drake, 2001; French and Swain, 2001). Drake (1996) asserts that where organisations refer to ‘empowerment ’and ‘participation’, they are usually referring to the overcoming of an individual deficit linked to the impaired body and not to a process whereby disabled people enter roles of power in the organisation or society. On the other hand, health and welfare professionals are empowered by the State, which views them as experts able to define need, and gives them authority to set the agenda for rehabilitation and stipulate the elements that constitute a successful outcome (Drake, 1996; Oliver and Sappi, 1999). French and Swain (2001) suggest that rehabilitation professionals are invested in maintaining this status quo within the welfare sector, as their roles and their livelihoods might be threatened by a disruption which could place disabled people in a position of control regarding organisation resources and agendas to manage their own access to services.

Need is defined by rehabilitation professionals within an understanding of impairment as individual, bodily deficit which, if it cannot be remedied by medical intervention, must be managed within the process of rehabilitation with the goal of reintegrating the impaired person into society. Failing this, the disabled person must be relegated to permanent residential care (Davis, 1999; Drake, 1996). These scholars, therefore, recognise rehabilitation as a normalising force (Drake, 1996). Welfare organisations encourage the public to give donations towards the work of rehabilitation or care, thereby forming a public perception of disabled people as passive recipients of professional and public goodwill (Drake, 1996; French and Swain, 2001; Hevey, 1992). The focus of rehabilitation, therefore, is viewed by these authors as the alteration and improvement of individual impaired bodies, supported by the gifts of a concerned public, rather than as an engagement with the role of society in producing disabling environments (Davis, 1999; Drake, 1996; French and Swain, 2001; Oliver, 2004). This underpins and entrenches practices within welfare organisations that are criticised by proponents of the social model as individualistic, apolitical, and based on the maintenance of normative body ideals. Further, such practices are seen as potentially stripping disabled people of their agency, and either completely removing or seriously damaging their claims to full citizenship (Drake, 2001).

Proponents of the British Social Model, academics and activists alike, saw great promise in its potential to disrupt and redistribute power within rehabilitation organisations and, ultimately, to end the practice of institutionalised charity altogether (Barnes, 1991; Drake, 1996). They posited that if both disabled people and society could come to understand disability as a materially constituted phenomenon, and if barriers to access and participation were subsequently removed, then the model of the traditional charity as a mediator of the needs of disabled people would become obsolete (Barnes, 1991). Indeed, social model concepts have remained the rallying point for much disabled activism in the United Kingdom and elsewhere, particularly in the Global North, and while the eradication of the traditional charity has not been realised, the model has influenced a number of fundamental shifts in the positioning of disabled people in relation to rehabilitation services in these contexts. Examples of changes influenced by social model theorising include the shift from institutional living to independent living, from care managed by the state to direct payment systems, and the continued strengthening of politically active disabled people's Movements (Blackmore and Hodgkins, 2012; Shakespeare, 2014).

Even among its critics the British Social Model is recognised as marking a radical political moment of reframing, which had a profound impact on the lives of people with disabilities (Goodley, Hughes and Davis, 2012; Shakespeare, 2014). Ultimately, however, this materialist conception grew out of a particular political moment in a specific context, and critics argue that it has stagnated and has imposed a hegemonic position in ways which limit disability theorising in diverse disciplines and contexts (Goodley, Hughes and Davis, 2012; Grech, 2015). Moreover, broader applications of a materialist disability conception have been equally criticised as being unable to account for both the nuances of disability experience and the pervasive operation of disablism (Garland-Thomson, 2011; Shakespeare, 2014; Tremain, 2017; Watermeyer, 2013).

2.1.2. Critiques of the social model

2.1.2.1. Problematic dichotomies

There are two critiques which problematise the dominance of the materialist social model that are pertinent for the work that follows. The first concerns the operation of strict dichotomies in social model theorising. It is argued that these splits, between 'impairment 'and 'disability', 'the body 'and 'the social/material world 'and 'the personal 'and 'the political', limit understanding of disability, not merely conceptually but as complex lived experience (Corker, 2001; Garland-Thomson, 2011; Shakespeare, 2014). Critiques assert that maintaining these splits serves to discount the body. They suggest that the social model, and associated political activism, is invested in eschewing the reality of bodily experiences of impairment and prohibits the expression of struggle or grief associated with embodying impairments, as these are thought to be harmful to the political movement of disabled people (Garland-Thomson, 2011; Shakespeare, 2014; Watermeyer, 2009). Shakespeare (2014) outlines several arguments for why the rejection of the centrality of embodied impairment experience in conceptualising disability is simply unhelpful. He suggests that this rejection results in a problematic growth of suspicion towards medical professions, diagnosis and treatment. He also notes some inevitable limitations of the 'barrier free world 'for which the social model is not able to account. As Popplestone helpfully articulates:

> 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: 130).

The real life she refers to is, critics argue, not able to be satisfactorily framed by a purely materialist conception of disability (Popplestone, 2009; Shakespeare, 2014). Tremain (2017), moreover, asserts that the impairment/disability binary of social model theorising produces impairment as merely a natural foundation for the socially constructed discrimination referred to as disability. In other words, in this view, impairment is necessarily intrinsic, pre-discursive and ontologically uninteresting. I turn to discuss her critique, which is based on Foucauldian principles, below (see section 2.1.3.3.3.).

A second area where critics assert that social model binaries prove inadequate is in consideration of the psychic. Social model theorising has largely neglected the psychological, notwithstanding the work of Reeve (2004) and Thomas (2004), which offers some engagement with the psycho-emotional impact of experiences of impairment and disability, albeit rather narrowly. While we must acknowledge that the discipline of psychology has often simply pathologised disabled people, a wholesale rejection of psychology and its concepts is problematic if we are to fully apprehend the operation of disablism and other forms of oppression (Hook, 2012; Watermeyer, 2013). For both Hook (2012) and Watermeyer (2013), psychic processes, imaginings or fantasies of bodies deemed to be different – a transaction at the level of the unconscious that serves to maintain a coherent, acceptable self through the abjection of a detestable other – are essential in understanding the embedding of various oppressive systems and the perpetuation of inequality in the social world. Furthermore, neglect of the psychological denies the relevance of the psychic lives of disabled people and leaves a significant gap in our ability to apprehend the complexity of the experience of impairment and disability, as well as the repertoire of responses available to disabled people negotiating the disablist world (Lourens, 2018; 2020; Watermeyer and Swartz, 2008; Watermeyer, 2013; 2016).

Critics argue that the splits upon which social model theorising has come to rest provide little space for exploring the embodied or psychic lives of disabled people outside of a unified political disabled identity, and that the social model, and the Disabled People’s Movement it frames, is involved in exerting a normalising force of its own (Blackmore and Hodgkins, 2012; Corker, 2001; Grech, 2015). The notion that eschewing these parts of impairment and disability experience will protect and reinforce political action towards the eradication of disablism leaves us with a problematically limited disability concept that cannot fully account for the operation of disablism (Lourens, 2018; 2020; Watermeyer and Swartz, 2008).

2.1.2.2. Limiting hegemony

The second critique pertinent to the work that follows, particularly given its location in the Global South, concerns the hegemonic status claimed by social model theorising. Critics have asserted that the British Social

Model has denied the legitimacy of other social theories in disability scholarship and, in so doing, has stifled critical engagement with disability within diverse contexts and disciplines (Goodley, Hughes and Davis, 2012; Grech, 2012; Grue, 2011; Shakespeare, 2014; Tremain, 2017; Watermeyer, 2013). Goodley, Hughes and Davis (2012) suggest that while the value of social model theorising as a tool for activism, as well as its significant academic and political history, should not be disregarded, there is a need to look beyond the confines of social model theorising towards the employment of other social theories which may enhance our understanding of disability. Similarly, Watermeyer (2013: 2) asserts that disability cannot be fully captured within any theoretical framework and that, as Disability Studies scholars, we must be open to using diverse concepts, we must "make the most of what each framework offers". This seems of particular importance for work located in the Global South, given the critiques of social model hegemony which have emerged from this context.

These critiques bear a noticeable similarity to the work of African feminists critical of the imposition of forms of Western feminism onto African women in African environments. They are critical of the unproblematic export of the political aims of Western feminism onto nuanced and complex African political, social, economic and cultural contexts (Mohanty, 1991; Thiam, 1986). Connected to this, Western feminist research priorities and methodology are viewed as largely unsuitable and irrelevant for the situations of African women (Mbilinyi, 1992). Finally, African feminists problematise forms of neocolonial control, intellectual and political, emanating from Western feminists, and a discursive positioning of African women as 'backward' and in need of Western intervention (Mama, 2000; Mohanty, 1991). Similarly, scholars interested in the growth of a relevant and robust Southern Disability Studies have problematised the pervasive uncritical export of the British Social Model and materialist disability conceptualisations in general (Grech, 2015; Meekosha, 2011).

These scholars assert that the political aims and research priorities of much social model framed activity in the Global North are unsuitable, irrelevant and even harmful for disabled people living in Global South contexts (Grech, 2012; Kim, 2011; Meekosha, 2011; Singal, 2010). As Grech states:

> For many disability theorists, the majority world is simply an object of curiosity and study, written about from the detached comfort of their Western offices. From this position, all the world is made to look the same, simplified, reduced and homogenised, which in turn permits the sale of one's own epistemologies to everyone, everywhere (Grech, 2012: 57).

Kim (2011) suggests that social model hegemony and associated international human Rights discourse position disabled people in the Global South as requiring rescue by Western disability concepts, researchers, policies and programmes. As with the critiques of Western feminism above, a discourse which demonises contexts and cultures in the Global South as "hell for disabled people" (Kim, 2011) legitimises the uncritical hegemony of the social model as being necessary to civilise the contexts and rescue the disabled people living in them (Grech, 2012).

Furthermore, Global South critiques highlight the problematic dichotomies produced by social model theorising, asserting that they are unable to apprehend the complexity of disability experience. For example, Meekosha (2011) suggests that in locations where impairment is overwhelmingly connected to a lack of access to healthcare leading to undiagnosed and mismanaged illness, a disability concept for the Global South would be able to accommodate both robust political activism from disabled people and drives to prevent large-scale impairment through awareness and treatment programmes. In other words, the social model's eschewing of the body and suspicion of medical intervention is ill-suited to contexts where extreme poverty frames impairment and disability experience (Grech, 2012; Meekosha, 2011). There are also very real ways in which the Global North, through colonialism, has produced the conditions for large-scale impairment in the Global South which Western theory, research and policies seldom acknowledge (Grech, 2015; Meekosha, 2011). Grech (2015: 18), importantly, is also critical of more abstract or "playfully critical" projects emanating from so-called Critical Disability Studies in the Global North, as these are, he cautions, not free of hierarchies and are likely to be wholly irrelevant "to disabled people preoccupied with very material poverty and oppression, for whom decolonisation is about freedom of their land, labour, religion, knowledge and bodies". This point will be returned to later in connection with this work's use of Foucauldian principles (see section 2.1.3.3.).

2.1.3. The use of Foucauldian principles in disability studies

2.1.3.1. Discourse, power and knowledge

In light of the critiques of materialist approaches to disability theorising offered above, the work presented here begins from Foucauldian principles concerning the operation of discourse, power and knowledge. Foucault's concepts, I suggest, are useful tools for exploring the operation of disablism and the disciplinary systems at work in shaping disabled subjectivity. It is important to acknowledge that there are a number of criticisms which question the usefulness of Foucault's concepts for work in Disability Studies (Hughes, 2005; Shakespeare, 2014). Moreover, similar critiques to those levelled at the social model, concerning decoloniality, have been made of work in so-called Critical Disability Studies (Grech, 2015). Before turning to a discussion of these critiques, however, this section defines the Foucauldian concepts used in this work. In so doing, I will begin to address some of the concerns raised by critics of Foucault.

Underlying many criticisms of the use of Foucauldian analysis in Disability Studies is a misapplication of the term 'discourse', as referring exclusively to language (Tremain, 2017). On the contrary, discourse refers to "all those rules, systems and procedures which constitute, and are constituted by, our 'will to knowledge'" (Young, 1981: 49). Foucault's concept of discourse, therefore, is more than merely linguistic (Hook, 2001; 2007; Tremain, 2017). Rather, discourse is a far richer concept where materiality in the form of institutional and social practices must be considered as both constituted by and productive of discourse (Hook, 2001). According to both Hook (2001) and Tremain (2017), the concept of discourse has been underestimated and largely depoliticised. Hook states:

> From the outset then Foucault is involved in a concerted attempt to restore materiality and power to what, in the Anglo-American tradition, has remained the largely linguistic concept of discourse. It is equally clear that he wants to centre the analysis of discourse within the field of political action (Hook, 2001: 43).

Hook is also clear that this richer understanding of discourse as defined by Foucault by no means suggests a collapse of the textual and the material. This would, he cautions, lead us to a place where text and language could be overemphasised so that, for example, the use of politically correct language could be viewed as addressing discrimination or, more jarring, we could theorise torture as a dialogue (Hook, 2007). Nevertheless, conceiving of discourse as nothing but "a thought dressed in its signs", in other words, limiting discourse to a practice of merely bridging thought and speech, reduces it to what can be traced back to text (Foucault, 1981: 65). This obscures the events which surround discourse and those which it produces (Hook, 2001; 2007). The above discussion is crucial in addressing a significant critique from Disability Studies and elsewhere which views discursive enquiry as limited, trapped in language and, therefore, apolitical and unable to account for materiality (Hughes, 2005; Shakespeare, 2014).

Furthermore, discourse is "strongly linked to the exercise of power" (Hook, 2007: 101). As affirmed in the work of scholars influenced by the social model, the power of the State and the power of recognised health professions underpins the right to stipulate and implement interventions and, ultimately, to know what is best for disabled people (Drake, 2001; French and Swain, 2001; Oliver and Sappi, 1999). However, Foucault conceives of power as more complex than a unidirectional constraining force (Hook, 2007; Tremain, 2005). In his view, "the continued preoccupation with juridical conceptions of power in modern political philosophy has obscured the productive capacity and subtle machinations of a form of power that began to coalesce at the end of the eighteenth century: namely, bio-power" (Tremain, 2005: 5). Foucault defines bio-power as a disciplinary force that aims to produce 'docile subjects' (Foucault, 1977). A docile subject is acceptable, knowable and productive within their particular societal context (Sullivan, 2005; Tremain, 2005). Therefore, bio-power is both a constraining and a productive force (Tremain, 2005; 2017). Bio-power operates through the classification and surveillance of the body, and is a force through which social norms are established and maintained (Tremain, 2017; Yates, 2005).

Bio-power is a multidirectional force and the surveillance upon which it relies operates at multiple levels – in institutions and communities, and within the self (Tremain, 2017). Discursive practices are the medium through which bio-power is exercised, and knowledge of society and self cannot, asserts Foucault, exist outside of the bounds of discourse and power (Hook, 2007; Tremain, 2005; Yates, 2005). This idea is captured in the term 'power-knowledge' (Tremain, 2005). However, the relationship between discourse, power and knowledge is not always one of agreement. As Foucault explains:

> Discourses are not once and for all subservient to power or raised up against it, any more than silences are. We must make allowances for the complex and unstable process whereby discourse can be both an instrument and an effect of power, but also a hindrance, a stumbling-block, a point of resistance and a starting point for an opposing strategy. Discourse transmits and produces power; it reinforces it, but also undermines and exposes it, renders it fragile and makes it possible to thwart it (Foucault, 1978: 100–101).

This understanding of discourse as fluid, and able to transform and disrupt systems of power-knowledge, is important in addressing another critique of the relevance of Foucauldian concepts for Disability Studies. This critique is concerned with the notion that Foucauldian concepts discount individual agency and offer no possibility for resistance (Hughes, 2005). I discuss this in greater detail later (see section 2.1.3.3.2.).

This study is aligned with the work of scholars such as Sullivan (2005), where Foucauldian concepts are used as a lens through which to critically interrogate the impact of rehabilitation at the level of subjectivity.
Sullivan’s interviews with spinal cord injured people about their experiences of undergoing rehabilitation revealed that rehabilitative practices impart something more than mere techniques; they are involved in the shaping of knowledge. He states:

> Obviously, any rehabilitation of the motor-impaired, paraplegic body will involve concentrated physiotherapy that aims to build up the upper body; however, the almost total emphasis on the restoration of physical mobility riled the majority of participants with whom I spoke. Many of them believed that the aim of this virtual fixation with restoration was to turn them into subjects of a certain kind, a fear that was clearly expressed by a young male: “All they do is give you physiotherapy, teach you how to dress yourself and do transfers. It’s like they are trying to turn you into a cripple.” (Sullivan, 2005: 40)

What Sullivan describes are discursive practices involved in producing knowledge about the self and perpetuating knowledge about people with spinal cord injuries for professionals and for society in general. In this, he argues, the paralysed body is problematised and emerges as an object of professional and public knowledge, and paralysed subjects are produced (Sullivan, 2005). His work is not linguistic, but investigates the power-knowledge which shapes institutional practices, and what these practices produce. Importantly, his work recognises that these practices operate upon bodies, and are indicative of power dynamics which may have very real implications for those undergoing rehabilitation (Sullivan, 2005). Later, I will address the question of whether Foucauldian analysis is able to account for embodied experience (see section 2.1.3.3.3.).

Foucauldian concepts enable us to consider how it is that we know what we know (Allan, 2005; Cameron, 2001; Yates, 2005). For example, recognising knowledge as a product of systems of discourse and power provides space for us to question the ontology of categories. Yates (2005) demonstrates this as he explores the constitution of the category of ‘learning difficulty’. He asserts that learning difficulty is a clearly defined category constituted by professional knowledge, which stipulates particular ways of being for those categorised as ‘learning disabled’. Bio-power, as conceptualised by Foucault, is invested in the maintenance of this kind of clearly defined category, not only in order to manage those who, in this case, are deemed to have learning difficulties, but also to establish clear boundaries of normalcy against which all individuals must measure themselves. This is the concept of the ‘constitutive other’ – that we can be secure in our knowledge of who we are because we know who we are not. Erevelles explains this in relation to Foucault’s work on reason and madness. She says:

> In order for the coherency of subjects to be maintained, reason and madness are constituted as binary opposites that appear to be immune to exchange (Erevelles, 2005: 55).

In other words, in Foucault’s view, knowledge of the self is contingent upon knowledge of the other. This concept of the constitutive other offers an account of the pervasive nature of disablism, suggesting that society is invested in maintaining a disabled other against which normalcy can be measured and claimed. Hughes (2019) presents a historical sociology of disability which traces the ways in which human validity, particularly that of Western, White, wealthy men, has been assured through the symbolic and real invalidation of disabled persons. Within a validating binary, constructed throughout Western history, the normate community has been able to maintain a belief in their worth, propriety and acceptability through making monsters, demons and fools out of disabled people (Hughes, 2019). There are links here to psychoanalytic concepts, which are useful in broadening the discussion of the interrelated concepts of discourse, power and knowledge (Hook, 2012; Watermeyer, 2013).

2.1.3.2. Discursive practices and psychic investments

Before turning to address some of the critiques of the use of Foucauldian concepts in Disability Studies, it is important for the work that follows to broaden the discussion of discourse, power and knowledge by considering an interplay between discursive practices and psychic investments. As a starting point I want to draw on the work of Hook (2012). This work offers an approach to theorising racism which recognises the limitations of both discursive and psychological perspectives on their own and the need, therefore, to acknowledge both the discursive and the psychic in understanding the persistence of racism in the social world. Hook states:

> [W]e cannot properly apprehend racism if we have failed to understand adequately what sustains it, what lends it potent affective qualities, what supports its most visceral aspects (Hook, 2012: 49).

In Hook’s view, it is not discourse that lends racism its potency and, therefore, discursive enquiry alone cannot account for the “visceral aspects” of racism. Rather, he asserts that it is through recognising psychic investments in racism that we are able to understand how racist discourses take hold and persist in the world. Hook (2012) focuses, in particular, on the racist ideology of apartheid in South Africa. He suggests that apartheid's machinery of racialised separation, which benefited Whites and relegated Blacks to circumstances of extreme material deprivation, was sustained by an interplay of racist discourse and anxious fantasies of otherness. Apartheid racism was founded on discourses of separation – separate development, separate spaces, separate toilets, separate eating utensils – which were consistently transmitted through law, media, education, spatial boundaries and more. However, according to Hook (2012), it is only when we recognise the anxious fantasies of otherness informing these discourses, and a psychic investment on the part of White South Africans in the maintenance of an abject Black other, that we are able to understand the deep-rooted nature of apartheid racism. Furthermore, anxious fantasies of otherness, usually related to fear of contagion, did not only inform the discourses of apartheid racism but were, in turn, sustained and strengthened by these discourses. It is important to be clear that what Hook (2012) suggests is an interplay between discursive practices and psychic investments rather than a simplistic acting of discourse on the psyche. He asserts that if all that was required for transformation was altered discourse, then racism would not exist in post-apartheid South Africa. The fact that racism persists in South African society, despite the fact that there are no longer any political, economic or social benefits to be had from racist speech or behaviour, suggests that racism is not merely a discursive phenomenon and that discursive enquiry alone cannot account for its potency and persistence.

Similarly, some scholars have suggested that recognising an interplay between discursive practices and a psychic investment in the maintenance of a denigrated disabled other sheds light not only on how disablism operates but also on why it persists. Shakespeare (2014), despite being wary of such enquiry, nonetheless recognises the usefulness of some psychoanalytic concepts for exploring the underpinnings of disablism. His own often-cited notion that through narrow and negative cultural representations disabled people are made "dustbins of disavowal for the aspects of embodiment which non-disabled people [find] troubling" (2014: 51) is easily connected to the psychoanalytic concept of 'projection'. Watermeyer (2013: 66) explains this as an 'unconscious transaction' where the figure of a disabled other, imbued with frailty, difference and the unknown, assures those who are deemed able that they are whole, acceptable and knowable. This resonates with the concept of the constitutive other, which refers to a societal investment in the maintenance of a disabled figure against which normalcy might be measured and claimed (Erevelles, 2005; Hughes, 2019; Michalko, 1998).

Recognising an interplay between discursive practices and psychic investments concerning the relationship of self and other sheds light on the ways in which disablist discourses take hold, pervade the social world, and impact the social positioning and material circumstances of disabled people:

> An examination of the often demeaning social circumstances of disabled persons poses important questions about projective identification. Do modern societies produce disabled persons who are

> marginal, dependent, uneducated and emotionally damaged in order to maintain a material other who may live out these split-off parts on behalf of the dominant group? (Watermeyer, 2013: 75)

Like Hook (2012), Watermeyer recognises that socially entrenched disablist discrimination cannot be fully accounted for by discursive enquiry nor can it be truly addressed through merely transforming the discourse surrounding disability. Resonating with Hook's (2012) theorising of apartheid racism, Watermeyer asserts that, "if disablist discrimination was not rooted in unconscious life, simple educational interventions would overcome it" (2013: 64). Understanding disablism as involving an interplay between discourses and anxious fantasies of otherness related to mortality, vulnerability and difference, enables us to apprehend, as Hook (2012) suggests of racism, "its visceral aspects".

2.1.3..3. Questioning the relevance of Foucault in theorising disability

2.1.3.3.1. Rejecting rehabilitation

There are three critiques of the use of Foucauldian principles in Disability Studies which need to be addressed in light of the foregoing discussion and in preparation for the work that follows. The first is a concern that Foucault's concepts foster an unhelpful suspicion of the processes and practices of diagnosis, treatment, rehabilitation and care interventions for disabled people (Shakespeare, 2014). Foucault identified his position as one of "hyper or pessimistic activism" where everything must be viewed as "dangerous" (Foucault cited in Tremain, 2005: ix). In keeping with this position, scholars using Foucauldian concepts in Disability Studies are as critical of the discursive practices underpinning the operation of traditional charities, as they are of those at work in the reforms of rehabilitation and care services seen in recent years and largely influenced by social model-based activism (Blackmore and Hodgkins, 2012; Drinkwater, 2005). For example, Drinkwater (2005) suggests that supported living involves a different dispersal of power rather than emancipation.

These scholars assert that Foucauldian concepts are able to unmask otherwise hidden systems of discourse, power and knowledge at work to produce disabled subjectivity. These concepts have been used by some scholars to frame critiques of rehabilitation for people with disabilities as a normalising force (Drinkwater, 2005; Sullivan, 2005; Yates, 2005), and to shed light on the hidden or taken-for-granted systems of power-knowledge within which both providers and receivers of rehabilitation services might be enmeshed. A Foucauldian approach, these scholars suggest, has the potential to prompt an examination of how rehabilitation services are shaped by and, in turn, shape our society's understanding of disability and view of disabled persons.

Nevertheless, it is important to stress that these Foucauldian-framed critical approaches, and indeed the present work, are by no means wholesale rejections of rehabilitation, training or other development services for disabled people. For example, the work of Sullivan (2005: 35), which interrogates rehabilitation for people with spinal cord injuries using Foucault’s concept of ‘disciplinary power’, acknowledges the absolute necessity of these interventions, stating:“ If the paralysed body were not invested with specific techniques and knowledge, it would quickly deteriorate and die”. At the same time, he asserts the importance of recognising what these processes do in shaping subjects by stipulating acceptable behaviour, that is, telling disabled people who they are and how they must be. similarly, Yates (2005) does not suggest an abolishing of care services but a critical rethinking of them in order to address the problems they present to their users. This qualification is important in light of the Global South critiques discussed above, which stress the necessity of such services, especially in locations where poverty and unemployment are rife, and resources and support are in short supply (Meekosha, 2011).

2.1.3.3.2. Precluding resistance

Some Disability Studies scholars have been critical of the use of Foucauldian concepts for theorising disability, characterising them as inherently apolitical and distanced from the activist goals of disability politics. However, an accurate understanding of Foucault’s concepts reveals them to be, in fact, concerned with the material and the political. Again, an understanding of discursive practices as not confined to language alone is essential, as Hook explains:

> [O]ne should approach discourse not so much as a language, or as textuality, but as an active 'occurring', as something that implements power and action, and that also is power and action. Rather than a mere vocabulary or language, a set of instruments that we animate, discourse is the thing that is done (Hook, 2001: 53).

Moreover, a recognition of Foucault’s concept of power as not only disciplinary but also productive, as fluid and multidirectional, offers a response to critics who contend that his concepts of discourse, power and knowledge preclude agency and resistance (Hughes, 2005).

For example, Friedner (2010) suggests that the force of bio-power which underpinned the relegation of hearing- impaired people to separate spaces, notably special schools, was also a catalyst for the formation of deep- rooted community bonds, Deaf culture and a politically active movement of Deaf people. Blackmore and Hodgkins (2012) suggest that the emergence of the Disabled People’s Movement in the United Kingdom, influenced by the British Social Model, exemplifies a resistance to dominant disability knowledges and a resistance of power through the mobilisation of a new discourse. Moreover, Drinkwater (2005) and Sullivan (2005) present, in their respective research, examples of individuals who reject or resist the rehabilitative practices they are exposed to. These scholars assert that the apprehension, through a Foucauldian lens, of the taken-for-granted workings of power can prove to be a catalyst for resistance.

Similarly, Grech (2012) draws on Foucault's power-knowledge concept and the idea of maintaining docile subjects as he problematises the uncritical export of Northern disability knowledge onto Southern contexts. He questions the power-knowledge dynamics which underpin, and are invested in maintaining, a discourse of "ill treatment" of disabled people in the Global South who, as a result, require rescue from Northern disability theorising and activism (Grech, 2012; Kim, 2011). In this regard, Tremain's (2017) argument, influenced by Foucauldian principles, for historicising and relativising discussions of both impairment and disability is important as it rejects the notion of a universal disabled identity. This kind of work, which exemplifies the ability of Foucauldian analysis to be critical of knowledge systems as they are embedded through discourse and entangled with power, is useful when speaking about decoloniality. It shows how Foucault's concepts can be used to critique coloniality, making his ideas politically relevant to the Global South.

2.1.3.3.3. Eschewing embodied experience

A further critique contends that a Foucauldian framework is unable and unwilling to apprehend the realities of embodied impairment experience, leaving the disabled body to be regarded simply as a product of discourse (Hughes, 2005; Shakespeare, 2014). Once again, reducing the concept of discursive practices to language proves problematic, as this forms the impression that Foucauldian scholars are involved only in word play, seeking to account for embodied impairment experience as a product of language and denying real experiences of incapability, limitation, struggle and pain (Shakespeare, 2014). On the contrary, bio-power as defined by Foucault is of the body (Sullivan, 2005; Tremain, 2005; 2017). Sullivan (2005: 33) explains that bio-power is directed towards the social body by means of "the administration of populations", as well as towards the individual body.

Returning to rehabilitation, Sullivan (2005) recognises the reality of a bodily transition from non-disabled to paralysed experienced by individuals who enter rehabilitation services – an experience of bewilderment, profound loss and pain. As described by one of his research participants:

> [I]t was really, really painful, so I said, "Oh, well, what's your position on pain relief here?" And she said, "Are you in pain?" And I said "yes." And she said, "That's good, because it means you've got feeling, doesn't it?" and walked off. And I just had to lie there in agony until the afternoon shift (Sullivan, 2005: 37).

This experience of pain does not have to be obscured within a Foucauldian framework. In seeking to problematise the systems of medicalised power, knowledge and discursive practices which frame the denial of this person's knowledge of her own body, her real and significant pain is seen as being connected to her positioning within the rehabilitative relationship as a passive recipient of medical expertise (Sullivan, 2005).

Tremain (2017) asserts that Foucauldian analysis does not seek to erase the body and its experiences but rather to explore these as contextually and historically contingent. Foucauldian analysis, she explains, avoids recourse to a decontextualised (that is, natural) body, and experience as a property of certain types of bodies. Tremain is critical of the impairment/disability binary of the social model, as well as of the theorising of so-called 'new materialism', which she suggests essentially reinscribes this binary. The impairment/disability split, she asserts, maintains impairment as a natural foundation upon which discourse operates, in other words, as prediscursive, rather than being itself a historicised and relative concept. Furthermore, she responds to critics who say that a lack of sight, for example, necessarily leads to an aesthetically impoverished experience, by drawing out the ways in which notions of beauty are contextual (Tremain, 2017). This also problematises the fantasy of blindness as an aesthetically impoverished existence, a discourse which may evoke pity, sadness or fear, and limits the responses available to visually impaired people. An example is French's (2004) account of her parents' desperation for her to see a rainbow leading to her understanding that her disability evoked anxiety in others and must, as a result, be denied. A Foucauldian approach, asserts Tremain (2017), broadens engagement with the concept of identity, viewing it as neither inherent nor inevitable, and draws us back to the potential of Foucauldian concepts for facilitating resistance.

2.1.4. Drawing on critiques of coloniality

2.1.4.1. Rehabilitation as a 'civilising force'

Alongside Foucauldian principles, this work draws on critiques of coloniality in thinking about rehabilitation as a 'civilising' force. Ravaud and Stiker (2001) suggest some resonance between colonial systems of control and those exerted over disabled people, supported by the notion of a universal human (the status claimed by the dominant power) towards which all others must be drawn. They point out that diversity is "insurmountable" and that, consequently, the other must be controlled and relegated so as not to threaten the ideal of sameness (Ravaud and Stiker, 2001: 494). Hughes (2019) asserts that violent colonial conquest could only succeed on the basis of relentless othering and that in the early modern period similar strategies as had been used for centuries in the othering of disabled people were used to produce the ethnic other as monstrous, demonic and lacking all self-control, wisdom, cleanliness and propriety. Hevey (1992) also notes a similarity between medical and colonial images in the form of photographs. These photographs depict the authority held by medical professionals and White colonisers over the bodies of patients and Black subjects who passively await their improving interventions (Hevey, 1992).

Fanon (1952) suggests that colonial dominance was enforced through two connected processes: an external, that is economic, process and a subsequent internalising of inferiority, that is, a psychic process. Under colonialism, he asserts, Black subjects were exposed to hostility from without through a consistent devaluation of self and culture, which became internalised. Ultimately, Black subjects came to understand that if they were to gain any kind of status, they were required to separate from blackness; they were bound to perform acceptably, as stipulated by White colonial dominance (Fanon, 1952; Hook, 2012). This is the “Black skin, White masks” split which Fanon’s work explores:

> [I]f it is the case that all that is repugnant and undesirable is black, and that I, as a black man or woman, order my life like that of a moral person, then I am simply not a Negro…I know only one thing, which is the purity of my conscience and the whiteness of my soul (Fanon, 1952: 193).

The understanding of oneself as abject – the recognition that one embodies the fearful fantasies of others and must manage a particular performance – resonates with disability (French, 2004; Kleege, 1998; Lourens, 2020; Watermeyer and Swartz, 2008).

Kleege (1998: 56), in her open letter to the late Helen Keller asks, “What did you do with the rage, Helen?” She questions Keller’s well-publicised“ plucky, chirpy self-reliance” (1998: 56), asking how much of her “can do” attitude was a required performance necessary to escape the institutionalised life of most other people with disabilities at the time:

> Once you figured out that the only way your words would be read by anyone was if you took on the role of the first, original disability poster child. So you vowed to be the best damn poster child the world has ever known. I guess I can't blame you if the insipid, feel-good aphorisms got to be a habit. But level with me, Helen. Give me something I can use. “Get with the program,” you could say. “Show them your weakness and they'll put you away in the blink of an eye. You're here by sufferance. They'll only tolerate you as long as you keep up the front. Nobody likes a grumpy cripple”. (Kleege, 1998: 59)

Behind the front, suggests Kleege, is an uncivilised and unruly blindness, the wild and wilful Keller before her taming. What is suggested here is a mask worn by Keller which could have slipped, if she had allowed it, to reveal a “sneer of derision” or a “tear of rage”. The notion of a mask worn by Keller in order to hide the true face of difference and secure a place in sighted society is reminiscent of Fanon’s (1952) White mask. In both there is recognition of a need to separate oneself from the negative discourses which define the other, the uncivilised, the savage, the feared, and perform in ways which signal acceptability within the terms of the dominant group. To wear a mask is to collude with the dominant group’s fantasies of otherness.

The notion of rehabilitation as both a normalising and a civilising force is confirmed in the accounts of rehabilitative interventions discussed in the next section. Before turning to these, however, and in light of the use of critiques of coloniality in this work, it seems important to briefly address a problematic tendency in both Disability Studies and critical race theory to collapse disability and race.

2.1.4.2. Collapsing disability and race

Although the above discussion has made reference to some helpful parallels between postcolonial and disability theory, it remains important to avoid drawing simplistic links by conflating experiences of racism and disablism, and racial and disability identity. This could blur the categories by, for example, theorising Blackness as disability or disability as Blackness (Bell, 2012; Bolaki, 2012; Shakespeare, 2014; Witek, 1988). Disability offers an easy metaphor for social oppression and has, critics argue, been used in feminism and some critical race theory to exemplify the marginalising impact of both sexism and racism in ways which tend to alienate disabled people and obscure disability experience (Samuels, 2002). Likewise, Disability Studies has tended to overlook racialised experiences in ways which limit its analysis (Erevelles and Minear, 2010). Bell (2012) argues that disability has been marginalised in African American Studies and that, similarly, work in disability has largely been produced by White scholars and has focused on the experiences of White disabled people. As a result, both disciplines lack an important perspective.

Erevelles and Minear (2010) and Jordan (2005) present work which benefits from the analysis of multiple axes of identity, the operation of various types of marginalisation, and intersecting discursive practices related to disability, race, gender and poverty. Jordan (2005) problematises the operation of discursive practices in education which uncritically link Blackness, masculinity, problematic behaviour and disability. She argues that recognising these practices is essential when considering the significant numbers of Black male students categorised as learning disabled, relative to other groups in the United States. Similarly, Erevelles and Minear (2010) show how racism is woven together with disability, gender and class, and assert that without understanding this complexity, the violence that is done to individuals at this intersection of identities cannot be satisfactorily apprehended.

The work presented here is located in South Africa, a context subject to the legacies of colonialism and apartheid, where the disability experiences of the participants, the majority of whom are people of colour, are undoubtedly entangled with their racialised experiences and location in a society which remains, in many ways, racially polarised. On the other hand, disability scrambles categories and disrupts simplistic links. In South Africa, although race, class and disadvantage correspond, disability often complicates this familiar picture (Watermeyer, 2019). If this is overlooked, the socio-economic challenges faced by disabled people can be significantly compounded. Consequently, the kind of intersectional approach exemplified above will form an essential part of the analysis which follows.

2.2. Blindness and Rehabilitation

I now turn to focus on visual impairment. One foundational influence of the present research is the autobiographical accounts of a number of scholars with visual impairments who have explored the role of rehabilitation in shaping their self-perceptions. Their accounts, variously theoretically framed and contextually situated, suggest that rehabilitation services provide not only essential skills but also a sense of what it means to be blind and what is expected of blind people in the world. It is this added layer of influence with which the current research is concerned, and it is for that reason that I have chosen not to review formal theory on the practice of visual impairment rehabilitation, emanating from disciplines such as occupational therapy and social work (Fletcher, 1999; Scheiman, 2011). Instead, I draw on the limited, yet in-depth autoethnographic literature on how visually impaired persons experience rehabilitation, and make sense of its possible effects.

This section begins with a discussion of the way in which many of these accounts describe the onset of blindness as a threat to belonging. They suggest that belonging can only be restored through either a sighted performance, which is usually not sustainable, or a performance indicating a “closeness to sight” (Michalko, 1998: 77). I then turn to a discussion of how this latter performance is taught to people through rehabilitative processes, and also consider the relational nature of these rehabilitative interventions. This section ends with a brief discussion of the investment of the broader public in rehabilitative interventions. It considers how, through extending both funds and public approval, society at large is involved in strengthening the drive of rehabilitation towards the production of model, that is acceptable, blind people.

2.2.1. Accounts of vision loss and rehabilitation

2.2.1.1. The onset of blindness as a threat to belonging

The onset of blindness in many accounts is described as a threat to belonging. Michalko (2002) describes experiencing the onset of vision loss as a significant threat to his sense of place in society – what he calls his “homeland”. A homeland, he explains, is a place of easy and secure belonging. His sense, even as a child, was that his homeland did not welcome blindness and that, if he did not carefully conceal the effects of his sight loss, he would be exiled. He describes exile as marginalisation, being prohibited from participation and viewed as a failure, and as a body “gone wrong”. In a similar way, Kuusisto (1998) describes how his place in the world was made uncertain by the onset of sight loss. He recalls as a child overhearing the “gloomy voices” of his mother and a social worker arguing about “where [he] should be in the world” (Kuusisto, 1998: 13). In his account, Kuusisto constructs two separate worlds, the world of sight and the world of blindness. These worlds are populated by distinct sets of people, things and activities. For Kuusisto, the world of the blind is populated by social workers, white canes and basket weaving – a terrible bondage in contrast to the freedom of the bike rides he enjoyed as a member of the sighted world. Like Michalko (2002), he understood that in order to avoid being relegated to the marginal world of the blind he had to maintain his status as sighted, he had to manage the effects of sight loss. He describes this as entering “an impossible contest with the sighted world” (Kuusisto, 1998: 14). Both Michalko (2002) and Kuusisto (1998) encounter signals from society which communicate to them that they are not and cannot be who they once were and that sight loss poses a serious threat to their status and place in the world.

Accounts of the onset of blindness as a threat to belonging are often bound up with other axes of identity. Michalko (2002), for example, experienced visual impairment as a significant threat to his masculinity. He describes how, when his vision loss became known to his high school peers, their “feminising taunts” served to exclude him from being viewed as “one of the guys”, as acceptably masculine. He recounts that he responded:“ first, with several crying bouts (in the private realm of the feminine), then with several schoolyard and street fights (in the public realm of the masculine)” (2002: 21). In order to regain his masculine status, Michalko needed to adopt the kinds of masculine performances prescribed and expected within his homeland. This resonates with Hammer’s (2012) research, which describes various strategies of “appearance management” employed by a sample of visually impaired women in Israel. These women, Hammer found, were invested in carefully managed, often time-consuming and expensive performances of acceptable femininity related to dress, make-up and grooming. For these women, maintaining an acceptably feminine appearance, in spite of sight loss, was important for ensuring social inclusion.

Popplestone (2009) presents a slightly different perspective as someone who was born completely blind. Nevertheless, resonating with Michalko’s (2002) description of threatened masculinity, she describes how, throughout her childhood and adolescence, she was consistently located outside of stereotypical gendered expectations. She recalls how her mother responded when, at the age of around six, she announced her plans to marry and have children:

> My mother takes both my hands and utters a little pain-ridden laugh: “No, Baby. You should be making different plans…When you grow up you will not have babies, you will not get married. The kind of person you would want to marry, the kind of person you would deserve, would not marry a blind person” (Popplestone, 2009: 137).

Popplestone considers how this might be theorised as liberation, a release from narrow expectations, but that, for her, being excluded from these gendered expectations was just that – a painful exclusion. She explains how, in order to refute the belief that as a blind person she was incapable of fulfilling the roles expected of women, she became committed to locating herself firmly within these stereotypical roles, becoming, as she puts it, “hell-bent on just one thing – to be someone’s wife and someone’s mother” (2009: 137). In the face of threats to their gendered belonging, both Michalko (2002) and Popplestone (2009) had to adopt acceptable gendered performances.

In a similar way to Michalko (2002), Botha and Watermeyer (2018) explore the onset of blindness as a threat not to gendered belonging but to racialised belonging. This work explores how I experienced my own sight loss as a threat to my place in Whiteness and privilege within the context of the institutionalised racism of South Africa’s apartheid ideology, which was based upon the maintenance of racialised splits inextricably linked to spatial boundaries. I recount the experience of briefly attending a special school for blind learners which was designated for so-called ‘coloured’ children[3] under apartheid. For me, this experience was of being thrust into marginality and being connected to marginal people:

> As I sat in the blind school hostel dining room, the fabric of separation created by apartheid was torn and I came face to face with the embodiment of not belonging. My classmates were, for me, the shadow, not only of ability in a society which marginalises the disabled, but also of Whiteness, of privilege, of acceptability in a racist society where Whiteness, privilege and acceptability were inextricably linked (Botha and Watermeyer, 2018: 10).

During this formative experience it was clear to me that it was my sight loss which was threatening my place in what Michalko (2002) might call ‘the homeland of Whiteness’. Like Michalko (2002) and Kuusisto (1998), I recognised that in order to regain my place, it was necessary to separate myself from blindness. Many accounts, especially from individuals with some residual vision, detail attempts to escape from ‘the world of blindness’ through adopting carefully managed sighted performances. Kuusisto refers to this as “attempting bravely to see” (1998: 10). These performances are understood as essential for maintaining a sense of identity and belonging in the face of relentless messaging, from families, rehabilitation professionals and the public, that the onset of blindness has significantly altered one’s place in the world. As a result, many accounts describe vehement attempts, on the part of visually impaired people and sometimes their families, to remain separated from the things of blindness – special schools, rehabilitation programmes, and assistive devices and techniques in order to deny disability.

At this point, it is interesting to draw in the work of French (2004). Unlike Kuusisto (1998), French did not escape enrolment in a special school for the blind. However, in comparing their accounts, it seems that whether one is drawn into the world of the blind or not, the message remains the same:“ attempt bravely to see”. French (2004) recounts how, throughout her time at various special schools, she was encouraged to deny her disability and any struggles associated with sight loss. This took various forms. For example, she recalls an experience of being photographed using a bulky and largely ineffectual visual aid. Her sense is that this photograph was being taken in order to promote the usefulness of this particular aid. Although this device made no impact on her ability to see, and was rather uncomfortable, she recalls being keenly aware that in order to please the adults around her she had to appear to have been assisted – she had to pretend to be able to see. In contrast, she describes another situation where blind people were encouraged to use no visual aids in order to appear visually capable. She recognises that in both cases she was being encouraged to deny her disability in order to comfort the anxieties of the adults around her.

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[3] In South Africa, the term ‘coloured ’refers to persons of racially mixed parentage and was a racial categorisation manufactured during apartheid which remains in use today.

As mentioned in Chapter 1, blindness is surrounded by many negative cultural meanings related to loss of knowledge, lack of control, disconnection and descending darkness, which feed into anxious fantasies about the experience of blindness (Barasch, 2001; Kleege, 2005; Michalko, 1998; Paterson, 2013). However, Barasch (2001) argues that alongside these negative ideas about blindness, historical depictions suggest that blind persons were revered in some ancient societies, where they were viewed as prophets and as able to communicate with the divine. He suggests, therefore, that attitudes towards blind persons have often been ambiguous (Barasch, 2001). For Barasch, the idea that blind persons may possess a higher spirituality offers a counterpoint to negative fantasies about blindness and blind persons. In contrast, Scott (1969: 4) suggests that this idea, in fact, builds into a fearful fantasy of blindness as a separate world, which is "less gross and materialistic than our own" but where darkness still prevails (see section 4.4.).

It is against the backdrop of these fantasies that those who experience sight loss must make sense of who they are and where they belong in the world. As we have seen above, this negotiation of self and place involves a relentless series of trade-offs, as blindness and all of its negative implications must be defended against. Kuusisto (1998) describes how, as a child, he buried his spectacles in the backyard, forfeiting their considerable assistance in order to remain seen as a part of the sighted world. French (2004) describes how, in order to comfort the anxieties of her parents, she would often pretend to be able to see things that she could not. I suggest that underpinning both their actions was a drive to create distance between themselves and the figure of a shadowy blind other. As we saw earlier, Kleege (1998) questions to what extent Helen Keller was bound to a performance portraying a positive image of blind persons as cheerful, capable and inspirational in order to counteract the lurking fantasy of an unruly and raging blind figure, suggesting that this performance was what rescued Keller from institutionalisation. Kleege questions what performances blind persons might be drawn into and the rage they might be prohibited from expressing. In relation to Kleege's questions, Reymann's (2003) account of her experience with partial and deteriorating sight is interesting. In telling her story, she foregrounds her strength, resilience and choice to "fight" in order to shape her life. In this account, she draws a clear distinction between those who, like herself, are committed to "shaping life actively" despite visual impairment, and "those who are being shaped by life" (Reymann, 2003: 107). In her account, I suggest, a shadowy other – one who is inactive and helpless, perhaps even unwilling and lazy – emerges in contrast to the figure of an individual determined to live, and actively pursue, a good life. For Reymann, an essential component for living life actively is the gathering of skills to cope with vision loss.

The sighted performances described in the above accounts are ultimately unsustainable. As shown by Botha and Watermeyer (2018), Kuusisto (1998) and Michalko (2002), the realities of vision loss will eventually prohibit its concealment. When this happens, a new kind of performance is required in order to maintain some sense of belonging in the world. Michalko suggests that society requires that those who lose their sight perform a "closeness to sight" (1998: 77). This is what he and others suggest is the ultimate objective of rehabilitative interventions.

2.2.1.2. Normalisation and the shaping of ‘model behaviour’

What many accounts of sight loss suggest is that rehabilitation services play a central role in shaping the self-perceptions of blind people – in particular, determining what blindness means for their identities. In the forgoing discussion we saw how, for Kuusisto (1998), overhearing his mother’s conversation with a social worker revealed to him that blindness was a separate world, which he must attempt to escape. We saw how French (2004), through exposure to various rehabilitative interventions, came to understand that blindness was not an acceptable way to be and, in response, adopted performances to comfort those around her, and disguise her disability to protect others from her blindness. Michalko (1998) suggests that rehabilitation’s shaping of self-knowledge is connected to the kinds of activities that constitute what is thought of as appropriate help for people who have lost their vision. He says:

> What counts as ‘help’ has taught me more about our society than it has about blindness. It has taught me what our society thinks blindness is and how our society tells blind persons what they are, how to act, and how to conceive of themselves (Michalko, 1998: 3).

The definition of rehabilitation is to restore to former status (Michalko, 1998). However, Michalko points out that once an individual is passed into rehabilitation services, sight itself is usually not restorable. He asserts, therefore, that what is being restored in rehabilitation for visually impaired people is not sight but a “closeness to sight” (1998: 77). The objective of rehabilitation, in his view, is the creation of an individual who, despite being unable to see, is able to fit into and operate in the sighted world. For Michalko, rehabilitation is a normalising force, invested in producing “persons who happen to be blind”, referring to individuals who have been given the techniques and devices required to reintegrate into the sighted world on its terms (1998: 6). He suggests that in rehabilitation blindness is understood as the “shadow of sight”. In other words, blindness is only ever defined in relation to sight and as a deficient condition in relation to sightedness (1998: 82). As such, rehabilitation for people who have lost their sight is, he suggests, invested in reaching out towards sightedness, instilling the understanding that blindness is a distortion of sight – its undesirable shadow (Michalko, 1998).

Hughes (2019) traces societal responses to disabled people from the violent disposal of disabled infants in antiquity to charitable acts of mercy practiced for the spiritual gain of the generous giver in the Western Christian Middle Ages. He notes with the emergence of Capitalism a trend towards the assimilation of the bodily differences of disability through medical intervention and, where correction is not possible, the removal of disability difference into institutions. He shows through presenting a historical sociology of disability how ideas about correction are rooted in narratives of disability invalidation which can be mapped across Western history and suggests that, therefore, contemporary practices in rehabilitation should critically consider adherence to the notion of correction as an ideal rehabilitative outcome.

A piece of work which, despite having been produced more than fifty years ago, resonates with the present discussion as well as with the findings of this research, is Scott's (1969) critique of American blindness agencies. In this work, Scott suggests that rehabilitative processes are processes of adult socialisation for those who lose their sight. They are involved in "the making of blind men [sic]". There is a subtle difference between this view and the view of rehabilitation as a normalising force found in the work of Michalko (1998). According to Scott (1969: 19), the aim of rehabilitation is to "instil in blind people certain model behaviour patterns and attitudes". In other words, Scott views rehabilitation as a process which produces compliant blind people. He suggests, therefore, that behaviours that have come to be viewed as inherent to blind people are, in fact, learned roles. In contrast to Michalko (1998), Scott suggests that rehabilitation is involved in underscoring, even creating, difference rather than attempting to normalise it. Important for the work presented here, Scott recognises the instilling of "model behaviour patterns" as a relational process. Like French and Swain (2001), he asserts that rehabilitation workers occupy positions of power, facilitating and controlling the rehabilitative process. Furthermore, his review of the operation of American blindness agencies found that recipients of rehabilitative interventions were viewed as successful when they were able to view their predicament from the perspective of rehabilitation workers and comply with the programme as stipulated by the workers (Scott, 1969). This is, he suggests, achieved through a goal-driven process supported by a system of rewards and punishments involving the ascribing of certain labels onto service recipients. He explains:

> The implications of being labelled "uncooperative" are serious. Such a label prevents him [sic] from receiving basic restorative services. The uncooperative client is assigned low priority for entering preferred job programs. Workers for the blind are less willing to extend themselves on his [sic] behalf.

As a result, the alert client quickly learns to become "insightful," to behave as workers expect him [sic] to (Scott, 1969: 79).

What we see here is how oppositional behaviour towards rehabilitative interventions might be understood by rehabilitation workers in superficial terms, rather than as connected to the kinds of complex negotiations of belonging described above (Botha and Watermeyer, 2018; French, 2004; Kuusisto, 1998; Michalko, 2002). Moreover, Scott (1969) suggests that many blind service users come to understand the requirements for compliance as stipulated by rehabilitation workers and adopt the appropriate performance; that is, rehabilitation workers set the agenda and service recipients recognise the need to comply.

Despite the subtle difference in their views of rehabilitation, both Michalko (1998) and Scott (1969) recognise that rehabilitation services are involved in telling blind people who they are and how to behave. Blind people, they suggest, are told that their blindness is a particular kind of problem and that work, facilitated by rehabilitation experts, must be done on them in order to address their predicament or, to be more specific, their state (Michalko, 1998; Scott, 1969). The blind person is told that she is dependent on the expertise of the rehabilitation worker, that she must receive their work, and that she is their work:

> That's what I'm like, I'm like a person who needs a worker. I need to be worked on. They work on me. They work with me. They do work to me. Yes, she thought, they are workers. I'm like their project. Where do they go when they go to work? They go here, they go there. They go wherever people like me are (Michalko, 1998: 15).

This work – to shape model blind people – is supported by fantasies of blindness as helplessness, dependency and darkness, which workers, blind service recipients and the broader public recognise as that which must be rejected (Michalko, 1998; Scott, 1969). This leads to a problematic inflexibility in rehabilitation programmes and outcomes. For example, Els (2001) asserts that in much rehabilitation work independence is defined as complete self-care, whereas disabled people often come to view independence as the ability to control and manage their own care. She suggests that a drive within society to reject vulnerability impacts on opportunities for disabled people, and society in general, in terms of marshalling networks of support and exploring interdependence as a means to facilitate greater autonomy (Els, 2001). Similarly, French's (2004) account, discussed above, demonstrates a deep societal investment in rehabilitative processes that are able to diminish the difference of visual impairment.

2.2.2. The role of the public in rehabilitation: investing in solving the problem of blindness

Scott (1969) asserts that communities are invested in the processes of rehabilitation as offering a solution to the problem of blindness. Moreover, he suggests that rehabilitation organisations gain legitimacy for their work through public approval. Despite this, the public and rehabilitation providers often interact in relatively superficial ways, and he suggests that where rehabilitation workers, service recipients and the public do interact, these are usually highly contrived events involving carefully chosen service recipients. These recipients either display the kinds of 'model behaviour' described above or, as a way to underscore the importance of rehabilitation work, negative characteristics of dependency, helplessness and struggle (Scott, 1969). Similarly, Silverman (2015) describes the use of blindness simulations as narrow engagements with the experience of blindness which serve to strengthen fearful blindness fantasies. These blindness simulations involve sighted individuals having to complete various tasks under blindfold. Eating while blindfolded or in a very dark room, called "dinner in the dark", is often used by organisations as an awareness activity and/or fundraiser (Silverman, 2015). In her 2015 review of research on the impact of such blindness simulations, Silverman found that while these can promote empathy, they are most often experiences of frustration, and sometimes fear, which result in a sense of deep relief that one is not blind and diminished belief in the ability of blind people to accomplish even the simplest tasks. These exercises also give the impression that blindness is experienced as complete darkness, which is, in fact, not the case for the majority of people classified as blind (Paterson, 2013; Silverman, 2015). In short, these exercises often achieve the opposite of their stated goal; that is, they intensify difference and reinforce what most people suspect about blindness, that it is an experience dominated by fear and renders one completely incapable. These fantasies of dependency are, scholars suggest, the driving force behind public investment in the rehabilitation industry, both financially and in terms of approval (French and Swain, 2001; Scott, 1969).

Hughes (2019) locates the roots of charitable giving in the Western Christian Middle Ages where acts of mercy and generosity were key to a moral economy based on displays of propriety for gaining the approval of both God and men. Disabled people were the mediators of the social status and the salvation (sometimes the saintly ambitions) of the masculine clergy and aristocracy, and even presented an opportunity for women and the poor to maintain some social status and spiritual currency (Hughes, 2019). These Acts of charity, suggests Hughes, secured the invalidation of disabled people in the imaginations of the non-disabled as both bearing divine punishment for sin and as requiring the benevolent care of the morally pure. Disabled people provided a benchmark of social and spiritual failure against which social and spiritual validity could be measured and secured (Hughes, 2019). Considering contemporary rituals of charitable giving, Longmore's (1997) work on telethons in the United States recognises the operation of an alliance between rehabilitation workers and the public around the figure of the dependent disabled service recipient. He suggests that the public appeals made during telethons comprise an exchange between two distinct groups, the 'takers' and the 'givers', whereby the 'takers' receive responses to their appeals and the 'givers' have their morality publicly recognised. Even where there is no public acknowledgement, there is still an understanding that good has been done, that givers can feel like an integral part of a "moral community" (Longmore, 1997: 140). However, he further asserts that neither the takers nor the givers would exist if it were not for a third group, that of the disabled person, positioned as unfortunate and in need of both the takers and givers to change their situation (Longmore, 1997). Within this charitable exchange, Drake (1996) recognises a problematic paradox. He suggests that although their images pervade material requesting public support, disabled people remain silenced – mere objects of charity – within the charitable appeals of organisations (Drake, 1996; Hevey, 1992).

In drawing this section to a close, it is important to reiterate that what is being questioned by the above-cited scholars is not the necessity of rehabilitative interventions, the importance of the work of professionals or the value of essential skills and techniques for adjusting to life with blindness (French and Swain, 2001). Rather, what is being questioned are the dynamics of power at work in rehabilitation services, as well as the ways in which exposure to rehabilitation, and relationships with rehabilitation professionals, shape the self-perceptions of people who have lost their sight (Michalko, 1998; Scott, 1969). The work presented here poses similar questions in the context of South Africa.

2.3. Visual Impairment in South Africa

In this final section I present a brief discussion of visual impairment in the context of South Africa. The section begins by outlining the South African disability landscape, with particular reference to the legacy of apartheid. I suggest that in considering disability, rehabilitation and welfare in the South African context it is crucial to recognise the systemic issues, connected to a history of racialised oppression, which bind race and poverty, and influence ideas about the spaces which individuals are expected to occupy. However, I also suggest that uncritical links between race, poverty, disability and disadvantage in the South African context have problematic consequences for how disability is understood in our society. Thereafter, I turn to focus on the situation of blind South Africans, in particular with regard to the significant challenges they face in accessing education and employment.

2.3.1. The South African disability landscape

It is essential to recognise that, as with all spheres of South African society, the history of rehabilitation for disabled persons is shot through with race-based inequality. Prior to the installation of a democratic government in 1994, the disability sector operated within apartheid's racist ideology of segregation, which functioned to politically, economically and socially exclude Black people from South African citizenship. Certain institutions, often funded by the apartheid government, were earmarked to provide services to Whites exclusively, while very little support was available for Black disabled people (Howell, Chalklen and Alberts, 2006). Despite the formal abolishing of the apartheid system in the 1990s, South Africa, and its disability sector, remains deeply impacted by this legacy.

Rehabilitation, training and other services for persons with disabilities are located in NPOs which rely on both public and private funding streams in order to offer services at no cost. Although South Africa has seen some significant disabled people's activism, bound up with the struggle against racialised oppression (Howell, Chalklen and Alberts, 2006), we have not experienced a moment of large-scale, politically rooted disability reframing of the sort seen in the United Kingdom (Barnes and Mercer, 2004; Oliver, 2004; Shakespeare, 2014). However, the Social Model approach to theorising disability pervades global disability politics and has influenced much of South Africa's post-apartheid disability legislation (Howell, Chalklen and Alberts, 2006; Newman, 2013). This has not, however, had the same radical impact on the operation of disability NPOs in terms of transforming leadership or programmes as seem in the Global North (Drake, 1996; French and Swain, 2001).

When it comes to NPO services, the legacy of apartheid's privileging of White people has a noticeable impact. The vast majority of those who must rely on these services, work in protected workshops, and subsist on government disability grants are Black, while those who are able to access private services, assistive resources and greater family support, financial and practical, are overwhelmingly White. Apartheid's legacy also continues to impact the resources and infrastructure of many special schools located in rural and township[4] areas, while schools formerly designated for White disabled children remain better resourced and are often geographically and financially out of reach for Black families (Soudien and Baxen, 2006). Consequently, any

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[4] 'Township' refers to an under-developed and racially segregated urban area formed as a result of the apartheid Group Areas Act (1950).

examination of disability in South Africa must recognise the significance of systemic issues connected to our post-apartheid context which maintain the bonds between race and poverty, as well as the cycle of poverty and disability identified by many Disability Studies scholars working in the Global South (Barron and Ncube, 2010; Watermeyer, 2019).

Furthermore, in considering a notable lack of racial diversity within many blindness sector service organisations, we must acknowledge that the anxious fantasies which sustained the racist ideology of apartheid, through the cultivation of fear and hatred towards a Black other, are deeply rooted and persistent (Hook, 2012). These fantasies, which weave together ideas about Blackness, poverty and degeneracy continue to influence the maintenance of racialised spatial boundaries and beliefs about the kinds of people who are expected to inhabit certain spaces in present day South Africa (Botha and Watermeyer, 2018; Hook, 2012). Ideas about welfare, blindness, Blackness, poverty and degeneracy can become easily entangled against this backdrop (Botha and Watermeyer, 2018). For example, one of the service users in this study said: "The [organisation] is 90% Black and coming from my background…I've never been in a place where I've had to live with Black people…you're always brainwashed into thinking it's a bad thing". This participant suggests that becoming a recipient of public welfare involves transgressing boundaries that would otherwise have maintained a clear separation between self and other. It is, I suspect, in order to maintain these boundaries that many who are racially and/or socio-economically privileged marshal their resources in order to escape the marginal space of public welfare. In exploring the operation of rehabilitation services in South Africa we must remain aware of a legacy of racial othering which continues to shape ideas about what it means to inhabit the space of public welfare, who is expected to inhabit this space and who is not.

Nevertheless, an uncritical and wholesale binding up of race, poverty, disability and disadvantage, as alluded to earlier, is problematic in that it prohibits certain groups from being able to claim disadvantaged status, thereby blocking their access to systems designed to address inequality (Botha and Watermeyer, 2018; Watermeyer, 2019). An example of this is the fact that South Africa's Broad-Based Black Economic Empowerment (BBBEE) policy, designed to address large-scale historical inequality in terms of skills development and employment, includes only Black disabled people as a designated group (Newman, 2013). Although the Employment Equity Act (EEA), another piece of post-apartheid employment legislation, is not racially specific in its definition of disability, it is BBBEE, with its scorecard system of points and ratings, that is by far better monitored and more important for business in terms of accessing contracts, tax incentives and other rewards. Given the staggering rates of unemployment for disabled people across racial categories, this places White disabled people in a tenuous position, as the privilege of Whiteness tends to obscure the disadvantage of disability. Thus, it is important to recognise the ways in which disability complicates a familiar picture of corresponding race, class and disadvantage.

The South African disability landscape, therefore, can be complex to navigate, as race-based splits which attribute privilege and struggle along exclusively racial lines threaten to obscure the operation of other forms of social oppression (Watermeyer and Swartz, 2006; Watermeyer, 2019). Watermeyer and Swartz (2006) suggest that while race has become viewed as an issue of social oppression, in many spheres of South African society disability remains understood as a problem of the individual body. This has a significant impact for disabled people of all races in terms of education, employment and citizenship rights in general. In summary, to engage with the experience of disabled South Africans is to apprehend a complex interweaving of race, socio-economic status, disability, and various other axes of identity.

2.3.2. The situation of blind South Africans

According to the World Health Organisation (WHO), ‘legal blindness’ is defined as a visual acuity of less than 3/60 in the better eye (Dandona and Dandona, 2006). Consequently, legal blindness includes a broad array of conditions and levels of visual difficulty. In South Africa, the National Guideline on Prevention of Blindness published in 2002 estimated that 0.75% of the population experienced visual impairment (Sacharowitz, 2005). More recent statistics from the 2011 census data report an overall population of disabled people at 7.5%. Of those surveyed, 11% reported what the census refers to as “difficulty seeing”, including a broad spectrum of visual impairment from mild to severe difficulty. The proportion of those who reported severe difficulty was substantially lower at 1.7% of the total population. Unsurprisingly, the prevalence of “seeing difficulties” increased with age. According to the census data, 49% of individuals over the age of 85 experience some degree of difficulty. The majority of individuals who reported severe visual difficulties were from rural areas (StatsSA, 2014). Importantly, a 2015 study found that socio-economic factors, such as access to healthcare and employment, influence the self-reporting of visual impairment and, therefore, visual impairments often remain undiagnosed and untreated especially in low income areas of South Africa (Naidoo, Jaggernath, Ramson, Chinanayi, Zhuwau and Overland, 2015). Moreover, the majority of visual impairment in South Africa results from preventable or treatable conditions, including Glaucoma and cataracts. Therefore, links between blindness, poverty and access to healthcare and health-related information are evident (Sacharowitz, 2005).

In terms of education, a 2015 report on the state of the 22 special schools for the blind in South Africa revealed an overall lack of resources, under-equipped teachers and a low standard of education offered to visually impaired learners (Fish-Hodgson and Khumalo, 2015). In the majority of these schools, blind learners have limited subject choices and are seldom offered any career guidance (McKenzie, Kelly and Shanda, 2018). Moreover, in terms of disability more broadly, it has been found that special schools do not adequately prepare disabled young people for tertiary education (Howell, 2006). Visually impaired students at a tertiary level are a notable minority and they often face challenges of access to reasonable accommodation, as policies on inclusion are yet to be properly implemented in the majority of universities (Lourens and Swartz, 2019).

Unemployment rates for disabled South Africans, according to the 2011 census, increased with the severity of the difficulty reported (StatsSA, 2014). Factors influencing the employment of disabled people in South Africa include the education they have received, the age of onset of their disability, negative attitudes towards disability, and the complex intertwining of race, poverty and disability, which impacts on factors such as access to assistive devices and tertiary education (Emett, 2006). In addition, processes of recruitment are often difficult for disabled people to navigate, and programmes focusing on integrating people with disabilities into the workplace are inadequate (McKinney and Swartz, 2019). It has been suggested that inflexible elements of South Africa's social security system may also impede disabled people's ability to seek formal employment (Engelbrecht and Lorenzo, 2010). Unemployment rates for blind and visually impaired people in South Africa are staggering, estimated at 97% (SANCB, 2016). Given the dire situation of both education and employment, many blind South Africans turn to NPOs for support, not only in terms of rehabilitation services, but also for skills training, sheltered employment and/or job seeking support.

Conclusion

In light of the material challenges described above, it is important to evaluate the relevance of the present study. Does this work fall into the category of "critically playful" as described by Grech (2015)? I don't believe so. Grech is strongly opposed to the export of abstract projects, which "may constitute a gross offence to disabled people preoccupied with very material poverty and oppression" (2015: 18). While this is an important caution, we should not view work interested in disability, discourse and identity as necessarily apolitical and irrelevant to discussions concerning the eradication of poverty and discrimination (Tremain, 2017). On the contrary, we have seen that Foucauldian concepts are able to trace the operation of pervasive disablism and account for the material implications of otherwise taken-for-granted systems of power-knowledge (Sullivan, 2005; Tremain, 2005; Yates, 2005). In line with these scholars, this work takes the view that Foucauldian analysis is useful as a lens through which to apprehend the deep roots of oppression, and may also be mobilised as a tool for dismantling oppressive systems (Blackmore and Hodgkins, 2012; Friedner, 2010).

However, we have also seen that discursive enquiry alone is not sufficient to account for the potency of racism, disablism and other forms of oppression (Hook, 2012; Watermeyer, 2013). Therefore, this work explores an interplay between discursive practices and psychic investments in order to offer a deeper consideration of how certain discourses take hold and persist. In this regard, critiques of coloniality offer valuable insight into the external and internal operation of oppression – that is, an interplay of materiality, representations and psychic investments – as well as how oppressed groups are drawn into colluding with oppressive systems as a means to escape negative discourses and fantasies (Hook, 2012; Ravaud and Stiker, 2001).

Understanding the challenging circumstances faced by the vast majority of people with visual impairments in South Africa sheds light on the position of influence occupied by NPOs. For many of the participants in this study, in the face of profound experiences of exclusion and discrimination, NPOs seem to be the only places to turn for answers and support. Although the experiences of visually impaired persons in this study resonate with those of the blind scholars discussed in this chapter, there are several issues specific to South Africa's unique landscape which must be considered. This work, therefore, seeks to extend the kinds of critical engagements offered by French (2004), Longmore (1997), Michalko (1998) and Scott (1969), concerning the operation of rehabilitation and the shaping of subjectivity, to the South African context.

CHAPTER 3
METHODOLOGY

3.1. Research Design

This study includes two research phases. In Phase One I conducted a discourse analytic review of existing digital documentary sources, namely, the copy of organisation websites, in order to map the discourses employed by organisations as they represent themselves in the public realm. In Phase Two I gathered qualitative data using semi-structured interviews with both service providers and service users at several organisations in order to explore, firstly, the discourses which frame organisation operations and, secondly, the ideas about blindness which are produced and reproduced within relationships where help is given and received.

3.1.1. Phase One: a discourse analytic review of organisation websites

In Phase One I engaged with existing digital documentary sources as a means through which to apprehend the public face of organisations, referring to the ways in which they represent themselves, their work, their beneficiaries and blindness or visual impairment in the public realm. I conducted a discourse analytic review of website copy from eight organisation websites. These organisations, which provide rehabilitation and/or development services for visually impaired adults, operate across five provinces in South Africa, namely, the Eastern Cape, Free State, Gauteng, Kwa-Zulu Natal and Western Cape. The process of identifying these organisations as well as ethical considerations and data analysis are discussed further in the sections to follow.

According to Gibson and Brown (2009), documentary sources can provide insight into what life might be like in a particular society, the experiences of individuals, and/or the functioning of organisations. These sources are also able to provide a useful comparative framework for other empirical data. It is important to reiterate that blindness sector non-profit service organisations are the primary providers of blindness-related services in South Africa and are positioned as experts on visual impairment and the design and implementation of appropriate rehabilitative and/or development interventions for those who lose their sight. These organisations are, therefore, in a position to produce and broadcast discourses which construct blindness as a phenomenon. In light of this, before turning to the accounts of service providers and service users, I explore the discourses broadcast by organisations in the public realm and question whether and to what extent these discourses are deployed within actual organisation operations. This first research phase can therefore be viewed as a backdrop to the rest of the study.

The focus on website copy rather than other documentary sources is based on the assumption that most organisations recognise this medium as an important part of their public relations, and likely the primary way in which potential donors, those researching visual impairments and available support, those experiencing sight loss, and other interested parties will make contact with them. Although there certainly are ethical considerations involved in working with this kind of data (Gibson and Brown, 2009), organisation website copy was easy to access and offered a wealth of information, including mission and vision statements, organisation history, information about services offered, newsletters, information about upcoming events, and profiles of staff and beneficiaries. The review of website copy focuses exclusively on the text and does not include analysis of visual elements on the websites. Although this would add an interesting layer of analysis to the work presented here, as a visually impaired researcher who would have to rely on a third-party description of the images, I chose not to pursue this.

3.1.2. Phase Two: semi-structured interviews with service providers and service users

In Phase Two I conducted semi-structured interviews with eight service providers and eighteen service users at four organisations operating in the Western Cape. Shakespeare (1996) recognises the value of qualitative methods, and semi-structured interviewing in particular, for research with disabled people, as these methods privilege participant voices. Nevertheless, he urges researchers to remain aware of the dynamics of power involved in qualitative interviewing.

Conducting semi-structured interviews calls for skilled communication, the building of rapport and the ability to guide a conversation without influencing the interviewee (Gibson and Brown, 2009). My skills as an interviewer have been significantly honed through the undertaking of two postgraduate research projects, both making use of qualitative interviewing methods and focused on the experiences of people with disabilities. Participant recruitment, research procedures, ethical considerations and data analysis are discussed in the sections to follow.

3.2. Framing

As noted, this study uses Foucauldian concepts, and, in particular, the interrelated concepts of discourse, power and knowledge, as a lens through which to critically interrogate the operation of rehabilitation services. In line with scholars such as Drinkwater (2005), Friedner (2010), Morgan (2011), Sullivan (2005) and Yates (2005), I have used these Foucauldian concepts in order to explore the production of knowledge about blindness through practices in rehabilitation, and how this relates to power. This work is not situated within the kinds of discourse analytic approaches exemplified by Parker (1992) or Potter and Wetherell (1987), which view discourse as text and/or speech interactions through which objects are constructed. To be clear, I have not used Critical Discourse Analysis (CDA) for this study, as described by Cameron (2001). Rather, in approaching discourse as practice, I have drawn on the principles for a critical discourse analytic approach outlined by Hook (2001; 2007). For Hook (2007:100), discourse is a term that is “both overused and under-defined”. He asserts that while discourse analytic work makes frequent reference to Foucault, Foucauldian concepts, and discourse in particular, tend to be misapplied. A return to Foucault’s conceptualisation of discourse as “situated far more closely to knowledge, materiality and power than it is to language”, would extend the critical potential of discourse analytic work (Hook, 2007: 132). This work would, he explains, recognise a multidirectional constitutive relationship between discourse, power and knowledge within particular socio-historical contexts, understand the text as an instrument of power and not as power in itself, and recognise that discourse analysis must, therefore, move between textual and extra-textual elements (Hook, 2007: 134–135). As discussed in the previous chapter, this richer and more accurate understanding of discourse is key in addressing critiques from several scholars which posit that discourse analytic work is merely an exercise in linguistic nitpicking, with little to offer a politically-engaged Disability Studies (Hughes, 2005; Shakespeare, 2014).

Hook (2007: 101) asserts that a “sound critical discursive analytic methodology” requires a skeptical orientation towards knowledge – as produced and entrenched by discourse and power. In order to capture this idea, he cites Said (1983):

> the will to exercise…control in society and history has also discovered a way to clothe, disguise, rarefy and wrap itself systematically in the language of truth, discipline, rationality, utilitarian value, and knowledge. And this language in its naturalness,authority, professionalism, assertiveness and antitheoretical directness is….discourse (Said cited in Hook, 2007: 104–105).

This resonates with Fairclough (1995), who states that discourse analytic work must be involved in “denaturalising” ideologies, that is, interrogating the interplay of discourse, power and knowledge in the production of ideas which would otherwise be accepted as common sense. For Fairclough (1995: 27), the denaturalising of ideologies is about “showing how social structures determine properties of discourse, and how discourse in turn determines social structures”. This interplay between the discursive and the material is key, according to both Fairclough (1995) and Hook (2001; 2007), if discourse analytic work is to make a critical contribution and remain politically relevant. More than this, Hook (2001; 2007) asserts that, without a recognition of discourse as practice “ –a violence which we do things” (Foucault, 1981: 67) – discourse analytic work will remain problematically trapped in textuality. Hook is clear that discourse analytic work must recognise discourse as event, in line with Foucault (1981), as this enables us to apprehend the material underpinnings of discourse, as well as its material effects. Importantly, understanding the relationship between discourse, power and knowledge as multidirectional allows the possibility of resistance – the emergence of an alternate discourse (Blackmore and Hodgkins, 2012; Friedner, 2010; Hook, 2007; Sullivan, 2005).

The work presented here aligns with this view of discourse and discourse analytic work. It adopts a critical position in considering the knowledge which props up the design, implementation and expected outcomes of rehabilitation services for visually impaired persons. It aims to explore the interplay between this knowledge, relationships of power in rehabilitation, and the very real circumstances which those who enter rehabilitation services must navigate.

A Foucauldian approach also demands that we, as researchers, turn inwards to interrogate the dynamics of discourse, power and knowledge in our own disciplines and research processes (Allan, 2005; Hook, 2007). This resonates with feminist research approaches, where reflexivity is prioritised (Palmary, 2006). According to Palmary (2006), reflexivity is more than simply a once-off disclaiming of bias – a first person confessional statement of who the researcher is – but rather a continuous engagement, on the part of the researcher, with the bearing of their particular position on all aspects of the research process. To this end, before turning to a description of research procedures, I offer some reflections on my positionality. In addition, throughout this chapter I make reference to the ways in which I have attempted to maintain reflexive engagement and remain accountable to participants.

3.2.1. Reflecting on my positionality

As discussed in Chapter 1, many of the questions posed in this research have been influenced by my experiences as both a user and a provider of services for visually impaired adults. In particular, the question of what might be communicated to visually impaired persons about their status as they undergo rehabilitation, is rooted in my own experiences of negotiating a sense of self and belonging alongside receiving essential services such as mobility training and computer literacy. On the other hand, my experience of working as a service provider in a blindness service sector NPO has shaped questions about what we, as practitioners, might be drawn into, having been steeped in particular discourses framing rehabilitation professions related to health and normalcy.

My unique and complicated positioning has, on the one hand, been helpful. In particular, being able to view rehabilitation services from the perspective of both a user and a provider has enabled me to remain empathetic as a researcher. For me, empathy has been key in avoiding simplistic splits which rely on criticisms of individual service providers rather than a critical interrogation of the complex discursive practices framing rehabilitation within which both service providers and users are enmeshed. On the other hand, this positionality has required that I navigate the complexity of being an insider/outsider researcher, as described by Keiklame (2017).

The South African blindness sector is a tight network and, as a result, I am known to many service providers and users. In relation to service users, my status as an insider, as a fellow visually impaired person, was certainly helpful in developing trust and rapport. However, I was aware that my role might be easily misconstrued – that is, I might be viewed by service users as still connected to organisation structures and programmes. Therefore, I did not interview any individual who I had previously worked with as a service provider and I was careful to ensure that my role as an independent researcher was clearly explained. Still, it was challenging for me not to slip into the role of career coach during these interviews, especially as many of these interactions felt similar to those I had with service users in my previous employment. I did, in some cases, follow up with participants on issues raised during their interviews. For example, I sent a weblink to a bursary application to a participant wanting to pursue further education, and I assisted another participant to access the assistive software on her mobile phone. Keikelame (2017: 222) grapples with similar acts of reciprocity in her own work, questioning the "ethical correctness" of her actions while also recognising an African ethic of reciprocity, that is, Ubuntu, the belief that one's humanity is deeply connected to the humanity of others. In a similar way, for me, these small acts of reciprocity are part and parcel of belonging to a visually impaired community where practical advice is often shared.

With regard to the recruitment of service provider participants, once again, my insider status, as well as trust built within the blindness sector over several years, proved helpful when approaching organisations for assistance. At the outset, I grappled with the fact that one of the identified organisations had previously employed me. While I considered excluding this organisation on these grounds, it is a well-established role player in the blindness service sector and I believe that this research would have been negatively impacted had it not been included. However, as with service user participants, I did not include any service providers who I had previously worked with, rather interviewing the two staff members who had been appointed after my time at this organisation.

Besides my insider status, there are aspects of my positioning which are significant in terms of the power dynamics involved in qualitative interviewing (Willig, 2001). My racial, socio-economic and educational status position me as an outsider, particularly with regard to the vast majority of service users, and also in relation to some service providers. Willig (2001) urges qualitative researchers to remain aware of the impact of gender, class, culture, language and other factors on our interpretation of participant responses. In this regard, I found that keeping a fieldwork journal was helpful. Still, my positioning as a visually impaired person often complicated the power dynamics. When interviewing service providers, my status as a former service user could obscure my role as the researcher. In Chapters 6 and 7 I make reference to a particular incident where a service provider addressed me as a product of his profession. For this service provider, the primary relationship in the room was not that of researcher and participant but that of service provider and service user. At times it was challenging to manage these dynamics; however, they offer further insight into the power relations which frame rehabilitation.

3.3. Participants

3.3.1. Phase One: identifying organisation websites

This study includes organisations offering all or some of the following services: orientation and mobility (O&M)[5] training, adjustment to blindness training, Braille training, computer literacy training, other soft skills courses (for example, life skills and/or work readiness), career development support, and job placement in formal employment or sheltered employment workshops. This study excludes schools, sports or social clubs for persons with visual impairments and organisations raising funds for medical research.

In order to identify organisation websites for Phase One, I made use of the South African National Council for the Blind (SANCB) membership list of over 100 organisations providing various services for visually impaired people. Organisations had to be registered NPOs providing direct rehabilitation and/or development services to visually impaired adults in order to be included. They were also required to have an established web presence, that is, a website of their own. Using this criteria, eight organisation websites were identified across five provinces, namely, the Eastern Cape, Free State, Gauteng, Kwa-Zulu Natal and Western Cape. No organisations were identified in Limpopo, Mpumalanga, Northern Cape or North West, as those found were either schools or social/craft groups with no established online presence.

3.3.2. Phase Two: identifying service provider and service user participants

Once again, I made use of the SANCB membership list in order to identify suitable organisations to engage with for the second research phase. This phase was limited to the Western Cape. In line with the above-mentioned requirements, four suitable organisations were identified. The Western Cape has the highest concentration of SANCB members and these organisations are all well established within the South African blindness sector.

I made contact with each of these organisations in early 2018 to request assistance with the recruitment of both service provider and service user participants for this study. I made initial contact with organisation management via email, including a formal letter and project information sheet (see Appendix A). I approached the recruitment of service providers and service users quite differently, recognising the particular vulnerability of service users. Before turning to an explanation of these recruitment strategies, I provide a brief description of each organisation below. In order to protect the identities of participants, I do not name these organisations here but refer to them as Organisations A, B, C and D.

Organisation A was founded in the 1920s and is located in a busy industrial area of the Cape Metropole. Currently, this organisation offers a variety of short training courses for visually impaired adults, including

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[5] O&M is a rehabilitative intervention which instructs visually impaired people on how to safely navigate their physical environments. It includes training in how to use a white cane and how to make effective use of sighted guidance. It also involves training in spatial awareness and some elements of household management, also called ‘skills of daily living’. O&M practitioners must undergo accredited training in order to work in organisations or as private consultants. However, they are not required to register with the Health Professions Council of South Africa (HPCSA) as, at the time of writing, O&M is not recognised as a health profession.

O&M, Braille, computer literacy and life skills. It offers training in craft work, and also has a protected employment workshop and an office dedicated to job placement and career support. Programmes at this organisation can span anything from six to eighteen months with many service users returning for additional courses and ongoing career and/or social work support. Service users at this organisation comprise a mixture of individuals experiencing sight loss later in life and those exiting the special school system seeking further development training, work readiness and/or job placement support. The majority of these service users come from disadvantaged communities.

Organisation B is located in an affluent suburban area and provides one-on-one assessments for individuals experiencing sight loss, primarily focused on the provision of appropriate assistive devices. The organisation also runs support groups located in various suburban areas across the Western Cape. Many of these support groups are directly connected to retirement centres and, consequently, the majority of those who attend are older persons. Moreover, given the location of these groups and the organisation itself, service users are, for the most part, White, middle-class individuals. The support offered by this organisation is ongoing, with many service users in regular contact with service providers and attending a monthly support group over an extended period of time. Organisation B also partners with a number of public hospitals and clinics in order to provide assessments and assistive devices to individuals from disadvantaged communities, but these individuals are seldom channeled into existing support groups and there were, at the time of this research, no support groups in low-income areas.

Organisation C was founded in the late 1800s and is located in a small town 120km from Cape Town. This organisation has recently been restructured and its operations split between two separate entities. However, at the time when this research was conducted, between June and November 2018, Organisation C included an accredited training college, residential facilities, a technology centre and protected employment workshops, as well as job placement and career development support. The training college, where this research was focused, offered a one-year training programme including computer literacy, business practice and call centre practice. Due to particular funding requirements, the majority of service users at the training college were youth under the age of thirty. Additionally, the vast majority of service users at this organisation were from disadvantaged communities and, like at Organisation A, included those who had lost their sight later in life as well as those coming through special schools seeking support into further education or employment. As there was access to a residential facility, this organisation was able to assist individuals from across the country and further afield.

Organisation D is located in a residential area on the Cape Flats[6] and offers services to both adults and children with visual impairments. Regarding services to adults, the organisation offers rehabilitation services including

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[6] During apartheid, under the Group Areas Act, ‘coloured’ communities in Cape Town were forcibly removed from their homes and relocated to an area known as the Cape Flats. This is a vast, low-lying area located to the South East of Cape Town’s central business district.

O&M, Braille, computer literacy and daily living skills, for example, cooking and household management. As with Organisation A, the time span of programmes at this organisation is variable, with some service users remaining for up to eighteen months and returning for additional training. Unlike Organisations A and C, this organisation focuses on rehabilitation and therefore very few of their service users had come through schools for visually impaired learners. Rather, the majority of service users at this organisation were adults who had lost their sight due to illness or accident. Like Organisations A and C, the vast majority of service users at this organisation came from disadvantaged communities. Organisation D also includes a residential hostel and places importance on sport and recreation as part of their programmes.

3.3.2.1. Recruiting service providers

Two service providers were recruited from each of the above organisations. In my initial correspondence with organisation management, I requested the opportunity to interview two staff members who work directly with visually impaired service users. In order to be included, these staff members also had to have worked in the organisation for at least a year. Organisation management recommended suitable individuals, providing me with contact information so that I was able to approach potential participants directly. I did this via email, including an introduction letter and project information sheet (see Appendix B).

Below, in Table 1, I present a summary of the demographic information of the service provider participants. This summary includes the gender, race, job title and employment duration of each participant. With regard to race, participants are identified as Black, Coloured, Indian or White in line with the racial categorisations found in employment equity legislation and other frameworks designed to address racial inequality in South Africa. Some service provider participants were registered with particular health professions such as occupational therapy (OT) or social work, while others were not registered health professionals. In the table below, I indicate whether a participant is registered as a health professional with an asterisk next to their job title. The names presented in this table are pseudonyms used to protect the privacy of participants. In order to further protect participants, this table does not directly connect service providers with any particular organisation.

Table 1: Service provider information

Participant	**Gender**	**Race**	**Job title**	**Duration**
David	Male	Black	O&M trainer	1 year
Donelle	Female	White	Trainer	5 years
Helen	Female	White	OT*	5 years
Isabella	Female	Coloured	Manager/OT*	20 years
Kay	Female	White	OT*	26 years

Participant	**Gender**	**Race**	**Job title**	**Duration**
Kelly	Female	Coloured	Manager/trainer	23 years
Mia	Female	White	Manager/trainer	28 years
Zoe	Female	Black	Social work*	1 year

There are several points to highlight in relation to the above information. Firstly, it is interesting to note the 50/50 split between those service providers who are registered health professionals and those, mostly working as trainers/facilitators, who are not. Service provider participants who had not studied in health-related disciplines came from a variety of educational backgrounds, with some holding qualifications in IT, education and the humanities, while others had no formal tertiary education. At the same time, those who had studied formally in health disciplines reported little prior knowledge of visual impairment or disability and described having to learn on the job. This resonates with the findings of Scott (1969) that "professional blindness workers", as he calls service providers, are a heterogenous group where expertise is often connected to experience rather than to professional, accredited and/or regulated training. Both Kelly and Mia are examples of service providers who, through many years of experience, have moved into senior positions within their organisations. Scott (1969) is concerned that professional blindness workers, who may be unable to transition easily into other employment, often become personally invested in the survival of their particular programmes and, therefore, might be opposed to any innovation seen as being threatening to their livelihoods. Furthermore, in his research into American blindness service organisations, Scott (1969) found that the design and implementation of blindness services often relied on the expertise of experienced professional blindness workers and that, consequently, programmes were often not subject to any formal accreditation or regulation and the content of these programmes could vary from organisation to organisation. Although this has changed significantly in the United States in recent decades, the process of regulating blindness services in South Africa is ongoing.

Secondly, although I did not conduct an audit of organisation staff demographics and cannot, therefore, draw any definitive inference, it is interesting to note that the vast majority of service providers put forward for this study were women. It is also important, particularly in relation to the service user information presented below, to note the racial demographics of service providers in this study. I consider racial dynamics in Chapter 7, questioning how intersecting race and privilege might impact experiences of rehabilitation and rehabilitative relationships. Finally, although not reflected in the above table, it is important to note that one of the service providers, Kelly, is visually impaired. I decided not to exclude service providers who were visually impaired, recognising that many visually impaired people are drawn to work in the blindness sector and that these individuals might add an important perspective.

3.3.2.2. Recruiting service users

I planned to recruit four service users from each organisation. In my initial correspondence with organisation management I requested the opportunity to present my intended research to their current service users. This was a way for me to make contact with service users directly, ensuring that they were able to make their own choice about whether to participate or not. Approaching the recruitment of service users in this way also allowed me to gather contact information and take the process of enrolment forward without involvement from the organisation. This was important for protecting the privacy of service user participants, many of whom chose to be interviewed away from organisation premises. During these short presentations I introduced myself and explained the project aim, objectives and procedures, including how participant confidentiality would be ensured. After each presentation I gathered the contact information of those who were willing to participate and then chose four participants from each volunteer group. I chose participants based on ensuring a balanced sample in terms of gender, race, age and level of visual impairment. I made contact with these participants telephonically in order to set up a suitable interview time. In some cases, individuals who had initially expressed interest decided not to participate. Individuals were not obligated to give a reason for choosing not to participate and there was no clear indication as to why these individuals (three in total) chose not to take part. This situation was manageable, however, as I had gathered approximately twelve volunteers from each presentation. Participants were provided with an introduction letter and project information sheet in Braille, enlarged print and/or accessible electronic format depending on their preference (see Appendix C). This information was also made available, for both service users and service providers, in English, Afrikaans or Xhosa.

Three out of the four organisations approached to assist with participant recruitment permitted me to engage with service users directly as described above. Management at one organisation, however, did not agree to this request. Instead, this organisation insisted that they recommend four service user participants to be interviewed at the organisation’s premises. During these interviews it became clear that, while these participants had all accessed services at the organisation, at least three of them were involved in other activities, either as volunteers or employees. These activities included assisting service users and facilitating training courses, as well as public relations and/or administrative duties. Two participants, in particular, positioned themselves as service providers throughout their interviews. While this certainly complicated my research plan, I chose to include these interviews and make specific reference to them in Chapter 7. This incident was challenging to navigate and I was concerned, firstly, that the confidentiality of these service user participants would be compromised and, secondly, that these accounts would be biased. However, with regard to my first concern, I believe that the measures taken to protect participant privacy in this study do extend to these participants. In order to address my second concern, I decided to include two additional service user accounts. Via my network of visually impaired contacts, I approached two individuals who had previously attended services at this organisation, both of whom agreed to participate. In this way I was able to get a balanced perspective on this particular organisation.

Below, in Table 2, I present a summary of service user information including gender, race, age and whether or not a participant has some residual vision. Here, I use the racial categories explained above. I also indicate whether a participant has accessed services multiple times and/or at various organisations with an asterisk next to their name. As with the service providers, the names presented here are pseudonyms chosen by the participants in order to mask their identities. Moreover, in the below table, as with the service provider information presented above, I do not draw any connection between the participants and the particular organisations they attended.

Table 2: Service user information

Participant	Gender	Race	Age	Residual Vision
Amy	Female	White	65 plus	Yes
Andi *	Male	Black	18 - 29	Yes
Aubrey *	Male	Black	30 - 39	Yes
Belinda *	Female	White	30 - 39	No
Henrietta	Female	White	65 plus	Yes
John *	Male	Coloured	30 - 39	No
Kathryn	Female	White	65 plus	Yes
Lifa	Female	Black	40 - 49	Yes
Lilla	Female	White	50 - 64	Yes
Melissa	Female	Coloured	40 - 49	Yes
Mike	Male	Coloured	18 - 29	Yes
Monique	Female	Black	18 - 29	Yes
Nikita *	Female	Coloured	50 - 64	No
Nohombile	Female	Black	30 - 39	Yes
Nyska	Female	Indian	30 - 39	Yes
Pumla *	Female	Coloured	40 - 49	No
Roeshdie *	Male	Coloured	18 - 29	Yes

Vusi	Male	Black	30 - 39	No

There are several points to highlight here. Firstly, it is notable that a majority of service user participants have some residual vision. It is important to recognise the diverse circumstances of these participants, particularly in light of the fantasy of descending darkness found within much organisation public face material (discussed in Chapter 4) and a set of strict binary concepts framing rehabilitative discourse (discussed in Chapter 6). Secondly, it is interesting to note, given what we will see about the promises held out to the public in organisation public face material, that several of the above participants had attended multiple rehabilitation and/or development programmes. Finally, it is notable that at three out of the four organisations included in this phase of the study, all but one of the service users who volunteered to participate were people of colour, while at the remaining organisation those who volunteered were all White women. I make special reference to the intersection of race, privilege and the particular rehabilitative spaces which service users come to occupy in Chapter 7. I now turn to a detailed description of the research procedures.

3.4. Procedures

3.4.1. Phase One

Phase One involved a discourse analytic review of the copy of eight organisation websites. The analysis included the complete copy of each website. I did not, however, include file attachments found on the websites such as forms, policy documents or annual reports. At the outset, it was important to understand the ethical issues surrounding the use of digital documentary sources. Here, I drew on recommendations from the Association of Internet Researchers (AoIR). According to guidelines published in 2012, there are two important questions to consider when using online data. These are, firstly, whether human subjects are involved and, secondly, whether it is reasonable to assume that the ‘online research space’ is understood as ‘public’ by the users of that space (AoIR, 2012). With regard to the former, this phase of the research did not involve human subjects. It did not involve the observation of individuals’ online behaviour, online interaction with human informants/participants or analysis of individuals’ online activities, for example, blogs, chats or posts. With regard to the latter, it is reasonable to assume that organisations understand their websites to be public spaces and, therefore, the content of these websites to be in the public realm. Consequently, according to the AoIR guidelines (2012), informed consent was not required for this first research phase.

Nevertheless, I took certain precautions in order to protect the privacy of the organisations included in Phase One. Firstly, I do not make any direct reference to any organisation and avoid any description which might identify an organisation. Secondly, as suggested in the AoIR guidelines (2012), I do not use any direct quotations from the websites analysed in this work so that organisations cannot be identified by means of an internet search. Where I have made use of particular phrases found on organisation websites, these have been entered into a search engine to verify that they do not identify the organisation in question.

3.4.1.1. Data analysis

As a starting point for the analysis of organisation website copy, I developed the following set of questions:

- How are visually impaired service users positioned within the copy?
- How are service providers positioned within the copy?
- How are the organisation services described within the copy?

Using these questions to guide my close reading of the website copy, I found that visually impaired service users were passively positioned across the sample in relation to organisations and their workers as well as members of the public. The public constitutes a third party present across the sample, which the above questions had not anticipated. In fact, it became clear that the primary target audience of organisation website copy was the public, addressed as "you" and "your" throughout the sample and appealed to for support in the form of donations and/or volunteering. In light of this discovery, I revised my initial analytical questions as follows:

- How are visually impaired service users positioned in relation to organisation services and service providers?
- How are visually impaired service users positioned in relation to members of the public and within public appeals for support?

Guided by these questions, I explored the implications of the third-person positioning of visually impaired service users across the sample of organisation public face material. The findings from this first research phase are discussed in Chapter 4.

3.4.2. Phase Two

Phase Two involved gathering qualitative data by means of semi-structured interviews with eight service providers (organisation staff who work directly with visually impaired adults) and eighteen service users (visually impaired adults) across four organisations operating in the Western Cape. The process of gathering this qualitative data, from making initial contact with organisation management to completing the transcription of interviews, spanned approximately eight months, from May to December 2018. The strategies employed for the recruitment of service provider and service user participants are discussed in detail above. Once participants had been identified, I made contact with them individually in order to set up a suitable interview time and venue. The below subsections offer detailed descriptions of the research procedure after participants had been identified and contacted.

3.4.2.1. Informed consent

I ensured that each participant had access to the project information prior to their interview. This information was made available in English, Afrikaans or Xhosa. For visually impaired participants, the project information was also made available in large print, Braille, accessible electronic format and/or audio recording. Before each interview session I confirmed that the participant had read and understood the project information. I made sure to reiterate at the start of each interview session that there was no obligation to participate, that the participant could refuse to answer any question and that they could withdraw at any time with no consequence and no obligation to give an explanation. Each participant was given an opportunity to ask any questions they might have had before signing the consent form (see Appendices B and C). For visually impaired participants, a tactile marker[7] was attached to the consent form prior to the interview session so that these forms could be signed independently by the participant. Visually impaired participants were also given the option to sign using their fingerprint or to give verbal consent on the audio recording. All participants agreed to sign the consent form, with one giving verbal consent.

3.4.2.2. Semi-structured interviews

As per the project information sheet, participants were asked to attend one face-to-face interview session of approximately an hour. As these were semi-structured interviews, rather than a strict interview schedule, I developed an interview guide for each participant group, comprising five broad discussion topics with several open-ended questions under each topic heading (see Appendix D). These interview guides were not strictly adhered to but were used to provide a loose structure for the interview sessions. Questions were not asked in any particular sequence and follow-up questions were used throughout the interviews in order to encourage participants to elaborate further where necessary. Hence, although all discussion topics were touched upon, each interview took a very different shape.

Semi-structured interviews should allow space for discussion, that is, for the voices of participants to be heard and for them to be able to question and/or problematise the topic under investigation using their own terms and/or concepts (Willig, 2001). Researchers must be open to an evolving process, not permitting prepared questions to dominate the interview space but, rather, using them as a means through which to encourage participants to speak about particular issues and/or experiences. Semi-structured interviewing, therefore,

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[7] Before each interview I had a sighted person attach a paperclip to the consent form to mark the place where the participant was expected to sign. This simple solution allowed me to assist the participant to sign the form without needing to ask for assistance from anyone else. I was concerned that requiring a third party to assist with signing the consent form might compromise participant confidentiality, particularly if an interview was taking place at an organisation.

involves maintaining a careful balance between ensuring that the interview discussion remains focused and allowing participants to take the discussion in other directions, thereby exposing issues that the researcher might otherwise have overlooked (Willig, 2001).

Semi-structured interviews also promote rapport and allow space for exchange between researcher and participant (Shakespeare, 1996). For example, in the below exchange between myself and Kathryn she was able to move into the role of interviewer, questioning me about my own experiences in relation to what she had just shared about losing her sense of independence:

> Kathryn: I had to give up driving and everything…and you…did…you were eight weren't you?
>
> Michelle: I was very young, I was two when I was diagnosed but I lost the bulk of my vision in my late teens so I've never driven, I don't really know that…
>
> Kathryn: So you don't miss that?
>
> Michelle: Ja, I don't really know that level of independence but I do see…
>
> Kathryn: Can you cook?
>
> Michelle: Yes, but it's a process. (laughs)

In this extract there is a sense of mutual vulnerability. This kind of interaction is, according to Shakespeare (1996), an important part of ethical practice, creating a reciprocal and more equitable space. This problematises the notion of research as a one-sided extracting of personal information. However, creating this more equitable space was often complicated by the power dynamics which framed each unique interview session. To address this, I had to remain intentional about my interactions with participants, showing them that their contributions were valued as key knowledge, sometimes drawing on my own experiences in reflective responses to what they were sharing and encouraging them to ask questions of their own.

Part of setting up each interview was selecting a venue where the participant would feel most comfortable. While all service provider participants chose to be interviewed at their respective organisations, the majority of service user participants asked to be interviewed elsewhere. Several service users chose to be interviewed at their homes. While there are certainly ethical considerations involved in entering a participant's home, I realised that for the majority of service users, who do not have easy access to transport, home was the most convenient and comfortable space for them. Still, I was keenly aware of the need to show respect and express gratitude for being welcomed into these spaces (Keikelame, 2012). I conducted two service user interviews at a residential hostel where participants were staying for the duration of the rehabilitation programme they were attending. These participants, however, asked to be interviewed on a Saturday when most staff were not on the premises, further ensuring their privacy. Other interviews were conducted at coffee shops local to the participants. I reimbursed those who had to pay for transport to the interview session. Only five service user participants were interviewed on organisation premises. One of these participants chose to be interviewed at the organisation where she was attending training, as this was most convenient for her. With regard to the other four, as described above, one of the organisations included in Phase Two did not permit me to make direct contact with service users in order to recruit participants. This organisation also stipulated that participants be interviewed on their premises. Although not ideal, as mentioned above, I believe that the measures put in place to protect participant privacy in this study extend to these participants. This is discussed in the following section.

All but one of the interviews were conducted in English. Participants were, however, invited to participate in their home languages. In my initial contact with each participant, along with setting up a suitable interview time and venue, I asked whether they would prefer to be interviewed in a language other than English. Only one participant asked to be interviewed in Afrikaans and during her interview she spoke a mixture of English and Afrikaans. As this is my second language, I was able to conduct and transcribe this interview myself, as well as translate extracts where necessary.

It is important for researchers to remain engaged with the unfolding research process. To this end, as suggested by Gibson and Brown (2009), I developed an interview analysis sheet (see Appendix E). Using this analysis sheet, I was able to reflect on each interview, noting similarities and differences between participant responses, points of particular interest raised by the participants, recurring words, phrases and concepts emerging across the interview data, and questions, terms or concepts which participants found problematic. This information was valuable, as it allowed for a consistent evaluation of research questions. These interview analysis sheets were also useful for indicating data saturation and as a reference for data analysis.

3.4.2.3. Transcription

All participants consented to having their interviews recorded. I transcribed all 26 interviews myself which, although time-consuming, helped me to stay connected to the data. I used an unfocused method for transcription, as explained by Gibson and Brown (2009), which renders audio recordings into text as they occurred but is not as detailed as methods which record inflection and intonation. I did, however, record nonverbal elements of the interview interaction, such as laughing, sighing or gesturing where this was important for interpretation.

Audio recordings were stored on my personal computer, which is password protected. Once transcription and data analysis were complete, these recordings were destroyed.

Having completed the transcription, as well as an in-depth reflection on each interview facilitated by the interview analysis sheet, I found that there were no ambiguities or areas requiring further clarity. Therefore, it seemed there would be little to gain from follow-up interviews, initially proposed to take place telephonically. I chose, consequently, not to inconvenience the participants and did not pursue these.

3.4.2.4. Data analysis

In line with the discursive analytic approach of this work, data were coded at the discursive level, that is, the analysis was focused not on what participants were saying but on what discourse was doing (Cameron, 2001; Hook, 2001). I approached data analysis inductively in that I did not organise data according to a predetermined thematic framework but rather allowed themes to emerge from the analysis of data itself. Still, Srivastava and Hopwood (2009: 76) assert that "patterns, themes and categories do not emerge on their own" and that data analysis will always be influenced by a researcher's interests, in other words, what a particular study is aiming to discover as well as the theoretical ideas which frame that study. Data analysis in this study has been shaped by my interest in discovering the discourses which service providers and service users are involved in producing and reproducing, how these discourses underpin the functioning of rehabilitation services and, crucially, the knowledge about blindness which frames and supports the rehabilitative project. I am interested, moreover, in how this knowledge shapes the focus, activities and culture of organisations as well as the self-perceptions of visually impaired people.

At the outset, I recognised that it was important to approach the data set in two ways; firstly, as two broad sets of accounts from service providers and service users, and, secondly, as four distinct sets of accounts from individuals involved in particular organisational ecosystems. I therefore organised interview data into six cross- sectional clusters as follows:

- Service providers (8 interviews)
- Service users (18 interviews)
- Organisation A (6 interviews)
- Organisation B (6 interviews)
- Organisation C (6 interviews)
- Organisation D (8 interviews)

I approached data analysis as a process of comparing and contrasting accounts, and tracing 'discursive threads' within and across service provider, service user and organisational clusters. I use the term 'discursive threads' to refer to recurring words, phrases and/or descriptions pertaining to both practical and relational aspects of rehabilitation. My analysis aimed to trace the ways in which these discursive threads weave together, forming/supporting or disrupting/complicating certain overarching narratives which frame rehabilitative practices. For example, the phrase “stand alone”, used to describe a rehabilitative outcome (discussed in Chapter 6), could be traced across the service provider data cluster. This phrase, therefore, constituted a discursive thread which when viewed in light of other threads such as the negative phrase “sitting at home”, could be seen to support a narrative of independence as complete self-sufficiency and an overall imperative to cope which framed rehabilitative interventions. As mentioned above, a discursive thread might also be a recurring description of a particular experience, institutional practice or relationship. An example is the recurring description of unappetising food found across three organisational data clusters. If we accept, along with Young (1981: 49), that discourse is “all those rules, systems and procedures” which come to shape our knowledge of the world and ourselves, then the serving of unappetising food must be viewed as a discursive practice and must prompt us to ask what this experience might signal to service users about their value.

In order to keep track of comparisons and the tracing of discursive threads across data clusters, each data extract was labelled according to whether it contained service provider (SP) or service user (SU) data and whether the participant was from Organisation A, B, C or D. I found that the digital tools which many researchers use for the coding of data were largely inaccessible to me as a visually impaired person. Consequently, I had to code data manually which, although time-consuming, enabled me to remain deeply immersed in the data. The interview analysis sheets were a useful tool for data analysis as, taken together, these initial reflections formed a kind of preliminary analysis. By working through this set of reflections I was able, at the outset, to identify several discursive threads and to begin tracing some significant similarities and differences across data clusters. With these preliminary findings as a foundation, I then returned to the 26 interview transcripts. I approached this as a cumulative process, moving through the four organisational data clusters and continuously collapsing discursive threads into larger categories. Once this process was complete, I worked through the findings, combining categories and organising these into cohesive themes. For example, the discursive thread “stand alone” was drawn together with other service provider descriptions of independence, eventually forming part of a theme concerning service provider descriptions of strictly defined service outcomes. I explain how findings have been organised and presented in this study below.

3.5. Ethical Considerations

This chapter has already touched on several ethical considerations pertaining to both research phases. However, given that Phase Two involved accessing the personal experiences of individuals, many of whom were potentially vulnerable, I provide a summary of the ethical concerns for this research phase here.

I obtained ethical clearance for this study from the University of Cape Town Human Research Ethics Committee in March 2018. This clearance was granted up until March 2019 and all data collection procedures were completed by November 2018. As described above, all participants were provided with the project information in either English, Afrikaans or Xhosa and, for visually impaired participants, in an accessible format (see Appendices B and C). Before signing the consent form, participants were given an opportunity to ask any questions about the project information and I made sure to reiterate that they were not obligated to participate and could withdraw at any time with no consequence.

Although this study held minimal risk for participants, there were, nevertheless, several important factors to consider and address. Firstly, it was essential to ensure participant privacy and confidentiality, especially given the potential vulnerability of service user participants relying on organisation services. In order to achieve this, pseudonyms, chosen by each participant, were used in order to protect their identities. Furthermore, I avoid descriptions which may identify an individual and I do not draw direct connections between participants and the organisations they are involved in. The process of service user recruitment, and allowing service users to suggest suitable and convenient interview times and venues, were further ways in which I sought to protect participant privacy. Finally, I transcribed all interviews myself, meaning that no third party had access to these, and as soon as transcription and data analysis were complete, all interview recordings were destroyed.

Conclusion

This chapter has described the two-phase qualitative research process undertaken in order to address the research questions posed within this study. A discourse analytic approach, as described by the work of Hook (2001; 2007), was used in order to analyse the data. Throughout this process, I attempted to remain reflexive, that is, aware of the bearing of my particular positioning on all aspects of the research. Of central importance was ensuring that all participants were engaged with in an ethical manner and that their privacy and confidentiality were protected.

The following chapters present a discussion of the research findings. Chapter 4 is focused on the findings from Phase One and presents a broad view of the discourses employed by organisations as they represent their work in the public realm. Beginning the discussion of findings from the interview phase, Chapter 5 considers how experiences which surround the onset of visual impairment might have an impact on how individuals engage with rehabilitation services. Chapter 6 explores the interplay between discursive practices and fantasies about blindness in the design, implementation and management of rehabilitation services. Drawing the discussion of findings to a close, Chapter 7 explores the power dynamics present in rehabilitation organisations and in relationships between service providers and service users.

CHAPTER 4

MAPPING DISCOURSES IN ORGANISATION PUBLIC FACE MATERIAL

In this chapter I discuss the findings from Phase One, in which I conducted a discourse analytic review of the copy of eight organisation websites. The findings presented below offer a broad view of the discourses employed by organisations as they represent their work in the public realm, many of which are enacted within their operations as well as in relationships between service providers and service users discussed in the following chapters. Therefore, throughout this chapter I draw on examples from the analysed websites, and include several references to interview data from Phase 2 which resonate. This chapter can be viewed as a backdrop to the rest of the study, and many of the points discussed here are expanded upon in the chapters to follow.

To be clear, the chapter does not offer a linguistic critique of organisation public face material as an end in itself. The findings presented here are not intended as an exercise in political correctness, nor are they a critique of the essential services described on organisation websites. Rather, they offer an exploration of constructions of blindness and blind persons broadcast by organisations in the public realm, questioning what these might reveal about an interplay of discourse, fantasy and relationships of power in rehabilitation. Referring back to Chapter 2, Hook (2001; 2007) cautions us against a narrow conceptualising of discourse as text alone, showing how this can lead us to a place where, on the one hand, materiality is disregarded and, on the other, the subtle world of fantasy is obscured. As discussed in the previous chapter, it is useful to think of discourse analysis as a tool for tracing dynamics of power-knowledge, which have very real effects (Hook, 2007; Tremain, 2017).

I began the analysis of website copy by asking: how are visually impaired service users positioned; how do they appear in organisation public face material? Strikingly, I found that visually impaired service users were persistently referred to in the third person, and positioned as passive recipients of both the work and services of organisations and the goodwill and gifts of the public. Service users only appear in the copy in relation to the interventions/services they have received, or the funding which facilitates these interventions/services. The analysis revealed the presence of three distinct groups within the website copy. First, the organisation and its workers are positioned as the active facilitators, drivers and doers of rehabilitation and development work. They are the “us”, “our” and “we” in the sampled copy and their work is its primary focus. The second group is the public, who are the “you” and “your” in the copy, that is, its primary and intended audience. The third group is made up of visually impaired service users, who are positioned passively as “them”, “their”, “they” and “the”.

Below I make some suggestions about what the implications of this third person positioning of visually impaired people might be. Firstly, I suggest the existence of an alliance between organisations and the public, around the figure of a passive recipient of services who appears to play little active role in their own creation and who is positioned as an object of organisation work and public charity. Secondly, in light of this, I suggest that the service outcomes described throughout the sampled websites constitute a promise, of an ideal and acceptable blind subject, held out to the public in exchange for their donations and support. Thirdly, I discuss the construction of a rehabilitation journey, focusing on how this linear view of services and outcomes legitimises the role of organisations and strengthens their claim to public support through the maintenance of polarised fantasies about blindness. Finally, this chapter suggests that the discursive positioning of service users in the third person builds into a discourse of blindness as a separate world, confirming socially entrenched stereotypes of blindness as a fearful and darkened reality that is largely unknowable for those who can see. Fantasies of darkness shadow the promises made by organisations to transform, shape and improve, and are, I suggest, the spectre against which these promises offer a defence.

The idea that organisations are working to shape blind people into socially acceptable subjects appears central to the message communicated by the sampled public face material. Resonating with Drinkwater (2005), Sullivan (2005) and Yates (2005), I argue that within organisation public facing discourses, blindness emerges as both an individual and collective problem. These discourses, in turn, produce knowledge for both blind persons and society about what constitutes a docile blind subject (Foucault, 1977). In his 1969 book, *The Making of Blind Men*, Scott explores how blindness services are involved in socialising people who have lost their sight into socially acceptable roles. I make several references to this work, now fifty years old, below, as it remains strikingly, even alarmingly, relevant to the findings presented here. That this work remains so resonant today must prompt us to consider the deeply entrenched nature of discourses related to health, normalcy and the experience of blindness, which continue to shape public and professional knowledge about what it is that blind people need to do, and what they must demonstrate, in order to be viewed as successful recipients of rehabilitation.

4.1. An Alliance around the Blind Subject

Three parties can be found within the copy of organisation websites: the “us”,“ our” and “we” of the organisation itself, the “you” and “your” of the reader appealed to for support, involvement and donations and the “they”,“ them”, “their” and “the” of the visually impaired service users. The overwhelming majority of direct appeals on these websites are made by organisations to the public motivated by various kinds of action taken for, around, towards and on behalf of blind people. This resonates with Drake’s (1996) critique of the role of the traditional charity and Longmore’s (1997) work on telethon rituals, discussed in Chapter 2. In line with their assertions, the findings presented here suggest that the descriptions of blindness and blind persons in organisation public facing material support a socially entrenched belief that blindness renders individuals into incapable, unfortunate and needy subjects. In this regard, a key concern is the real world implications of these representations in terms of whether visually impaired persons are viewed as full citizens, stakeholders in the rehabilitation process or capable of being agents in meeting their own needs. As Drake states:

> Against this background[of charitable imagery], disabled people have a hard time promoting quite different images and messages which may include, for example, that they are full citizens whose rights are denied them, or that the way in which non-disabled people have built the urban environment excludes many disabled people from public places and social life (Drake, 1996: 157).

Below I will outline the positioning of service users on organisation websites in relation to, firstly, active and altruistic organisations and their workers and, secondly, a concerned and generous public.

4.1.1. Active and altruistic organisations and their workers

In the website copy there is a notable contrast between the descriptions of service users and those of organisation workers. Service users are seldom described in terms other than those which refer to their impairment such as “blind”, “partially sighted”, “low vision” or “visually impaired”. They are also referred to in relation to services they receive, as “learners”, “trainees” or “residents”. Some examples of how service users are referred to across the sample include:

- Visually impaired people, blind people, partially sighted people
- The Blind, the partially sighted, the visually impaired
- These people/folk
- Persons who lost their sight, persons who have gone blind
- The blind and partially sighted community
- Our blind and visually impaired, our adults, our learners, our residents, our members, our clients, our customers
- Learners/the learner, students, candidates, members/the members, participants, residents/the residents, clients/the clients
- The people we serve

While some of this language suggests that service users occupy positions of influence – for example, “client”, “customer” and “member” – this is undercut by persistent third-person language, which establishes service providers as the experts in charge of the rehabilitation process. For example, a site where service users are called “clients” at the same time describes the role of their management team as “making decisions for the welfare of our clients”. Another site makes brief mention of service users as “our bosses”, stating that they have the power to end the employment of organisation workers if they choose not to participate in services. Again, this suggestion of a powerful position held by service users does not ring true in light of the discourses employed by organisations in presenting their work to the public. Additionally, given a noted imbalance of power in rehabilitation organisations (Drake, 1996; French and Swain, 2001), it is questionable whether this forgoing of services would be possible in reality. Scott (1969) asserts that blind people are bound to comply with rehabilitation organisations as the services they receive are essential. They are also unlikely to turn elsewhere, as they may not have the means to do so, such as to pay for private services. Moreover, alternatives are limited and they are likely to have similar experiences elsewhere.

Exceptions to the descriptions cited above are rare and inconsistent across the sample. There is one reference to service users as “hard working”, one site refers to service users as “our talented artisans”, and another to “our inspirational members”. The latter 2, possessive descriptions, reflect the success of organisation services more than the character of service users. They are descriptions of what service users have received through, in the former case, craft training and, in the latter, training in skills to adjust to sight loss. Only one site refers to blind and visually impaired service users as South Africans, significantly drawing attention to the citizenship rights of visually impaired people. However, this site also positions the organisation as advocating on behalf of those who cannot speak for themselves. Consequently, this description of citizens remains couched within constructions of service users as inactive. A number of sites mention the inclusion of visually impaired people on their staff and boards of management, but this also does little to disrupt the positioning of the majority of service users as passive.

Organisation workers are described in more detailed terms, with reference to positive characteristics of hard work, expertise and care. Some examples of this descriptive language include:

- Dedicated, loyal, tireless, hard-working, motivated, striving, long-serving
- Capable, extremely able
- Possessing unique skills, excellence, academic accomplishments, talented, experts
- Caring, devoted, selfless, compassionate, tender, courteous, smiling

It is often the case that staff members are pictured next to paragraphs detailing their roles and accomplishments. In some cases these staff members are also people with visual impairments. While this might offer some disruption of socially held beliefs which associate blindness with incapability, these visually impaired staff members are a small minority. Hence, the overwhelming majority of service users are, as Drake (1996) and Longmore (1997) suggest, faceless within this kind of material. Even where particular service recipients are named, there is something unsettling about their discursive positioning. For example, one site includes a success story which details a service user's return to work with the headline: "[Service user] is back at work,

thanks to [organisation]". Throughout this story the service user is referred to by his first name but remains positioned as a third-person recipient of services described as "solutions" to the problems of his blindness. The story details various stages of intervention through which he was guided: referral, assessment and training. The effort and action in this story is attributed to the organisation and its workers and, ultimately, they receive gratitude and recognition. However, it is the service user who must bear the responsibility of integration – learning new techniques and adjusting to assistive devices. The story makes no mention of adjustments to the workplace or employment as a human rights issue. Some sites do, however, acknowledge the ways in which visually impaired persons are marginalised in society. 2 sites, in particular, display notable contradictions in their copy as the importance of self-representation and access to human rights are promoted alongside the third- person language and charitable appeals discussed in this chapter. I suggest that this contradiction has to do with the bound up nature of blindness rehabilitation and charity in the South African context. None of the sampled organisations are fully funded by the government and, consequently, charitable gifts play an important role in their survival. We must consider, therefore, how organisations might be bound to the kinds of charitable appeals described in this section as an essential part of ensuring that they remain financially viable.

Undoubtedly, people are being assisted to gain greater mastery and to access opportunities through the services offered at organisations. The websites describe an array of services which provide essential skills and techniques for people who have lost their vision or for those coming out of the special education system, which often leaves gaps, for example, in the areas of work readiness and computer literacy. However, what I am critiquing are pervasive discursive practices which position visually impaired people in problematic ways, building into socially entrenched discourses of blindness as a problem and potentially prohibiting blind people from being recognised as stakeholders in their own growth, development and success.

4.1.2. A concerned and generous public

The persistent third person positioning of visually impaired service users is arguably most jarring in sections detailing the training courses and services offered by organisations. Here, the use of the third person to refer to visually impaired people suggests that the reader is assumed not to be a potential user of these services. Rather, the reader is told about the services and their impact on visually impaired people's lives. These interventions are, the language suggests, developed for and around service users, who are shaped and improved through the efforts of organisations to, among other things:

- Equip visually impaired people with the skills they need

- Uplift blind and visually impaired persons
- Raise awareness about blind and visually impaired people
- Support/assist blind and visually impaired people
- Cater for the needs of blind and visually impaired people
- improve the quality of life/fitness/financial position/social skills of visually impaired persons
- Empower visually impaired and blind people
- Make them financially more independent and/or end the cycle of poverty for them
- Care for blind and visually impaired persons
- Advocate and actively lobby on behalf of visually impaired persons

The sample includes only one direct invitation to potential users of a low vision service to make an appointment for assessment. Beyond this, there are 2 other phrases directly addressing visually impaired people on 2 of the reviewed sites. These are connected to the importance of knowing one's rights as a visually impaired employee and/or job seeker. In the vast majority of cases, therefore, where direct appeals are made, these are for donations, partnerships and volunteers in support of the work of organisations. The reader is invited to participate as a supporter of services, not to make use of the advertised services, which implies that the targeted reader is a concerned and generous public rather than a service user exploring potential service options. We must consider what encountering this website copy might feel like for someone with a visual impairment. How might this material, which presents blind and visually impaired people with descriptions of themselves as those who need uplifting, improving and changing, as people who are unable to advocate for themselves or drive the agenda for the meeting of their own needs, be significant in shaping their self-perception? Furthermore, what might the framing of services as a charitable exchange between organisations and their donors do in terms of shaping blind persons' perception of their status and place in the world? The accounts of service users presented throughout the following chapters suggest that what potential service users might need is engagement which holds them at the centre as key stakeholders, decision makers and agents in the rehabilitation process (see Chapter 7). Importantly, this does not necessarily have to come at the expense of appeals for financial support from the broader public.

The direct appeals found on organisation websites fall into 2 categories. Firstly, there are appeals for donations and volunteers and, secondly, there are invitations to participate in various kinds of awareness activities. In the case of appeals for public support of organisation services, partners, donors and volunteers are positioned, like organisations and staff, as playing an integral and active role with regard to visually impaired service users. Examples of how this role is described include:

- Support, help, assist, fund, sponsor, donate, volunteer, partner
- Change a life forever

- Equip yourself with knowledge in order to provide help when needed
- Play an integral part
- Make the difference
- Get involved
- Become a friend
- Leave a lasting legacy

In contrast to the action of partners and donors, visually impaired people are positioned as passive recipients of goodwill. As Longmore (1997) asserts, for an alliance between organisations and the public to be maintained, it is essential that their work and giving be focused towards those who are positioned as helpless or unfortunate. Service users are sometimes overtly referred to as “not fortunate” or “less fortunate”, while in other instances misfortune is implied by appeals to “make a difference” or “change a life”. Misfortune is most often directly and exclusively linked to the fact of impairment, thereby binding up meanings about blindness, suffering and lack. An example of this is an appeal for donations found on one site where the public is reminded to be grateful for the pleasure of being able to see, something that unfortunate blind people cannot enjoy.

In other cases, misfortune is connected to both visual impairment and poverty, with the public being appealed to for food parcels and care packages to support service users described as “indigent” or those who cannot meet their own basic needs. While it is important to recognise that many visually impaired people do live in circumstances of extreme poverty, an unproblematic binding up of blindness, poverty and need feeds into an understanding that those making use of organisation services represent a homogenous community. Furthermore, it implies a logic of causality where poverty is assumed to be the inevitable outcome of blindness. The following is an extract from an interview with a service user who explained how such appeals can shape a narrow public perception of blind persons:

> I was just reading on their Facebook page today, “Ho! Ho! Ho! It’s Christmas time! Make Christmas better for those less fortunate, those blind people”. And it irks me because what are you doing? Yes, we know that blind people have less chance of employment so we are poorer but don’t do that…it drives me bonkers when they do that because this is how…everybody that’s on [organisation] Facebook page, all their donors…are reading that, “the blind/destitute at [organisation]”. No wonder I don’t fit in that, I’m not destitute…How many of us are not fitting the mould that they, as the organisation, are creating for the public perception to perceive of us?
> – Belinda

It is important to be clear that the role of organisations in providing much-needed assistance in terms of relief for service users living in circumstances of poverty is necessary and essential. Nevertheless, appeals which draw no distinction between blindness and poverty, and position service users, regardless of socio-economic status, as unfortunate and inactive recipients of public charity, feed into narrow and negative meanings for blindness and the experience of blindness as well as the experience of poverty. Added to this, the majority of the sampled websites offer no commentary on the intersection of blindness and poverty, which is underpinned by ongoing discrimination of many kinds and the legacy of apartheid. In this regard, 2 of the sampled websites display a more helpful approach, as their copy recognises that the experience of blindness is impacted variously by factors such as socio-economic status, HIV status and race and gender in the South African context.

The forgoing discussion reaffirms an objectification of service users as products of organisation work and public charity. Within this public face material, service users are ascribed no active role in their own processes of growth or development. Rather, these sites are advertisements to the public, detailing the work being done and promising certain outcomes in exchange for public support. These outcomes can, therefore, be viewed as a currency in the maintenance of an alliance between organisations and the public around the figure of a passive service recipient being shaped, moulded and made.

4.2. The Currency of Four Key Service Outcomes

The direct appeals found throughout organisation websites promise various things in exchange for the generosity of the public. These, I suggest, constitute currencies holding this alliance together. Some of these currencies are tangible, for example:

- Donors are named and thanked publicly on organisation websites
- Longstanding donors receive memorials or have facilities at organisations named for them
- Donors receive tokens such as pins, stickers or badges to commemorate their gift
- Corporate donors receive tax and/or public relations benefits

However, currencies are mostly intangible. The first of these has to do with the knowledge that good has been done. Longmore (1997: 140) suggests that this is about givers being able to view themselves as part of a “moral community” – that is, giving is a momentary turning away from individualist, consumerist culture. For example, one site states that donors can “take pride” in helping the blind. A second currency is the promised gratitude of visually impaired service users. Scott (1969) asserts that blindness workers often view gratitude as the only form of reciprocation possible for service users. According to him, there is an understanding in blindness services that gratitude is an essential part of service relationships between blindness workers, donors and service users, and, accordingly, service users come to recognise displays of gratitude as important for ensuring their continued access to services. Over and above these, however, the key currency in the alliance between organisations and the public appears to be the promise of service intervention outcomes.

The outcomes of services outlined on organisation websites read as promises held out to the public, detailing how their money will be used to ensure the production of visually impaired people able to integrate into society on its terms. The analysis found four key service outcomes that were common across the sample and which are also present in the data collected from service providers (see sections 6.2. and 6.3.). The first of these is independence. The websites define independence as "self-reliance", which is described as "living without assistance", "not having to rely on someone else" and "preventing a life dependent on the State and on others". Often directly paired with independence, the second key service outcome is productivity. A phrase used several times across the copy promises that service users are being equipped for "independent and productive lives". Productivity refers to "financial self-sufficiency", "economic independence" and "participation in business". In essence, then, productivity refers to employment. Third, and connected to these, is the ability to live "active lives", referring to fulfilment found through the ability to participate as a community member.

Finally, the service outcome which forms the foundation for the above three, is a blind individual who is able to cope. The language used in relation to coping is that of "despite" or "in spite of", referring to the overcoming of challenges and adversity linked to sight loss. According to the websites, coping despite blindness is something that is learnt. These clearly defined service outcomes build into a discourse of the coping blind person which is a key driver of relationships of comparison, surveillance and prohibition in rehabilitation (see section 6.3.). The promise of a coping blind person on organisation websites resonates with Michalko's (1998) description of "persons who happen to be blind", in other words, blind subjects who can be seen to live "normal lives". Important indicators of successful coping, according to the sampled copy, include social and technical skills, knowledge, confidence and tenacity.

Beyond these four key service outcomes, some sites do make mention of other focus areas of their interventions. Four websites mention mental and emotional well- being. These sites describe counselling of various types as part of their services, and linked to adjustment, coping and integration. Some sites recognise the significant trauma of sight loss, and some stress the importance of a holistic approach that includes caring for mental health. The problematic consequences of an uncritical binding up of mental health and the imperative to cope are discussed further in Chapter 6. Physical health and fitness as an important service outcome is mentioned on three sites. These organisations include sport and exercise as a regular part of their programmes. Only 2 of the sampled websites recognise service user awareness of human rights as a key outcome of their services.

The four key service outcomes described here are not, in themselves, problematic. In fact, data from the service users in the interview phase reflects, unsurprisingly, the desire for greater independence, to be active, to work, to study and to participate. Below are several examples:

> I want to do other things, I don't want to be stuck.
> – Nohombile

> My dreams is to go further with my studies.
> – Aubrey
>
> I just wish I can get a good job that is gonna pay me well.
> – Lifa
>
> [W]ithin the last four or five years I've just been on a mission of trying to find a way for me to sustain myself and also for me to move forward and to develop.
> – Nyska

What does appear problematic is that these outcomes, especially those referring to action and participation, are not modelled, either to the public or to potential service users, on the sampled websites. The figure of a confident and tenacious blind individual exiting organisation services seems at odds with the largely silent and faceless service users populating the website copy. Furthermore, and returning to the question of how encountering these descriptions of blindness on organisation sites might be experienced by people with visual impairments, I suggest that there is something about the idea that one needs to be made into an "independent and productive" person that may feel dehumanising (Hughes, 2019). The blind people represented in organisation public facing material are stripped of character, knowledge, achievements or experience, and this may suggest to visually impaired readers that the onset of blindness has fundamentally altered their personhood. Additionally, drawing on Foucault (1977), this material appears to promote a perception of blindness as something to be subdued, an unruly reality in need of domestication. The promise that "independent and productive" blind persons are being made offers assurance to the public that blindness can be brought under control, as blind people are shaped into successful parts of the societal machinery.

Many of the organisation mission and vision statements found on their websites focus on the achievement of an empowered and integrated blind community with access to equal opportunities. However, the work to achieve this is directed towards the visually impaired service users alone. Across the sample, integration is described as a process of "preparing", "skilling" and "aligning" the service user with society, and it is ultimately the service user who must bear the responsibility for integration by demonstrating that they possess the ability to cope in spite of sight loss. As Drake (1996) asserts, what is being created is not empowerment, in the sense of entering positions of influence, but rather techniques to adapt to individual deficits in order to fit, as far as possible, into society on its terms. This is exemplified in website sections where employment is discussed. In this copy, work on the blind individual, including "thorough screening", "professional preparation" and the provision of technical skills, is far more in focus than adjustments to the workplace or work on the attitudes of potential employers. One site states that their services assist visually impaired people to "keep up" with sighted peers and another that their services "connect blind people with the world they live in". Further, these sites pay noticeably little attention to issues of access, attributing problems, challenges and barriers to sight loss and blindness. Only one site makes reference to barriers of access for integration and participation. However, this site goes on to refer to these as the "barriers of blindness", which serves to relieve the public of any responsibility for the eradication of these barriers. A further 2 sites make mention of accessibility as a key concern of their work but say little more about this. It is notable that many website sections addressing potential employers resemble charitable appeals for donations. For example, one site appeals to the public to "partner with us for integration".

This focus on shaping blind individuals to meet the requirements of the sighted world is evident in the interview data as well. In these data, while organisations are constructed as safe spaces where visual impairment and associated struggles are allowed, it appears that service users are ultimately being equipped to go back into the more hostile sighted world where they are required to cope. The below service providers spoke about their work to ensure that service users were equipped to manage the requirements of sight:

> A lot of people have commented that the [support] groups is the one place where they are allowed to be visually impaired because everywhere else they have to just cope and pretend, not pretend, but…the world requires them to see as much as possible and to engage with that.
> – Kay

> [I]t's like every month they come and they're just topped up and then they can go on, they can manage.
> – Helen

In considering these extracts it is helpful to recall what Michalko (1998: 77) suggests about the imperative for blind people to perform a "closeness to sight". For these service providers, this appears to be the goal of their work. Neither the requirements of the world nor the things which visually impaired people are prohibited from expressing outside of the safe space of organisations appear to be questioned. Interestingly, a number of interview participants used the contrasting phrases "in here" and "out there" to refer to organisations and the world respectively. This is suggestive of a closed, safe space of preparation and a more hostile environment which visually impaired people must eventually enter. It is important that we consider what service providers may be communicating to users, having been steeped in the discourse of subduing blindness. I expand on this discussion in Chapter 6.

The service users displayed an awareness of the imperative to adapt themselves in order to integrate into sighted society. For example, Nikita described a ten year period of isolation and depression which came to an end once she had learnt how to "fit into the world". Below, she describes the changes she had to make in order, firstly, to avoid the exclusion of being forced back into the isolation she endured before and, secondly, to mitigate the new vulnerability she experiences as a visually impaired woman:

> Ten years that I sat at home, that I did nothing, went nowhere, sat, cried, I've now learned how to fit into the world…in the beginning I didn't know who I was now, I used to be able to see, a person lives as they choose…you go where you want to, you see the danger, you face it but you can see it coming…I'm blind, now I must face the danger without being able to see it…but it made a difference in my life, it made me gentler, I'm not as aggressive as I used to be.
> – Nikita

Her words "in the beginning I didn't know who I was now, I used to be able to see" capture the sense of dislocation, of being adrift, described by many other service users in this study. For Nikita, becoming reintegrated into the world has involved significant changes in her behaviour – she can no longer live as she chooses; she must, as she said later, become "the least" and exchange her aggression for passivity. We might ask ourselves how her experiences, of isolation and depression at first and later of real physical vulnerability, have made her susceptible to being told who she is and how she must behave in order to be included. I continue this discussion in Chapter 5, considering how experiences of profound dislocation might make individuals particularly vulnerable to the messaging of rehabilitation services concerning who they are now that they are blind.

In the forgoing discussion we have seen how organisation public facing material presents the public with a view of rehabilitation services as processes through which acceptable blind subjects are shaped. This material appears to be invested in promoting a message of otherness brought under control, which is uncomfortably evocative of the kinds of colonial control discussed in Chapter 2 (Hevey, 1992; Hughes, 2019; Ravaud and Stiker, 2001). Furthermore, as with the maintenance of colonial power, fantasy plays a fundamental role in legitimising the operation of systems to produce docile blind persons (Hughes, 2019; Hook, 2012; Watermeyer, 2013). The analysis found that, across the copy, the polarised figures of a pre-intervention and post-intervention blind subject, flanking a linear rehabilitation process, were used to strengthen the legitimacy of organisation operations and appeals for public support.

4.3. A Constructed Rehabilitation Journey and Polarised Blindness Fantasies

Across the sample, the language used is suggestive of a linear rehabilitation process, or journey, starting from all-encompassing loss and ending with seamless social integration. The construction of rehabilitation as a linear journey is mirrored in the interview data (see section 6.2.). For now, I will focus on how this journey discourse appears in organisation public face material, suggesting how it might strengthen the alliance between organisations and the public.

Organisation websites present the four key service outcomes as the fixed, full and complete end point of rehabilitation. A constructed rehabilitation journey with a fixed end point offers the public a picture of a linear, predictable flow of disability experience, from loss and dependence, through organisation processes, to promised service outcomes and integration. This assures them that something is being done about the problem of blindness. Key to this construction is the maintenance of binaries demonstrating what service users are being drawn away from and what they are being drawn towards. In particular, the language of becoming found on the websites implies that service users are being provided with skills and imbued with characteristics which they did not possess prior to entering rehabilitation. For example, one site states that they are equipping blind people to "become independent and productive members of their society". Several websites make reference to "dignity" as something which service users have lost and which is being restored to them through rehabilitative processes. One site states that they are assisting blind people to "achieve dignity", and another states that their programmes equip blind and visually impaired people to "live dignified and productive lives". The implication is that to become blind is necessarily to lose one's dignity: that service users arrive at organisations undignified, unskilled and with no citizenship. Furthermore, it is interesting to consider how encountering a description of oneself as without dignity and therefore needing to have dignity restored through the intervention of someone else is, itself, an assault on one's dignity. Hughes (2019) speaks to this in his historical tracing of the roots of disabled indignity in the non-disabled imaginary, suggesting that the social positioning of disabled people as both "good to mistreat and good to be good to" traps them in perpetual indignity.

In critiquing the language of restoration on organisation websites I am not suggesting that loss is merely a linguistic construct (Hughes, 2005). On the contrary, I am proposing that this kind of language promotes a limited understanding of the experience of blindness, which may constrain blind persons in terms of the experiences and emotions they feel able to voice (see Chapter 6). Many service user participants described the onset of visual impairment as an experience of profound loss and a threat to their sense of belonging:

> I started thinking…okay, if my eyesight is like this…if it's this blurry and I have to be at work, I have to work…just like everyone else…I can't use glasses, no operation can be done…that was the first time I cried…because I realised if my vision is gonna remain like this I'm gonna lose my job.
> – Lifa

> [I]t was a very difficult time because I was losing my eyesight, I lost my job and my marriage was failing and so it was like everything all at once…I'm terrified that my income is going to go and I'm going to lose my eyesight and not be able to work again.
> – Nyska

It can be seen in these examples and throughout service user accounts of experiences that are often significantly traumatic, that the onset of blindness touches all spheres of an individual's life. While many of the websites do acknowledge this trauma and the onset of blindness as a profound loss, the way in which this loss is described can be problematic, supporting a view of blind persons as incapable, unfortunate and needy. Moreover, that service users report experiences of significant social and personal dislocation is not questioned within the website copy but accepted as the expected outcome of vision loss, which is thereby attributed to blindness alone. For example, there is little evidence of any interrogation of access or attitudinal barriers preventing someone like Lifa from being retained in employment. Rather, the copy includes several references to blindness as a "problem" and to organisation services as "solutions".

Across the copy, the service outcomes positioned as the end point of organisation interventions are subtly, yet consistently, shadowed by their opposites. For example, the websites present a transition from dependence, described as reliance on others and on the State, to independence, described as needing no, or very minimal, assistance, and being self-reliant or "standing alone", which is a phrase used by several service providers. In this way, dependence and independence are positioned as binary opposite concepts with little space for thinking about interdependence, the building of networks of support, or the ambiguous nature of independence generally (Else, 2001; French, 1993).

The establishment of binary start and end points for a linear rehabilitation journey emerged in all of the service provider interviews. While these data will be discussed fully in the following chapters, below are a few examples of how public face discourse is reflected in the ways in which service providers presented the work of rehabilitation and their role:

> [B]eing able to facilitate somebody engaging with their disability and finding solutions and taking them from a place often of hopelessness and despair to beginning to see the possibility of living with this condition…and then beginning to restore independence.
> – Kay

> [W]hen you can point to say, "You see this gentleman, he was like this in the beginning but look at what he is now"…it makes you feel good that at least you've done a difference in somebody's life.
> – David

> I'm very passionate about developing people and helping people on their journey…I find it very rewarding when somebody walks through our door…having had that experience of hopelessness and helplessness and then helping them on the road to their adjustment to blindness and then seeing them a year, 2 years, five years down the line…they've…had the courage to face their adversity, they've…acquired the skills to cope independently.
> – Kelly

The passive positioning of service users persists in these extracts as service providers position themselves as the facilitators of processes which transform those who have lost their sight from what they were to what they are. In these accounts independence and coping are shadowed by hopelessness and helplessness, as that which must be transformed, overcome and left behind. That these extracts indicate relationships of control and paternalism, where service providers appear to be gaining similar benefits to the public in terms of positive feelings about their roles as helpers of the helpless, will be discussed in Chapter 6.

In order to avoid a one-dimensional view of organisation services, it is crucial to be clear that the perception of service users being moved from a place of dislocation and struggle towards greater mastery and security is not irrational. In fact, several service users articulated their experiences at organisations using the same language of journey linked to self-improvement, hope and change:

> The courses that they offer make a difference in a lot of lives, then you're computer literate, you can speak in public…a lot of people who come here are changed…they are better people when they leave here.
> – Nikita

> I didn't wanna socialise anymore and I was always afraid of going out and having to depend on other people (becomes tearful) sorry…I think now, I'm not so worried…it's really brought me back to who I was before.
> – Nyska

> I managed to heal after being here…I was very impatient with everything and everybody…but when I came here, slowly, after talking to other blind people, after the adjustment group, then slowly, slowly, slowly, I can say today, I've accepted and I'm okay with what's happening to me.
> – Vusi

These service users, despite having encountered many difficulties at organisations, felt that they were not where they had started, and that they had received something of value. Nevertheless, in light of the foregoing, it remains important to interrogate the consequences of a constructed rehabilitation journey, especially with regard to the fantasies about blindness which it perpetuates. These polarised fantasies leave little space for the acknowledgement of sight loss as a complex and nuanced experience where growing mastery and ongoing struggle can coexist (Lourens, 2020; Watermeyer, 2009). An important concern is what the discourse of rehabilitation as a linear journey prohibits in terms of expressions of ongoing struggle. In other words, what silences might the service users be drawn into as a result of exposure to the discourses surrounding integration outlined above? If integration is presented as contingent upon the blind individual's portrayal of positive traits, then we must consider to what extent the service users are compelled to distance themselves from characteristics of loss and struggle, constructed in negative terms, as they acquire skills and techniques (see section 6.2.).

Throughout the copy, the figure of pre-intervention blindness is a shadowy one, lurking in what is not said, while the blind subject who demonstrates successful intervention outcomes is foregrounded. A significant way in which organisation public face material establishes and maintains the former shadowy figure is through subtle constructions of blindness as a separate world, a fearful and darkened reality against which organisation services and their promised outcomes defend. These constructions can be seen especially in descriptions of awareness activities designed to educate the public about blindness, blind people and the experience of blindness.

4.4. Constructions of Blindness as a Separate World

As mentioned above, direct appeals found on the sampled websites are either aimed at receiving donations and other forms of support from the public, or they are invitations for the public to participate in awareness activities. Across the sample there are three kinds of awareness mentioned. The first is awareness about the human rights of people with visual impairments. In this regard, four websites mention their work to advocate, lobby and promote with/to "key decision makers" for/on behalf of the blind. Once again, a result of the persistent third-person positioning of service users is that rights awareness does not seem aimed at visually impaired readers but rather towards the public, government and, occasionally, employers. Secondly, the websites include awareness about the prevention of blindness. Several sites include content about eye health, as well as phrases appealing to the reader such as "do not take your eyes for granted" or "care for your eyes". These appeals, read in contrast to the descriptions of services offered to "the blind" and couched within discourses which position these service users as passive recipients of charity, set the blind figure up as a cautionary tale. Thirdly, one of the stated goals of organisations is to raise awareness about blindness, blind people and the experience of blindness. This kind of awareness, also called sensitisation, is connected to activities such as workshops, organisation tours, talks and dinners in the dark among other things. Although the goals of these activities – to erode fear of difference and to build understanding and compassion – are laudable, the ways in which they are described on organisation websites suggest that these awareness activities build into constructions of blindness as a separate world. In other words, what I consider in this section is how these activities might be involved in strengthening, rather than disrupting, difference (Silverman, 2015).

Several websites use language which constructs a whole and then separates "the blind" out from that whole. For example: "we all struggle but for the blind…", "it's important for us all but for the blind…" and "it's important for us all and no different for the blind". Even the latter, which draws blindness into a shared need, still essentially separates it from "the rest of us". It is clear that the third-person positioning of service users influences the way this copy reads, constructing an "us" and "them" split. A further example is the communication element of much awareness training. Four websites advertise activities or include resources to teach "the sighted" about "how to communicate with the blind" by setting out certain codes for appropriate interaction. The constant juxtaposition of terms such as "the sighted/the blind", "the sighted community/the blind community" or "the sighted world/the blind world", build into the idea of a significant gap between those who can see and those who cannot, which must be carefully bridged. These communication how to guides, often featuring lists of “do’s and don’ts”, could be viewed as a stipulation of boundaries to regulate and make the presence of blind people socially tolerable. The idea that there are accepted rules and prescriptions of best practice for communicating with people who, by virtue of the perceived need for such communication guides, are deemed other, evokes something of the colonial. In particular, this is the idea that the presence of difference must be managed by all parties, following certain accepted procedures for appropriate interaction (Hook, 2012; Ravaud and Stiker, 2001). Again, the role of fantasy in shaping and underpinning these rules, as well as building into the establishment of disability or racial difference in the first place, is key (Hook, 2012; Hughes, 2019). There is also a charitable element to these awareness activity invitations. One site, for example, invites the public to “come and interact” with service users as their Mandela Day[8] service, not a natural interaction but, rather, a manufactured and limited time to engage with visually impaired people as a charitable act.

Another element of these awareness drives is blindness simulation. Four of the sampled websites advertise some form of blindness simulation, involving an activity done under blindfold. These activities are designed to allow the public a “glimpse into a blind person’s journey” or “to step into their shoes for a moment in time”. A critique of these kinds of activities was discussed in Chapter 2 (Silverman, 2015). What is interesting to note about these activities is how they offer the public an opportunity to know what it is like to be blind while, at the same time, establishing blindness as utterly unknowable. The below quote from a service provider is helpful in explaining this:

> I thought I knew until I really attended the dinner in the dark…everything was pitch dark and I said I’ll never ever again pretend that I know, I know nothing…but that even…drive me…on to try and do something that can make it better, not better just improve, add value…that’s my calling.
> – Mia

Although Mia claims to “know nothing”, what she does know is the “pitch dark” she experienced during this simulation. This, we must assume, has played some role in shaping her understanding of the experience of blindness and her role as a service provider. Her experience of this simulation appears to have built into a fantasy of blindness as darkness, and as something that must be made better. However, as “make better” becomes “add value”, there is a glimmer of the uncomfortable reality of the permanence of blindness – that there is no actual solution to the “pitch dark”. The “glimpses” offered by blindness simulations are into a darkened world, confirming what many participants probably suspect about blindness in the first place. It is the “moment in time” quality of simulations that leaves participants with the sense of blindness as an unknowable reality (Silverman, 2015). Put another way, as the fantasy of a dark world is confirmed, what remains unknown is how this reality is bearable for those who must live in it (Paterson, 2013). It is in contrast to this fearful fantasy of darkness that organisations present the public with the figure of the independent,

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[8] Mandela Day is an international commemoration of the life and service of Nelson Mandela observed annually on the 18th of June. On this day people are encouraged to spend 67 minutes serving their community in some way.

productive, active and coping blind recipient of services. What the accounts of many service users in this study suggest, however, is that this ideal blind subject is also a fantasmatic figure – a promise held out to the public of the problem of blindness solved (see sections 6.3.2. and 6.4.). Blindness simulations are often advertised as fun and social experiences which, in light of the profound fear, trauma and loss described by those who have experienced sight loss, seems somewhat inappropriate. Sites also describe these simulations as transformative, life-changing and “eye opening”. The latter is an example of a particular kind of wordplay which uses sight and vision as metaphors. This is present across the sampled copy.

A final finding from the website review with regard to constructing blindness as a separate world is the metaphorical use of the concepts of sight and blindness. This feeds into another blindness fantasy linked to knowledge and spirituality (Barasch, 2001; Hughes, 2019; Scott, 1969). One website, for example, opens with the quote, “No one is as blind as those who refuse to see”. This removes sight from the body and makes it a spiritual quality which, this quotation seems to imply, is more attainable by blind people who have had their physical sight removed. Hughes (2019) explores the contradictions in how blindness is positioned in the non-disabled imaginary as a fate worse than death, signifying a lack of morality and wisdom on the one hand and as allowing for the possession of special prophetic abilities on the other. The latter, embodied in the (often mythical) figure of the ‘blind-seer’, Hughes calls the “original super-crip”. However, this figure is not redeemed, as a seer without light she remains trapped in symbolic and real invalidation and indignity (Hughes, 2019).On the websites sight is also used as a metaphor for knowledge, ambition and the drive to succeed. Many sites use the well-known Helen Keller quotation, “Knowledge is love and light and vision”, a wordplay offering the promise that knowledge can penetrate the darkened world of the blind and restore something of what has been lost. This returns us to the role of restoration claimed by organisations. The promise of restoration, not of physical sight but of knowledge, is a means through which organisations can assure the public that, despite its permanence, something is being done to address the problem of blindness. In closing this section I quote from Scott (1969), who offers this strikingly resonant description of a socially constructed “blind world” – a separate and darkened world against which we must all defend:

> It is supposed that the blind dwell in a world that is apart from and beyond the one ordinary men [sic] inhabit. This world, which is believed to be less gross and materialistic than our own, is said to be infused with a spirituality that gives its inhabitants a peculiar purity and innocence of mind…At the same time, this world is thought to be filled with melancholy; expressions of playfulness and humour are out of keeping…The blind are assumed to be frustrated, cursing their darkness as they reflect back to the days when they could see (Scott, 1969: 4).

Conclusion

The review of organisation websites revealed that, throughout this public facing material, visually impaired service users are spoken about in the third person, and are passively positioned in relation to the work of organisations and the goodwill of the public. A key question in relation to these findings is what encountering this material might communicate, both to the public and visually impaired persons, about the experience of blindness and the expected roles, capabilities and status of blind persons. We have seen how, within a constructed alliance between organisation workers and the public, blindness emerges as a problem, as well as an object of professional knowledge (Sullivan, 2005; Tremain, 2005; Yates, 2005). This can be seen in descriptions of “solutions” to the problem of blindness. This material establishes organisations as the experts who know what blind persons need, and presents a view of blind persons as unable to take charge of their own lives. As Drake (1996) suggests, this has real world implications for visually impaired persons, who may not be recognised as capable of full citizenship.

The findings presented here reveal an interplay of discourse, fantasy and relationships of power surrounding engagements between organisations and the public, the public and visually impaired service users, and organisations and service users. By drawing on some interview data in this chapter, I have already begun to show how this public realm discursive activity is enacted in organisation operations and relationships between service providers and service users. The following chapters expand on this, asking what might be imparted to blind service users, beyond the practical, as they undergo rehabilitative processes. Before turning to this question, however, it is important for us to understand something about the experiences of those who approach organisations for assistance. These experiences can be obscured by discourse which constructs a simplistic link between blindness and loss, drawing those who have experienced sight loss into a set, linear and largely practical process of restoration. Consequently, what we might miss are the particular predicaments of individual people who are experiencing the trauma of sight loss, including such experiences as a lack of understanding from medical professionals, family and/or employers, fear of the future, and a series of assaults on the self. Apprehending this layer of experience is, I suggest, an important starting point for understanding what service users bring to rehabilitation services, in particular, involving their vulnerability to being told who they are and what their place in the world is now that they are blind.

CHAPTER 5

EXPLORING WHAT SERVICE USERS BRING TO REHABILITATION

[Y]ou sit there and you be blind, that's what your life is gonna be like now

– Pumla

In this chapter I begin the discussion of findings from Phase Two, in which I conducted semi-structured interviews with eight service providers and eighteen service users across four organisations operating in the Western Cape. Before turning to a discussion of rehabilitative processes and relationships in the following chapters, this chapter considers who is coming through the doors of rehabilitation organisations – what they have been through, and what emotional state and subjective position they are in.

The majority of service users in this study became visually impaired later in life. Each participant shared their own unique story about the onset of their visual impairment. However, the particular predicaments described by each participant were about far more than the loss of their sight. Participants described experiences of significant dislocation from society and self, and having to negotiate a new social and personal reality. Exploring these experiences is important for two reasons. Firstly, it is necessary in order for us to apprehend a layer of experience that might otherwise be overlooked within the largely practical concerns of rehabilitation, as crucial as these are. The accounts of service users present a complex picture of sight loss, disrupting the discourses broadcast by organisations through their public facing material. We have seen that this material attributes loss, difficulty and dislocation to visual impairment alone and constructs blindness as a problem that is able to be solved by the fixed, linear, predictable and practical solutions of organisation services. In contrast, service user accounts offer us much-needed insight into an internal negotiation – the sense making which those who lose their sight must do against the backdrop of discursive practices and fantasies which shape ideas about blindness, what blind people need, what they are capable of, what they can be, and how they should behave.

Secondly, beginning this discussion by focusing on the voices of service users, hearing their experiences of sight loss, dislocation and struggle, allows us to view organisation services as part of a broader picture. Considering what those who experience sight loss have been through prior to entering rehabilitation prompts questions about how organisation services are implemented, how service users are engaged with, what is being offered, what elements are helpful, and what people might need in addition or instead.

This chapter includes four sections. Firstly, I consider the experiences of medicine and engagement with medical professionals described by visually impaired participants. I discuss the impact of these experiences on how those with newly discovered visual impairments begin to make sense, not only of their situations, but of themselves. Secondly, I consider the series of assaults on the self which many participants described. I discuss how socially entrenched discourses and fantasies about blindness begin to shape an understanding, in those who lose their sight, that they are no longer who they once were. Thirdly, I discuss the experiences of fear and social anxiety reported by several participants, and consider how these contribute to feelings of dislocation. Finally, I consider how participants experienced entering rehabilitation services. I discuss how, alongside positive experiences, many participants described rehabilitation, and especially the taking on of assistive devices, as a further assault on the self, and part of a process of 'being made into a blind person' (Scott, 1969; Sullivan, 2005; Tremain, 2017). I suggest that service users might be particularly vulnerable to the influence of authoritative voices on how best to manage the effects of sight loss, given their experiences of dislocation and exclusion.

5.1. Experiences with Medicine and Medical Professionals

Some stories of sight loss begin with a slow, troubling realisation that something is physically not quite right, while others are sudden and traumatic. Both lead to engagement with medical professionals as answers, diagnoses and treatments are sought. In this regard, participants described processes that were often lengthy, frustrating, stressful and frightening, involving multiple appointments, referrals, tests and operations, not to mention the discomfort, pain and anxiety caused by their physical symptoms. These experiences were shared across socio-economic circumstances, by participants from various backgrounds, using both private and public healthcare. However, it was clear that for those participants from disadvantaged circumstances, the material consequences of sight loss were considerably more dire in terms of loss of income, lack of family support and access to resources. Below are three extracts which exemplify the experiences shared by many participants in terms of onset, discovery and diagnosis of visual impairment:

> It was quite frightening…no one could tell me what it was, even specialists finally couldn't…I didn't know what symptoms I was going to get…so it's the unknown…Which is more frightening than anything…and…having to explain to people all the time, you can't see…being dependent…I'd been independent all my life, I'd been a businesswoman…and I just had to give everything up…it was hard

> and everybody used to phone me and say, “What’s wrong?”…and you can’t explain…and you feel quite desperate.
> – Kathryn

> I went to the doctors. They do all the tests…everything was normal…Then I was so frustrated, I was so depressed because the headache was very, very bad…Then I become blind, just suddenly, blind on my right eye. Then I was stressed again and I went to…eye doctors and even specialist…but they didn’t recognise what was happening in me…then…I became partially blind on my left one…then I decided to quit [my job]…because I was not coping at all…then I decided to just sit at home, frustrated, depressed.
> – Nohombile

> I started thinking…okay, if my eyesight is like this…if it’s this blurry and I have to be at work, I have to work…just like everyone else…I can’t use glasses, no operation can be done…that was the first time I cried…because I realised if my vision is gonna remain like this I’m gonna lose my job…when I said that to the doctor…she didn’t even want to comment…I’m sure she knew or she didn’t want to promise something that is not there.
> – Lifa

What we see in these extracts are individuals experiencing displacement: from work, from community and from self, and who, as a result, are having to make sense, not only of their physical symptoms, but of what sight loss will mean for their identity and place in the world. For Kathryn and Nohombile, the inability of medicine to provide satisfactory explanations for what they are experiencing in their bodies, besides being hugely anxiety provoking, indicates that they are undergoing something life altering, that their lives will be fundamentally different from now on. In these accounts, medicine offers no assurance that there may still be possibilities for retaining capability, participation and employment. As a result, Kathryn, Nohombile and Lifa give up their work – a traumatic experience for all of them. In these extracts there is a sense that life as it was has been interrupted and that these participants are unsure how to move forward. Later in her interview Nohombile expressed this by saying:“ I don’t want to be stuck”. There is also something more subtle expressed in these accounts concerning loss of control. For these participants and others, experiences with medicine conveyed the understanding that their choices had become limited, that they were no longer in charge of their own destinies, as Kathryn said:“ I just had to give everything up”. In these accounts we begin to see the significant role of medical professionals in signalling to individuals that they are no longer who they once were, that sight loss has caused a fundamental change at the level of identity.

Medicine and medical professionals are, I suggest, hugely influential at this traumatic time of physical and emotional upheaval. Michalko (1998) speaks to this when he asserts that the medical diagnosis of visual impairment is a formative voice in the experience of those who lose their sight. He suggests that this voice, as well as the voice of rehabilitation, reverberates continuously and has a significant and long-term impact on individuals. He says:

> My infancy, childhood, and adolescence are not over merely because I have already lived through them. Instead, living through them means that they are with me forever. My discovery of blindness, the diagnosis of my blindness, my adolescent blindness, and the rehabilitation of my blindness are with me forever and are voices that I continuously hear (Michalko, 1998: 157).

What this suggests is a complex picture: an interplay of experiences and relationships, underpinned by discourse, through which visually impaired people must navigate and against which they must shape an understanding of who they are – who blindness has made them. I suggest that, for many of the participants in this study, it was the silent response of medical practitioners which began to shape an understanding that they had become not only a medical, but a social problem. I use the term ‘medical silence’ to refer to the fact that many participants reported receiving little information, assurance or advice from medical professionals, either about their physical symptoms or the available rehabilitation services. Rather, the often aversive behaviour of medical professionals signalled to individuals that they had lost something more than their sight – that their place in the world was no longer secure.

According to Michalko (1998: 65–66), there are certain questions that medicine is not able to answer, which render medicine silent. Lifa’s question about losing her job is one such question. This question cannot be answered medically; it must be referred to rehabilitation. The process of referral, suggests Michalko (1998: 54–55), holds meaning for those being referred. This process communicates to individuals that there is nothing medically to be done, that the restoration of sight is not possible and that one is, at least in medical terms, a hopeless case. What is left, Michalko (1998: 77) asserts, is the hope of restoration, not of sight, but a “closeness to sight”. However, what he assumes in this description of a handing over from the medical to the rehabilitative voice, writing from a Northern context, is a clear, accepted and functioning system of referral, which was not the case for many participants in this study. While some participants did describe a clear process of referral, from hospital to rehabilitation services at NPOs, most were not directly referred and reported receiving little information or support from ophthalmologists or other medical professionals about how to move forward. Below are two examples of participants who described having to search for available services:

> [A]fter staying home for six or seven months, literally doing nothing…one evening I called into a radio station…I asked if there’s anybody who’s listening to the radio who might know a place where I can be trained as a blind person so that I can continue to…live life and at the same time manage to be productive again.
> – Vusi

> because I wanted to become Braille literate and how do you do that? Where do you do that? So [organisation] was the only place we could find…we did research and had to find them.
> – Belinda

It is clear that both Vusi and Belinda wanted to gain the necessary skills for adapting to blindness in order to move forward in their lives. In this they are not exceptions. However, Belinda has the support of her family, the "we" she refers to, who assisted her to find appropriate services, while Vusi displayed a rare boldness in contacting a local radio station for assistance. Not all service users had access to networks of support or possessed the assertiveness displayed by Vusi.

In the extracts cited earlier, we begin to see the impact of a lack of referral as individuals are told by medicine that they are no longer who they once were, and that their lives will be fundamentally different from now on, before being set adrift into the unknown. Kathryn must "give everything up", Nohombile is given no indication that she has any other option than "to sit at home", and Lifa's doctor greets her anxiety with ominous silence. In many other cases, lack of referral resulted in individuals enduring lengthy periods of isolation, exclusion and emotional turmoil:

> I withdrew from public life to a large degree because I was comfortable at home, I didn't have to go out there so…my life became…protected in a way, which I don't think was altogether a good thing.
> – Lilla

> [F]or ten years I sat at home and cried, cried every day, I went nowhere for ten years.
> – Nikita

> I've become so closed off…I didn't wanna socialise anymore and I was always afraid of going out and having to depend on other people.
> – Nyska

> I withdraw myself from the outside world…I would say I was very unhappy.
> – Mike

The above-cited individuals describe having lost their sense of belonging; they have been displaced from the community. Lilla is to some extent an exception as she was offered the opportunity to be boarded with a pension. While she and a few other participants who had been medically boarded enjoyed greater financial security, they described feeling excluded, isolated and depressed in much the same way as those who had left employment with no compensation. Nikita uses the phrase "sat at home", which is one that can be seen throughout the service user data. This phrase powerfully captures the inaction, tedium and hopelessness experienced by many service users who found themselves, once diagnosis had been confirmed, feeling dismissed by both medicine and society.

From the above discussion it is clear that there are serious systemic problems influencing how those who lose their vision come to understand their situation, that is, what visual impairment means for their capabilities, their future prospects and their status. It is beyond the scope of this study to go into an in-depth discussion here. However, it is notable that some medical professionals appear to operate within a framework of problematic discourses which connect sight loss with incapability, dependency and lack. From the above extracts, there is much to consider about how, having experienced being dismissed by medicine and set adrift into a new reality of dislocation and insecurity, the participants in this study appear to have experienced significant trauma. Under such circumstances they are likely to be desperate for answers to such questions as: How do I move forward in my life? What am I capable of? (and most importantly) Who am I now?

5.2. A Series of Assaults on the Self

I suggest that the accounts of those who have experienced sight loss describe a series of assaults on the self, consisting of the various ways in which they are told that they are no longer who they once were. As shown above, especially for those who experienced sight loss later in life, engagements with medicine and medical professionals were often the beginning of these. Participants described becoming patients and then, when the permanence of visual impairment was confirmed, being dismissed by medicine and having from there to navigate loss of sight, independence, capability, employment and status. While the signalling of medical professionals has a profound impact on the sense making of those experiencing sight loss, it is not the only source of messaging about blindness which individuals are exposed to.

We must recognise that those who lose their vision have, throughout their lives before sight loss, been exposed to a variety of discourses which shape accepted knowledge and inform fantasies about blindness and the experience of blindness (Scott, 1969). Individuals must, therefore, make sense of their visual impairments against a backdrop of socially entrenched knowledge about what the experience of blindness is like, how blind people behave and what blind people are able to do and to be. Below are two examples of the kinds of anxious fantasies expressed by many participants about what the rest of their lives would be like:

> I keep on worrying about that, what am I going to do, I can’t sit and knit squares and dish cloths for the rest of my life, I might have another twenty years ahead of me…I really don’t want to sit up in a chair…in a corner…and just sit and knit squares, that would drive me insane.
> – Henrietta

> I thought you just sit there, you don’t make your own coffee, you don’t make your own tea, you sit there and you be blind, that’s what your life is gonna be like now.

> – Pumla

Henrietta imagines a future of inaction, of sitting in a corner and adding no value to the community. She also uses the language of “sitting at home”, and expresses the anxiety that blindness will obscure her value and all the things she has to offer. Pumla’s extract, which I have used to head this chapter, suggests that, in her life before blindness, she had some knowledge about what it is to be blind. This knowledge informs her fantasy of what the rest of her life will be like. The finality of the phrase “that’s what your life is gonna be like now” is striking. Her internal voice, influenced by the external voices of, we can assume, medicine, media, culture and community, tells her who she is now and, having experienced the trauma of dislocation, she is open to internalise this messaging. These participants paint a picture of rejection and loss of control as they imagine themselves “sitting there”, unable to contribute, to move through the world or to take action to meet their own needs. Of course, it is vital to acknowledge that these participants are describing anxious fantasies that are very real possibilities, as shown by Nikita, who “sat at home” for ten years.

Unemployment was experienced by all of the interviewed participants. As shown in the previous section, individuals were seldom referred to organisations who might assist them to retain employment and were offered little indication that continuing in work was possible. Consequently, the majority felt forced to resign from their jobs, while a privileged few were medically boarded. Loss of employment was foregrounded in many participant accounts as a significant trauma, having a profound effect on physical and emotional well-being as well as status in the community. For most participants, work was an important factor in being viewed as an independent, capable, active and contributing person. This has to do not only with loss of income but also the bound up nature of work and identity: that what one does is a crucial part of who one is. We saw above, in Kathryn’s account, that in having to stop working, she was losing part of her identity as a businesswoman. Similarly, Amy explained how she had to become accustomed to needing and receiving help, and that she found this particularly difficult as someone who had worked for many years as a health professional:

> I spent all my life helping people to be independent, that’s the whole goal and purpose of physiotherapy…And so for me to realise that I was now so dependent myself was quite a crisis.
> – Amy

Elsewhere in her interview, Amy referred to her accessing of assistive services as “having made the hurdle” into becoming a receiver of help. Although she described this as a largely positive experience, it involved crossing a threshold into a new reality where, instead of helping people to be independent, she is dependent on the help of others. In these extracts, there is a sense that something of her identity was lost through this process.

It seems that for many participants, their experiences with employers, as with medical professionals, are significant in signalling to them that they no longer have a place in productive society, that they have no value to add. Below are two examples of this:

> [I]t just so happened that the company I worked for merged with another company and of course a 58 year old woman with a visual problem, you're not really…there's so many others, so I just packed it in.
> – Henrietta

> I was job hunting and then I felt like, okay, I can do nothing, I can't work.
> – Melissa

Like Kathryn, Henrietta has to "give everything up" and make sense of who she is now, framed by the anxiety that she expressed earlier, that she will end up discarded in the corner knitting squares. In her extract we can also see the intersection of blindness and age, which are both subject to discourses that position individuals as inactive and unable to contribute meaningfully (see section 6.3.). Melissa, like Pumla and many others, comes to the realisation that she "can do nothing" through the experience of being rejected by various employers after her vision loss. In these extracts we see a further way in which those who lose their sight are dislocated from their place in the world and given negative messages about their value. It is no wonder, then, that many participants described feelings of fear, anxiety and uncertainty, as well as of being misunderstood by society, their families and communities.

5.3. Fear and Feeling Misunderstood

For many participants, the onset of blindness, and the instability of their visual conditions, was a cause of profound anxiety:

> [T]he thought of going completely blind scares me every day…I don't know how I would handle it…when you've had your eyesight and then you lose it, it's very difficult to make that adjustment and so, for me, I find it very heartsore.
> – Nyska

> I'm still difficult to accept the fact that I'm going to be blind one day, it's scary not knowing when.
> – Mike

There are imaginings here: What will it be like if and when I lose my remaining sight? What will blindness mean for my future prospects? These imaginings are connected to very real possibilities for these participants: the possibility of further sight loss, the possibility of unemployment, loss of income and of facing an isolated future. Participants expressed the fear of physical sight loss, but also anxiety connected to the knowledge that society is inaccessible, dismissive of and prejudiced towards those with visual impairments and, indeed, disabilities generally.

Several participants expressed anxiety about being in society and interacting with people who might not understand them or their needs. For example, Monique, who had attended a special school, shared that she was afraid to go to university:

> I was scared to go to university after matric[9] last year…I never went out from [home] before…so I thought, okay, let me go to [organisation] and it's blind friendly so why not?
> – Monique

Monique had been accepted to study at university but chose instead to do a year-long programme at an organisation offering development services for people with visual impairments because she was afraid to move away from spaces that were "blind friendly". Later in her interview she said that she mostly regretted this decision. Like Monique, several participants drew a distinction between spaces that were accepting, understanding, safe, or "blind friendly", and a hostile, inaccessible and unsympathetic outside world where they felt out of place.

Many participants shared experiences of feeling misunderstood by society, and also in their families and immediate communities. These were related to their physical circumstances and, in particular, what they were able or unable to see, what their needs were and how they could be assisted. Participants also experienced a lack of empathy for what they were experiencing on an emotional level. In essence, there was a sense that: "My family, my friends and my community do not know what it is like for me". Resonating with French (2004), Kleege (1998) and Kuusisto (1998), several participants shared how they felt compelled to maintain a certain performance. They also described struggling to make their experience understood, and how they were regularly misread by those around them:

> [I]t's difficult to be with sighted people because they don't quite accept you…The amount of times I get asked, "How much can you see? Can you see that over there? Can you see this? Can you see?" (laughs). You feel like faking it too: "Yes, I can see that, that's beautiful".
> – Henrietta

> It's very tough…because people, they don't understand if ever you've got a problem of eyes. Sometimes you don't greet them because you don't see them. They think maybe now you are so proud and arrogant…and then it's not easy…to explain myself to everybody that I've got problems of eyes.

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[9] Matric refers to the final year of schooling in South Africa.

> – Aubrey

Henrietta’s description of a desperation within others for her to see is reminiscent of French’s (2004) description of how she felt compelled to comfort those around her by denying disability and performing sight. Elsewhere in her interview, Henrietta said: “My husband has not the foggiest idea of what I can see and what I can’t see”, indicating that even in her closest relationships she finds no understanding for what she is experiencing. Similarly, Aubrey feels pressure to be seen in a certain way. Across the interview data, visually impaired participants described the difficulty of negotiating blindness stereotypes, which produce a simplistic understanding of blindness as complete loss of vision – that is, darkness (Paterson, 2013; Silverman, 2015). Therefore, Aubrey and others present the world with something difficult to categorise and make sense of – a blind person who can see. These participants must navigate this space, following social convention as much as possible, constantly at risk of being misinterpreted as rude or arrogant, and consistently having to claim and reclaim their place in the world.

5.4. Entering Rehabilitation Services

In light of the discussion so far, it is no wonder that the discovery of assistance was, for most participants, hugely significant. On entering organisation services many participants felt relief at being understood by both service providers and a community of visually impaired people. For many, entering rehabilitation restored some sense of belonging, signalling that they had found their place and were, at last, to be offered answers, guidance and the opportunity to gain greater mastery over their lives:

> I went nowhere for ten years before I went to [organisation]…that was a nice experience for me and it was a journey because now I can be amongst people who have the same problem as me, I can talk about it.
> – Nikita

> It was very nice because [service provider] understood what was wrong with me from the beginning and…she would explain it…she is extremely understanding.
> – Kathryn

> [T]hey don’t look at you differently; they treat you as normal. I’m a very shy person and when I came here I really opened up.
> – Mike

> I promise you, when they taught me how to make my first cup of coffee I came home and I was just so ecstatically happy about it.
> – Pumla

Nikita is able to leave her home and interact with a community of people who can relate to her experience. Significantly, she is able to talk to others about her problem, a contrast to the isolated image of her sitting at home and crying we saw earlier. Kathryn, who described the burden of constantly having to explain herself, finds that a service provider understands her and will explain her situation to others on her behalf. Mike, who withdrew himself from the outside world, finds a safe space where he feels understood and where he is not treated differently. Pumla, who imagined a life of dependency and inaction, is taught how to make her own coffee, signalling that she is not doomed to the life of "sitting there and being blind" she had imagined. These are just a few extracts among many service user accounts detailing positive experiences of entering rehabilitation services.

For many participants, a key benefit was becoming part of a community of service users at organisations, feeling connected and understood by others who could relate to what they were going through:

> [I]t's nice to know that there are other people out there with problems…otherwise I think I would feel very alone, really very alone…it's nice to go there and just relax and know that other people are also not going to be able to see the biscuits coming down the table…if you sit in a group of sighted people they just expect everybody to see.
> – Henrietta

> We communicate with one another, black, white, pink, blue…we chat with one another, make friends, greet each other, you're happy to see each other every day. If I'm away for two days they ask, "Where were you?"…They support each other very well.
> – Nikita

> [W]e understand each other. We've been through a lot in terms of being blind and…we lived in different communities so people have their own thoughts and own ideas about blindness.
> – Monique

These extracts describe connection, comfort and care – things that individuals failed to receive from medical professionals, employers and their communities. Henrietta describes the comfort of not having to perform sight, and of having her needs understood and recognised, which is a contrast to her earlier cited extract. Interestingly, Nikita's extract stresses the fact that the friendships she has built are with people from all races. This was a factor mentioned by some participants, that blindness and services at organisations had brought them into contact with people they might not otherwise interact with. Monique also describes a diverse community of service users. For her, this community is involved in supporting each other in the face of the ideas about blindness they have been exposed to in their various communities.

However, several service users described entering rehabilitation services as a difficult process and a further assault on the self. For some, coming to rehabilitation organisations compounded their sense of displacement. Several participants expressed reluctance to be associated with blindness. This is not surprising given the negative signalling about the place, status and worth of blind people which many were exposed to:

> [I]n my normal life I'm not with visually handicapped people so it's an opportunity to see how others are doing, share my issues.
> – Lilla

> I've seen…the visually impaired or blind people walking about and I didn't want to be seen as being blind. But…after a while, I discovered that, look, I actually need help to adjust to the new way of living…but I also refused coming here [to organisation] simply for the fact that I didn't want to be known or seen as a blind person.
> – John

Lilla draws a distinction between the services she attends and her "normal life" as well as between herself and "visually handicapped people". In this way it appears that Lilla is defending against being "seen or known as a blind person", as John put it. Similarly, John expressed a kind of instinctive knowledge that blindness was something he must separate himself from. He understands something about what it would mean for him to be seen as blind because he has been an observer of blind people himself (Scott, 1969). In his account we can see the operation of surveillance, which is a key instrument of bio-power (Tremain, 2017). On entering rehabilitation John was no longer able to evaluate himself as separate from "the blind or visually impaired people". Instead, he became subject to the gaze of sighted persons, an other against which their social acceptability could be measured and affirmed (Hughes, 2019; Tremain, 2017). John must assume that whatever thoughts he had at seeing "the blind people walking about" are now the thoughts of others who see him as one of those blind people. His account suggests that, in accepting the assistance of rehabilitation services, he is, in a sense, becoming a blind person. Tremain (2017) draws a distinction between 'having 'an impairment or disability and 'being made 'impaired or disabled – a distinction which John's account speaks to. She asserts that subjects are "made disabled and impaired through innumerable elements of the apparatus of disability, including an accelerating array of social policies, administrative decisions, medical and scientific classifications and examinations, techniques of surveillance and registration, cultural representations, aesthetic practices, and academic research" (2017: 128).

A hierarchy of impairment, capability and need appears to exist within the rehabilitation organisations in this study. This was demonstrated in that several participants, especially those with some residual vision, presented clear boundaries between themselves and other service users who they positioned as more severely impaired, less capable and/or worse off:

> [O]thers are totally blind, others are partially sighted and, again, I told myself, you know what, I'm better than them so at least I must help them.
> – Nohombile

> It was exciting to see so many people who I'm sharing the disability with and that's when I realised that my problem, it's not that big when I look at other people because I can be able to walk by myself. I do whatever that I want to do.
> – Lifa

> I would wait…for the…clients…collect them out the van, take them to their class, I collect them at the entrance door.
> – Mike

> I had to get used to people not being able to see, where you have to help someone…the adjustment to help people find their way even though I get lost and you will get lost with me, but then what was nice was they would explain to me, "We have to turn left here, and we have to turn right there"…so the adjustment was to just help, help them where you can.
> – Melissa

Through comparison, Lifa is able to establish herself more favourably along a spectrum of capability. In a similar way to Lilla, it appears that this allows her to remain somewhat separated from those who she deems to be less capable than she is. From these extracts, we can see that another way in which service users might gain a more favourable position within the hierarchy of impairment is through taking on a helping role. Notably, these participants use the third person to describe service users with more severe visual impairments in the same way as the organisation public facing material discussed earlier. These participants appear to enact the "normalising operations" identified by Tremain (2017: 82). She identifies comparison, differentiation, hierarchy, homogeneity and exclusion as key aspects of the disciplinary force of normalisation, and as the instruments through which difference is made known (Tremain, 2017: 83). Therefore, I suggest that in presenting such comparisons the above service users are involved in efforts to separate themselves from the difference of blindness and resist being objectified as blind (Tremain, 2017). In other words, these comparisons, a phenomenon found in subordinated groups, protect the self from negative discourses and fantasies, and allow individuals to maintain some status and sense of place through the maintenance of an other, in this case a blind person who lacks certain capabilities. I expand on this discussion in the following chapter (see section 6.3.1.).

5.4.1. Rehabilitation as a further assault on the self

Across the service user data there is a sense that entering rehabilitation had an impact at the level of identity. In particular, participants described the taking on of visible assistive and mobility devices as an experience of being made into a blind person, resonating with the work of Sullivan (2005). Nikita, for example, described the very negative experience of being given her first cane after being discharged from hospital. Like so many participants, she felt that medicine had dismissed her, sending her on her way with nothing but a marker of the kind of person she had become. Neither her nor her young son, also affected by this experience, were offered any further information or support:

> Now, that was not nice for me because the first time that I got the stick at Tygerberg hospital…now they gave me this stick, now I must walk with this stick but they didn't give me training, just the stick…and now we had to walk from Tygerberg hospital to Tygerberg station with this but, when we go out, my son take it from my hand, he said, "No!" (gestures) And…when we get at home, I'm looking for the stick, it was gone…it was the first experience…the children was young, maybe they break it or something like that.
> – Nikita

The transcript does not do justice to the way in which Nikita expressed her son's visceral reaction to the cane. When telling this story she gestured violently to suggest that he had taken it from her with some force. Young as he was at the time, her son seemed to have recognised that the cane was a marker of something negative, something that he did not want his mother to be seen to embody. There is so much fear, anger and shame held in this account, emotions which both Nikita and her son were left to deal with completely unsupported. One wonders what actually happened to that first cane. As in Pumla's account, the phrase "now I must walk with this stick" expresses something about the profound change being experienced by Nikita: now you are blind, now you must sit there, now you must walk with this stick, now this is how your life is going to be, now this is who you are. Like in John's account, the reality of her vision loss and the receipt of the cane seem closely connected for Nikita, as though in holding the cane she has become blind. In fact, elsewhere in her interview she said: "Now you feel like a blind person because you have a white stick in your hand." This is reminiscent of the participant in Sullivan's research who said: "It's like they are trying to turn you into a cripple" (2005: 40).

Several participants expressed similar feelings about assistive devices, and especially the white cane – that in submitting to the use of visible mobility and assistive devices, something about who they are was being irrevocably changed. Consequently, many participants were reluctant to use mobility aids at all. What the below extracts show is that the taking on of techniques and devices for adjustment to blindness is not a simple matter of discovering a fitting solution to the problems of sight loss, as organisation public facing material suggests. Rather, it is a complicated negotiation of a new reality including the need to defend against negative discourses and fantasies about blindness, as well as having to make sense of who one is becoming:

> I can’t…imagine myself with a cane…other than a hiking cane…but I guess if I knew I needed it I wouldn’t hesitate but then, when do you know that you need it?…do you have to have a terrible fall into the traffic or have a near miss?
> – Amy

> I can’t use that because I’m not accepting it yet so I think…I must go to the doctor then if…there is nothing or they are not helping me then maybe I will accept and I will…use a cane.
> – Nohombile

> I would not walk with a cane…because I’m still very shy or scared of what people think or say or even do…I don’t go out much, that’s because I don’t feel comfortable going out, I feel more comfortable at home.
> – Mike

As with Henrietta and Pumla, imagining what their futures are going to be like now that they are blind, these extracts are thick with imaginings about what being marked as blind will signal. In Amy’s words “I can’t imagine myself with a cane” there is a suggestion that she, in fact, has imagined herself with a cane. In her view, a hiking cane is an acceptable form of support, the kind used by many people who, like Amy, hike with their husbands. A white cane, however, is imbued with fantasies of the darkened world of blindness. In light of these fantasies, Amy is, unsurprisingly, unable to imagine herself as the kind of person who would use a cane – a blind person. Mike, like many other participants, is keenly aware of the gaze of others and imagines what they might think or say or do once they recognise him as a visually impaired person. Elsewhere, he explained a particular predicament which he faces as someone with partial sight. Using a cane, he asserted, could, through communicating the message that he is visually impaired, gain him access to assistance and cause people to be more patient and understanding. On the other hand, because he does not present an easily identifiable image of blindness, the use of a cane could cause people to doubt the legitimacy of his impairment. Many participants had some level of remaining vision and were unclear about whether, and to what extent, they needed particular visual aids or techniques – as Amy asked: “When do you know that you need it?” This is an issue that I will return to in the following chapter in the context of considering how organisations implement interventions (see section 6.4.2.).

With regard to the above extracts, there is also something to be said about acceptance. For Nohombile, the use of a white cane will mean that she has accepted that nothing else can be done to restore her sight, that she is now a visually impaired person. Acceptance is an important concept in rehabilitation; it is viewed as the emotional companion to the practical techniques, skills and tools of adjustment to blindness. The service provider data, discussed in the following chapter, shows how practical coping and acceptance are thought to exist in a virtuous circle as follows: A service user who receives the appropriate practical rehabilitation services will, service providers suggest, accept their blindness and be able to “get on” with life; as a service user accepts that they need assistance, they will become more open to the practical interventions offered by organisations. This will be discussed in more detail in the following chapter (see section 6.3.). For now it is important to flag something which the above service user extracts reveal. This formula, which connects practical coping and acceptance, appears to overlook the complicated negotiations of self and place which service users are involved in, and the ways in which the imagining and actual usage of assistive devices can feel like an assault on the self. Nohombile has been undergoing a rehabilitation programme for a year, her problem has been dismissed by medicine as insoluble, and yet she has not come to the expected place of acceptance. Similarly, Nikita described an ongoing process of adjustment which was consistently difficult for her:

> For me, it's like I'm still a sighted person. I still walk and talk like a sighted person it's just that I can't see and I'm dependent on other people's help every day… And it's so hard but I try to adjust every day, the adjustment is still happening but every day I learn to adjust and to do what the blind do.
> – Nikita

At the time of this interview, Nikita had been blind for more than twenty years and had been involved in various rehabilitation and development programmes for more than ten years. And yet, in her words she draws a clear distinction between herself and "the blind". She recognises that there are specific things that blind people do which she is still learning how to do. Therefore, her statement disrupts the virtuous circle described above in that, despite her long-term involvement with rehabilitation services, Nikita does not identify herself as a blind person, and the things of blindness still feel uncomfortable for her. The service providers in this study view so-called resistance as part of a linear process of grief which the majority of service users will begin to recover from when they realise that there are solutions available for the problems of their blindness (see section 6.3.). As a result, ongoing resistance is somewhat baffling for service providers. I suggest that what is overlooked in this construction of the rehabilitation process is the complex internal negotiation which service users, like Nikita, are involved in.

More than this, I suggest that service users are also constantly having to defend against the real possibility of returning to spaces of inaction, isolation and exclusion experienced by many before coming to rehabilitation services. Before coming to rehabilitation, Nikita spent ten years in a state of profound depression, isolated and excluded from the world. Her account prompts us to consider how, in light of difficult experiences, those who experience sight loss might be particularly open to being told who they are and how they should behave in order to regain some sense of belonging and defend themselves from the risk of returning to a place of dislocation. I suggest that experiences of inaction, isolation and exclusion persistently haunt service users and have an impact on their engagement with rehabilitation services. The below extracts, where several service users express their disappointment in the services they received, are examples of this:

> I was so excited…to come to [organisation]…because I was bored, I was so bored to stay at home…but as the time goes on, that's whereby the problem starts…I noticed, no…this is not what I've applied

> for…but they explained to me…that you are not going to do the computer only here, you're gonna start with Life Skills and do all those courses.
> – Aubrey

> I was disappointed…but I didn't want to go back home and…do nothing so, okay, let me do it.
> – Monique

> Initially, I was expecting for a little bit more of a better qualification from the brochure that I received…but…the thing is, the course is good, I must admit it's added quite a lot of value…but…in the working world…they see your qualification…so that was something that didn't really sit that well with me but…I've made peace with it now.
> – Nyska

It is evident that for these service users involvement in rehabilitation services is far preferable to "staying at home". This is not surprising given the depression, frustration, tedium and hopelessness described by many participants throughout this chapter. However, it does seem that they are haunted by a shadow of their pre-intervention selves and the real possibility that they might return to a place of isolation and exclusion. This shadow is, I suggest, part of what makes service users particularly vulnerable to the influence of the authoritative voice of rehabilitation. Having experienced significant trauma, they might be especially open to being told, by professionals who demonstrate that they do understand what individuals are going through, who they are now that they are blind, how best to cope, and how to behave in order to ensure that they are not excluded again.

In drawing this chapter to a close, the words of Scott (1969) are once again surprisingly pertinent. In his study of the shaping influence of rehabilitation organisations on the identities of those who lose their sight, he recognised the vulnerability of service users to the voices of those positioned as experts. The authority of these experts, he suggests, is gained from a general social acceptance that they are the ones who know what blind people need and from the fact that those who lose their sight often have no place to turn to other than to the organisations offering services for visually impaired people. He says:

> [I]t is widely held that agencies for the blind are the legitimate and proper agents for the care of the blind. They are said to be staffed with highly qualified, well-trained experts who possess special knowledge about, and insight into, the complex and puzzling problems of the blind. Most laymen [sic] feel that it is natural and proper for a blind person to turn for help to an agency for the blind. These views create in the newly blinded person a positive psychological set, a readiness to accept workers for the blind as the persons best qualified to help him [sic]. Although disillusionment and doubt may later set in, during the earliest phases of his [sic] socialization into the role of client, while he [sic] is

> most vulnerable to the beliefs, ideas, and advice of others, the average client accepts workers for the blind as the experts who will solve his [sic] problem. For a majority of blind persons, this acceptance is reinforced by the fact that there are no alternatives to these agencies in the community (Scott, 1969: 75–76).

Conclusion

This chapter has sought to offer some insight into the experiences of service users prior to entering rehabilitation, providing a foundation for the discussion to follow. These service user accounts offer us a broader perspective on the factors which influence how individuals engage with rehabilitation services. In light of the very painful experiences which many participants recounted, it is no wonder that entering spaces that felt safe, supportive and understanding was significant. Undoubtedly, the gaining of techniques, skills and tools for adjusting to sight loss as well as becoming part of an understanding community has positive benefits. Alongside these, participants were involved in a complex internal negotiation of identity, place and worth, and experienced entering rehabilitation and the taking on of assistive devices as a process of being made into a blind person – an assault on the self. Their accounts reveal a deeper layer of experience, which is likely to influence how they relate to rehabilitation services, engage with techniques and devices, and whether they feel able to question or raise concerns about the way services are implemented.

In the following chapter I turn to an in-depth discussion of the discourses which underpin the operation of rehabilitation services. As the following chapters explore the design, management and implementation of rehabilitation services – in particular, how these services shape the subjectivity of blind persons – the accounts of service users presented in this chapter will help us to consider what the accepted methods of rehabilitation might lack, and what individuals might need in addition or instead.

CHAPTER 6

INVESTIGATING THE DISCOURSES FRAMING THE OPERATION OF REHABILITATION SERVICES

In this chapter I continue the discussion of findings from the interview phase. I turn to consider the discourses which frame organisation operations, referring to the processes and activities of rehabilitation. This chapter considers the ways in which the discourses found in organisation public facing material are deployed within organisation operations. Beyond this, I question what assumptions about health and normalcy providers of rehabilitation services, and indeed all of us, might be drawn into as a result of having been steeped in the prevailing discourses on both rehabilitation and blindness. This chapter draws on service provider accounts of the rehabilitation process. Among other things, I consider their descriptions of the structure and implementation of programmes, the expected outcomes of rehabilitative interventions, and how they understand their roles in relation to service users. The critique I offer in this regard is not a criticism of individual service providers. Rather, my aim is to identify what discourses have come to underpin the work of rehabilitation and what assumptions we all may be colluding with having been exposed not only to these discourses, but also to fantasies about blindness, which influence what we may perceive as appropriate assistance for those who lose their sight.

Recall from Chapters 1 and 2 that in art, literature, philosophy and religion, blindness has been connected to loss of knowledge, control and agency, divine punishment and the fear of descending and permanent darkness (Hughes, 2019; Kleege, 2005; Michalko, 1998; Paterson, 2013). Cultural representations present us with a blind figure who is often silent " –a blank figure" onto which the assumptions of sighted authors can be projected (Paterson, 2013: 160). These representations also produce anxiety for the sighted, presenting them with an imaginary of blind persons as living in a world of isolation and darkness (Barasch, 2001; Hughes, 2019; Paterson, 2013; Scott, 1969). Paterson (2013: 165) explores how the pervasiveness of metaphorical connections between blindness, darkness and abjection contribute to "an inaccurate imaginary of blindness by the sighted". He asserts, in line with Michalko (1998), that "the absence of functioning eyes renders those without sight essentially incomplete, extraordinary and a source of anxiety for the sighted" (2013: 160). Throughout this chapter we must keep in mind what both service providers and service users might feel compelled to hold at bay, in terms of threatening ideas about blindness which are, I suggest, never far from consciousness. To face these threatening ideas, suggest Hughes (2019), entails recognising human frailty and vulnerability. In his view, it is the reluctance of humanity to face itself that has established and maintained the invalidation of disabled people over centuries (Hughes, 2019).

This chapter includes four sections. Firstly, I explore some overarching aspects of the culture in organisations, in particular with regard to the roles which service providers and service users are expected to occupy. This section discusses the ways in which service providers position themselves as the exclusive active facilitators of a constructed rehabilitation journey, and sets the scene for those to follow by offering some insight into the context within which rehabilitative activities take place and the power dynamics at play. Secondly, I revisit the discourse of journey found across the public face material and service provider accounts of rehabilitation work. This linear construction of rehabilitation, I suggest, has a significant influence on how rehabilitative activities are managed. In this section, I also begin to show how service user accounts of rehabilitation often complicate, disrupt and contradict service provider narratives. Thirdly, and in light of this, I discuss how journey discourse supports an imperative to cope and a discourse of the coping blind person. This section has two subsections. The first of these explores how a culture of coping in organisations relies on comparisons and surveillance at multiple levels. I investigate the ways in which an imperative to cope in organisations gestures towards an imagined blind figure who 'stands alone 'within the discourse of the coping blind person. The second subsection focuses on the possible emotional consequences of an imperative to cope, drawing on theoretical work concerning the ways in which constraints may be placed on the expression of emotions of disabled persons by virtue of their occupying a disablist society, which is resistant to acknowledging disability-based struggle (Lourens, 2018; Thomas, 2004; Watermeyer, 2009; 2013; 2016). Fourthly, I consider the way in which journey discourse is underpinned by binary constructs, forming fixed beginning and end points for the rehabilitation process. In this section, I discuss two binary constructs found within interview data: firstly, constructions of dependence and independence and, secondly, a binary opposition between the concepts of sight and blindness. I suggest that these constructs influence not only the design, implementation and ideal outcomes of rehabilitation services, but also a set of boundaries dictating appropriate behaviour for visually impaired people, within which they must locate their own position and sense of self.

6.1. Service Providers as the Exclusive Active Facilitators of Rehabilitation

The analysis of interview data found that the clearly defined roles for service providers (as the exclusive active facilitators of rehabilitation) and service users (as passive recipients of organisation work and public goodwill) seen in organisation public facing material are reflected in service provider accounts of rehabilitation work. Service providers described "drawing alongside" service users to guide them through the set stages of a rehabilitation journey. In these descriptions, as well as those of the equipping, improving and uplifting work of rehabilitation found on organisation websites, there is a sense that service users are being shepherded by service providers, who firmly set the agenda for how the rehabilitation process will unfold. Service providers also set the tone of organisation culture. This can be seen in several service user accounts describing strict organisation rules and structures within which they often felt managed and controlled:

> [I]t's still the same place as school. There they protect you like school…you sleep here, you study, everything there is inside…it's like I'm still at school.
> – Monique

> [S]ome of the rules or decisions, it's almost like they are for kids…"you cannot do this, you cannot do that, you can do this but you cannot do that"…it's not like if they find me speaking to a staff member…it's gonna be a problem, but they know, and we all know that, they say you cannot make friends.
> – Vusi

> I was expecting to be around a lot of blind adults who were doing skills training…I expected a very relaxed environment because we are adults, I expected that if I wanted to go out and have 16 cigarettes a day I would be doing that, but everything was very structured…you'd be told, "move, move"…to me, it felt very nannied, very baby-sat, very controlled, institutionalised control…I hated it…"Sit here, you can't go here, you must do this…must do that"…it just felt cold.
> – Belinda

There are some things raised in these extracts which I will return to in the following chapter, which deals with the functions performed by rehabilitative relationships. In particular, the following chapter considers the operation of disciplinary power through practices of institutional control found in rehabilitation, as well as what being drawn into institutional life might signal to service users about their status. For the present discussion we are interested in how, in the daily activities of organisations, service users are positioned as subordinate to the rules, structures and procedures of rehabilitation prescribed and enforced by service providers. These extracts suggest that service users are not viewed as active stakeholders in their own process of development. Rather, many felt patronised by the limitations placed on them.

In rehabilitation services, it seems that there is a possessive element. This found expression in the review of public face material where organisations often refer to service users as "our". As service providers claim a role as the active facilitators of the shaping work of rehabilitation, it appears that service users are left to occupy a passive position as the work being done. Below are two service provider accounts which capture this:

> [Y]ou (addressing the researcher directly) are an asset…nobody can even think that you are a blind…that shows you already, somebody did some work…in your life…there are times when you think of the primary person that…trained you right from the scratch…"this person made a major impact in my life, now look where I am"…even if I did not train you…but I know this is part of my work, somebody did it on my behalf so I'm happy…at least an orientation and mobility specialist did some work on this individual.
> – David

> I wish, that day, that the guys that go into the workplace, I wish from the Grade R teacher, everybody along the way that contributed could see the end result…and actually you need a choir that can sing a song just for that moment, 'This is what we all worked towards'.
> – Mia

There is a suggestion in these accounts that those who undergo rehabilitation have little to do with their own creation. Rather, these descriptions suggest that the successful service user represents a series of contributions which have formed them into a finished product able to integrate into society. This is most clearly demonstrated in David's statement: "At least an orientation and mobility specialist did some work on this individual". David's account also draws attention to the attitude of enduring gratitude towards the specialist expected from blind people who have been worked upon. It is interesting to note that the "you" David refers to in this extract is the researcher. For him, the principle relationship in the room was not between me, as a researcher, and him, as a participant, but between him, as a rehabilitation professional, and me, as his grateful creation. This extract demonstrates a fascinating assertion of power as David reminds me of our roles, asserting himself as a part of the profession responsible for the creation of people like me. When rehabilitation work is successful, according to David, "assets" will result. I say more about the idea that rehabilitation is involved in the shaping of 'assets', referring to blind individuals who present as admissible members of society in the following section. These extracts resonate with the ways in which several scholars have theorised the operation of power in rehabilitation, drawing on Foucauldian concepts to suggest that rehabilitation exercises a constraining and productive force which renders disabled persons into objects of knowledge for society (Drinkwater, 2005; Sullivan, 2005; Yates, 2005). Importantly, although service users are positioned and/or viewed as passive, in reality they are not passive at all. Service users in this study were involved in making sense of their identities, claiming positions within organisational hierarchies, building networks of support, and sometimes resisting the stipulations of rehabilitation regarding how they relate to their blindness. As Yates (2005: 77) asserts, we must acknowledge that "people relate to themselves in an active fashion".

We observed an alliance between organisations and the public in the review of organisation public face material. In line with Longmore (1997), I suggested that the operation of this alliance allows "givers" (a concerned and generous public) to feel part of a "moral community". I also suggested that service providers, in positioning themselves as facilitators of a restorative process for people seen as helpless and hopeless, are able to gain similar benefits in terms of positive feelings about their role as helpers. This can be seen in the below extracts:

> I just feel so good, I just thank God…"God, I want to thank you, at least I've made a difference in this person's life".
> – David

> I think it makes you a better person in some sort of way because you're not just living in your own little office…you need to be more thoughtful…it makes you more thoughtful and more…appreciative.
> – Zoe

> I was…always a compassionate person…I think…you appreciate everything more, and I'm always telling my two teenage boys that they must appreciate what they have…just talk to other people about what we're doing here and about the stories of some of the [service users]…you just make people more aware of the struggles that other people have.
> – Donelle

These service providers describe the positive feelings they gain from helping service users in much the same way that feelings associated with charitable giving are described on organisation websites. In this, we can see the way in which rehabilitation services are bound up with and viewed as charity. Service users are positioned as charitable objects, and thereby set up as less fortunate and needy. Both Zoe and Donelle describe their growing appreciation in response to comparing their circumstances to those of service users. In particular, Donelle's extract communicates a sense of 'there but for the grace of God', as she encourages her sons to be grateful for what they have in comparison to the service users she works with. In this extract, service users are set up as figures of struggle, an other against which privilege can be measured and status assured. We have already begun to see how relationships between service users are often characterised by othering, as individuals seek to establish themselves favourably along a spectrum of impairment, capability and need in relation to those deemed less fortunate. It appears that a culture of othering in organisations extends to service providers, who are able to constitute themselves as whole and acceptable in relation to the visually impaired people they work with (Hughes, 2019). We must consider what being positioned in this way signals to service users about who they are, where they belong and what is possible for them, as well as how the above-cited statements feed into societal knowledge about the status of blind persons.

There is much more to say about organisational cultures and service user experiences of being drawn into institutional life. For now, as we turn to consider the discursive underpinnings of rehabilitative activities, we must bear in mind that these activities take place against the backdrop of organisational cultures where strictly defined roles for service providers and service users are maintained. These roles are strengthened by the view of rehabilitation as a charitable endeavour, where service providers are viewed as the experts responsible for shaping visually impaired persons into socially acceptable subjects (Tremain, 2005; 2017).

6.2. Journey Discourse in Rehabilitation

In Chapter 4 we saw how organisation public face material constructs rehabilitation as a linear process. I suggested that this material presents the public with an idea of rehabilitation as a journey, promising fixed and expected outcomes for service users. I discussed how these promised outcomes hold out a figure of ‘blindness brought under control’ to a public eager to be assured that blindness can be subdued and integrated successfully into the societal machinery. Accordingly, organisation websites promise the shaping of blind individuals who are able to integrate into society on its terms. These individuals are expected to demonstrate action, independence and productivity, and that they are able to cope in spite of blindness. In short, with the support of Kleege’s (1998) work on the unruliness of blindness, it may be argued that what are being produced are docile blind subjects (Foucault, 1977; Sullivan, 2005; Tremain, 2005). As with this public face material, the analysis of interview data found that service providers construct a linear and predictable rehabilitation journey comprising set stages, procedures and outcomes which, their accounts imply, are experienced in a similar way by most service users. As in the reviewed website copy, service providers view a successfully rehabilitated, coping subject as one who is able to manage, bear up and continue in spite of sight loss.

To be clear, in the below discussion I am not questioning the value of coping in itself. There are common-sense benefits to coping, some of which we have seen in service user accounts in the previous chapters, related to gaining greater mastery, opportunities to participate, freedom of movement and confidence. What I consider below, however, is a firm imperative to cope found within rehabilitative discourse, which brings with it an experience of having to reject certain inadmissible parts of the self as one is required to assume a role in the discourse of the coping blind person. This imperative can serve to stipulate acceptable ways of being for service users, shadowed by a fantasy of degeneracy which haunts the blind figure (Kleege, 1998; Michalko, 1998; Paterson, 2013). As with the public face material reviewed earlier, service provider constructions of a rehabilitation journey are flanked by polarised fantasies of blindness. On the one hand, an unruly pre-intervention blind figure who is dependent, inactive, incapable and depressed must be defended against by both service users and service providers. On the other hand, a coping, capable and socially acceptable blind subject is held out as the successful outcome of rehabilitation work. I argue that the imperative to cope found within interview data does not say to service users, “it is good to cope”, but rather, it tells them that they must cope or risk remaining relegated to marginal social positions. The coping described by service providers was found to involve two interconnected elements; one practical and one emotional.

Practical elements of rehabilitation, concerning the acquisition of techniques, skills and tools for adjustment to blindness, are foregrounded by service providers as driving the rehabilitation journey. These elements are described as "solutions" and as part of a set process of problem-solving, including functional assessments, training and work placement, whereby service users are equipped to manage their visual impairments. In this, blindness emerges as a particular problem around which professional and public knowledge can coalesce (Sullivan, 2005; Yates, 2005). It is notable how, in the below extracts, these practical interventions are constructed as simple:

> [T]here are often people that are not able to read and…there's such simple solutions…it actually won't take you your hour to solve the problem.
> – Helen

> [A]fter they've had…training in soft skills or computer skills, the next thing that they are going to do, because we've got a job placement officer here…the job placement officer liaise with the social worker…and they are placed, then they get jobs.
> – David

> When they come here most of them can't type…you know that a blind person can't function properly with the outside world…if they can't do work on a computer… so first of all…I have to learn them how to type and then we teach them Word, Excel and all that.
> – Donelle

There is a sense that if service users are just provided with a simple solution – an appropriate device, skills training or computer literacy – their blindness will no longer be as problematic and they will regain functionality for inclusion in society. In these extracts we can see the established flow of rehabilitative procedures and the way in which service providers express complete confidence in the processes they are involved in facilitating.

Interestingly, this forms a stark contrast with accounts from service users. We have seen that service users often experienced the taking on of practical techniques and assistive devices as an assault on identity. Moreover, on a material level, some service users described feeling frustrated by processes that felt irrelevant or did not deliver on what was promised. For example, David seems sure of the outcome of the training he offers, which is placement in employment. He presents this as a relatively simple, step-by-step process. In contrast, service users at the same organisation described feeling unsupported and disappointed by the job placement programme:

> [T]hey said, yes, they going to help us but there is a queue, there's a lot of students who were…there before us, so maybe they can but not now…I don't feel okay, it's bad, but I want to do something, I will push by myself.
> – Nohombile

> I went to the job placement officer…she said, "No, we can't guarantee you a job and you first need to do the other courses"…but I did that already…I did that somewhere else…they want me to do the full other courses which I'm not interested…when I first did my assessment at [organisation], they said it's 50/50…they are looking for a job for me and I must look for a job for me and they do have a database…where they can just put my CV…but now they talking…a new language.
> – Roeshdie

This programme seems to be challenged by a lack of capacity. Nevertheless, these service users felt that they had been promised assistance with seeking work, which was not delivered. Their utterances express a mixture of disappointment and resignation, which is reflected in many other service user accounts. This is one example of how service users in this study contradicted and complicated service provider narratives. In particular, they disrupt the construction of a linear and straightforward rehabilitation journey by highlighting gaps in service delivery, and present experiences of sight loss, rehabilitative interventions and outcomes that are more nuanced.

The second element of a constructed rehabilitation journey involves the development of inner strength, resilience, determination and self-sufficiency. The end goal of this emotional journey is the notion of acceptance, a state of mind made outwardly visible by a service user's receptiveness to rehabilitative interventions, as well as their drive to "get on" with life. As suggested in the previous chapter, practical coping and acceptance are constructed as operating in a virtuous circle. Below are some extracts from service providers which demonstrate this:

> [P]eople in the beginning…are angry and don't really want to be there…And, a year or two later, they're able to giggle in the group and think, "Do you remember what I was like when I started?"…but one does have to acknowledge that it's a journey for every single person and some people take a long time to begin to engage with the condition and other people, as soon as they realise there's solutions, start embracing it quickly and move on faster.
> – Kay

> [T]o see the difference…even in the initial consultation, from somebody who comes in and you can just see depression and heaviness written all over them and then they go out with a smile on their face and they feel as if they can take on this challenge that has…often just been foisted on them…it's very exciting to be part of that journey.

> – Helen
>
> [I]f I see that the person is now mobile, they are independent, they are now longing for other things…you can even hear the client telling you…“I wondered, if I were to know how to get to UNISA[10]”, they are now talking about UNISA which was even outside their periphery during the time when you were training them, or during the time when you found them…which means there is something that you’ve instilled in them which has inspired them to want to study more…which is different from when a person is saying, “Hey, I’m not able to cook, I’m not able to do this”.
> – David
>
> I see impact in a client’s walk through the door, crying every day about the fact that they’ve tragically lost their sight and six months down the line I see…somebody who has come to the space where they’re actually going through the grieving process of their blindness…it’s good to see their adjustment in that regard and their healing…some clients walk in here holding onto our driver’s arm…and you see them 6 weeks down the line navigating their way on their own.
> – Kelley

Clearly, these service providers want to see people attain greater mastery and confidence through the training and services they facilitate. As asserted in the review of organisation public face material, this is by no means irrational. We have seen that service users also desire growth, development and transformed circumstances, and in some cases use the language of journey to describe their experiences of rehabilitation. The experiences described in these extracts are undoubtedly real and significant for individuals who have often come to rehabilitation services from places of dislocation, isolation and exclusion. However, referring back to a question posed in Chapter 4 and in light of the discussion so far, I suggest that it is essential for us to consider what the unintended consequences of this journey discourse might be. In particular, a key question to consider is what the construction of a rehabilitation journey might prohibit.

Kleege (1998) explores this question with regard to her own experience of sight loss where, having attained certain techniques and the assistive devices required to participate, she is prohibited from giving expression to ongoing frustration, grief and rage in the face of her blindness and a world which remains difficult to navigate. She says: “I should be grateful, cheerful in the face of such minimal inconveniences” (1998: 56). In the above extracts there is a suggestion that rehabilitation, conceptualised as a journey, requires that we leave loss, grief, hopelessness and anger behind as capability is gained. As Kleege (1998: 59) says of the performances which Helen Keller may have been bound to: “Show them your weakness and they'll put you away in the blink of an eye. You're here by sufferance”. In thinking about how rehabilitative processes might be organised around producing blind subjects who are socially palatable, who are able to take their place as part of the machinery

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[10] University of South Africa

of society, and who understand that integration and the maintenance of a social place is their responsibility, we must return to Foucault's (1977) concept of docility. The discourses which frame rehabilitation services produce knowledge for visually impaired people about what constitutes an acceptable blind subject, how they should view themselves and how they should present themselves in the world (Sullivan, 2005; Drinkwater, 2005). In turn, acceptable blind subjects are knowable for society; as Sullivan (2005: 33) asserts, rehabilitation produces bodies that are "calculable, comprehensible and compliant". Although the discursive production of a socially acceptable blind subject might appear to disrupt the kinds of negative cultural beliefs about blindness we have seen previously, I argue that the discourses surrounding the operation of rehabilitation can serve to strengthen a socially entrenched belief in the inherent degeneracy of blindness. As rehabilitation discourses produce knowledge about what acceptable blindness looks like, they remind both visually impaired people and society about what must be rejected. Therefore, a fantasy of degeneracy which shadows the rehabilitation process is also at work. I use the term 'degeneracy' in an attempt to capture the characteristics with which this shadowy figure of blindness is imbued – inferiority, abjection, deprivation, intolerable difference and a lack of self-control.

I suggest that rehabilitation services are shadowed by the question of what might happen if blind individuals do not attain a place of practical and emotional coping. In this regard, a story about the life of Helen Keller featured on one of the organisation websites reviewed in Phase One offers us insight into what this shadow of coping and rehabilitative success might look like. The story describes both Helen Keller and her blind teacher, Anne Sullivan, as children who were unruly and wild. It describes Anne "kicking, screaming, spitting and biting" and Helen inhabiting a "world of darkness and temper tantrums" before they were both reached by gentle but firm efforts to tame them. These images of degeneracy, and cultural meanings for blindness which pervade the world (Paterson, 2013), build into a set of ideas about what blindness will naturally tend towards, in short, an unruly way of being. I suggest that these ideas are key drivers of an imperative to cope, where individuals are prohibited from expressing nuanced emotions in response to experiences of struggle, and where, as seen in their accounts, service providers demonstrate an at times obsessive need to see subjects who approximate the centrepiece of the coping blind person discourse emerging from rehabilitation services.

6.3. An Imperative to Cope

In addition to material barriers to inclusion, Disability Studies scholars have identified the relational and psycho-emotional aspects of disablist oppression (Lourens, 2018; 2020; Reeve, 2004; Thomas, 2004; Watermeyer, 2009; 2013; 2016). Their work brings to light the ways in which conditions are maintained which make it difficult for disabled people to express, and even to feel, negative emotions related to the experience of both impairment and socially engendered disadvantage. In particular, they suggest that attention has often been diverted away from the emotional life of disability in dominant materialist disability theorising amid concerns that acknowledging struggle will enable the belief that disability is a personal tragedy and a terrible existence to regain its hold (Thomas, 2004; Watermeyer, 2009). There are very real social risks attached to acknowledging difficult parts of impairment and disability experience, or "to show[ing] the belly" (Lourens, 2020: 6). Consequently, scholars have described how disabled people may strategically silence themselves in order to retain access to essential social resources (Lourens, 2018; Watermeyer and Swartz, 2008), protect others from having to face disability difference, pain and struggle (French, 2004; Lourens, 2020), and to avoid being associated with negative disability stereotypes and, therefore, dismissed by society (Kleege, 1998; Lourens, 2018). These scholars assert that silencing expressions of the struggles which form part of experiencing impairment and navigating an inaccessible world does not mitigate inequality for disabled people, but rather compounds it (Watermeyer, 2009; 2016). Too often, integration into a disablist world requires that people with disabilities mould themselves to fit a non-disabled ideal (Thomas, 2004). Part of this involves suppressing expressions of grief and confessions of practical and emotional struggle (Watermeyer, 2009; 2016). Being limited in this way by social demands is argued to be significantly damaging to disabled persons' sense of belonging and self (Lourens, 2018; Watermeyer, 2013). This section explores how rehabilitation might be complicit in creating a potentially harmful demand that disabled people manage the image they present to the world.

We have seen how the public facing discourses framing rehabilitation services place ultimate responsibility for social integration onto visually impaired individuals, who must adapt to sight loss and demonstrate that they are able to be independent and productive citizens. This imperative to cope found in organisation public facing material was reflected in service provider descriptions of the goals of rehabilitation services:

> [W]e want to (sigh) enable people to…live with their low vision, whatever that means for them…to live the best they can.
> – Helen

> I…want also to assist people with disabilities and to see them growing from where they are…until…the time when they would be able to stand on their own.
> – David

> [T]he main thing is, the organisation wants to skill people who are blind for them to be able to survive in society…so that the…person being skilled can be able to stand on their own.
> – Zoe

> We want them to be ready to go into a working environment and be able to work just like a normal sighted person…they must be able to function on their own and just be productive in a working environment.
> – Donelle

Several service providers used variations on the phrase “stand alone” in order to describe the ultimate goal of their activities. This phrase, as well as Donelle’s use of the phrase “function on their own”, indicates the way in which many service providers understand coping – as a fixed concept involving complete independence and self-sufficiency. Emerging in these service provider accounts is a discourse of the coping blind person, who is an image of blindness brought under control. This image is the antidote to a fantasy of degeneracy. The coping blind person is able to integrate seamlessly into society by portraying positive traits connecting them to the ideals of normalcy. This resonates with the assertion that rehabilitation drives towards the production of “persons who happen to be blind” (Michalko, 1998: 6). For Donelle, the coping blind person demonstrates that they are no different to “a normal sighted person”. In this extract, the normalising force of rehabilitative interventions (Hughes, 2019; Ravaud and Stiker, 2001), often more subtly implied in service provider data, comes clearly into relief. Foucauldian scholars recognise that the establishment and maintenance of social norms is a key instrument of bio-power, regulating the bounds of social acceptability and supporting the emergence of measures for the classification, control and objectivisation of “social anomalies through which some people have been divided from others” (Tremain, 2005: 7). However, these scholars also remind us that a key aspect of Foucauldian bio-power is the potential for resistance (Blackmore and Hodgkins, 2012; Friedner, 2010; Tremain, 2005). Accordingly, there is the potential for the prevailing power-knowledge in rehabilitation to be resisted, in particular, if the operation of this power-knowledge is unmasked (Hook, 2007; Tremain, 2017). In light of the discourse of the coping blind person, I suggest that we consider how rehabilitation workers miss the possibility of reframing the difference of blindness as something which could be valued in the world, and how a critical examination of the discourses surrounding rehabilitation holds potential to produce counter-knowledge about blindness, disrupting a potentially harmful imperative to cope.

Stepping aside from this discussion for a moment, it is interesting to note how Helen’s voice, cited above, seems to stand slightly apart from the other service providers. Her definition of the ideal outcome for service users is somewhat less strict. She suggests, with the phrase “Whatever that means for them”, that coping or “living with” visual impairment might look different for each individual. It is significant that Helen works mostly with older people. Across the interview data it was clear that older people were not held to the same expectations of participation, independence and productivity as younger service users. It seems that older people, therefore, have to navigate not only the discourses framing sight loss and rehabilitation, but also those which shape societal knowledge about what older people are expected to do and to be. This was problematic for a number of older service users who found that they were unable to access services and who, as a result, felt rejected by rehabilitation workers:

> [T]he last time I phoned I actually said, “I don’t want to tell you how old I am”, and she said, “Why not?”, “Because when I tell you how old I am you’re immediately going to write me off because I’m too old”. She says, “No, it’s not like that at all”…well (laughs) they haven’t phoned me yet. I want to learn stuff, I don’t know where to go…they’ve probably got their hands full with younger people who

> need to get out into the workforce still, I'm finished with all of that, I'm a retired person…so, it's not really important but as I say, I might still have another twenty years ahead of me.
> – Henrietta

> [B]ecause of my age, they said I'm old so they cannot take me so that was the reason why last year I couldn't come.
> – Lifa

Henrietta and Lifa, like many other service users, desire growth, skills and fulfilment through occupation but are unable to access the services which may be able to open these possibilities. At the same time, a number of service providers expressed frustration at being limited by government funding, which often did not include provision for services to older persons, essentially preventing them from being included in programmes. Here, Foucault's bio-power, the management of the social and individual body, offers us a useful perspective. It enables us to consider how older persons might be disregarded as having no productive potential by government and the organisations it funds and, therefore, be excluded from rehabilitation programmes focused on shaping productive blind subjects (Tremain, 2005; 2017). It is not within the scope of the present study to discuss this in detail. However, it is important to note the impact of intersecting axes of identity.

6.3.1. A culture of coping: comparison and surveillance

The analysis of interview data found that a culture of coping was fostered across organisations. By this I mean that not only were programmes designed and implemented to produce subjects resembling the image of the coping blind person standing alone, but relationships, between service providers and service users as well as within service user communities, encouraged coping. The imperative to cope, therefore, was not only about an individual gaining social acceptance and possibilities for social integration; it was also understood as a duty which those nearing the end of the rehabilitation process owed to those at the beginning, to model success and to encourage others that transformation is possible. Below are two examples of service providers describing the significance of service user relationships where coping is modelled:

> [T]o see how other people have coped and have overcome or how they are struggling and how they are managing their struggles so I think…the relationships that develop within the group…are hugely meaningful.
> – Kay

> [R]emember, this person is not going to stand on their own alone, he's going to pull other people…for example, in your (addressing the researcher directly) case right now, can you see now you are an asset…

> – David

In these accounts we can see how service users might be encouraged by service providers to set an example for others. In Kay’s extract, it is notable that service users must either display coping and overcoming or show that their struggles are being managed, while admitting that they are not managing does not appear to be an option. For David, service recipients have a responsibility in that their success will “pull other people” towards becoming “assets”. For him, an asset is a person who is, despite their visual impairment, not thought of as blind. Through demonstrating some kind of significant achievement, David suggests, an asset is able to present society with an alternative to accepted blindness stereotypes and thereby benefits the whole community of visually impaired people. In this, the community element of coping is clear – each blind individual has a responsibility to disrupt social stereotypes and, in so doing, draw the community towards greater acceptability and inclusion.

Several service user accounts demonstrate a corresponding investment in this culture of coping, embodying the understanding of their responsibility to set an example, especially for those who are newcomers to rehabilitation services. For example, John felt that he played a valuable role as a reference for newly blind people, offering them a figure of a coping blind individual:

> I meet people who knows that I’m blind, who knows of people who have become blind, who use me as a reference…“I’ve seen this blind guy, he’s doing this, that and the other”, and I’m far from cool or good or perfect but I find some sort of being valuable…that people can refer to me as a person who comes from this organisation.
> – John

John understands that he is responsible not only as an ambassador for the organisation he is a part of, but for how others might come to view blindness and the experience of blindness. He asserted that as a reference for newly blind people he could counter their anxiety about limited capability and show them that there were still possibilities. Undoubtedly, for an individual experiencing sight loss, encountering someone like John, who is capable, confident and employed, has the potential to be hugely encouraging. What we should consider, however, is what John might be drawn into portraying and what he might feel compelled to deny, having been surrounded by an organisational culture underpinned by an imperative to cope, as well as the discourse of the coping blind person.

Similarly, several service users described feeling inspired by the example set by others – especially by those with more severe visual impairments. Again, this is not problematic in itself. We have already seen that service users derive benefits from feeling part of an understanding community of visually impaired people. However, we must remain aware of the firm imperative to cope which appears to frame interactions in organisations, and question what this might prohibit for service users:

> We've just had a newcomer into the group who obviously was in a crisis with her vision and was embarking on a trip overseas…people offered advice about flying…how to cope with the airways and how to cope with travel…then as soon as she came back from overseas, she…reported back…which was so amazing because she was so brave travelling on her own…and the crises she'd experienced as well, so it's not all the positive stories…and we were all kind of blown away by how she coped with that…it was an inspiration.
> – Amy

> [T]hey inspire me to be the best version I can be of myself…[John], because of listening to him and his background, but there he is now, how can I say, totally blind and I wouldn't look at him as a blind person 'cause he's very active, mobile and he's very happy, so I think he has the biggest impact on me.
> – Mike

On the surface there seems to be little wrong with the role modelling and the sharing of stories about coping described here. However, I suggest that these interactions form part of a facilitated, collective culture which, while providing encouragement, prohibits individuals from sharing experiences outside of the ideals of rehabilitation. Therefore, mutual support was facilitated when this took the form of modelling well-adjusted and positive responses to blindness, but not when it involved the sharing of feelings of being overwhelmed, hopeless or misunderstood. This can be seen in Amy's extract. Although the individual she describes experienced crises, they were able to show how they managed these, inspiring the rest of the group. Similarly, Mike described how he is inspired by John's example of action, mobility and happiness despite his blindness. Because of his coping behaviour, Mike separates John from blindness saying: "I wouldn't look at him as a blind person". For Mike, the positive traits displayed by John cannot exist alongside total blindness and, as a result, he does not consider John to be a blind person. Therefore, John is effectively separated from blindness by demonstrating both coping and emotional well-being. In a similar way, David separates those who he sees as "assets" from blindness, stating that nobody would think of them as blind persons. Blindness, especially "total blindness", is maintained as a negative reality in both of these instances. Those who are able to demonstrate positive traits, such as independence, capability, success and happiness, are no longer associated with this negative imagined figure.

In the previous chapter, I discussed the phenomenon of comparison found within service user relationships. We saw how many service users, especially those with residual vision, drew comparisons between their circumstances and those who they deemed to be worse off. I suggested that through these comparisons individuals were able to position themselves more favourably along a spectrum of impairment, capability and need and, in so doing, defend against persistent and negative discourses shaping knowledge about blindness and blind people. On the other hand, those who were negatively evaluated were left to contain the negative characteristics attributed to blindness (Shakespeare, 2014; Watermeyer, 2013). From the above-cited extracts, we can see how these kinds of comparisons are also a means through which an imperative to cope is furthered in organisations. The service users cited above feel encouraged, inspired, and perhaps even compelled, to cope by comparing their situations with those who demonstrate that they are coping, both physically and emotionally, despite more dire circumstances. Kleege (1998: 56) speaks to this when she describes feeling compelled by those around her to compare her situation to that of Helen Keller in order to realise her relative advantages and, in gratitude, to resolve to cope: "'Things could be worse,' they say. 'Think about Helen Keller'". The culture of coping found within organisations appears to operate on two levels. Some service users, especially those with more severe visual impairments, feel responsible to set an example for those coming into rehabilitation services, while others, especially those with residual vision, are urged, through comparing their circumstances to those deemed worse off, to manage their own impairments more effectively. What seems evident here, in line with Foucault (1977), is the multidirectional flow of power, as well as surveillance operating at multiple levels, as individuals monitor their own behaviour and the behaviour of others in their community in relation to an imperative to cope and a need to preserve a collective reputation.

6.3.2. Emotional well-being and an imperative to cope

We have seen how coping is viewed in both practical and emotional terms. Below are several examples of service users who demonstrated or described an imperative to cope on an emotional level:

> [S]he comes over and she says, "Are you alright?" and I just burst out crying. She said, "What's the matter?"…it was just one of those things…I'm sure everybody has a pity pond that they sit with their feet in…as long as I know it's there…and I can get out of it.
> – Henrietta

> I was treated like everyone so I didn't even know that I was different until…I visited another community…so they talked a lot of stuff, so I was confused because I didn't know I was different…my parents told me…I should always be strong so…I did mind just a little bit but when I talked to my father about it he was like, "Fine, you're different, so what?"
> – Monique

> I accepted it immediately, because…I have children, and hoping and yearning and feeling angry at the world is not going to help.
> – Melissa

> [A]fter hearing blind people talking loud, laughing and so on and so forth, that was the first thing that struck me…you know what, even though I'm blind I'll need to take this sadness away, I'll need to take this depression away.

– Vusi

These service users discard their emotions associated with the profound loss described in the previous chapter as negative, useless or self-indulgent. Henrietta, with her use of the phrase “pity pond”, suggests that her sadness is an unjustified ‘feeling sorry for herself’ rather than a rational response to the anxiety she feels about her future, seen in Chapter 5, and the way she feels misunderstood by both friends and family. In Monique’s extract, we can see how families can be involved in promoting an imperative to cope, as she says: “My parents told me I should always be strong”. Undoubtedly, Monique experiences support from her parents; in fact, throughout her interview she stressed the close relationship she enjoys with her large family. Nonetheless, the guidance she receives, in terms of responding to prejudice, encourages stoicism in the face of difficulty, potentially denying the expression of emotions connected to feeling rejected, excluded and judged. While not being critical of this family’s means of coping with the very real struggle of her having lost her sight, what we see here are aspects of the silencing of emotional life alienating Monique from grief and, hence, in theory at least, from parts of herself. Melissa feels compelled to cope, both physically and emotionally, by her circumstances, as she says: “I have children, and hoping and yearning and feeling angry at the world is not going to help”. She understands that reintegrating into society in order to support her children requires certain behaviour, including the control of emotions which she deems useless and obstructive. Vusi, on experiencing blind people socialising and expressing happiness, feels urged to “take this depression away”. Notably, this is his responsibility and appears connected to the development of a stoic attitude. The imperatives to cope described by these participants predate their entrance into rehabilitation, and arguably they have placed these imperatives upon themselves. What is at issue, however, is that the responses described above are affirmed within rehabilitation organisations, where grief appears equally unwelcome.

What we can see in the above extracts is how, as they negotiate a sense of belonging, expressions of grief seem foreclosed for these individuals. This resonates with what Watermeyer (2016) asserts about “melancholic suspension”, the disallowing of grief, as being key to underpinning and maintaining disability inequality. Drawing on Cheng (2000), Watermeyer considers similarities between racial and disability inequality, particularly how marginal groups are compelled to contain grief connected to experiences of socially engendered inequality as they strive for a place of belonging within societies dominated by White, middle-class and non-disabled norms. What Watermeyer (2009; 2016) suggests is that, in the face of pervasive disablism, structural inequality and assaults on the self, social survival is often contingent upon the rejection of vulnerable parts of the self and an eschewing of loss in the lives of disabled people. He says:

> [S]ome disabled people may be driven, via a myriad of subtle, culturally communicated ‘moral imperatives’, to commit life and limb to being ‘not disabled’, to overturning stereotypes by taking pains to disprove their implications. The response to the ascription of dependency may thus be vigorous independence; assumptions regarding vulnerability may be countered with stoicism; characters seen as sullied with loss may dissociate from it in any form (Watermeyer, 2009: 95).

However, inequality persists as a result of a social investment by the dominant group in the maintenance of a denigrated other (Cheng, 2000; Watermeyer, 2016). In line with this, Watermeyer (2016: 123) describes disabled individuals as "occupying an invidious position, involving both alienation from one's emotional self, and experiences in the social world which repeatedly point to one's failure to assume the ideals which secure real belonging". This invidious position is reflected in the above accounts as these individuals draw away from their rational emotional responses to loss. In light of this, we must consider whether rehabilitation should offer something else, and what benefits could be had from services where space is deliberately made for the processing of grief and trauma.

Building on the above discussion, it is interesting to consider how service providers describe emotional well-being in their accounts of rehabilitative processes. In service provider data, negative emotions were associated with the beginning of a rehabilitation journey and constructed in similar terms to dependence, incapability and inaction, as problems of blindness in need of solutions. These solutions are primarily practical. As one service provider said:

> [Y]es, it's good talking to the psychologist, it's good off-loading, but I still come home and I still can't do A and I still can't do B and I can't do C, but walking in here I had the opportunity to speak to somebody, but more than that I had the opportunity to gain the skills of what I missed most, making myself a cup of coffee, walking to the cupboard and identifying my clothing…that type of thing.
> – Kelly

Kelly draws on her own experience of sight loss to suggest that practical adjustment to blindness should be prioritised in rehabilitation. As seen in previous service user accounts, these practical elements can have a positive impact on emotional well-being. However, in the above extract and those cited below, there does seem to be a problematically narrow understanding of psychological health, and a focus on practical mastery at the expense of the psycho-emotional well-being of service users.

Three out of the four organisations included in this phase of the research offered counselling services as part of their programmes. Service provider data suggests, however, that these services serve to promote the management of emotions in order to draw service users towards locating themselves within the discourse of the coping blind person. Counselling is, therefore, an instrument of the imperative to cope. Emotional well-being was constructed within the framework of a rehabilitation journey and, accordingly, service users were expected to move along a trajectory of emotional stages which culminated with acceptance. In other words, as with a bereavement model of loss, grief is confined to a particular zone – the early stages of discovery, diagnosis and rehabilitation – which service users are expected to move through and beyond. This is a model for adjustment to disability which has been found to not reflect the complexity of disabled peoples' experiences

(Watermeyer, 2009). Below are two examples of service providers speaking about the role of counsellors and counselling services:

> [W]hen I see that a client is going through this psychologically, I will then have to give them counselling…they say what they are going through and then I help them on how to overcome such…I'm not going to overcome the challenge for them, but…I will help them to solve their own problems.
> – David

> I think they have a lot of personal problems…but I can also say that we have a counsellor here…it's once a week she comes…if there's a big problem somewhere then we can call her and she will come and talk to them.
> – Donelle

In these extracts, service providers speak about counselling in similar terms to practical techniques for adjustment to blindness, as a relatively simple solution to a straightforward problem. Although it is not uncommon for disabled people to describe the onset of impairment as traumatic (Watermeyer and Swartz, 2016), in David's extract we can see an imperative to cope as he understands that service users have a responsibility to overcome their "emotional problems". What we must consider, as we did earlier in relation to the need to see practical coping, is what fantasies about blindness might flank this clearly defined grieving process in rehabilitation, subsumed under David's rubric of "emotional problems". In other words, a key question is what service providers and service users imagine would also emerge if feelings of grief were allowed to be shown and explored. Given the shadow of an unruly blind figure sketched earlier (Kleege, 1998; Paterson, 2013), I suggest that this has to do with unravelling control and a sense that the imagined face of loss, grief and abjection will bring with it emotions that are simply too overwhelming to contemplate.

Several service users disrupted these service provider narratives, expressing that attention to psycho-emotional well-being was lacking in the services they had received and that counselling services couched within a linear grief model were not able to address their experiences of loss:

> We need counselling…because I'm not coping at all with my condition that I'm having…the social worker, what is she doing? It's only for your assessment, only about the condition that you are having and then the skills that they are having…there's nothing like counselling.
> – Nohombile

> [Y]ou go and you talk to the counsellor and that is very helpful but that counsellor's a social worker…this is not social worker bullshit, this is big stuff, people have got life-changing experiences, total trauma. There's no one that you can really deal with trauma with, that should be first on the

> list…you need to not just learn how to cook and learn how to read Braille and learn how to walk with a cane, you need to be given the tools to live a well-rounded, mentally well life.
> – Belinda

These service users, once again, disrupt the construction of a virtuous circle of practical skills and growing emotional well-being presented by service providers. For both Nohombile and Belinda, practical interventions cannot address the trauma they have experienced. Belinda asserts that the counselling she has received at organisations was not adequate in assisting her to make sense of her situation – what she refers to as the “total trauma” she has experienced. The contrast between these service user accounts and those of service providers suggests that an imperative to cope can have serious consequences for service users, who may feel that their negative emotions are not welcome. Again, we can refer to Watermeyer’s (2016) use of the concept of melancholic suspension in framing pervasive disablism, and consider how linear rehabilitative processes might strengthen a social imperative for people with disabilities to dispense with grief in order to secure a degree of belonging in the world.

From the discussion so far, we can see the overarching influence of journey discourse on how rehabilitative interventions are designed and implemented, as well as the way in which success is measured. In the following section, I consider some practical implications of binary constructs in rehabilitation in terms of how service users are able to respond to their visual impairments.

6.4. Binary Concepts in Rehabilitation

Across both service provider and service user data, binary constructs can be found, connected to the fixed, linear and predictable flow of rehabilitative processes. I have mentioned several of these already. For example, the phrases “in here”, referring to the safe space of organisations, and “out there”, referring to a more hostile society, which service users must enter or re-enter having been equipped by rehabilitation services. A second example is the images of “sitting at home”, used to describe the figure of pre-intervention blindness, capturing inaction, incapability and depression, which exists in opposition to “standing alone”, used to describe the ultimate outcome of rehabilitation services. The above discussion has begun to show how the maintenance of these kinds of binaries can have consequences for service users, who may be drawn into a culture of coping where struggle, and the expression of emotions viewed as negative, appears to be prohibited. Below, I present two further examples of binary constructs found throughout the interview data. These are, firstly, the construction of a binary split between dependence and independence and, secondly, between sight and blindness. I discuss how these constructs influence not only the design, implementation and ideal outcomes of rehabilitation services, but also the construction of a set of boundaries dictating appropriate behaviour for visually impaired people.

6.4.1. Dependence and independence

As seen in the review of public face material, independence is one of the key service outcomes which organisations hold out to the public as a promise of the kinds of blind individuals being shaped by their services. Similarly, in service provider accounts of rehabilitative processes, independence is foregrounded as centrally important to the production of coping and, I argue, of socially acceptable subjects (Sullivan, 2005; Tremain, 2005). Service providers construct independence in definite terms, as the ability to complete a variety of tasks with no, or at least minimal, assistance from others. Below are some examples of how service providers describe independence:

> [T]his organisation is there to empower people who are visually impaired so that they would be able to stand on their own out there and be able to lead a life that is…quality…that means to say they will be able to lead a life independently with the minimum help.
> – David

> For a person to be able to operate without anybody having to help him or her, like mobility, moving to places, work on the computer on their own…and…just to operate like normal sighted people.
> – Donelle

> [B]eing able to do basic tasks for yourself and then being able to use that tasks to better your life…being able to access other opportunities outside, work, social circles, those types of things.
> – Kelly

In these extracts we can see the very clear terms which define independence for these service providers. For David, independence is about individuals "standing on their own", a phrase which describes complete self-reliance. Donelle understands that the role of rehabilitation is to facilitate individuals towards being able to "operate like normal sighted people". For her, a key part of this is ensuring that visually impaired individuals do not need to ask for assistance and are able to move through the world on their own. Kelly recognises how demonstrating independence influences other aspects of life, and that being able to do various tasks "for yourself" is key to accessing economic and social opportunities. Similarly, David recognises that independence and growing quality of life are closely connected. In this regard, I suggest that we consider the influence of prevailing discourses of health and normalcy which service providers are steeped in. These discourses produce disability as a problem of the individual body and a problem for society (Drake, 1996; 2001). Foucauldian scholars assert that the problem of disability emerges in relation to the construction of social norms (Tremain, 2005; 2017). Accordingly, the problem of blindness is defined in relation to the social norm of sightedness: "the meaning of blindness is wrapped in the cloak of its immersion in a sighted world" (Michalko, 1998: 8). In other words, we may view the professional knowledge and practice which coalesce around the blind subject as being governed by the norm of sight and, consequently, driving towards this norm (Michalko, 1998; Tremain, 2005). These influences, combined with the signalling of an often inaccessible world where difference is unwelcome, are factors which underpin the fixed construct of independence for these service providers. In light of socially entrenched disablist ideas and practices which stipulate who is acceptable, who is able to participate and who is given opportunities (Tremain, 2005), it is unsurprising that service providers feel responsible for shaping individuals able to demonstrate complete capability and self-reliance in order to be welcomed by society. However, adherence to this fixed concept of independence may obscure the complex lived experience of service users and, I argue, limits their responses to the practical challenges of sight loss (French, 1993; Watermeyer, 2013).

An example of how service users disrupted the fixed definitions of independence seen above is the way in which they described a connection between growing independence and a corresponding growth in vulnerability. Their experiences suggest that the process of gaining independence is more complex than merely acquiring skills to do things alone, resulting in seamless social integration. Rather, greater independence intersects with vulnerability in complex ways:

> Then [service providers] tell me, "You must manage on your own, you mustn't ask for help"…but they're not in your position, it's not easy to become blind, it's difficult…there's a lot of obstacles, there's a lot of things that you must overcome…I don't even want to talk about it because it hurts me so much that I have to survive on the trains every day…what happens on the trains and on the stations, because I don't see it but you hear it and you feel it…
> – Nikita

> [T]axis is not every day safe…I spoke to one of the staff members and they said, "No, you can't rely every time on private transport", I said, "Yes…I know independence, but safety first…because you can't get independence when you're dead".
> – Roeshdie

> I can't tell everyone that I've got eyesight problem because they take advantage…I remember I went…to see another occupational therapist and I was telling her that I fall a lot…so this lady said to me, "Don't you think you need to use a cane?" I said to her, "I don't think I like using a cane because where I'm coming from, once they see that I'm using a cane, I'm carrying a handbag and I've got a phone, I'm gonna be a target, they're gonna rob me".
> – Lifa

Following her statement, Nikita went on to describe the terrible experiences she has had while taking public transport. She experiences a daily threat of abuse and sexual assault as she navigates a long commute on crowded and unreliable trains. She felt that the service providers she engages with had no true understanding of what she has to go through and, consequently, their urging her towards greater independence felt unsympathetic and harsh. Later, she said: "The staff should move amongst the students, speak to them so that they can know what we go through, the things that we must survive". In this we can see that visually impaired persons possess little meaningful authority over how organisations function (see section 7.2.). Even though some service providers are visually impaired persons, they appear to be drawn into organisational culture which, according to service user accounts, marginalises the voices and experiences of persons undergoing rehabilitation. In this regard, we must recognise the historical weight of charitable discourse which is difficult to shift. All of the above service user accounts offer a perspective on independence training and the process of moving into society that complicates otherwise simplistic constructions of independence. For example, Life points out that there is an unseen cost to taking on a mobility aid. As much as a cane might help her to be more secure in moving around, she is convinced that it will mark her as a vulnerable target.

Service user data suggests that the process of independence training and taking on assistive devices encompasses, for many, both benefits and serious costs, against which these benefits must be weighed. We saw in the previous chapter how taking on assistive devices, especially the white cane, could be experienced as an assault on the self. The below service user accounts describe the process of weighing the benefits of greater mobility and visibility against feeling that society views them differently:

> [Y]ou're attracting attention from others…they're looking at you and thinking, "Oh shame, she can't see"…but helpful…in the sense that people don't walk into you and you don't walk into them…so you feel freer…now that I'm used to it I'm okay with it…it was a bit of a thing at first…a little bit of…embarrassment.
> – Lilla

> [A]ll I knew about blindness was the fact that people walk with a long cane, and I wanted to get about and at the same time I didn't want to be seen as a blind person…
> – John

> I have a cane. I only use it when I travel in the morning. I enjoy it to a certain point…when you're getting a taxi in the morning, they would maybe help me or they would make things easy for me. Other than that, there's some people that just think I'm joking when I'm walking with the cane because they can see I still have sight left, so they would not take me seriously.
> – Mike

Lilla describes the benefit of feeling "freer" when she uses her cane, balanced with embarrassment. She feels the gaze of those around her and senses that she is being pitied by them. As an object of pity, she is stared at and then dismissed with the phrase: "Oh shame, she can't see". As discussed in the previous chapter, for John, taking on a white cane, with all of its significant benefits for moving through the world, will mean being “seen as a blind person”. Both Lilla and John recognise that using a cane will change the way society makes sense of who they are. Mike also has to navigate the way in which society responds to him. He must weigh up the benefits he gains from using a white cane with the cost of having to defend the legitimacy of his visual impairment.

The complexity described by service users in terms of negotiating their independence was not recognised by many service providers. In fact, only Helen, cited below, described independence in nuanced terms, demonstrating an understanding of the negotiations service users might be involved in. She said:

> [I]f it’s important for this person to be able to travel on public transport to work…that they…are able to do that, if they choose to actually have their partner drive them to work then, to me, that doesn’t mean that they’re not independent…they’ve had the opportunity to choose what they want and they’ve been able to…put that into place…I think it’s being able to take charge of your life and make decisions for yourself.
> – Helen

Focus on the importance of choice was absent across the rest of the service provider data in terms of the way in which independence was conceptualised. The construction of independence in binary terms has, I suggest, potentially serious consequences for the service users exposed to it. Despite the promises of organisation public face material, an image of a completely independent blind individual “standing alone” is, I argue, incompatible with the lived experiences of visually impaired people. As a result, blind people may find that the inevitable need to be assisted feels like slipping back into a socially rejected role (French, 1993; Watermeyer and Swartz, 2008). Many Disability Studies writers regard the power to make choices about one’s own life as independence (Els, 2001; French, 1993; Shakespeare, 2014; Watermeyer, 2013). This, in turn, relates to the emergence of a political consciousness and voice among disabled people, which can be undermined by the demand that one silently fulfil the daily tasks of life independently (Els, 2001; Watermeyer, 2013). This may also create pressure to forgo the networks of support they have built, as described by French (1993).

In light of the negotiations of benefits and costs, as well as the potential complexity of gaining greater independence described in the above examples of intersecting independence and vulnerability, it is unsurprising that many service users described their independence in more nuanced terms than the binary definition offered by most service providers. Taking charge of one’s own life may, at times, be facilitated rather than hampered by the assistance of others (Els, 2001; French, 1993; Watermeyer, 2013). As Else (2001: 606) asserts: “Independence depends not on separation from others but on particular and extensive sorts of interconnections with others and with the social and political fabric of one's community”. Below are a few examples of how service users have negotiated independence:

> I have good friends, I have someone who regularly…takes me shopping…which for me has become quite key…in terms of my independence…
> – Lilla

> So much of my independence is fulfilled by [my husband's] presence…he's here whenever I need help of any sort.
> – Amy

> I do everything on my own…I must wash my windows…I must sweep, I must wash, I must cook…that is independent…this is the only thing that I need…I need to be helped to the station, that's all…just onto the train and to climb out and to come here [to organisation]…but there's always help, even if I don't ask, someone will ask me, "Can I help?" and I'm not going to just throw that help away.
> – Nikita

These extracts describe the building and maintenance of networks of support. Especially for Lilla and Nikita, who have limited family support, these networks are essential and build into independence. Arguably, the building of support networks demonstrates significant interpersonal skills and self-confidence, which service providers did not seem to acknowledge. At the same time, these support networks are not uncomplicated. For example, like several other service users, Amy describes how her husband is key to her independence. For some participants, relying on support from close family or friends could be anxiety provoking and could put relationships under pressure (Lourens, 2018; Watermeyer and Swartz, 2008). Still, it seems that for the majority of service users independence is not the kind of "standing alone" described by David. Rather, it is a combination of using certain techniques and tools gathered during rehabilitation, and marshalling various social resources in building networks of support. In his research with spinal cord injured people, Sullivan (2005) described how individuals resisted the power-knowledge which supported the inflexible rehabilitation interventions they were subject to. The above-cited participants demonstrate this kind of resistance as they redefine what independence is and how they will mobilise resources to meet their needs.

6.4.2. Sight and blindness

The analysis of interview data found that the ideal end product of rehabilitative interventions was not a blind individual performing sight, as in the descriptions of 'passing for sighted' found in the accounts of Botha and Watermeyer (2018), Kuusisto (1998) and Michalko (2002). Rather, rehabilitation is involved in producing socially compliant blind individuals, who use appropriate techniques and assistive devices in order to integrate into the "sighted world" (Michalko, 1998; Scott, 1969). Drawing on Scott (1969), this research supports a view of rehabilitation as involved in teaching individuals how to fulfil the social role of a blind person. Accordingly, a clear binary between sight and blindness exists in rehabilitation, influencing the design and implementation of services.

This binary construct proved problematic for the majority of service users, who have some residual vision. In fact, only five out of the eighteen service users interviewed identified themselves as “totally blind”. The accounts of partially sighted service users suggest that rehabilitation services are organised strictly, with correct techniques being stipulated and interventions offered to everyone in the same way, regardless of visual impairment. Several participants experienced this as limiting, especially as they were encouraged not to use their residual vision, while others felt that certain interventions were irrelevant:

> Well, I don’t know if it worked because…I could still see then…so it was like cheating…I wasn’t doing it in the dark.
> – Henrietta

> I was doing Braille…but I didn’t even finish it because…instead of feeling those dots…I’m just looking…when I tried to feel them, I just want to look at them but the problem is…they make my eyes worse if ever I do that.
> – Aubrey

> [T]he kitchen was a bit tricky for me because I could see still, I must have been blindfolded, you need to learn to feel, you need to not keep it in front of your eyes…and then I didn’t trust my feeling and especially with the knife, I would take the blindfold off, because [trainer] is blind he won’t see that the blindfold is off…I would always cheat…at the end of the session he would always say, “Melissa, you didn’t have your blindfold on”, I said, “I did”, and then he says, “No, you watched, you made sure that you could always see”…so eventually I just decided, no, stop cheating, you need to learn how to do these things…so I had to build that confidence…so…I became obedient.
> – Melissa

In the previous chapter, I mentioned that several service users had expressed uncertainty about whether, and to what extent, they needed rehabilitative interventions or assistive devices. The above extracts suggest that a constructed binary opposition between sight and blindness, which dictates the operation of services, may be a factor in this. Henrietta, for example, is not clear whether the mobility training she received was helpful because this training does not seem to have been focused on her specific needs. Rather, she was trained in the same way as someone with no vision and, perhaps because of this, feels that being able to see is “cheating”. Similarly, Aubrey finds no value in learning Braille. For the above service users, the fact that they can see complicates their access to rehabilitation services as well as, I suggest, their ability to identify as visually impaired. Again, there seems to be a layer of experience and a set of complex negotiations which organisation services do not engage with. Instead, Melissa’s account points towards a rigidity in training, which prohibits people with some residual vision from exploring how that could be beneficial in accomplishing certain tasks. The idea that rehabilitation is invested in producing compliant blind people, adhering to particular techniques for coping, comes to mind as Melissa speaks about a process of becoming “obedient”. In this account we can clearly see the constraining and productive force of rehabilitation (Sullivan, 2005; Tremain, 2005). Melissa describes a disciplining process that gradually shaped her into a compliant blind person, albeit one who can “still see”.

The rigidity of training was not only experienced as problematic by service users with residual vision. Strictly defined concepts, compulsory courses and the prescription of correct techniques were experienced by many participants as limiting and, in some cases, harsh. For example, Belinda expressed feeling limited by the strict procedures and techniques she was taught during rehabilitation:

> [I]t felt like I was in a Charles Dickens thing…it feels very archaic…and I’m yet to find a blind organisation that doesn’t…it seems like the longer you are in the blind organisations the more…(sighs)…brainwashed in your thinking you become…when I was there I was told life skills stuff…sew buttons onto our clothing…and I’m going, “I ain’t sewing no buttons, I have a device for that”, “Oh, you won’t always have a device”, yes, I hear you, but…is there no other way? I’ve got so much clothing, where am I gonna get all these buttons? Surely there are other ways that can look forward instead of always going back to this old school stuff.
> – Belinda

In this extract Belinda is referring to the method of clothing identification which uses different sorts and combinations of buttons as tactile markers. She is given no space to question this longstanding, tried and tested rehabilitation method in favour of the technology she prefers. On one level, her resistance simply has to do with how she views the method of sewing buttons as impractical. As much as her question “where am I gonna get all these buttons?” is tongue-in-cheek, she does not see the sewing of buttons as the best solution to the problem of identifying her clothes. At another level, her resistance to sewing buttons appears to recognise and reject the requirement that she assumes the role of a compliant blind subject (Sullivan, 2005). We have seen glimmers of this kind of resistance throughout the service user accounts in this chapter. However, resistance appears to be difficult in the face of deeply entrenched power-knowledge in rehabilitation. Service providers, empowered as professional experts, organise and manage rehabilitative procedures within the bounds of strict binary constructs. These binary constructs, strengthened by a pervasive discourse of rehabilitation as a linear journey, can result in services feeling limiting and prescriptive for service users who, in fact, are involved in a complex negotiation at the level of identity.

Conclusion

These findings prompt us to consider, firstly, the discourses entrenched within rehabilitation services. an overarching influence in rehabilitation is a discourse of journey, which constructs rehabilitation as a linear process and expects service users to progress along fixed stages towards becoming socially acceptable and compliant blind subjects. This discussion has suggested that journey discourse in rehabilitation strengthens, rather than disrupts, a prevalent construct of blindness which associates it with degeneracy (Kleege, 1998; Michalko, 1998; Paterson, 2013) through establishing a figure of pre-intervention blindness which must be defended against. Having been steeped in this discourse, we must recognise what service providers, and society at large, may be enacting and recreating in terms of the meanings of blindness.

Secondly, the findings presented here suggest that rehabilitation services are framed by discourses which construct strict boundaries and expected outcomes within which service users must make sense of experiences that are more complex than this framework allows. What is not in question are the benefits of coping, of managing and of possibilities for thriving. However, what this chapter has considered is an imperative to cope which can promote the rejection of parts of the self deemed inadmissible, and which can thereby exert control over how individuals are able to respond to the particular situations they find themselves in. I have suggested that rehabilitation is complicit with the drive to limit the ability of disabled persons to express negative emotions related to both the experience of impairment and social disadvantage (Lourens, 2018; 2020; Thomas, 2004; Watermeyer, 2009; 2013; 2016). Through maintaining a firm imperative to cope, it may be that rehabilitation contributes to a state of melancholic suspension experienced by some people with disabilities (Watermeyer, 2016). In this regard, a question to consider is how rehabilitation services could be transformed into spaces where, unlike in the outside world, expressions of grief and trauma are welcomed, and what possible impact this would have on individuals navigating the new world of blindness.

Finally, we have seen how service providers occupy positions as the exclusive active facilitators of rehabilitation services, in relation to service users who are passively positioned. This does not mean that service users are, in fact, passive. On the contrary, throughout the forgoing discussion we have seen how visually impaired persons are involved in active processes of sense making for themselves. Nevertheless, we have seen that adherence to strictly defined roles in rehabilitation builds into an image of blind persons as needing to be drawn away from negative characteristics and toward embodying traits associated with a discourse of the coping blind person. These findings begin to reveal the significance of relationships in rehabilitation in terms of the ways in which meanings for blindness and the experience of blindness are exchanged within relationships where help is given and received. This is discussed in the following chapter.

CHAPTER 7

CONSIDERING THE SIGNALLING OF REHABILITATIVE RELATIONSHIPS

It’s just the way they treated adults was really taking something from them

– Belinda

In this chapter, which draws the discussion of findings from the interview phase to a close, I consider the signalling which may be present in rehabilitative relationships. This chapter explores what these relationships might impart to service users about who they are, where they belong and what is expected of them as blind individuals in society; in other words, how knowledge about blindness produced through the practices of rehabilitation can be an influence in shaping the subjectivity of blind persons (Sullivan, 2005). Throughout the below discussion I question what the positioning of service users within the fabric of organisations might signal to them about their status, their value and their place in the world. I consider aspects of daily life at organisations beyond the activities of rehabilitation, exploring those things which surround the provision of skills training and other services. It is important to note that three out of the four organisations included in this phase of the study require full-time attendance from service users and two of these offer residential facilities for service users. This means that the majority of service user participants were either living at organisations or attending full days of training throughout the week in order to complete programmes that can span anything from six to eighteen months. I have suggested that those who come to rehabilitation services might be particularly vulnerable to being told who they are now that they are blind, given the significant trauma of sight loss and associated dislocation from society and self. The findings presented below suggest that, at this vulnerable time, individuals are drawn into institutional life and become subject not only to the rehabilitative agenda prescribed by organisations and their workers, but also to the influence of organisation culture more broadly.

For Foucault, institutions are key spaces for the operation of the constraining and productive force of disciplinary power, the management of individuals or groups, and the shaping of docile subjects (Tremain, 2005; 2017). Foucauldian scholars assert that institutions such as asylums and other designated spaces for disabled bodies emerged in Western history as a product of industrialisation as a tool of bio-power, a way to classify and manage "accidents, illnesses and various anomalies" (Tremain, 2017: 80). Disability invalidation, however, is deep-rooted in history (Hughes, 2019). The well-established social role of disabled people as the invalids against which normate value can be secured continues to underpin the exclusion of disabled bodies and efforts to assimilate them through practices of normalising correction (Hughes, 2019). In Chapters 5 and 6 we have seen how rehabilitation organisations are spaces of comparison and surveillance where, arguably, individuals are drawn towards the embodiment of an ideal, socially manageable blind subject (Sullivan, 2005; Tremain, 2005; 2017). This chapter will extend the discussion, exploring the operation of disciplinary power within relationships where help is given and received, as well as the influence of organisation culture in shaping blind subjectivity.

The chapter includes three sections. Firstly, I consider the maintenance of certain relational boundaries, which are viewed by a majority of service providers as important for ensuring professional, efficient and successful programmes. In contrast, I consider service user perspectives which suggest that these professional boundaries might be experienced as detachment, disinterest and rejection, signalling that service users are not adults on an equal footing but, instead, objects of rehabilitation work. Secondly, I explore the communication channels available to service users, in particular, whether and to what extent they felt able to table grievances or raise concerns. In this regard, service users described experiencing a lack of communication and transparency within organisations which appeared to signal to them that they are not valued stakeholders. Finally, I discuss a culture of 'grateful receiving' found in organisations and consider how entrenched charitable discourse can further erode the status of service users as adults on an equal footing, thereby diminishing agency, stakeholdership and citizenship.

This chapter is headed by a quotation from Belinda: "It's just the way they treated adults was really taking something from them". In these few words she captures a central finding in this study. This is the proposition that rehabilitation can be a paradoxical experience – that the gaining of the necessary techniques, skills and tools for adjusting to blindness could be valuable for individuals, and yet they could simultaneously feel that something significant was being taken from them at the level of identity. This is most starkly visible in service user descriptions of organisational culture.

7.1. The Maintenance of Professional Boundaries

Throughout the service provider data, it is apparent that clearly defined relational boundaries are established and maintained in organisations. They suggest that these boundaries are important for asserting the authoritative position of service providers as professionals and ensuring that programmes run efficiently. Below are three examples of service providers explaining the relational boundaries they maintain with service users. It is interesting to note that these participants had moved from being service users into positions as service providers:

> [T]here was a time when I…became the instructor to some of the peers that I…met along the way, so that was a huge adjustment, that transition…we were first sitting around a table having laughs and conversations…now I need to adopt a professional attitude 'cause I actually have to deliver a service.
> – Kelly
>
> [I]f I can put it to you this way, we're not friends but we're not nasty to each other…what we want our clients to understand is the education part about things, [organisation] is very, very strong on education…and whatever will deter…we're not friends but we're good.
> – John
>
> [I]f you have a problem you can come to me…and tell me…so it's like open relationships that we have here with clients and staff…when I speak you listen, sometimes you do get…people that would think, "I'm older than you and you're young, I won't listen to you"…but we would lay the rules down before we start…I make that clear, "I know you're older than me and there is respect in that but I'm not here to judge you, I'm not here to put you down, I'm here to help you be independent", but sometimes guys do forget that…which is not very nice, but if you put your foot down…they do listen. I don't know what they say behind our backs though.
> – Melissa

These participants suggest that it is important to remain somewhat separated from service users in order to ensure professional, efficient and quality service provision. In these extracts, there is a sense that relationships on a more equal footing might jeopardise the work of organisations to educate, to equip and to uplift people with visual impairments. For Kelly, offering a professional service and maintaining her authoritative position requires that she separate herself from those who were once her peers. Despite her own visual impairment, organisation culture dictates that it is no longer appropriate for her to share "laughs and conversations" with those who she must now assist. In the same way, John describes clearly defined roles and relational boundaries: "We're not friends but we're good". Interestingly, Melissa appears to understand her role as similar to that of a schoolteacher. In fact, there is much about the picture sketched by these service provider extracts, and those cited below, that calls to mind the disciplinary structure and hierarchies of a school setting. A number of service users recognised this similarity. For example, Monique, cited in the previous chapter, said,“ It’s still the same place as school”, and Vusi felt that “Some of the rules or decisions, it’s almost like they are for kids”. In this regard, it also seems significant that at two of the organisations included in this phase of the study, service users addressed service providers with titles such as Mr or Mrs, further asserting a separation between service providers as authorities and service users as subordinates, regardless of age, experience or background.

Considering the comparison, hierarchy and surveillance characteristics of disciplinary power (Tremain, 2017), we can see how becoming service providers establishes these participants favourably along a spectrum of impairment, capability and need found within organisations. Like those individuals with residual vision who position themselves as helpers of the blind, these service providers are able to draw a clear separation between themselves and negative blindness stereotypes. Interestingly, in spite of the open friendliness described by most service providers, in Melissa’s statement “I don’t know what they say behind our backs though” there is a hint of mistrust, which was found to characterise rehabilitative relationships.

These extracts begin to demonstrate how service providers are positioned in the organisational hierarchy – as authoritative professionals who must manage not only the operation of rehabilitative interventions but also the service users themselves. This can be seen in Mia’s account, where she described her role as that of a mother figure to service users but felt that this had to be balanced with the need to maintain discipline:

> I try to separate the mother role…which comes naturally…it’s easy for me to move into…I provide and I help with transport and money and clothes…it’s just part of the world…where we work, there’s always a need… or somebody confides in you about a problem and I try to solve it…but I know it’s also me that have to keep the discipline, make sure that everything is run smoothly, so I relate easily to the guys but I sadly also have to be the…disciplinarian.
> – Mia

Mia was not the only service provider to describe relating to service users as a parent. David, although speaking more metaphorically, said: “I don’t do baby dumping…when I have nurtured a client…I equip them…like my baby…I will have to work with them until…the end”. In these extracts, relating to service users as nurturing, caring parental figures is presented as positive without recognition of a risk that this might build into paternalistic organisational culture. We can see an enactment of charitable discourse as service users are positioned as unfortunate and in need of the altruistic nurture of concerned service providers. In her account, Mia presents her role as a mother figure in contrast to her role as the disciplinarian. I argue, though, that both of these roles may incorporate control, patronising service users and maintaining their subordinate position. Elsewhere in her interview, Mia explained that discipline entails instilling particular values into service users who come from backgrounds where, as she put it, “there was lack of certain discipline and expectations and quality”. For Mia, discipline involves teaching service users responsibility, punctuality and good manners, all things which she sees as vital to their eventual entry into the workforce: “We enforce those things because we feel that’s required to go into the workplace…it’s late in their lives but we try to instil it”.

There are several issues to consider here. There is certainly value in service users, especially those who have never been employed, learning about the world of work and gaining skills for work readiness. However, there is also resonance in service provider accounts with narcissistic colonial ideas, as service providers position themselves as part of a benevolent group of people working to uplift the abject and discipline them into acceptable subjects (Hook, 2012; Hughes, 2019). Notably, at Mia’s organisation the vast majority of service providers are White, while service users are mostly Black youths from impoverished communities. Service providers at this organisation described service users as coming from “bad backgrounds” and explained that there were sometimes problematic incidents arising at the organisation involving the meeting of two distinct cultures. I suggest that there is a troubling split at work which positions service providers as rescuing those who are disadvantaged not only by sight loss but by a lack of “discipline and quality”, traits accepted as inherent to impoverished communities which are, given South Africa’s apartheid past, also Black communities. As noted earlier, the critiques I present in this work are not intended as criticisms of particular service providers. Yet, we must consider the discourses which service providers like Mia may be replicating, especially in light of South Africa’s political history and complex socio-economic landscape. We must also consider the racialised fantasies of degeneracy which might shape service providers’ ideas about the tendencies of poor, Black and disabled people, and underpin the drive towards control, discipline and the imperative to cope discussed earlier (Hook, 2012; Hughes, 2019; Watermeyer, 2013).

7.1.1. The influence of racial and socio-economic privilege on experiences of rehabilitation services

At this point, let us pause to briefly consider the racial dynamics of these organisations. As stated in Chapter 3, the research design did not include an audit of organisation staff and beneficiary demographics. However, based on the sample of participants, as well as impressions formed during the research process, some broad inferences can be drawn. In terms of service providers, Organisation A appears to include the most racially diverse staff compliment, as well as several visually impaired staff members and one senior manager with a visual impairment. The vast majority of service providers at Organisation B and Organisation C are White, while the vast majority of service providers at Organisation D are Coloured. Organisation D also includes several visually impaired staff members and one visually impaired person in senior management. As mentioned, all but one of the potential participants from Organisation A, Organisation C and Organisation D were people of colour, while all of the potential participants from Organisation B were White.

The services offered by Organisation B are unique in that, rather than full-time skills training programmes, the organisation provides individual consultations, advising service users about coping with sight loss and appropriate assistive devices. The organisation also offers monthly support groups facilitated by service providers. These services appear to provide greater space for active participation from service users. Notably, this organisation stands out as an exception in regard to rehabilitative relationships and, to some extent, organisation culture. While service providers at Organisation B position themselves as drivers of the rehabilitation process in much the same way as the other service providers, they demonstrate a more relaxed attitude towards relationships with service users. In contrast to the extracts cited above, the service providers from this organisation described relationships with service users as friendships built over time and through sharing the emotions associated with the rehabilitation journey:

> [T]here is a sense of friendship and a lot of the relationships have moved to a different place.
> – Kay

> [W]hen…you've shared tears with people, you're changed…you don't just move away from that…there are people who become friends.
> – Helen

It is interesting to note in these extracts how the building of friendships with service users is not discouraged as a hindrance to the rehabilitation process. As stated, service providers as well as the vast majority of service users at this organisation are White, middle-class women over the age of fifty. While this demographic similarity may explain the ease with which relationships formed, shared racial identity or stage of life did not seem to disrupt the strict relational boundaries found in other organisations, as we saw in the above extracts from Kelly, John and Melissa. It is also notable that service users from this organisation did not describe the sense of being drawn into the fabric of an organisation and becoming subject to certain institutional practices as others did. In light of deep-rooted racial inequality in South Africa, it is worth considering how the racial and socio-economic privilege of the service users at organisation B combine to position them on a more equal footing with service providers, and impact their experiences of rehabilitation services.

Regarding livelihoods, the circumstances of the service users at Organisation B are considerably less dire than those of the service users at the other three organisations. Although the majority of participants from Organisation B have reached retirement age, the positive impact of their access to financial resources, assistive devices and family support can be seen in their accounts of the onset of sight loss, exiting the workforce and moving into retirement. Those who did experience sight loss during their working lives had the option of medical boarding with sufficient compensation and/or family members able to financially support them. However, it is notable that only one participant out of the four in this organisational cluster described receiving reasonable accommodation in the workplace while the others described situations where they felt compelled to leave their employment. This suggests that the low rates of retention in employment for persons who acquire disabilities cut across racial and socio-economic status. Although leaving the workforce was an emotionally difficult process for several of these participants, their experiences form a sharp contrast with those recounted by individuals from already disadvantaged circumstances. This is demonstrated by comparing the circumstances of Henrietta and Nikita. Henrietta exited employment early, at the age of fifty-six, once her visual impairment began to impact negatively on her productivity. She moved into retirement with a pension while her partner (the main breadwinner) continued to work for several more years. She has access to various assistive devices and private transport. In contrast, Nikita (currently aged fifty-six) is a single parent and was, up until the onset of her visual impairment, the sole breadwinner. She lost her job as a packer in a factory and now subsists on a government disability grant. She has attended (and continues to attend) training services at various blindness service organisations in the hope that she might be placed in some kind of employment.

It could be argued that the difference in experiences of rehabilitation services between service users from Organisation B and those from the other three organisations has simply to do with the age of the majority of the service users attending Organisation B and the resulting fact that the services at this organisation have a different focus. However, the above comparison of Henrietta and Nikita suggests that there is significance attached to the racial and socio-economic privilege of the service users at Organisation B. Further, the lack of racial diversity in the other organisations begs the question of where Working-age, White people with visual impairments are located. My own experience suggests that the largely favourable circumstances of the majority of White South Africans enables them to avoid much engagement with public welfare and exposure to the disciplinary practices of organisations. However, as discussed in Chapter 2, we must be careful not to draw simplistic conclusions about the situations of individuals as this might hinder their access to services. For example, a participant shared the difficulty she experienced in accessing an organisation's transport service: "'How can you not have a car?' Those were things that were brought up to me…my White privilege…was very against me there…the collective White privilege".

For almost all of the participants from Organisation A, Organisation C and Organisation D, their disability grant is their only source of income. Only two of these participants were medically boarded, having worked in sales and insurance. Other participants were employed as factory workers, shop assistants, one was a sound technician and another a lab assistant, while others were unemployed prior to the onset of their visual impairments or were first-time job-seekers exiting high school. Like Nikita, many of these individuals were the sole breadwinners in their families prior to losing their employment and all face the significant barriers to accessing education and other resources which characterise South Africa's racialised socio-economic landscape. Assisting individuals to regain or attain gainful employment is, therefore, a central priority of Organisation A, Organisation C and Organisation D, which may account for the disciplinary practices discussed in this chapter. However, two questions to consider as we proceed are, firstly, whether it is possible to rethink these practices, particularly in light of the accounts of service users who feel disregarded as autonomous adults and equal stakeholders and, secondly, what these practices do in the lives of visually impaired persons, particularly those who are further marginalised.

7.1.2. Service user perspectives on rehabilitative relationships

We turn now to service user perspectives. For many service users, entering rehabilitation organisations restored some sense of belonging as they felt drawn into an understanding community. When asked about their relationships with service providers, of central importance for service users was having the sense that they were supported and understood by the service providers they engaged with:

> [S]he's very, very supportive and what I love about her, she says, "Take your time, don't rush"…that's what I love about how she does have the patience.
> – Roeshdie

> [T]he people and the environment is so friendly…everybody around is always wanting to help you and they want you to achieve things.
> – Nyska

> [W]ith [service provider]…I'm very free, I'm open with her, I can talk anything I want to talk with her and she's also a person that is free-spirited and let a person feel comfortable…actually, that's how I feel…with everyone…they make a person feel comfortable.
> – Andi

> I can speak my mind, they would understand, they're very understanding so that makes it very easy for me to go to them and speak to them about anything.
> – Mike

These extracts describe service providers as supportive mentors who service users look to for help and advice. For Roeshdie and Nyska, this support is connected to the rehabilitation process; both describe patient and positive service providers guiding them through skills training. For Andi and Mike, two of the youngest participants in this study, service providers appear to be a source of guidance on broader issues not necessarily related to the rehabilitation process. Kelly, a service provider, also gave this impression when she described young people coming to seek her advice. She said: "They're young ones…they'll talk about, 'So how did you meet your husband?' and we'll talk about dating issues…I don't mind investing in them in that way". She recognised that there was often a lack of family support and that she was, especially for younger service users, an important source of information and advice.

From the above extracts it is clear that relationships with service providers can be an important source of encouragement and assurance for service users, not only in their rehabilitation processes, but also as they negotiate other aspects of life with visual impairment. What many service users reported to be lacking in their relationships with service providers, however, was the sense that they were viewed as adults on an equal footing – that service providers wanted to connect with them on a personal level and saw them as more than simply the recipients of their work:

> [Service provider] is good in facilitating and we don't talk with personal or other stuff, we just focus on what we're doing…she is always busy with the computer…so I'm not sure if she will have time to chat, maybe just to chat…for 10 to 20 minutes…but the problem is she's always focusing on the computer.
> – Nohombile

> When it's graduation time then they are very welcoming, they hold functions and invite the students…we're part of [organisation] so we can be part of such things. But one time there was a blind man here from overseas…we got name tags that were stuck onto us…they spoke about how blindness is handled in America and in Australia and here…then they gave opportunity for questions…and there wasn't an opportunity for us to ask questions and we're the people who have to live with blindness, it was the staff members who asked the questions…those are the things that make us so angry.
> – Nikita

> [T]he staff is keeping…a professional face…they don't have too much personal conversations…this is an adult institution, the boundaries will still need to be there but not necessarily saying that…the staff cannot be friends with the clients because…who must be friends of the blind if they themselves, as an organisation, they can't be friends with the blind…when it's lunchtime the staff go to the staff room and the clients must go that side, it's almost like they don't want staff and clients to mix.
> – Vusi

> [T]hey try to be friendly, they try to say they have a relationship, they'll come into the Braille room and say hello to everybody…but it didn't feel genuine to me.
> – Belinda

These extracts describe how the relational boundaries adhered to by most service providers, viewed as essential for efficient service provision, can be experienced by service users as cold, detached and uninterested. They sketch a picture of the power dynamics characteristic of organisation culture, the maintenance of an 'us' and 'them' separation within which service users can feel dismissed as individuals, equals and adult stakeholders. Both Nohombile and Vusi express a desire for greater personal connection with service providers and are met with responses that feel like rejection. Belinda describes interactions with service providers which suggest a degree of inauthenticity, leaving her unsure about the motives and sincerity of service providers. Nikita describes how service providers can behave inconsistently in relation to including service users. She recounts a particular incident where service users felt overlooked and silenced by more dominant voices. Her special mention of the name tags service users were given at this event is interesting. These name tags seem to signal something about being included as part of the organisation at this special event, which is then contrasted with the reality of being unable to have her voice heard, being denied recognition as a stakeholder and an expert in her own experience of sight loss and blindness. There is also something subtle in her statement "When it's graduation time then they are very welcoming" which suggests an organisation public face at odds with the reality experienced by service users. In fact, several service users expressed this, which is an issue I will return to below. Vusi recognises that the way in which service providers interact with him is likely to be mirrored in the outside world; as he said: "Who must be friends of the blind if they themselves, as an organisation, they can't be friends with the blind". He recognises a precedent set by organisations and their workers for how visually impaired people may be viewed and treated in society. In these extracts, we can see the interplay of power, knowledge and practice as the behaviour of those positioned as experts signals to service users about their status in the organisation and society more broadly (Drinkwater, 2005; Sullivan, 2005). In other words, these accounts demonstrate the ways in which rehabilitative relationships produce knowledge for service users about who they are and how they can expect to be viewed in the world.

In contrast to these service user accounts, several service providers identified respect as a value which underpins their work. According to their accounts, respect is demonstrated primarily through listening to service users and viewing them as individuals:

> [W]e really value the integrity and individuality of each client. We really try and stop and listen to the experience of the client and then try to work from there. We try to see the other person as someone of value and somebody who can contribute…we try and be as objective as we possibly can.
> – Kay

> [W]e are about listening to our clients needs, we don't craft a programme to serve our interests, we're always listening to, where's the gap, what do you feel is needed…we speak to the most marginalised of the blind community, we listen where the needs are and then we try to address from that angle
> – Kelly

> [T]o always see the family, the child, the client for who they are as opposed to only just seeing somebody who has a visual impairment, but to…see the person, I think that has got to do with how it is that you work with a sense of integrity and you work with a sense of respect.
> – Isabella

In light of Chapter 6, these extracts demonstrate an interesting paradox – that organisation values which appear to strengthen a service-user-led approach to rehabilitation are couched within the strictly defined concepts, processes and outcomes which frame rehabilitation services. There is, I suggest, a notable clash of ideals in several service provider accounts, as a person-centred and holistic approach taught to rehabilitation professionals comes up against two things; firstly, the deeply entrenched discursive practices in rehabilitation framed by a charitable model approach to disability and, secondly, the kinds of fearful fantasies about blindness sketched in the previous chapters. Thus, these service provider extracts, which aim to prioritise individual experiences and needs, exist alongside the imperative to cope, practically and emotionally, seen earlier. These ideals also seem to be in conflict with organisation cultures underpinned by strictly defined principles of independence, productivity and coping. Furthermore, in these extracts the separation between service providers as authoritative professionals and service users as passive recipients is subtly maintained. Specifically, the principle of listening to service users does not appear to disrupt the powerful positioning of service providers as ultimately in charge of the design and implementation of interventions.

The work of Drinkwater (2005: 267–268) offers us an explanation. He asserts that "the discourse of valuing" found in supported living organisations, in fact, obscures the workings of power-knowledge in relationships between service providers and service users. He states:

> It is as if values cancel out power…employees of the service agencies are exhorted to think constantly about values, rarely about power, never about power relations between service users and support workers—except where service users are deemed to behave in a "manipulative" fashion, in which case *they* are seen to attempt power play over *us* (Drinkwater, 2005: 267–268).

Drinkwater suggests that within power relations between service providers and service users, choice represents "a perpetual anxiety, a threat of disruption, unsettling of order and a constant object of negotiation and correction" (2005: 274). This can be seen in the following section in service provider and service user descriptions of communication channels and whether and to what extent service users were able to participate in decision-making at an organisational and individual level.

7.2. Communication and Transparency

Throughout their interviews, service users raised various concerns about daily life at organisations. These issues included the quality of food they were served, strict rules which felt patronising, whether the training they were receiving was properly accredited, and how donations of funds and goods were being managed. It is notable that many of the issues raised across service user data were not directly connected to rehabilitation services, but were related to organisation culture. Although the acquisition of essential skills felt lifechanging for many service users, this was set against a backdrop of institutional practices that felt problematic. Pumla, a service user, explained this when she said: "Beautiful service as far as training goes, yes, but whatever is connected with that, no".

An overarching issue raised by most service users was a lack of communication and transparency within organisations. Below are two examples of service users describing situations where they felt that they were being denied access to certain information and excluded from decision-making processes:

> [T]here are things that they don't tell us exactly…we used to have coffee in the morning, but suddenly they stopped that…nobody has told us exactly what is happening…I don't know whether…is running out of money…they decided by themselves…without consulting us…I think they were supposed at least to tell us what exactly is happening…we are all upset about that…we ended up…blaming those staff kitchen, maybe it's them…who are lazy.
> – Aubrey

> I think if they can disclose more information so that people don't assume things…they tend to hide…information, than to give out the information so that decision can be made…or students, they can take and make their own decision.
> – Lifa

Aubrey's extract offers us a glimpse into something of daily life at organisations. His experience demonstrates a connection between lack of communication and feelings of mistrust. Although they were based at different organisations, it is interesting that what Lifa speaks to in her extract is enacted in Aubrey's – that lack of transparency leads to assumption, suspicion and lack of trust at organisations. Central to both of these extracts is that service users feel excluded as stakeholders. For Aubrey, the removal of morning coffee is not his key concern. Rather, he and his fellow service users are upset by their exclusion from the process of decision-making and the apparent concealment of information. Similarly, Lifa's account suggests that service users experience an intentional concealment of information at organisations, preventing them from being able to make choices for themselves. These extracts sketch a picture of rehabilitative relationships that include an underlying tension, and organisational culture that, as Drinkwater (2005) suggests, has a conflict of interests at its core.

In response to questions about communication and transparency at organisations, service providers explained that there were available communication channels for service users to raise concerns or voice their grievances. The maintenance of these communication channels, I suggest, forms part of the professional approach to service provision described in the previous section. Specific protocols for communication between service users, service providers and organisation management may be intended to strengthen the relational boundaries we saw above. With this in mind, several service providers suggested that, while there were established channels to deal with their concerns, service users often became impatient and disgruntled because they were not able to understand the operation of professional procedures:

> There are channels, what has happened once or twice is when…the client thinks to himself, "No, but the manager is taking too long to deal with this" but then not quite understanding that administratively this needs to be dealt with…you need to understand that there is certain protocol that you would have to follow, so that is something that was then carried over professionally, so now clients understand that.

> – John

> [S]ometimes clients don’t understand that…there’s channels that you have to go through to get that problem to the manager…because you don’t hear feedback, you think that nothing has been done, but things are being done, the communication is there through channels…so that is where clients must understand the communication thing.
> – Melissa

The idea that service users are unable to grasp organisational systems and procedures, I suggest, can serve to legitimate their subordinate status within organisations and might, therefore, allow their concerns to be more easily dismissed by service providers and management. In other words, there is a sense in several service provider accounts that service users cannot be positioned as stakeholders because they lack the insight needed to make certain decisions. In addition, there is a suggestion in the above accounts that grievances arise and are aggravated because of a lack of understanding on the part of service users.

Similarly, Mia suggested that service user grievances were connected to their inability to understand certain concepts. In the below extract she describes an ongoing and escalating situation at her organisation where service users were wanting access to a stipend used to subsidise the organisation’s residential facility. She explained how service users were confused by the term “stipend”, believing that this money should be paid directly to them instead of being administered by the organisation to provide there food and lodging:

> [A]ccommodation and food and transport…all the services…is covered by the stipend but the students, in the world that they come from, stipend means money, so the moment the word stipend is used and they understand that there’s money paid for them, it change the whole dynamics and then people feel…“I want the money…the money’s supposed to come to me.”
> – Mia

Mia draws a connection between where service users come from and a lack of understanding, suggesting that, because they are poor, service users are not able to recognise the benefits they receive from the money being managed on their behalf. Again, we can see a clear delineation of roles as service providers are positioned as the experts who know what service users need, and service users are viewed as lacking discipline, understanding and the ability to manage their own needs. The interplay between powerknowledge, choice and stakeholdership, noted earlier, is evident here (Drinkwater, 2005). Several service users attending this organisation mentioned the issue of stipend management in their interviews, providing a contrasting account. They explained that, at the heart of the conflict, was the issue of choice. Service users felt that they should have the choice to either stay in the hostel or draw their stipend and make their own arrangements. As one service user said: “I think it would have been better if they were given that choice, I don’t think students will have left because of that”. It was felt that the majority of people would, in fact, choose to stay in the hostel, but what was at stake for these service users was their agency.

At this point, let us pause for a moment to consider how a charity model of disability can stifle the ability of service users to act as agents in their own processes of rehabilitation, growth and development. Unlike in some Global North contexts, South Africa does not have a direct payment approach to services and assistive devices, which would allow service users to access and manage their own funds. Rather, public and private funding is channelled to the organisations responsible for providing rehabilitation services and related benefits such as meals, accommodation and transport. This aspect of the policy environment underpins the divide we have seen throughout the foregoing discussion – that service providers are the dispensers and service users are the receivers of charity. Furthermore, we must consider how the positioning of service users within organisations, as objects of rehabilitation work and charity, as ill-equipped to make certain decisions for themselves and as lacking the understanding to be furnished with certain information, may leave impressions which are carried into their new lives as disabled people. There is, I suggest, a broader social price to being positioned as a receiver of charity, as Longmore states: “Anyone resorting to public welfare or private charity is regarded as neither fully a person nor legitimately a citizen” (1997: 151).

> It is unsurprising, therefore, that when asked how their relationships with service providers might be improved, a majority of service users spoke about the need for better communication and greater transparency. Even where they recognised established communication channels, service users felt that they were not being heard and that their grievances were being disregarded by service providers:
>
> Yes we are able to make a complaint but they don’t listen to us.
> – Nikita
>
> If ever…they can do this way…the staff meet us maybe in the hall and speak to us…instead of them having their own meetings but having the meetings with us as well…to know how do we feel and what do we want, what is our complaints…I think that will be better…calling us together as the students and the staff…to share with them at least for more than 30 minutes…I think that can make our relationship more good.
> – Aubrey
>
> It’s all about communicating which they don’t do…if we as [organisation] can also have that meetings with the students and with everyone because at the moment we don’t know where is [organisation] heading, what is their financial records…
> – Roeshdie

> We do have…a clients meeting where…each and every one of us would raise whatever concern they have…food has always been on the table many times…I used to be the one who used to raise that concern but I no longer…because I've noticed we're not getting anywhere when it comes to that…and the sad side would be the response sometimes when we raise these issues…one of the staff members will respond as if we're ungrateful…
> – Vusi

These service users express the desire to be recognised not only as autonomous adults but as valued stakeholders who are able to influence both day-to-day operations and the long-term strategies of the organisations they are a part of. Elsewhere in his interview, Roeshdie said: "We don't even know who's the board, we don't even know who's everybody on staff…it really, really hurts me as an individual because I know you need to know your leaders". It is interesting that Roeshdie does not appear invested in subverting existing structures. Rather, it is his exclusion as a valued member of this organisation, demonstrated in that he does not know the leadership, which hurts him. In Vusi's extract, it is noteworthy that gratitude is juxtaposed with questioning organisation procedures and hierarchies. As a result, Vusi must balance his legitimate concerns with an expectation that he express gratitude.

A further issue raised by service users with regard to communicating grievances was that they felt unable to "speak up" or "speak out". Both Monique and Lifa suggested that this has to do with a combination of factors including language, age and feeling intimidated:

> Most of us…cannot speak Afrikaans but all the staff do…[students] always complain…their teacher, sometimes he speaks Afrikaans during the teaching but they don't understand it…and they don't…speak up…they just keep quiet about it…I think they are scared or shy or something, I don't know.
> – Monique

> I think there is good communication with us older and people who are outspoken, but for the rest of the students I don't think there is much relationship because some students are not free to speak out…I'm not sure whether it's because of the language barrier, because they cannot express themselves well, so they rather keep the stuff in them and talk about it when they are with their peers…which is not helping in the situation where you have to address something.
> – Lifa

These extracts describe an imbalance of power where service users, especially those who are young and Black, feel unable to approach service providers to communicate their concerns. In Monique's account, in particular, there is an unsettling resonance with South Africa's apartheid past in her description of young, Black people being taught in Afrikaans[11]. Elsewhere in her interview she described how, while some service providers encouraged service users to speak their home languages, others did not allow this during class time. Monique related this response from a service provider: “She’ll be like, ‘Well, you guys wouldn’t like me speaking in Afrikaans, so I don’t understand if you’re talking about me or something’”. In this, we can see how language is embedded in the prevailing power structure. Language can also be experienced by service providers as a threat – a power play on the part of service users (Drinkwater, 2005). This is reminiscent of the mistrust expressed by Melissa in her question about what service users might say behind her back.

Lifa asserted that when service users did not address grievances directly with service providers but discussed these amongst themselves, this was fuel for assumption, suspicion and mistrust. We have seen that service users expressed doubt about the motives and sincerity of service providers, as well as whether and to what extent information was being withheld from them. In addition, several service users expressed the sense that they were not trusted by their service providers. This was particularly connected to the strict rules that both service users and service providers were expected to adhere to. For example, Nikita shared this experience:

> They ask a lot of questions about a lot of little details…if your facilitator asks, “Where were you yesterday?” And I tell her where I was and then she won’t believe me and then she says I’m lying…last week I went to the SASSA[12] office, we needed to change the SASSA card…so I stayed at home on Monday…then when I came here she asked me and I answered her…then she asked me if I had proof and I said, “No, I don’t have any proof because they didn’t give me any proof” then she said I could be lying and I said, “I wouldn’t lie”…
> – Nikita

This extract provides further evidence of the exertion of power through the institutional practices which surround the provision of rehabilitation services. Nikita and others are subject to certain strict rules and procedures which limit their agency and demand compliance. In this episode, Nikita was subject to the control of an authoritative service provider who required that she account for herself. She was no longer able to make decisions about when and how she would go about the daily tasks of life. Rather, having been drawn into institutional life, she must recognise her subordinate position and be prepared to prove her whereabouts. Once again, this extract suggests that the ‘us’ and ‘them’ split between service providers and service users is at times laced with mutual suspicion. As she told this story, Nikita also stressed that she was a grandmother with responsibilities that sometimes took her away from training. She said: “I’m a grandma of three…and if their father goes out and their mother goes out they must ask me and then what? Must I say no? Where must the

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[11] Education under apartheid was racially segregated according to the Bantu Education Act (1953). This brought all schools under the control of the State. In 1974 the apartheid government issued the Afrikaans Medium Decree, which forced all schools to adopt Afrikaans or English as their language of instruction. This meant that, in addition to the lack of funding, resources and infrastructure in Black schools, Black learners and teachers were now prohibited from using their home languages in education. This sparked the 1976 student uprisings in Soweto.

[12] The South African Social Security Agency

children go?" Another service user, Aubrey, also spoke to this when he said: "They forget…some of us we are elders and we've got responsibilities". What we see here are individuals having to navigate institutional life, which includes the controlling and limiting practices which frame the shaping work of rehabilitation and how these complicate their positions within families and communities. In this, it seems clear that the disciplinary power of rehabilitation is not open to being disrupted by concerns pertaining to the individual lives of service users (Sullivan, 2005).

Closing this discussion, I want to return briefly to a question posed in response to the review of public face material about what encountering such material might feel like for service users. For some, encountering this material fed into the mistrust we have seen throughout this chapter alongside the sense that they were not viewed as stakeholders. Several service users expressed anger and frustration at encountering organisation public relations activities presenting rehabilitation services in ways which contrasted sharply with their experiences:

> There are a lot of talks that they do on the radio and it actually makes a person angry when you listen to what they say…the promises that they make on the radio…then it's not true, then they don't do it.
> – Nikita

> [A]t the AGM they paint this beautiful picture…within their newsletters they paint the most beautiful picture about this place, and it's lies, it's blatant lies.
> – Pumla

Resonating with what we saw in the review of organisation websites, these service users suggest that organisations might be invested in a particular narrative – as Pumla put it, "a beautiful picture". Their accounts assert that what organisations present is often at odds with the reality experienced by those undergoing rehabilitation. These extracts describe real anger at the perceived way in which organisations misrepresent themselves in the public realm. But while Nikita and Pumla encounter organisation narratives, through radio and other media, they are in no position to question or counter the public message broadcast by organisations about them. This, too, is based on a foundation of charitable discourse which, these findings suggest, continues to frame rehabilitation for visually impaired people in South Africa. I now turn to a discussion of how this discourse underpins a culture of 'grateful receiving' in organisations, which appears to further erode service user agency and sense of self.

7.3. A Culture of 'Grateful Receiving'

In line with Scott (1969), I have suggested that a key currency in relationships between service users, service providers and public donors is gratitude. In this arrangement service users are expected to display gratitude in exchange for the assistance they receive from both altruistic service providers and a generous public. In Scott's

(1969) study he found that there are serious costs for those who resist this organisational and social demand for gratitude, and consequently blind individuals come to understand that it is simply more expedient to comply. He states:

> [E]very blind man [sic], whether he [sic] accepts or rejects the social identity imputed to him [sic], will be found to acquiesce at least some of the time. For example, several blind people have told me that when they use public transportation, fellow passengers will occasionally put money into their hands. When this occurs, a blind man [sic] cannot very well give a public lecture on the truth about blindness; in fact, to do anything but acquiesce and accept the gift will leave him [sic] open to charges of ingratitude and bitterness (Scott, 1969: 23).

As mentioned in Chapter 4, Scott (1969) further asserts that, given the bound up nature of rehabilitation and charity, gratitude is understood as the only form of reciprocation available to those who receive services.
Rehabilitation services operating as welfare do not release recipients from the burden of reciprocation, but demand proofs of gratitude from service users in exchange for the generosity of workers and donors (Scott, 1969; Hughes, 2019). This, according to Hughes (2019), is indicative of a long-established history of charitable giving which holds the validity of the giver at the centre, validating their generosity and maintaining the indignity (in fact, the inhumanity) of disabled persons in the non-disabled imaginary and actual social structures.

When asked about what motivates them, many service providers described their work as personally fulfilling and rewarding. For some, this was directly connected to the gratitude they received, or expected to receive, from service users:

> [T]here are times when you think of the primary person that trained you right from the scratch, you always think about that person…this person made a major impact in my life, now look where I am…
> – David

> [Y]ou feel that you mean something to the students…it's not like at the normal college where the students are there because they wanna be students…the blind students, I think they appreciate what you are doing.
> –Donelle

For these service providers, gratitude on the part of service users is assumed. As previously discussed, it is interesting to note that David is referring to me, suggesting that I must surely spend time thinking about the service provider responsible for my creation, in gratitude for my shaping into an "asset". Similarly, Donelle suggests that, unlike students at a "normal college", the young people she teaches truly appreciate what she does for them. There is something subtle in these extracts, and especially in David's imagining of my enduring gratitude, involving a fantasy of ever grateful service users, which confers value onto both service providers and their work.

Similarly, service user accounts recognise an expectation of gratitude. Many of these accounts express concerns about the quality of food served at organisations, but balance these grievances with expressions of gratitude. Three out of the four organisations included in this phase of the study provide daily meals for service users. Complaints about these meals were found across much of the service user data and the issue of food was a recurring answer to questions about the challenges service users face at organisations. Below are several examples, which offer us a further glimpse into daily life at organisations and how material realities may carry value-laden meanings:

> [T]he spaghetti, it's very, very soft, as if…they're going to feed…a baby who's like six months old…and there's no veggies, there's no fruits, not really very healthy but then it's food at the end.
> – Nohombile

> In the beginning…when I came here…[staff member] was in charge of the food, he'd buy it and then every class would get their food and then you could help yourself…milk, tea, coffee, sugar, butter and bread, spreads…and then, later…there were people that cooked, we ate off glass plates, glass cups and saucers and that was good, it was nice to eat off of a glass plate…and now that's shifted and that part, for me, is worse, you now eat off of a plastic plate, drink out of a plastic cup and nobody likes that because…it's not always properly cleaned…they also complain that the food is not always nice.
> – Nikita

> [J]ust putting the food in front of them and not even telling them that the food are there…I saw this with my own two eyes, they give leftovers from yesterday's food for the students which then doesn't taste nice…I feel that is so wrong because you need to, like you treat your customers outside, treat your students inside as well.
> – Roeshdie

> The food? You really wanna know? (laughs)…the food is horrible, out of seven days five times you'll eat crap and maybe two days it'll be nice.
> – Vusi

Before turning to the ways in which these grievances are balanced with gratitude, let us consider how service users describe unappetising food served on plastic plates and in a way that feels careless – as Roeshdie said: "Just putting the food in front of them and not even telling them that the food are there". In Chapters 2 and 3 I discussed how discourse is both constituted by and productive of social and institutional practices and, therefore, that materiality should not be excluded from conceptualising the interplay of discourse, power and knowledge (Hook, 2007; Tremain, 2017). In exploring the "physicality of its effects", we are able to apprehend the force of discourse (Hook, 2007: 122). There is something evocative about the descriptions above – the overcooked spaghetti, the leftovers and the dirty plastic plates. If we view these practices as discursive, we must ask what it is that they do (Hook, 2007; Tremain, 2017). I argue that the practices described above are both instruments of and results of power-knowledge in rehabilitation. They emerge as a result of societal and professional knowledge about what it means to be both a user of public welfare and a blind person, and also build into this knowledge. They may be important signals, communicating to service users that something significant concerning their social status has been lost. In this regard, Nikita's account is particularly interesting, describing notable changes in organisational ethos over time and a concerning regression in service user status at this particular organisation. Her account hints at the pervasive nature of charitable discourse in South African rehabilitation, as well as a seemingly uncritical approach to organisation activities in terms of what these might communicate to service users.

As mentioned earlier, one of the organisations included in this phase of the study was exceptional in terms of both rehabilitative relationships and organisational culture more broadly. As noted above, service users from this organisation did not describe becoming subject to institutional practices in the same way as others did. For example, one service user said: "They serve us so lovingly…they tell everybody what is on the plate in front of them…they make sure that everybody has access to everything that is offered easily, sensitively".
That this account forms a stark contrast with those cited above is not to say that this particular organisation is free from paternalism or the kinds of charitable discourse described throughout this work. In order to understand this exception, we must recognise the interplay between disability, privilege and place, which requires a critical questioning of the spaces individuals come to occupy within a South African disability landscape that is still deeply racially and socio-economically divided (Botha and Watermeyer, 2018).

As mentioned above, the concerns raised by service users were often offset by expressions of gratitude. This was something which service users seemed to understand as an expectation placed upon them as receivers of free services. Expressions of gratitude found in service user data often read as responses to an imperative demanded by organisational culture rather than as unmotivated thankfulness. The below accounts present examples of how the grievances brought by service users exist alongside an imperative to maintain an attitude of grateful receiving:

> [T]he food is not…nice, It's not nice at all but I appreciate it because I'm not paying anything for the food but it's not okay, it's not okay at all.
> – Nohombile

> [T]hey also complain that the food is not always nice but we must be content with that because we are just students.

> – Nikita

> [W]e raised an issue about food and then one of the staff members will respond as if we're ungrateful. Whenever I raise such I would say, "I'm not saying this because I'm ungrateful or I'm not being thankful, but I'm saying this as a concern"…then they respond to my concern would be, "But there are people who don't have food"…so anyway, I must just say thank you, at least I have food.
> – Vusi

In her earlier extract, Nohombile conceded "But then it's food at the end", in spite of her complaints about unappetising and unhealthy food. In this, as well as her above-cited statement "But I appreciate it because I'm not paying anything for the food", there is resignation, a sense that, because she is a receiver of charity, she must appreciate what she is able to get. As with those service users cited in the previous chapter, who expressed disappointment in the limited job placement assistance they had received, these service users seem to understand that they must appreciate what they do receive. In these above extracts we can also see an imperative to be grateful, in Nikita's phrase "We must be content with that" and Vusi's "I must just say thank you, at least I have food". Added to this, Vusi's care in framing his concern "I'm not saying this because I'm ungrateful" suggests that there might be a cost attached to being viewed as non-compliant (Drinkwater, 2005; Scott, 1969). The vulnerability of service users who have in many cases come from dire circumstances – affected by loss of work and income, dislocation from society and self – may limit their ability to resist the demands of organisational culture. I began this chapter with a quotation from Belinda: "it's just the way they treated adults was really taking something from them". In many ways this statement is a summary of the discussion presented in this chapter, that for many service users the experience of receiving essential rehabilitative interventions, was also an experience of loss – the eroding of status, agency and identity. In this work, the vast majority of service user accounts describe experiences that are paradoxical, where the gaining of important techniques exists alongside assaults on the self, and where individuals can feel supported, understood and accepted, and yet disempowered.

Conclusion

Service providers locate themselves and their work within particular ideals – professionalism, respect and the valuing of individuals. Service users, on the other hand, described their relationships with service providers as inconsistent. Drawing on Drinkwater (2005), I argue that at the heart of these contradictory perspectives are dynamics of power-knowledge which are not acknowledged. Although the language of empowerment is used throughout organisation public facing material, it appears that this does not refer to service users occupying positions of power in terms of organisation structures. Rather, empowerment appears to be defined in line with Drake's (1996: 152) critique of the traditional charity as: "the overcoming or assuaging of individual incapacities in the every day lives of disabled people".

Taken together, the findings presented in Chapters 5, 6 and 7 offer an insight into a layer of experience in rehabilitation which can easily be overlooked. Using a discursive lens has enabled us to consider the impact of rehabilitation services not at a practical level but at the level of meaning. In other words, this work has questioned how these services might be involved in shaping the subjectivity of blind persons – in short, telling them who they are, where they belong and how they are expected to behave. We have seen that the experience of rehabilitation can be paradoxical, as individuals receive essential, even "life-changing",services, while having to navigate a new sense of self and belonging against a backdrop of limiting rehabilitative discourse and institutional practices which can strip them of agency, stakeholdership and citizenship. This work prompts us to consider what a more empowering environment for the receipt of rehabilitation services might look like, and how services could be provided in ways which disrupt prevailing power dynamics and organisational cultures.

Finally, unpacking the discourses and connected fantasies about blindness which have come to frame and support rehabilitative practices sheds light on a societal investment in promoting particular ways of being for visually impaired people, prompting us to consider what service providers, service users and, indeed, all of us might be colluding with in terms of an acceptable blind subject (Kleege, 1998; Michalko, 1998; Scott, 1969). Understanding a layer of experience in rehabilitation beyond the practical, at the level of identity, is crucial if organisational cultures and problematic institutional practices are to be transformed.

CHAPTER 8

CONCLUSION

Visually impaired participants in this study described the onset of sight loss as a significant trauma – a dislocation from society and self. We have seen how very real experiences of isolation, exclusion, fear, depression and vulnerability signal to those experiencing sight loss that they are no longer who they once were. The onset of visual impairment draws individuals into a framework of meanings about blindness within which they must navigate a new sense of belonging and of self. I began Chapter 1 with a quote from Scott (1969), where he suggests that visually impaired individuals, particularly those who experience sight loss as adults, draw on knowledge about the lives, behaviours and capabilities of blind persons produced within society in order to make sense of who they are and where they now belong. As we have seen, the cultural beliefs about blindness which underpin this knowledge are overwhelmingly negative and fuel anxious fantasies involving descending darkness, dependency, incapability, need and loss of control. This prior knowledge about blindness shapes the expectations that those who experience sight loss have for what their lives will be like, as Pumla said: "I thought you just sit there…you sit there and you be blind, that's what your life is gonna be like now". We have also seen how, mingling with an internal suspicion that life will be very different, the responses of medical professionals, employers, communities and families signal to those who lose their sight that something about their identity and their status in the world has been irrevocably changed.

In short, those who experience visual impairment have to navigate not only the reality of sight loss – the material effects of blindness – but also a societal view of blind persons as inherently incapable, needy and degenerate. Understanding this is essential if we are to grasp not only the physical circumstances but also the emotional state and subjective position which individuals entering rehabilitation find themselves in. Furthermore, this understanding sheds light on the position of influence occupied by rehabilitation organisations and workers in relation to individuals who can feel set adrift in the world. Resonating with Michalko (1998), this work recognises rehabilitation as significantly influential in shaping the subjectivity of blind persons, not least of all because of the dislocation experienced by many prior to entering rehabilitation services. In other words, I suggest that, given the trauma of sight loss and related experiences of exclusion, those who come to rehabilitation might be particularly vulnerable to being told who they are and how they must behave in order to regain some sense of self and place.

8.1. Two Overarching Discursive Practices in Rehabilitation

This study has investigated the operation of discursive practices in organisations providing rehabilitation services for visually impaired adults in South Africa. It has attempted to sketch a picture of the discursive framework into which those who come to rehabilitation services are drawn and to understand the significance of rehabilitative relationships in strengthening this framework. It has traced the interplay between discourse, power and knowledge in rehabilitation services, as well as the ways in which anxious fantasies about blindness influence the design, implementation and management of services for visually impaired persons. The key findings presented in the preceding chapters can be summarised into two overarching discursive practices, which can be traced across organisation public facing material, and rehabilitative activities and relationships. These are, firstly, the discursive construction of rehabilitation as a journey, which underpins an imperative to cope found within organisations, and secondly, the discourse of rehabilitation as charity/goodwill, where service users are positioned as passive beneficiaries in relation to active service providers and a concerned public. Below, I summarise each of these in turn, drawing together threads from across the four previous chapters, before turning to some recommendations and closing reflections.

8.1.1. Journey discourse: prescribing acceptable ways of being for visually impaired persons

Across both the sampled public face material and the interview data, rehabilitation is constructed as a linear journey. The end point of this rehabilitation journey is a service recipient who demonstrates that they are able to cope in spite of sight loss. This work has not questioned the value of rehabilitative interventions, nor has it sought to obscure the significance of coping, managing and thriving for visually impaired persons who might have experienced profound exclusion. However, this work has questioned the operation of rehabilitation as a disciplinary force invested in shaping docile blind subjects, and the trade-offs required from service users in exchange for the possibility of social acceptance (Drinkwater, 2005; Sullivan, 2005; Tremain, 2005).

The discourse of rehabilitation as a linear journey relies on the maintenance of polarised fantasies about blindness which are “immune to exchange” (Erevelles, 2005: 55). In other words, the successful service user must demonstrate that they have left dependency, incapability, grief and struggle behind. A constructed rehabilitation journey tends to bind up practical mastery and psycho-emotional well-being, expecting that these will operate in a virtuous circle. But this prohibits the expression of emotions viewed as negative and limits the practical responses available to service users. In short, rehabilitation services are underpinned by an imperative to cope, both practically and emotionally. A culture of coping found in rehabilitation organisations influences relationships between service providers and service users, as well as interactions among service users who, through drawing comparisons, locate themselves within a hierarchy of capability. In this regard, we have seen that surveillance, comparison and exclusion of those deemed unacceptable operates at multiple levels (Tremain, 2005; 2017).

An imperative to cope in rehabilitation requires that service users reject inadmissible parts of the self in order to present themselves as palatable to society (Kleege, 1998; Lourens, 2020; Watermeyer, 2013; 2016). This work has suggested that rehabilitation services are invested in defending against a shadowy figure of pre-intervention blindness and anxious fantasies involving blindness as a darkened and separate world (Hughes, 2019). We have seen how an image of the successfully rehabilitated, coping blind person is foregrounded in organisation public facing material, while a degenerate figure of pre-intervention blindness lurks behind what is not said. The image of a completely self-sufficient blind subject is a promise – a currency held out by organisations to the public assuring them that in exchange for their support something is being done to address the problem of blindness. However, this constructed figure of blindness brought under control does not disrupt societal beliefs which draw connections between blindness and degeneracy. Rather, through relying on the maintenance of polarised fantasies about blindness, journey discourse strengthens these beliefs, requiring that service users adhere to the acceptable ways of being that are stipulated within rehabilitation in order to defend against being socially excluded.

8.1.2. Charitable discourse: the material consequences of being objectified as a product of organisation work and public charity

Rehabilitation services for visually impaired adults in South Africa are viewed as a charitable endeavour. Consequently, within organisation public facing material visually impaired service users are passively positioned as the products of organisation work and public goodwill. This discursive positioning is enacted in organisation operations and has material consequences for visually impaired people, who are not viewed as adults on an equal footing to service providers nor as stakeholders able to make decisions for themselves. On entering rehabilitation services individuals are drawn into organisation cultures that are characterised by an imbalance of power, as service providers occupy the position of authoritative experts in relation to service users, who are viewed as lacking capability, professionalism and discipline. These unequal power dynamics are strengthened by organisational procedures, rules and policies which maintain strict boundaries between service providers and service users.

Alongside gaining valuable skills, those undergoing rehabilitation programmes sometimes felt as though they were losing something fundamental. Belinda captured this paradox when she said: “The way they treated adults was really taking something from them”. Many service users described experiencing rehabilitation services as an assault on the self – an experience of being made into a blind person (Sullivan, 2005; Tremain, 2017). We have seen that service users are involved in navigating the physical effects of sight loss, as well as being viewed within a framework of societal knowledge about blind persons and becoming subject to the institutional control of public welfare. They must negotiate a trade-off, as real support, understanding, acceptance and warmth, not to mention valuable practical aspects of rehabilitation, can only be gained through entering an unequal space where visually impaired persons are expected to occupy passive positions as the grateful recipients of welfare.

8.1.3. Docile blind subjects

We can see how those who come to these services are drawn into a complex landscape of meanings about the roles, capabilities and expected behaviour of blind persons. On the one hand, service users are told that in order to regain a place in society they must demonstrate self-sufficiency, independence and capability, while on the other the charitable discourse framing these services requires them to occupy passive positions as the grateful receivers of goodwill who are subject to strict procedures, rules and policies. Although the former figure of self-sufficiency seems at odds with the latter, I suggest that they are one and the same. Even if a service user is able to regain a social place – for example, entrance into education and/or employment – they are still viewed as the creation of rehabilitation and rehabilitation workers. They are expected to demonstrate enduring gratitude towards the organisations responsible for their making. Moreover, appeals to employ people with visual impairments found in organisation public facing material read in the same way as charitable appeals for donations, suggesting that the gaining of a social place is just as contingent upon the goodwill of society as it is on the efforts of visually impaired persons to portray a socially acceptable image. Kleege (1998) sees this mixture of “plucky self-reliance” and gratitude in the public persona of Helen Keller, the ultimate rehabilitation “poster child”.

While discursive practices which construct rehabilitation as a linear journey on the one hand and as a charitable endeavour on the other might appear contradictory, they are both invested in producing docile blind subjects and demonstrating to the public that blindness is able to be subdued, managed and normalised (Drinkwater, 2005; Sullivan, 2005; Tremain, 2005). We must recognise that, like service users, service providers are drawn into a framework of meanings about blindness, blind persons and the role of rehabilitation professionals in relation to those who lose their sight. Therefore, throughout this work I have avoided viewing the discourses which service providers produce and reproduce in isolation. Rather, I have considered what service providers, service users and society in general might be unconsciously colluding with, having been steeped in the discourses that have come to underpin rehabilitation services.

8.2. Recommendations

There are several ways in which the work presented here could be expanded. Firstly, this study has engaged with a relatively modest sample of organisations, service providers and service users. It would be beneficial, therefore, to extend the kinds of questions posed within this study to similar organisations across South Africa. It would also be interesting to discover approaches and/or programmes involved in disrupting the discursive practices found to operate within the organisations in this study. Furthermore, an expanded sample would enable a more in-depth exploration of the ways in which various axes of identity intersect with visual impairment and how these intersections impact on individual experiences of rehabilitation. Although this study has touched on how intersections of sight loss, age, race and socio-economic background might influence the rehabilitative spaces which individuals inhabit, I feel that this could be more thoroughly explored.

In this work we have seen an assumption in rehabilitation that practical interventions designed to build towards sustainable livelihoods for visually impaired people will necessarily result in growing emotional well-being, referring to emotional and mental health, personal fulfilment and sense of self. Similarly, a unidirectional link between gainful employment and well-being exists within the kinds of materialist approaches to disability theorising critiqued in Chapter 2. There is space for future work to further explore and problematise the constructed virtuous circle of practical and emotional coping found within this study. This future work would recognise access to gainful employment as having the potential to build into well-being, but would aim to investigate other significant factors influencing whether and to what extent visually impaired South Africans feel able to claim a place in society. In other words, it would view sustainable livelihoods and emotional well-being as interrelated yet distinct, and would consider the ways in which certain imperatives connected to accessing employment, and inclusion in society more broadly, might disallow aspects of emotional life. This work would aim to answer the question of what visually impaired people might need from rehabilitation in addition to practical services as they negotiate a sense of self and social place.

The present study has sought to explore how knowledge about blindness and blind persons is produced and broadcast by rehabilitation organisations, and is strengthened through the maintenance of taken-for-granted disciplinary systems. The power of these systems and the persistence of this knowledge rests in the fact that they are accepted as self-evident, and that questions about why we know what we know about blindness, blind persons and what those who lose their sight need are seldom asked (Blackmore and Hodgkins, 2012; Hook, 2007; Tremain, 2017). Given the circumstances of extreme material deprivation faced by the vast majority of visually impaired persons in South Africa, as well as the pervasive disablism in society, it is not surprising that service providers, committed to seeing service users gain greater mastery for the purpose of social integration, are not asking these questions or considering how their work might, in fact, be colluding with negative cultural meanings which underpin disablist oppression. A key recommendation, therefore, is that this work be used as a means through which to engage with organisation management, service providers and service users in order to encourage the asking of critical questions about the influential role of rehabilitation services in shaping what it means to be blind. Preliminary findings from this study were shared at the South African National Council for the Blind’s National Conference in 2019, which was an important starting point for facilitating a discussion with both service providers, service users and activists in the visual impairment sector around the issues raised in this work. Although planned feedback sessions with the research participants have been negatively impacted by the global Covid-19 pandemic, it is hoped that they will be able to take place in 2021. In relation to these kinds of engagements, Yates (2005: 84) draws on Foucault in cautioning “that there is a danger in speaking for and above others about their situation, and in formulating programmes of resistance for them”. He says of his own work, which investigates problems faced by users of care services, that expecting these problems to be solved by organisation workers and academics reinscribes the power dynamics in these services (Yates, 2005). He makes it clear that:

> [I]t is not possible to banish power per se, since it is a ubiquitous feature of human relationships. It is possible, however, to unmask the workings of particular forms of power, to highlight their costs, and the problems that people experience in relation to them, and, therefore, to problematise their existence (Yates, 2005: 84).

Throughout this work we have seen how, in spite of their passive positioning, visually impaired service users are involved in acts of resistance – marshalling networks of support, defining independence in their own terms, questioning accepted methods in rehabilitation and making choices about how they identify themselves. They are certainly involved in solving the problems they face in rehabilitation organisations, and we must recognise these acts of resistance as significant (Sullivan, 2005; Yates, 2005). Yates (2005) does not appear to be suggesting that researchers refrain from discussing the dynamics of power-knowledge in services for disabled people outside of the academic sphere, but that we remain aware of the power that we, ourselves, wield. In considering the power dynamics in rehabilitation we must also recognise that there are systemic issues at play concerning how rehabilitation is positioned as part of the welfare landscape and how it is funded and evaluated by government. This work recognises that organisations and service providers have to operate within a broader system of power-knowledge surrounding rehabilitation services in South Africa. However, given that these organisations are positioned favourably as experts, they hold the potential to disrupt the status quo through critically evaluating their work and their role.

Closing Reflections

This study has found that amid limiting discursive practices in rehabilitation, visually impaired service users are involved in complex negotiations of self and place. The question we are left with is: What might visually impaired people need in addition or instead as they seek and receive support from rehabilitation services? We must, for example, consider what it might be like for someone searching online for assistive services to encounter the descriptions of blindness and blind people often found on organisation websites. In contrast, we might imagine how being addressed as a consumer and key stakeholder, instead of as an unfortunate person in need of support from benevolent service providers and donors, would be important for individuals who might feel as though sight loss is eroding their agency and social status. Similarly, in light of the descriptions in Chapter 7 of institutional practices which patronise service users, expecting them to demonstrate grateful compliance, let us consider how organisations could be transformed to include and value the voices of service users. Consider how a more equitable space could enable service users to gain greater mastery without feeling as though something of who they are is being lost. Lastly, it is essential that we consider how inflexible ideas about how rehabilitation should unfold and what it should produce can be disrupted, allowing space for service users to make choices about how best to manage the practical implications of sight loss for themselves and to give expression to complex emotions which might include ongoing feelings of struggle, grief and loss.

Although this work has sought to trace discursive practices in rehabilitation services for visually impaired persons, it has shown that problematising the operation of these services should not be viewed as a purely discursive endeavour. It is essential to acknowledge an interplay between discursive practices and psychic investments if we are to understand the deeply rooted societal need to believe that blindness is being subdued by rehabilitation services. What is required, I suggest, is a turning inward on the part of rehabilitation organisations and workers to critically consider how their public face, service offering, procedures, expected outcomes and cultures might be involved in strengthening rather than disrupting a societal belief in blindness as a state of degeneracy. Importantly, service users should not be viewed as passive with regard to ideas about how rehabilitation services might be transformed. On the contrary, we must recognise the significance of the acts of resistance they are involved in, as well as the ways in which they may also be complicit in strengthening the normalising force of rehabilitation through drawing comparisons between themselves and those they deem worse off. In promoting a deeper understanding of what rehabilitation services do at the level of identity, this work hopes to contribute to this process of critical reflection.

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APPENDICES

APPENDIX A

INTRODUCTION LETTER AND INFORMATION SHEET FOR ORGANISATIONS

Dear _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

Request for assistance with research recruitment

My name is Michelle Botha. I’m a PhD candidate at the University of Cape Town, Division of Disability Studies, Faculty of Health Sciences. Currently, I am recruiting participants for a research study and I would be grateful for the assistance of [organisation] in this regard.

There are many different ways of thinking about disability and blindness, and this study aims to explore these different approaches. In particular, I aim to collect information on how beliefs about blindness relate to benefits, services and support for people with visual impairments found in South African non-profit organisations.

Within the study, I will include contributions from service providers (organisation staff who work directly with people with visual impairments) and service users (people with visual impairment making use of organisation services). Each participant will be asked to attend an interview of approximately one hour at a time and place that is convenient for him or her.

I will ensure that participants’ contributions are kept strictly confidential and that their privacy is protected. For more information on how the study will work, please refer to the information sheet attached.

I am requesting your assistance with contacting participants for this study. I would like the opportunity to engage with two of your staff members who work directly with visually impaired service users. I would also appreciate the opportunity to address your service users about the study in order to invite those who are interested to participate.

If you would be willing to assist with this request, please do contact me at the information provided. Please do not hesitate to contact me if you have any questions or concerns.
I look forward to hearing from you.

Kind Regards
Michelle

Project Title: Mapping Discourses on Blindness in South African Non-profit Organisations

Researcher: Michelle Botha
Mobile: 072 452 5300
Email: mishrbotha@gmail.com

Supervisor: Dr Brian Watermeyer
Contact Number: (021) 406 6463
Email: brian.watermeyer@uct.ac.za

Introduction:

My name is Michelle and I am a PhD candidate at the University of Cape Town. I am doing a study which is interested in beliefs about blindness and how they relate to the kinds of support that is offered to visually impaired people.

I would be grateful for the assistance of your organisation in the recruitment of participants for this study. I would like to include contributions from two of your staff members who work directly with service users. I would also appreciate the opportunity to address your service users about the study in order to invite those who are interested to participate.

This information sheet will provide you with information on the study and its procedures. The same information will be provided to each participant before they agree to participate in the study.

Purpose of the study:

There are many different ways of thinking about disability and blindness, and this study is based on curiosity regarding these beliefs. In particular, it is interested in how approaches to blindness relate to benefits, services and support for people with visual impairments found in South African non-profit organisations.
The study will gather information from both service providers and service users.

Study procedures:

The study will take place between March 2018 and November 2018. Participants will be asked to do the following:

- Attend an interview session with me. This session will take approximately an hour and will be scheduled at a time and place that suits the participant. Participants will not need to prepare for the interview as the questions are all about individuals' experiences and ideas.
- Be available for a short feedback session on the phone, where I will go through the transcript of the interview with the participant to make sure that I have written down their thoughts correctly.

Risks and benefits of the study:

I foresee no risks associated with taking part in this study. I will take actions to assure participants' privacy and confidentiality, which I explain below. Should any participant experience emotional distress as a result of their participation, they will be referred to appropriate support services.
This study provides an opportunity to contribute to the growing knowledge of disability in South Africa.

Privacy and confidentiality:

- The records of this study will be kept strictly confidential.
- Interviews will be audio recorded, and I will do the transcription myself. Once the study is completed and submitted the recordings will be destroyed.
- This research may be published in whole or in part and may be presented at conferences or seminars.
- I will not include any information in any publication or presentation that will make it possible to identify any participant.
- Within the study, participants' names will be kept strictly private.

- I will avoid any description which may make it possible for a participant to be identified.

Reimbursement:

Participants will not be reimbursed for their participation in this study. However, I will cover any costs participants incur in transporting themselves to the interview session.

Right to refuse or withdraw:

- Participation in this study is voluntary.
- Participants may choose to withdraw from the study at any time with no penalty and with no obligation to give a reason.
- Participants have the right not to answer any single interview question or to withdraw from the interview at any time and may ask that their interview material not be used.
- Participants may ask questions about the research at any point.

Reporting findings:

When the study is finished, the research findings will be presented to participants (and other interested parties within the blind sector) at a number of sessions. However, attending these is not compulsory. Participants may also request copies of the final study once it is completed.

If you have any further questions or concerns please do not hesitate to contact me directly at the details above. You may also contact my supervisor, Dr. Brian Watermeyer at the details provided above. If you have any questions regarding the rights and welfare of participants in this study you are welcome to contact the University of Cape Town, Faculty of Health Sciences, Human Research Ethics Committee Chairperson, Prof. Marc Blockman on (021) 406 6338 or marc.blockman@uct.ac.za.

Consent:
(this is the consent form which participants will be asked to sign before the commencement of the interview)

Your signature below indicates that you agree to take part in this study and that you have read and understood the information provided above.

I have had the opportunity to ask questions and have had them answered to my satisfaction.

Participant Name:

Signature:

Date:

Researcher Name:

Signature:

Date:

APPENDIX B

INTRODUCTION LETTER AND INFORMATION SHEET FOR SERVICE PROVIDERS

Dear _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

Invitation to participate in a research study

My name is Michelle Botha. I’m a PhD candidate at the University of Cape Town, Division of Disability Studies, Faculty of Health Sciences. Currently, I am recruiting participants for a research study and I would like to invite you to participate.

There are many different ways of thinking about disability and blindness, and this study aims to explore these different approaches. In particular, I aim to collect information on how beliefs about blindness relate to benefits, services and support for people with visual impairments found in South African non-profit organisations.

I received your details from [organisation]. I am approaching you to participate as a service provider working with people with visual impairments. Should you choose to participate, you will be asked to attend an interview of approximately one hour at a time and place that is convenient for you.

I will ensure your contributions are kept strictly confidential. For more information on how the study will work, please refer to the information sheet attached.

If you would like to participate or if you have any concerns, please do contact me at the details provided.

Kind Regards
Michelle

Project Title: Mapping Discourses on Blindness in South African Non-profit Organisations

Researcher: Michelle Botha
Mobile: 072 452 5300
Email: mishrbotha@gmail.com

Supervisor: Dr Brian Watermeyer
Contact Number: (021) 406 6463
Email: brian.watermeyer@uct.ac.za

Introduction:

My name is Michelle and I am a PhD candidate at the University of Cape Town. I am doing a study which is interested in beliefs about blindness and how they relate to the kinds of support that is offered to visually impaired people.

I would like to invite you to participate in this study. You have been identified as a possible participant because you work directly with people with visual impairments providing a support service within a nonprofit organisation.

This information sheet will provide you with information on the study and its procedures. Please read it carefully before agreeing to take part in the study.

Purpose of the study:

There are many different ways of thinking about disability and blindness, and this study is based on curiosity regarding these beliefs. In particular, it is interested in how approaches to blindness relate to benefits, services and support for people with visual impairments found in South African non-profit organisations.
The study will gather information from both service providers and service users.

Study procedures:

The study will take place between March 2018 and November 2018.

If you agree to take part in the study you will be asked to do the following:

- Attend an interview session with me. This session will take approximately an hour and will be scheduled at a time and place that suits you. You will not need to prepare for the interview as the questions are all about your experiences and ideas.
- Be available for a short feedback session on the phone, where I will go through the transcript of our interview with you to make sure that I have written down your thoughts correctly.

Risks and benefits of the study:

I foresee no risks associated with taking part in this study. I will take actions to assure your privacy and confidentiality, which I explain below. Should you experience any emotional distress as a result of your participation, you will be referred to appropriate support services.
If you choose to take part, this study provides an opportunity to contribute to the growing knowledge of disability in South Africa.

Privacy and confidentiality:

- The records of this study will be kept strictly confidential.

- Interviews will be audio recorded, and I will do the transcription myself. Once the study is completed and submitted the recordings will be destroyed.
- This research may be published in whole or in part and may be presented at conferences or seminars.
- I will not include any information in any publication or presentation that will make it possible to identify you.
- Within the study, your name will be kept strictly private.
- I will avoid any description of you which may make it possible for you to be identified.

Reimbursement:

You will not be reimbursed for your participation in this study. However, I will cover any costs you incur in transporting yourself to the interview session.

Right to refuse or withdraw:

- Participation in this study is voluntary.
- You may choose to withdraw from the study at any time with no penalty and with no obligation to give a reason.
- You have the right not to answer any single interview question or to withdraw from the interview at any time and you may ask that your interview material not be used.
- You may ask questions about the research at any point.

Reporting findings:

When the study is finished, the research findings will be presented to participants (and other interested parties within the blind sector) at a number of sessions. However, attending these is not compulsory. Participants may also request copies of the final study once it is completed.

If you have any further questions or concerns please do not hesitate to contact me directly at the details above. You may also contact my supervisor, Dr. Brian Watermeyer at the details provided above. If you have any questions regarding your rights and welfare as a participant in this study you are welcome to contact the University of Cape Town, Faculty of Health Sciences, Human Research Ethics Committee Chairperson, Prof. Marc Blockman on (021) 406 6338 or marc.blockman@uct.ac.za.

Consent:
(you will be asked to sign the below form before the commencement of the interview)

Your signature below indicates that you agree to take part in this study and that you have read and understood the information provided above.

I have had the opportunity to ask questions and have had them answered to my satisfaction.

Participant Name:

Signature:

Date:

Researcher Name:

Signature:

Date:

APPENDIX C

INTRODUCTION LETTER AND INFORMATION SHEET FOR SERVICE USERS

Dear _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

Invitation to participate in a research study

My name is Michelle Botha. I'm a PhD candidate at the University of Cape Town, Division of Disability Studies, Faculty of Health Sciences. Currently, I am recruiting participants for a research study and I would like to invite you to participate.

There are many different ways of thinking about disability and blindness, and this study aims to explore these different approaches. In particular, I aim to collect information on how beliefs about blindness relate to benefits, services and support for people with visual impairments found in South African non-profit organisations.

I am approaching you to participate because you make use of services for the visually impaired. Should you choose to participate, you will be asked to attend an interview of approximately one hour at a time and place that is convenient for you.

I will ensure that your contributions are kept strictly confidential. Your choice to participate will in no way impact your access to services at organisations for the blind. For more information on how the study will work, please refer to the information sheet attached.

If you would like to participate, please do contact me at the details provided. If you have any concerns or questions please feel free to contact me

Kind Regards
Michelle

Project Title: Mapping Discourses on Blindness in South African Non-profit Organisations

Researcher: Michelle Botha
Mobile: 072 452 5300
Email: mishrbotha@gmail.com

Supervisor: Dr Brian Watermeyer
Contact Number: (021) 406 6463
Email: brian.watermeyer@uct.ac.za

Introduction:

My name is Michelle and I am a PhD candidate at the University of Cape Town. I am doing a study which is interested in beliefs about blindness and how they relate to the kinds of support that is offered to visually impaired people.

I would like to invite you to participate in this study. You have been identified as a possible participant because you are a person with visual impairment making use of services for the blind or visually impaired.

This information sheet will provide you with information on the study and its procedures. Please read it carefully before agreeing to take part in the study.

Purpose of the study:

There are many different ways of thinking about disability and blindness, and this study is based on curiosity regarding these beliefs. In particular, it is interested in how approaches to blindness relate to benefits, services and support for people with visual impairments found in South African non-profit organisations.
The study will gather information from both service providers and service users.

Study procedures:

The study will take place between March 2018 and November 2018.

If you agree to take part in the study you will be asked to do the following:

- Attend an interview session with me. This session will take approximately an hour and will be scheduled at a time and place that suits you. You will not need to prepare for the interview as the questions are all about your experiences and ideas.
- Be available for a short feedback session on the phone, where I will go through the transcript of our interview with you to make sure that I have written down your thoughts correctly.

Risks and benefits of the study:

I foresee no risks associated with taking part in this study. I will take actions to assure your privacy and confidentiality, which I explain below. Should you experience any emotional distress as a result of your participation, you will be referred to appropriate support services.
If you choose to take part, this study provides an opportunity to contribute to the growing knowledge of disability in South Africa.

Privacy and confidentiality:

- The records of this study will be kept strictly confidential.

- Interviews will be audio recorded, and I will do the transcription myself. Once the study is completed and submitted the recordings will be destroyed.
- Your participation will in no way affect your access to the services you currently receive at any organisation for the blind and organisations will not have access to your contributions.
- This research may be published in whole or in part and may be presented at conferences or seminars.
- I will not include any information in any publication or presentation that will make it possible to identify you.
- Within the study, your name will be kept strictly private.
- I will avoid any description of you which may make it possible for you to be identified.

Reimbursement:

You will not be reimbursed for your participation in this study. However, I will cover any costs you incur in transporting yourself to the interview session.

Right to refuse or withdraw:

- Participation in this study is voluntary.
- You may choose to withdraw from the study at any time with no penalty and with no obligation to give a reason.
- Withdrawing from the study will not impact your access to the services you are currently receiving at any organisation for the blind.
- You have the right not to answer any single interview question or to withdraw from the interview at any time and you may ask that your interview material not be used.
- You may ask questions about the research at any point.

Reporting findings:

When the study is finished, the research findings will be presented to participants (and other interested parties within the blind sector) at a number of sessions. However, attending these is not compulsory.
Participants may also request copies of the final study once it is completed.

If you have any further questions or concerns please do not hesitate to contact me directly at the details above. You may also contact my supervisor, Dr. Brian Watermeyer at the details provided above. If you have any questions regarding your rights and welfare as a participant in this study you are welcome to contact the

University of Cape Town, Faculty of Health Sciences, Human Research Ethics Committee Chairperson, Prof. Marc Blockman on (021) 406 6338 or marc.blockman@uct.ac.za.

Consent:
(you will be asked to sign the below form before the commencement of the interview)

Your signature below indicates that you agree to take part in this study and that you have read and understood the information provided above.

I have had the opportunity to ask questions and have had them answered to my satisfaction.

Participant Name:

Signature:

Date:

Researcher Name:

Signature:

Date:

APPENDIX D

INTERVIEW GUIDES FOR SEMI-STRUCTURED INTERVIEWS

1: SERVICE PROVIDERS

Name of Participant:
Organisation:
Job Title:
Does the participant have a visual impairment or other disability?

Topic 1: How do service providers perceive and articulate the mission of the organisation?

What would you say is the mission of this organisation?

What would you say are the values of this organisation?
How does your work contribute to this?
Have you seen any changes in terms of the organisation’s mission or values over the time you have worked here?

Topic 2: What motivates service providers to do the work that they do?

How did you come to work for this organisation?
What drew you to this work?
What motivates you to continue working for this particular organisation?

Topic 3: How do service providers perceive their role in relation to service users?

What does your day-to-day work look like?
How would you describe the people who use the services of the organisation?
What role do you feel you play in the lives of service users?
How do you feel that you relate to the service users?

Topic 4: What challenges do service providers experience in their work with service users?

What day-to-day challenges do you face in your work?
How are relationships with service users challenging?
What challenges do you face from within the organisation structures?
What external challenges do you face e.g. from communities, families?

Topic 5: How do service providers define a successful outcome for a service user?

When does your work with a service user come to an end?
How do you know that your work has been successful?
Can you give examples of success stories?

2: SERVICE USERS

Name of Participant:
Organisation:
Other organisations attended:
Current Occupation:
Visual Impairment:

Topic 1: How do service users experience the services of organisations?

What do your day-to-day activities look like?
When you first arrived, what did you expect?
Were your expectations met?
Have you noticed any changes in the organisation in the time that you have been here?
What is your opinion on these changes?

Topic 2: What motivates service users to seek out and accept the support of organisations?

How did you hear about this organisation?
What caused you to approach this organisation?

Topic 3: How do service users relate to service providers and how do they experience service providers relating to them?

Which staff members do you work with the most?
How would you describe your relationship with these staff members?
How do you feel the staff of this organisation relate to you?
Are there ways that you feel relationships between you and the staff could be different?
How much do you know about the structure of this organisation?
What is your opinion on this?

Topic 4: What challenges do service users experience within the organisation and with regard to service providers?

What day-to-day challenges do you face at this organisation?
What challenges do you face in relationships with the staff members?

Topic 5: How do service users feel that they have been impacted by the services of the organisation?

How has your situation changed since coming to this organisation?
What has impacted you the most?
Do you feel that you have been impacted by this organisation?
Can you give examples of how you have been impacted?

APPENDIX E

INTERVIEW ANALYSIS SHEET TEMPLATE

Problems During Interview: (unintelligible questions, problematic words/phrases, moving between topics etc.)	**Useful Elements of Interview:** (flagging interesting points, recurring ideas, usefully articulated responses)
Differences Between Participant Responses:	**Similarities Between Participant Responses:**

Implications:	