

Exploring Visual Impairment from the Perspective of Visually Impaired Adolescents

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Declaration

Unless specifically indicated to the contrary, this dissertation is the result of my own work.

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Date:

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Abstract

This study explored the experience of disability as recounted by school aged, visually impaired adolescents. The primary aim was to explore the manner in which these adolescents thought about, understood and coped with their disability. A second aim explored the extent to which participants' experiences mirrored those reported in the literature. The design of the study was qualitative with an orientation toward social constructionism. Nine partially sighted and seven blind adolescents comprised the two cohorts of participants who participated in the study. One of the most notable findings supported the argument that disability is a socially constructed phenomenon. Some insights, drawn from psychoanalysis, were also found to be useful. Other findings, a critique of the study, and suggestions for future research are also provided. One of the most important of these involves evaluating the negative and positive consequences of inclusive education.

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1. Introduction

1.1. Disability in Context

Disability is an area which has recently been enjoying attention in both the international and the local context. On the global front, there has been a growing recognition of the need to include and address issues pertaining to disability in national and international policy development (Swartz & MacLachlan, 2009). The United Nations Declaration on the Rights of Disabled Persons and the Global Partnership on Disability and Development have assisted in this regard (ibid.).

In South Africa, legislation has been developed to better provide for disabled people. In 1996, the Constitution of the Republic of South Africa (No. 108 of 1996) came into effect. The constitution stipulated that all citizens be treated equally. Another provision of the Constitution made discrimination on grounds of disability illegal. Another important legislative framework which attempts to cater for the rights of disabled children is the recently passed Children's Act (No. 38 of 2005). The act requires that disabled children are accorded respect and treated equally to nondisabled children (Children's Act, No. 38 of 2005). The act also stipulates that appropriate and adequate support be provided to disabled children and their care givers (Children's Act, No. 38 of 2005).

Developments in other key areas signify the government's attempt to build an inclusive environment. In 2001, the Department of Education drafted Education White Paper 6 which aims to build a more inclusive educational environment in South Africa. According to White Paper 6 learners with special needs should be integrated into the mainstream educational environment (Department of Education, 2001). Suggestions for how this can best be achieved are proposed in White Paper 6 (Department of Education, 2001).

These and other key developments indicate that attempts are being made to improve the lives of disabled people. Important strides are also being made in the field of research. A growing body of research is concerned with shifting focus away from the more traditional individualistic approach to disability. Rather, the emphasis is placed on societal, political and psychological responses to impairment which have resulted in the continued marginalization and exclusion of disabled persons. Autobiographical and empirical accounts of the day-to-day experiences of those who live with impairments have led writers such as Watermeyer (2009) to argue that a commonality of experience

exists regardless of the nature of one's impairment. The current research was undertaken in the hope that findings obtained would provide a useful contribution to this growing theoretical understanding of how disability is experienced by the visually impaired.

1.2. Parameters of the Study

The study aimed to develop an understanding of the experience of disability as described by school age, visually impaired adolescents. The aim was to gain insight into how having a disability impacted upon their lives and to explore the ways in which they understood and have experienced their disability. An additional aim emerged as the study progressed. This aim sought to investigate the extent to which the participants' accounts would reflect similar themes to those generated by other studies and autobiographical accounts. Some writers in the field have generated the theory of a commonality of the experience of discrimination and difference for many disabled individuals. It was felt that should similarities be found to be present, this would strengthen the argument for the presence of such a commonality which is hypothesized to exist among disabled persons, irrespective of the nature of impairment.

Furthermore, the researcher, who is herself congenitally blind, wished to determine whether or not the narratives of the participants would in any way parallel her own experiences. The orientation of the study was that of social constructionism. The study focused on adolescents as they are in a critical stage of developing a self identity (Erikson, 1950; Sadock & Sadock, 2007). It was thought that gaining an understanding of the way in which adolescents understood and felt about their disabilities would generate findings which could inform intervention and policy making which affects disabled youngsters.

The research question was essentially about how the visually impaired youth had experienced their own disability and how it was perceived by others around them. The specific aspects of this self-perception included the following areas of focus:

- ❖ When and how did the participants become aware of their disability?
- ❖ What impact did they think it has had on their relationships with parents, siblings, teachers, peers and the general populace?
- ❖ What are their current feelings about being visually impaired?

- ❖ To what extent do the narratives of the participants parallel the accounts of variously impaired individuals which are reported in the literature?

The essential aim was to explore the lived experience of visual impairment amongst youth who were being educated at a boarding establishment for the visually impaired.

1.3. Overview of the Present Research

The thesis will commence by examining literature relevant to the topic under study. Issues such as conceptualizing disability, psychological approaches to disability and the extent to which visual impairment is thought to impact on development will be considered (Chapter Two). Chapter Three will provide an outline of the methodological approach which was employed during the course of the study. Included in this chapter are the design, sampling techniques and the method of data collection and analysis which were employed during the course of the study. A discussion of ethical considerations applicable to the study will also be provided. The next chapter will present the results obtained, adhering to an interpretive, thematic approach to analysis. Discussion of the results obtained will also be undertaken in this chapter. Critiques of the current research as well as suggestions for future research are presented in Chapter Five. The final chapter is a conclusion in which the findings will be summarised. A comprehensive reference list will follow the conclusion and relevant material will be included in the appendices.

2. Literature Review

2.1. Introduction

It seems that disability is a topic which has begun to receive more and more attention in academic circles. The presence in many universities of graduate and postgraduate courses in Disability Studies and the publication of various journals dedicated to the subject provide evidence for this growth in popularity. Despite these positive developments, material and social aspects of society continue to be designed in a manner which discounts the needs of disabled people (Mclain Nhlapo, Watermeyer & Schneider, 2006). Ongoing research has proposed new conceptualizations of disability and is critically examining the exclusion and marginalization of disabled persons from political, social and psychological perspectives.

In order to provide an understanding of the issues inherent in disability, this section of the dissertation aims to describe and consider prior literature which is relevant to the topic under study. The discussion will commence by considering the emergence of the phenomenon of disability. Different approaches to defining disability and visual impairment will be considered next. The focus will then shift on to the role of psychology in understanding disability. The work of writers who have utilized psychoanalytic concepts to further the understanding of the social and psychological processes which underpin responses to impairment will also be examined. The topic of human development and relevant developmental theories will be considered. The discussion will then focus on studies which have investigated the impact that visual impairment has on child development. Adolescence and the difficulties encountered by those in this stage of development will also be briefly discussed. The section will conclude with a consideration of qualitative investigations and autobiographical accounts of the experience of impairment.

2.2. The Emergence of Disability

It is argued that the phenomenon of disability emerged in the nineteenth century as a by-product of the industrial revolution in Britain (Marks, 1999). Finkelstein (1980, in Barnes, 1996) argues that prior to the industrialisation, people with impairments could participate in agriculture and small scale production which constituted the production process in that society. However, the industrial revolution saw the rapid growth of industry and the need for a homogeneous workforce. It was at this

point that the exclusion of people with impairments began as the tasks involved in production were not tailored to suit them (Finkelstein, 1980, in Marks, 1999). Finkelstein (1980, in Marks, 1999) argues that a wide range of new technologies will allow persons with impairments to resume full participation in productive and social life. The argument that disability emerged as an artifact of industrialisation in Britain has led to the development of conceptualizations of disability which argue that societal structures compound existing impairments. This argument emphasizes the constructed nature of disability rather than viewing it as a distinct entity located in the body of an individual.

2.3. Defining Disability

Disability is a term used in every day conversation by many people (Thomas, 2002). Thomas (2002, p. 38) notes that “In lay terms, referring to people with impairments as disabled signals that they belong to that group of people who cannot engage in ‘normal’ activities because of their ‘abnormal’ bodily or intellectual ‘deficit’ or ‘incapacity’”. However, this conception of disability is not accepted by authors in the field of disability studies (Thomas, 2002). In fact, the question of what is meant by the term disability is a topic of continuing widespread debate. Writers within many different theoretical orientations have developed their own definitions of disability. Three such approaches will be considered here: namely the so-called medical model of disability, the social model of disability, and the social constructionist approach to disability.

2.3.1. The Medical Model of Disability

The biomedical approach regards disability as resulting from an impairment of body or mind (Thomas, 2002). The model describes impairment as lying within the individual and regards a disabled person as deviating from normality (Shakespeare, 1996). This model rests on principles of Cartesian dualism whereby the mind and body are regarded as fundamentally separate entities (Marks, 1999). The aim of bio-medicine is to prevent impairment through detection and eradication where possible (Thomas, 2002). Where impairment occurs, the medical model aims to develop methods to “cure” it and restore “normal” functioning (ibid).

The biomedical approach has been criticized for a number of reasons. Firstly, it has been criticized for its dualistic approach to the individual and society, mind and body (Marks, 1999). With its focus on impairment as a physical/biological phenomenon, the model fails to take into account social

factors which impact on impairment (Watermeyer, 2000). Secondly, the model locates responsibility for disability within the body of the individual concerned (Watermeyer, 2000). Furthermore, modern medicine's concern with health promotion and self-care leads to victim-blaming of the disabled person (Marks, 1999). Thirdly, Shakespeare (1996) argues that quantitative research on impairment suggests that each and every person is impaired in one manner or another and that, as a result, it is unjust to locate it in a minority. Finally, critics have argued that medical practice, rooted as it is within the biomedical model, has inflicted more harm than good on persons with disabilities (Marks, 1999). For example, after suffering from polio, some disabled people have acquired permanent muscle damage from intensive rehabilitation (ibid). However, it is important to acknowledge that not all medicine is harmful and should not be considered so (ibid). A possible consequence of the model's individualistic focus is that society is absolved from any accountability or consideration of how various social structures may, in fact, compound existing difficulties. These and other criticisms have resulted in a growing dissatisfaction with this model of disability.

Dissatisfaction with the biomedical model has led to the development of alternative approaches to disability. One such model is known as the social model of disability.

2.3.2. The Social Model of Disability

The social model of disability, developed by disabled activists in the United Kingdom, has increased in popularity and is adopted by many advocacy organizations and disability activists as well as by many disabled people themselves (Marks, 1999). This is because it shifted focus away from individuals with impairments to social and material factors which were argued to produce disability (Shakespeare, 2006). In discussing the popularity of the model with disabled people, Shakespeare (2006, p. 30) states that "Suddenly people were able to understand that it was society which was at fault, not themselves."

The model draws a distinction between disability and impairment (Marks, 1999). It defines impairment as "the limitation in a person's physical, mental or sensory functioning" (Marks, 1999, p. 81). In contrast to the medical model, disability is not regarded as the inevitable consequence of impairment but as arising from a social environment which contains many barriers, preventing people with impairments from participating on an equal level in society (Schneider, 2006). Proponents of this model view disability as a form of social oppression whereby those who are

impaired are continually excluded and marginalized by social structures which do not cater for their needs (Oliver, 1996).

While the social model has provided an alternative approach to conceptualizing disability, it is not without criticism. Firstly, Shakespeare (2006) argues that proponents of the model have failed to develop the model since its inception during the 1970's. For Shakespeare (2006) this failure to develop has led to the social model hindering the development of both the Disability Movement and the field of Disability Studies.

The social model has been criticized for its failure to take the personal experiences of those with impairments into account (Thomas, 2002). Writers such as Oliver (1996, in Thomas, 2002) and Barnes (1998, in Thomas, 2002) argue that such personal accounts are not the concern of social modelists and emphasize the importance of challenging the broader social causes of disability. Writers, such as Hughes and Paterson (1997, in Thomas, 2002), argue that one cannot conceptualize disability if one does not take into account the personal experiences of disabled people.

The model's emphasis on disability as distinct and separate from impairment is argued to represent Cartesian dualistic thinking (Thomas, 2002). This distinction is also criticized by Shakespeare (2006). He argues that impairment and disability cannot be separated as one cannot exist without the other (ibid). He highlights the fact that in order for disability to occur, impairment must be present and that impairments are exacerbated by the social and material factors which are argued to constitute disability (ibid). He also argues that impairments cause difficulties which cannot be eliminated by barrier removal (Shakespeare, 2006). As an example, Sally French (1993a), who is herself visually impaired, notes that removal of social and environmental barriers will not provide a solution to the difficulties involved in interpreting nonverbal communication. It is also argued that the social model has failed to account for all the social factors impacting on disabled persons (Marks, 1999). For example, the model has largely ignored the impact that factors such as race, age and gender have in shaping the experience of disability.

A further criticism of the social model is that it does not consider the different kinds of barriers obstructing people with different impairments (Marks, 1999). For example, writers such as French (1993a) have criticized the model as only having the ability to focus on certain kinds of barriers while ignoring others. Marks (1999, p. 89) concludes that "the claims to develop a 'cross-impairment' analysis of disability actually only represents a limited range of experiences."

The social model is argued to make use of a problematic method of determining who should and who should not be included in the Disabled People's Movement (Marks, 1999). Social model proponents argue that one must identify oneself as disabled (Marks, 1999). Marks (1999) argues that such conceptions of identity are problematic as they presume the presence of a single, unified self. In fact, identity tends to be fluid and situationally constituted (ibid).

The final criticism is made by social constructionists. They argue that the social model is located in a modernist paradigm which emphasizes the existence of things such as impairment and disability, independent of the ways that culture constructs them (Marks, 1999). The social constructionist approach to disability will be considered next.

2.3.3. The Social Constructionist Approach

Social constructionism rejects the notion of a single "true" reality which exists "out there" independent of those who participate in it (Durrheim, 1997). Rather, social constructionists argue that reality is perspectival and emerges in a historical and cultural context which is influenced by social practice (ibid). While they do not reject the idea that there are certain truths, social constructionists argue that "truths and facts are always perspectival interpretations which can only emerge against the backdrop of socially shared understandings." (Durrheim, 1997, p. 178). One crucial tool through which realities are created and shared is language (Durrheim, 1997).

Writers such as Inkstead and White (in Watermeyer, 2000) make use of cross cultural comparison to point out the constructedness of the label of disability. They argue that in other cultures, this label does not exist (ibid). Marks (1999) argues that the focus should shift to a consideration of the emergence and reproduction of the label of disability within particular contexts. She argues that "rather than seeing disability as being a consequence of individual differences, it can be understood as a result of perceptions rooted in social practices which mark out some differences as being abnormal and pathological." (1999, p. 79).

2.3.3.1 The Role of Language in the Construction of Disability.

Marks (1999) argues that language is clearly implicated in the construction and maintenance of the notion of disability. Firstly, she considers the problem of labels such as ‘blind’, ‘deaf’, ‘cripple’, etc (ibid). To illustrate her argument, she uses the example of how such labels are used as insults in every day conversations (ibid). For example, a person who stumbles or collides with another person may be accused of being ‘blind’, the person who fails to hear something and asks for it to be repeated may be asked if she/he has gone ‘deaf’, etc. Marks (1999) argues that the result of using these labels in this manner is the continued creation and maintenance of negative images of disabled people. Marks, (1999, p. 139) states that “The assumption is that blind and deaf people cannot interact effectively with their surroundings and that people with learning difficulties have no capacity to understand at all. In other words, using impairments as terms of abuse generalises and exaggerates the effect they are seen as having.” Secondly, Marks (1999) argues for the usefulness of theories such as Speech Act Theory and conversation analysis as these approaches examine both the literal meaning as well as the function of statements uttered. These theories operate upon the premise that language constitutes a form of action, an idea proposed by the British philosopher, John Langshaw Austin (1962, in Marks, 1999).

In response to the realization that language has been used to constitute negative images of disability, some people, including disabled people themselves, are attempting to neutralize the role of language by re-appropriating it, and using it in ways aimed at reducing negative assumptions (Marks, 1999). The following sections will describe two such strategies, positive naming and defiant self-naming.

2.3.3.2. Positive Naming.

The strategy of positive naming attempts to employ terms with positive associations or to prevent a term being used to encompass the entire disabled person by limiting it to a specific aspect of the impairment (Marks, 1999). The aim of this strategy is to draw emphasis away from notions of deviance and limitation and replace these with notions of difference and capacity (ibid). Shearer (1996, in Marks, 1999) notes that unless an image is intentionally made positive, people will use it to confirm their previously held negative perceptions. Though Shearer was referring to images of mentally handicapped individuals, her argument can be applied to all categories of impairment. According to the medical sociologist and disability activist, Zola (in Marks, 1999, p. 147) “people have multiple roles and that they should not be 'reduced' to their disability.”

Critics of the positive naming strategy argue that these terms simply increase the number of euphemisms surrounding disability which are already in existence (Marks, 1999). These critics argue

that no 'real' differences exist between disabled people and others. As an illustration, Marks (1999, p. 147) asks "Why should a disabled person be 'a person with a disability', when a woman is not 'a person with an X-chromosome', an old person is not 'a person who has lived a long time', or an intelligent person is not 'a person with high levels of intelligence'?" One cannot assume that language change will bring about social change (Synerson, 1992, in Marks, 1999).

2.3.3.3. Defiant Self-naming.

The aim of this strategy is to celebrate difference and to advocate for the acceptance of disabled people (Marks, 1999). This strategy involves reclaiming previously offensive terms and using them as a means of self-description (Marks, 1999). For example, many of this writer's visually impaired friends refer to themselves as "Blindies" and often make jokes about the use of this term. Proponents of this strategy argue that acceptance should not depend on a disabled person having to conceal or overcome their impairment and associated difficulties (ibid). This strategy allows for self-representation by disabled people on their own terms and the self-representations which arise shape both images of disability as well as the relationship between disabled and non-disabled people (ibid).

2.4. Psychology and Disability

Proponents of the social model of disability have criticized the approach which some psychological theories have adopted regarding disability. Lenny (1993) argues that all psychological theories approach disability as something that an individual must work through and "come to terms with". It is argued that those who do not adjust to their disabilities are in a state of denial and are not psychologically whole (Lenny, 1993). Social modelists reject these approaches, arguing that such approaches locate disability within the individual (Abberley, 1993). Despite the criticism which psychology has received, writers such as Marks (1999) and Watermeyer (2000, 2002, 2006, 2009) have begun to argue that one cannot develop a clear understanding of disability without exploring and examining the psychological factors at play. These writers have emphasized the utility of psychoanalysis in the understanding of the unconscious mechanisms which underpin responses to disability. A consideration of the arguments presented by these and other writers regarding the utility of psychoanalysis will be provided in the next section.

2.4.1. Psychoanalytic Approaches to Disability

Two psychoanalytic approaches to disability can be discerned from the literature. The first, more traditional approach, is problematic as writers attempted to establish causal links between impairment and psychopathology (Watermeyer, 2000). Writers such as Watermeyer (2006) have begun to argue that psychoanalysis has the potential to greatly enhance our understanding of the complex phenomenon known as disability. Psychoanalysis is proposed as a theoretical framework for critically examining collective societal responses to disability by interrogation of individual, intrapsychic responses and the manner in which these determine collective action (Watermeyer, 2006). Both the traditional approach and the more recent developments will be considered below.

2.4.1.1. The Traditional Psychoanalytic Approach to Disability.

The work of psychoanalytic writers such as Freud, Klein and Fairbairn emphasized the role of key attachment figures such as family as essential influences on human development. For example, Freud (1964, in Shaffer, 1999) argued that parental responses to a child could influence whether a healthy personality developed or not. However, traditional psychoanalytic writing on disability has failed to acknowledge the importance of parental, familial and societal responses to disability and the extent to which these, rather than the impairment itself, mediates the development of adult psychopathology (Asch & Rousso, 1985, in Watermeyer, 2000). Watermeyer (2000, p. 25) states that “The accuracy of this observation is both compelling and disturbing, in that it demonstrates how issues or evocations associated with disability have led psychoanalytic researchers to disregard or suspend basic theoretical tenets of their orientation.” Such criticism of traditional psychoanalytic writing on disability resulted from work which tended to attempt to argue for the presence of a causal link between impairment and personality pathology (Asch & Rousso, 1985, in Watermeyer, 2000). Furthermore, many authors attempted to engage in an exploration of the extent to which the psychic impact of impairment is “preventable, inevitable or modifiable” (Asch & Rousso, 1985, p. 4, in Watermeyer, 2000).

A case in point is the work of Kenneth Wright (1991, in Watermeyer, 2002). Wright (ibid) argues that vision is a key element in the formation of secure attachments and healthy self concepts. It is argued that blind infants struggle to develop the concept of object constancy (ibid). This process

begins by forming an internal representation of an object and it is believed that vision is essential to this process (ibid). Due to an inability to develop a visual representation of the mother, it is argued that a flawed form of object constancy will be attained by congenitally blind infants (ibid). He concludes that congenitally blind persons in particular experience themselves and the world in ways which are fundamentally different from those experienced by sighted individuals (ibid).

Watermeyer (2002) undertakes a critical examination of Wright's assumptions and conclusions. He notes that Wright fails to consider other factors which may affect the development of object constancy and secure attachment (ibid). He does not contest the conclusion that the experiences of blind and sighted infants may be different but argues against the exclusive focus on impairment (ibid). He suggests that an exploration and interrogation of the social responses to blindness which blind infants are exposed to in parents, extended families and society in general needs to be undertaken before one attempts to gain an idea of the experience of these infants. Furthermore, he also recommends that the projections and projective identifications which parents engage in with regard to their children are also key factors to consider if one is to develop a more accurate picture of the experiences of blind infants (ibid).

Writers have tended to argue that persons with disabilities have poorly developed egos and make use of primitive defense mechanisms (Asch & Rousso, 1985, in Watermeyer, 2000). As a result of their poor ego development, it has been concluded that persons with disabilities are not suitable for analysis through psychodynamic psychotherapy as they would be unable to tolerate the ambivalence and rigour this process involves (ibid). In considering the writings of psychoanalytic authors who have adopted these arguments Watermeyer (2000, p. 25) notes that "A familiar picture created within this work is one of persons with disabilities struggling to contain heightened levels of undischarged aggression, relating to unmanageable feelings of helplessness, frustration and resentment, within the context of stunted ego development."

Watermeyer (2000, p. 23) notes that the rise of the social model of disability led to "a theoretical split which rendered the expulsion of psychoanalytic ideas from disability theorising on political grounds." However, authors such as Marks (1999) and Watermeyer (2006, 2009) have begun to argue that psychoanalysis has a potentially useful role in developing an understanding of disability and how it is produced. Marks (1999, p. xi) states that "Subjective and unconscious investments, identifications and the management of differences play a crucial role in the construction and experience of disability."

2.4.1.2. The Contribution of Psychoanalysis to an Understanding of Disability.

As mentioned above, writers have begun to utilise psychoanalytic tools and theory in developing an understanding of disability which highlights the role of society in the continued exclusion and marginalisation of disabled persons. Furthermore, these writers have also sought to explore the impact which continued marginalisation has upon the psychological wellbeing of disabled persons. Some of the work of these writers is examined below.

In discussing societal response to disability, Shakespeare (1994, p. 283) refers to disabled people as “dustbins” in society. Drawing on the work of the feminist writer Simone De Beauvoir, Shakespeare (1994) attempts to demonstrate how disabled people are constructed as “other” in society. De Beauvoir (1976, in Shakespeare, 1994) argues that it is not biology which leads to the oppression of women but the social and cultural meanings which are assigned to the different sexes. According to Shakespeare (1994) nondisabled people view disabled people as reminders of their mortality. He argues that people with disabilities are subject to the projection of unmanageable feelings, processes or characteristics on to them by non-disabled members of society (ibid). Viewing disabled people as “other” bolsters nondisabled people’s ability to feel good about themselves and assists in defining the bounds of normality (ibid).

Marks (1999) argues that psychoanalysis can assist in developing an understanding of how the process underpinning the view that disabled people are “other” unfolds. Writers argue that nondisabled members of society, when confronted by disability, make use of a number of defence mechanisms to facilitate dealing with their own unmanageable feelings (Marks, 1999; Watermeyer, 2000, 2006, 2009). Psychoanalytic writers and practitioners regard defence mechanisms as fulfilling two important functions. McWilliams (1997, p. 97) defines these functions as “(1) the avoidance or management of some powerful, threatening feeling, usually anxiety but sometimes overwhelming grief and other disorganizing emotional experiences; and (2) the maintenance of self-esteem.” Possible defences employed by non-disabled people include splitting, projection, reaction formation, and rationalization (Marks, 1999). Splitting results from an inability to tolerate ambivalence and causes a person to view others as either all good or all bad (Marks, 1999). A person who uses projection as a defence attributes unmanageable feelings or self-characteristics to other people or objects (Marks, 1999). In reaction formation, a person expresses one emotion to conceal the fact that

they are feeling the exact opposite of that emotion (Watermeyer, 2000, 2006, 2009). The final defence used is described by Marks (1999, p. 24) as follows: “Rationalisation involves a person justifying their unconscious impulses without being aware of their true source.” Watermeyer (2009) proposes another defence which does not form part of traditional defence mechanisms but which is relevant to disability. He refers to this defence as medicalisation (ibid). As was discussed earlier in the chapter, the biomedical view of disability ignores social aspects of the phenomenon, arguing that disability resides in the impaired individual (ibid). Biomedicine further emphasises a belief that impairment has occurred because of an individual’s negligent actions and that adopting strategies proposed by medical professionals will cure them (ibid). Watermeyer (2009) proposes that the victim blaming inherent in biomedicine allows society to reprise the role it plays in the exclusion and marginalisation of impaired persons. A conclusion which can be drawn from the arguments, presented above, is that the use of such defences influences the shaping of society in such a way as to place disabled persons in positions of continued exclusion and marginalization (Marks, 1999; Watermeyer, 2000, 2006, 2009).

The argument that disabled people are oppressed throughout their lives is no longer considered to be controversial but is now taken as fact (Watermeyer & Swartz, 2008). Given the tendency of society to respond to disability in a negative manner, the question arises as to how these responses impact on the psychological development and wellbeing of disabled persons. It is suggested that a consequence of continued exclusion and marginalization is the development of internalized oppression (Watermeyer, 2009). Watermeyer and Swartz (2008) argue that while this form of oppression forms a key part of the continued marginalization of disabled people, the mechanisms which underpin the process of internalized oppression are still being investigated. An understanding of how the process unfolds is proposed by Watermeyer (2009). The emphasis which society places on perfection and wholeness leads to those who are impaired being unable to comply with these standards (ibid). This is especially true for those whose impairments cannot be corrected by medical intervention (ibid). The impaired person is believed to split off and project unwanted aspects of self i.e. the damaged aspects of self (ibid). They then develop an identification with nondisabled persons and strive to be as ‘normal as possible’ in the hope of gaining acceptance in society (ibid). It is suggested that some of those who achieve a degree of acceptance in society project the split off parts of themselves on to other disabled persons who are viewed as more excluded than themselves (ibid). Watermeyer (2009, p. 209) notes that “The ubiquitous devaluing of disabled persons thus, via internal channels, manifests in the destructive closure, separatism and hostile attempts at positive distinctiveness which are characteristic of all demeaned out-groups.” In order to challenge the current state of affairs, it is

suggested that the continued splitting and projection of unwanted devalued aspects of self, coupled with identification with nondisabled society results in a maintenance of the current state of affairs which are faced by disabled people (ibid). Watermeyer (2009) concludes that the development of a conscious understanding and self awareness by disabled people is necessary if there is to be any positive change to the status quo.

Another important contribution to the understanding of how the oppression of disabled persons is maintained is provided by Watermeyer and Swartz (2008). These writers argue that the personal and psychic boundaries of disabled persons are frequently violated and distorted. It is argued that disabled people experience feelings of inauthenticity and of not being seen by society (ibid). It is thought that these feelings arise from socialization practices which enforce the idea that revealing aspects of one's experience as a disabled person is not acceptable as nondisabled persons cannot deal with them (ibid). Disabled people are often required to protect others from aspects of their experience (ibid). Furthermore, nondisabled persons tend to respond to disabled persons with feelings of helplessness and anxiety which spur them on to intrude upon the personal boundaries of disabled persons through the proffering of unwanted assistance which disabled people are forced to accept (ibid). Given that disabled people live in a reality in which there is inadequate provision of services tailored to their needs, it is not surprising that they are often required to engage in relationships in which their boundaries are frequently violated simply to gain the assistance they need to function and have their needs met (ibid).

A final concern stems from the fact that an inability to be real and to have all aspects of the self seen and accepted by others has negative implications for the development of an integrated sense of self as well as healthy patterns of relating to others (ibid). Watermeyer (2006) concludes that if disabled people are to become equal and accepted in society, disabled and nondisabled people need to engage in an open and critical examination of their internal responses to disability.

The work of writers such as Shakespeare (1994), Marks (1999) and Watermeyer (2000, 2002, 2006, 2009) suggest that psychology has the potential to make an important contribution to the development of a holistic approach and understanding of disability. While the researcher adopted an interpretive approach to the study, the work of the writers, mentioned above, had a significant impact on the analysis and discussion of the gathered data.

2.5. Child Development and the Impact of Visual Impairment

Thus far, this review has focused on theoretical and conceptual approaches to disability. The discussion now turns to a consideration of prior research involving visually impaired persons. A large amount of this research seems to be concerned with determining whether disability has an impact on so-called ‘normal’ development. However, before considering this research, it is important to have an understanding of what is regarded as ‘normal’ development.

2.5.1. Theoretical Approaches to Development

The area of human development is one which continues to provoke debate, questions and research. For many years, those interested in human development have considered questions such as the role of genetics versus that of the environment, whether or not development occurs in specific stages or is more flexible, and whether humans play an active or passive role in their development (Shaffer, 1999). Many prominent theorists have developed frameworks for understanding various aspects of development. Some well known theorists include Piaget, Freud, Erikson, Bronfenbrenner, Bowlby, Kohlberg, Vygotsky, etc (Shaffer, 1999). Each of these theorists has provided vital information to aid in the understanding of how the course of development unfolds (Shaffer, 1999). While a full description and consideration of the merits and disadvantages of each theory is beyond the scope of this review, three of the above theories will be considered here. These are Erikson’s theory of Psychosocial Development, Bronfenbrenner’s Ecological Systems Theory, and Vygotsky’s theory of Sociocultural Development. Aspects of each theory were found to be relevant to the participants’ narratives as will be illustrated later in this chapter.

2.5.2. The Theory of Psychosocial Development

With its focus on adolescence as a critical period in development was found to be relevant in the study as the participants were all in this stage of development. A description and critique of the theory is presented below.

While regarded to be a firm believer in the theories and arguments of Freud, Erikson based his theory of development on the argument that the part played by humans in their development is active and that cultural, rather than biological influences, are essential to optimal development (Mitchell & Black, 1996). This demonstrated a break from the Freudian theory of development which had argued that the role taken by humans in their own development is passive and that the force behind development is biological and sexual in nature (ibid). A further difference in the theories of Freud and Erikson is that while they both emphasize a staged approach to development, Erikson extended his view of development beyond adolescence (ibid). The focus on development through the life cycle has contributed to the continued popularity of the theory as an account of human development (Shaffer, 1999).

Erikson (1950) believed that optimal development is achieved by successfully resolving eight crises/conflicts which present at different stages of life. The point at which a crisis presents itself is dependent on the requirements of the social situation and a person's level of biological maturation (ibid). Successful resolution of a crisis allows one to move to the next stage of development while unsuccessful resolution will result in a person remaining at that particular stage (ibid). In a chapter entitled 'The Eight Ages of Man', Erikson (1950) listed the psychosocial stages of development as:

- ❖ Trust versus Mistrust;
- ❖ Autonomy versus Shame and Doubt;
- ❖ Initiative versus Guilt;
- ❖ Industry versus Inferiority;
- ❖ Identity versus Role Confusion;
- ❖ Intimacy versus Isolation;
- ❖ Generativity versus Stagnation;
- ❖ Integrity versus Despair.

While Erikson's theory is regarded as a popular theory of human development, it is not without criticism. Shaffer (1999) argues that while Erikson provides an account of optimal development, he gives little indication of how one would go about solving the problems presented at each stage. More specifically, there is no indication in the theory of what factors and experiences would ensure optimal development and which would hamper it (ibid). Despite these critiques, the theory remains a useful and insightful account of human development. Another theory which has been useful in aiding understanding of development is the Ecological Systems theory of Bronfenbrenner.

2.5.3. The Ecological Systems Approach

Urie Bronfenbrenner (1979) proposed a model which examines the various environmental influences and their impact on development. Unlike Erikson, Bronfenbrenner (1979) does not adopt a staged approach to development. Instead, Bronfenbrenner (1979) proposes a model in which development results from an interaction between an individual's biological characteristics and the various contexts within which they are placed. An individual is said to develop within several contexts, referred to as systems, each layered within the next and often described by using the analogy of a set of Russian dolls (Liddell, 2002). Those environments which are closer to a person are said to have the most direct influence on development and are referred to as proximal influences (Bronfenbrenner, 1979). Bronfenbrenner (1979) initially identified four key systems which impact on, and are themselves influenced by, the individual's development. He referred to these systems as the microsystem, mesosystem, exosystem, macrosystem and chronosystem (ibid).

- I. **Microsystem:** The microsystem refers to a person's immediate setting and includes family, school and peers (Bronfenbrenner, 1979). It represents the environment in which a person is directly involved (ibid).
- II **Mesosystem:** The mesosystem refers to the set of relationships between components of the microsystem (Bronfenbrenner, 1979). Optimal development occurs when relationships between these components are secure and healthy (ibid).
- III. **Exosystem:** The exosystem refers to a system which influences a person's development while the person concerned is themselves, not directly involved in it (Bronfenbrenner, 1979). The example of a parent/caregiver's work environment is often cited as an illustration of an exosystemic influence (Shaffer, 1999).
- IV. **Macrosystem:** The macrosystem refers to a broad set of social and cultural values, influences, policies, etc which impact upon a person's microsystem, mesosystem and exosystem and which ultimately shape the course of human development (Bronfenbrenner, 1979).

Bronfenbrenner later identified a fifth system known as the chronosystem (Liddell, 2002). The chronosystem represents the temporal aspect of the model (ibid). Liddell (2002, p. 99) notes that the

chronosystem “is concerned with issues related to historical era and changes in the person’s experiences over time.”

A strength of this theory is the recognition that environmental and biological influences interact in a reciprocal manner to influence the course of development (Shaffer, 1999). Furthermore, it allows for one to consider a biopsychosocial intervention to aid in achieving optimum development (ibid). However, it has been criticized as focusing too much on environmental influences and too little on biological influences (ibid). Furthermore, Shaffer (1999) argues that it is difficult to determine ‘normal’ patterns of development which can be universally applied as development is influenced by factors which differ from person to person and society to society. The model provided by Bronfenbrenner (1979) proved useful in conceptualizing the various systemic influences on participants’ lives.

While each theory is not without criticism, each seems to provide necessary elements in furthering the understanding of human development. Having gained an idea of what development entails, one can now turn to an examination of whether or not visual impairment impacts upon this process.

2.5.4. The Impact of Visual Impairment on Development

Many studies have been undertaken in which an attempt has been made to determine quantitative and qualitative differences between visually impaired children and their sighted peers. Four such studies are mentioned below.

Schwartz (1980) investigated the extent to which congenital visual impairment impacts on role-taking and referential communication. This study involved comparing the performances of visually impaired children, aged between seven and nine, with those of their sighted counterparts (ibid). The children were assessed on two role-taking tasks and one referential communication task (ibid). It was predicted that the visually impaired children would perform at lower levels than the sighted children as it was theorized that sight is essential for social and cognitive development (ibid). The results indicated that there were few significant differences in the performance of both groups of children (ibid). These results suggest that vision may not play such a crucial role in social cognitive development (ibid).

Another study was undertaken by Pava (1991) in which the social competence of visually impaired children was assessed. The social competence of 29 visually impaired children, aged between six and eleven years, was compared with that of a group of sighted children (ibid). Dimensions of social competence assessed included social problem-solving skills and emotional understanding (Pava, 1991). The study also compared assessments of competence and psychopathology done by parents and teachers (ibid). Finally, the study aimed to determine whether a relationship existed between visually impaired children's levels of social competence and their mothers' responses and levels of stress (ibid). It was predicted that: 1) visually impaired children would demonstrate poorer levels of social competence than their sighted peers; 2) teachers' assessments would indicate lower levels of social competence in visually impaired children and 3) a positive relationship would be found to exist between parental responses and stress levels and the social competence of their visually impaired children (ibid). Results revealed that the visually impaired children demonstrated the same levels of competence as their sighted peers (Pava, 1991). Where specific differences were found, these tended to favour the visually impaired children (ibid). Finally, a positive correlation was found to exist between parental responses and stress levels and their visually impaired child's social competence (ibid).

Hatton, Bailey, Burchinal and Ferrell (1997) assessed the development of 186 visually impaired children. The measure employed in this study was the Batell Development Inventory and growth curve analysis was used as a method of data analysis (ibid). Children involved in this study ranged in age from a year old to six years old (ibid). It was found that a positive relationship existed between a child's level of functional vision and their development (ibid). Thus as the level of functional vision decreased, so too did developmental age scores on the domains measured by the Batell Development Inventory (ibid).

Finally, Huurre and Aro (1998) assessed the psychosocial development of visually impaired adolescents. The sample comprised 40 boys and 14 girls and was compared with a sample of 385 sighted adolescents (172 boys and 213 girls) (Huurre & Aro, 1998). Findings suggested that no significant differences existed in the psychosocial development of both groups (ibid). However, it was found that visually impaired adolescents often experienced difficulty in making friends, experienced more feelings of loneliness and had fewer friends than their sighted counterparts (ibid). Furthermore, the self-esteem, social skills and school performance of visually impaired adolescent girls tended to be lower than that of their sighted peers (ibid). Huurre and Aro (1998) concluded that while the psychosocial development of visually impaired

and sighted adolescents was similar, visually impaired girls may require more support in their development.

Of interest is the fact that the researchers initial predictions tended to favour the nondisabled children. As was discussed earlier, Shakespeare (1994) argues that disabled persons are regarded as “other” by nondisabled people. Perhaps the predictions made by the researchers could represent a form of this othering. Furthermore, most of these predictions were proved to be false, suggesting that disability has less of a negative impact on development than was assumed. Considering the findings of Hatton et al (1997), described above, it seems prudent to note the caution which Watermeyer (2009) provides with regard to the definition of human development. Watermeyer (2009) cautions that psychological theories of human development are based on empirical data collected about nondisabled children. Thus it seems necessary to be careful when evaluating disabled children’s developmental progress in terms of such theories.

2.6. The Difficulties Faced by Adolescents

As the participants in this research are adolescents, it is perhaps wise to briefly consider some of the difficulties they face as these may prove relevant to the discussion of the results obtained.

Sadock and Sadock (2008) note that significant biological and psychological development occurs during this stage of life. Besides dealing with the biological changes they are undergoing, adolescents must also learn to take on more responsibility and are making decisions which could have significant implications in later life. One of the decisions adolescents typically have to make involves the selection of their future careers and to plan the remainder of their school studies in accordance with their choices. Mkhize (2005) notes that career-related decisions are changing in accordance with changes in the world of work. Influences on career decisions include an individual’s aspirations, the attitude and aspirations of their parents and extended families and the vast amounts of readily accessible information which has arisen from advancing technology (Mkhize, 2005). Availability of financial resources also influences a person’s career decision (Mkhize, 2005). It is clear that a number of influences affect the outcome of a career decision. To conclude, teenagers are adjusting to a number of changes and responsibilities. These include biological and social changes as well as various important decisions.

2.7. The Experience of Life with a Visual Disability

As mentioned above, many studies have focused on isolating quantitative and qualitative differences between visually impaired children and their sighted peers. While attempting to locate empirical studies of the personal experiences of visually impaired people, a large amount of literature relating to quality of life was uncovered. Studies such as those undertaken by Wolffson and Cochrane (2000), Stelmack (2001) and Varma, Wu, Chong, Azen and Hays (2006) have made use of and developed quantitative measures to investigate the quality of life and outcomes of rehabilitation of persons with visual impairment. While this literature is important, the researcher has chosen not to include it in this review. This is primarily because it attempts to quantify aspects of quality of life and to develop quantitative measures for assessing quality of life. Hornstein (1988) argues that quantitative methods are not suited to examining qualitative phenomena. Furthermore, the current study sought to develop a qualitative understanding of the experiences of visually impaired adolescents and these studies were found to have little relevance to this investigation.

The next section examines qualitative studies and personal accounts of the experience of visual impairment. The researcher has chosen to focus on certain studies and autobiographical accounts as these were found to be relevant in the interpretation of data.

2.7.1. Autobiographical Accounts of the Experience of Visual Impairment

Two autobiographical accounts of the experience of visual impairment are discussed in this section. The researcher has chosen to include them as she wished to determine the extent to which these experiences were mirrored by the research participants in this study.

French (1993b) describes her experience of disability in an article entitled 'Can You See the Rainbow? The Roots of Denial'. She describes how, as a child, she learned to deny her disability by pretending to see things she could not and never to complain (French, 1993). She learned that denying her disability resulted in love and care from adults in her life and any sadness or dejection she felt as a result of her disability had to be hidden as these would lead to

her being censured by those who cared for her (ibid). Throughout her life, denial seemed to dominate. As an adolescent, she was encouraged to adapt to the world and achieve in activities not usually associated with disability (ibid). As an adult, French (1993) notes that many of the difficulties experienced as a child are still present. For example she notes that “Disabled adults frequently provoke anxiety and embarrassment in others simply by their presence. Although they become very skilful at dealing with this, it is often achieved at great cost to themselves by denying their disabilities and needs.” (French, 1993b, p. 72). Furthermore, French (1993) argues that in order to survive in the world of work and to obtain employment the denial of struggles and needs which arise as a result of impairment is often essential. Even if one is not able to conceal it fully, there is still the tendency for disabled people to attempt to conceal or minimalise difficulties which they are likely to face (ibid). Furthermore, it is often up to the disabled person to teach others about their disability and this can lead to them earning negative labels (ibid). French (1993b) comments on the exhaustion and frustration that results when, as a disabled person, one has to combat negative attitudes and structures which increase difficulties and concludes that it is often easier to survive in inadequate environments than to fight for better ones. In conclusion, French (1993b) writes that though the reasons for doing so changed as she advanced through life, the dominant theme of denying her disability remained an essential task.

Stephen Kuusisto (1998) provided an autobiographical account of his life as a visually impaired person. Like French (1993), he learned to deny his disability as others were unable to accept it (ibid). Denying his disability did not simply involve pretending to see what he could not, but involved his engaging in high risk activities such as riding a bicycle on a busy street unaided (ibid). As he grew older, the denial seemed to become more and more internalized whereby he could not acknowledge his impairment to himself and others (ibid). To the world, he attempted to present a front of normality and constantly feared that his deception and the true nature of his impairment would be discovered (ibid). The energy involved in upholding the deception took a physical and emotional toll on him and he developed a deep sense of self loathing (ibid). However, as he grew older, he began to acknowledge his difficulties and to reach out for assistance (ibid). In concluding his story, he notes that gaining acceptance and understanding of himself have allowed him to accept available help and that he regrets not doing so earlier (ibid).

2.7.2. Qualitative Investigations of the Experience of Disability

Three qualitative studies of the experience of disability are presented below. While two of these are not exclusively focused on persons with visual impairments, the findings were found to be relevant during data analysis and interpretation.

Watermeyer (2000) conducted a study with visually impaired university students. The aim was to investigate accounts of university study by these students and to situate these within the context of visual impairment (ibid). Data was gathered in the context of a psychoanalytically oriented support group which later evolved into a psychotherapy group (ibid). A psychoanalytically oriented, interpretive approach was adopted during data analysis and interpretation (ibid). The study produced many relevant findings. The visually impaired participants experienced many negative social responses to their disability (ibid). Further findings indicated that participants concealed aspects of their experience which pertained to their disability-related struggles, feeling that nondisabled persons would not be able to deal with them (ibid). It was also felt that honesty resulted in negative stereotypes being applied to them and that they would be considered a burden by others (ibid). It is argued that the silence surrounding experiences of struggle as a result of impairment is generated through social messages which suggest that disability is shameful and that it is the responsibility of disabled people to protect others from these experiences (French, 1993; Watermeyer 2000, 2009; Watermeyer & Swartz, 2008). Many participants experienced difficulties in relationships and had even lost significant relationships due to loss of sight (ibid). It was also found that participants experienced their disability as shameful and felt that they aided others in their continued oppression (Watermeyer, 2000). Finally, participants experienced the world as ill prepared to deal with visual impairment and experienced frustration and sorrow that many of their needs were ignored or very poorly met (ibid). One consequence of this difficult situation was that many participants reported engaging in relationships which were experienced as unequal and, in some cases, discriminatory (ibid). Reasons given for continued engagement in these relationships centred around the necessity for gaining assistance to ensure one was able to function effectively (ibid). This finding has been replicated in later studies with persons who have different impairments. One of these will be considered later in this section.

Davis and Watson (2002) conducted research which investigated disabled children's resistance to social oppression. Their aim was to challenge previous research which had portrayed disabled children as passive victims of their impairments (ibid). Children ranged in age from 11 to 16 but an

indication of sample size was not provided. Employing an ethnographic approach, Davis and Watson (2002) conducted research in mainstream and so-called special schools. Results indicated that disabled children employed a wide array of strategies in resisting stereotyped identities which adults and nondisabled children attempted to ascribe to them (ibid). Davis and Watson (2002) also concluded that stereotypes were often reinforced by the teachers and caregivers with whom disabled children interacted on a daily basis. Strategies employed included acting out physically against others, verbal resistance and internalized resistance (ibid). It was also found that the manner of the resistance varied from child to child and could not be accounted for by a single set of factors such as class, gender or severity of impairment (ibid). In the same manner as nondisabled children do, disabled children employ a variety of behaviours, depending on the situation in which they find themselves (ibid). Davis and Watson (2002) argue that disabled children are not passive victims of impairment but are capable of social agency and are well able to choose when and how to resist. Furthermore, disabled children play an active role in shaping their lives and are as flexible in different social situations as their nondisabled counterparts (ibid). They conclude that further research is required to investigate the complex issues which underpin the lives of disabled children (ibid).

Watermeyer (2009) conducted an interpretative, psychoanalytically oriented investigation of the socially situated psychological experience of severely physically impaired adults. The data was collected in the context of a psychoanalytic group psychotherapeutic intervention with 5 severely physically impaired university students (ibid). While his study produced many relevant findings, the researcher has chosen to focus on particular areas. These areas include the imperative to silence, the distortion of psychic boundaries and the discourse of independence. While this study examined the experience of physically impaired adults, it is argued that while impairments may differ, the experience of discrimination and difference is common to all disabled people (ibid). The researcher found the findings relevant in the interpretation of collected data and was able to explore the extent to which the experiences of Watermeyer's (2009) participants mirrored those of her own participants.

Participants reported being aware that there were aspects of their lives they could not share with nondisabled others (Watermeyer, 2009). These unspoken aspects usually encompassed living day-to-day with an impairment and were not shared as they provoked high levels of anxiety and discomfort in nondisabled others (ibid). This finding is similar to French's (1993) explanation of how disabled people are often relied upon to protect nondisabled people from their impairments and the effect these have on their lives. Watermeyer (2009, p. 249) refers to an "imperative to silence" whereby

disabled people conceal important aspects of their lives in order to gain acceptance into society. This finding was also reported in Watermeyer's (2000) study of visually impaired university students and lends support to the suggestion that disabled people share a commonality of experience relating to disability.

Participants experienced frequent violation of their personal and psychic boundaries (Watermeyer, 2009). This finding is in keeping with the work of Watermeyer and Swartz (2008) who attempt to provide an account of the manner in which the boundaries of disabled people are violated and distorted.

Finally, the participants described instances when they had engaged in attempting to complete physical tasks independently as this was required by others (Watermeyer, 2009). Feelings of failure were associated with feeling dependent on others (ibid). Watermeyer (2009) argues that concepts of independence and dependency are constructed in terms of disablist social oppression. He adds that striving for the independence which society desires may lead to the neglect of disabled people's psychological needs and have a negative impact on quality of life (ibid). He concludes that the concepts of dependency and independence need to be critically examined in terms of cultural and material factors and reconstituted in a manner more in line with the needs and abilities of disabled people (ibid).

2.8. Conclusion

In conclusion, a consideration of the origin of the concept of disability reveals that it was an artificially created construct rather than a real, independent entity. The growing interest in the topic of disability has led to many conceptualizations and attempts to define it. This review has attempted to offer a critique of three of these conceptualizations. A review of the traditional approach which psychology adopts toward disability revealed unsatisfactory conclusions being drawn on the basis of impairment. Recent developments in psychoanalysis have rendered it useful in the explication of the relationship between social responses and cultural imperatives toward exclusion and the impact these have on disabled people. An exploration of the process of development and various theories which attempt to describe it has also been carried out. Considerations of research investigating the impact of visual impairment on development have revealed that visual impairment has a less negative impact than was previously thought. As the participants are adolescents, a brief discussion of career decision making in adolescence

emphasized the changes which have occurred over time in the world of work and highlighted various factors which influence the process. Finally, personal accounts and qualitative investigation of growing up with a visual impairment were included to consider possible parallels in the narratives of visually impaired persons. The discussion will now turn to the various methodological issues which arose in the course of the research.

3. Methodology

3.1. Introduction

This study aimed to develop an understanding of the lived experience of visual impairment by exploring the experiences of visually impaired, school-aged adolescents. This chapter provides an account of the aims, design, and method of data collection and analysis. A discussion of participant selection and recruitment will also be provided as well as a consideration of the various ethical issues and challenges which arose during the course of the study.

3.2. Aims and Rationale of the Study

3.2.1. Aims

As highlighted above, this study had one main aim:

1. To develop an understanding of the way in which visually impaired children experience their disability.

In order to achieve this aim, the following questions were considered:

- ❖ When and how did the children become aware of their disability?
- ❖ What impact do they think it has had on their relationships with parents, siblings, teachers, peers and the general populace?
- ❖ What are their feelings about being visually impaired?

An additional aim emerged over the course of the study. This aim centred on exploring the extent to which the experiences of the current participants mirrored those experienced by other impaired people. The literature suggested that a commonality of experience of discrimination and difference might exist among all impaired people (Watermeyer, 2009). The researcher therefore analysed the data with this hypothesis in mind.

3.2.2. Rationale

A review of the literature revealed that an attempt has been made to document the biopsychosocial differences which are thought to exist between disabled and nondisabled children. Recent research has sought to move away from a focus on differences, arguing that such a focus serves to entrench existing negative stereotypes and practices surrounding disability. Furthermore, empirical research and personal accounts of the disabled experience have elucidated the experience of disability by situating it in a political, social and psychological context. In line with this research, the researcher wished to investigate the experiences of the impact of visual impairment in adolescents to determine the extent to which their experiences would reflect similar patterns and themes described by other researchers.

The study may serve to provide insight into areas of difficulty encountered by the participants. This insight may be used to develop practical solutions to the reported difficulties and may inform practitioners who work in various clinical settings.

Furthermore, it would be unwise and dishonest of the researcher to deny the presence of a strong personal interest in the findings of this study. As a congenitally blind individual, the researcher wished to find out whether the accounts provided by the participants in any way paralleled her own experience. This personal interest was carefully monitored by both the researcher and her supervisor to ensure it did not impact negatively on the study in any way.

Finally, findings obtained in this study may generate further research.

3.3. Research Design

What separates research from other forms of observation is the underlying plan or research design (Durrheim, 2002). Durrheim (2002, p. 29) defines a research design as “a strategic framework for action that serves as a bridge between research questions and the execution or implementation of the research.” The research design informs the research at each stage including the sampling techniques, methods of data collection, analysis and interpretation (ibid). As the current research was aimed at developing an understanding of the experience of visual impairment, a qualitative research design was deemed most suitable to fulfill the research purpose.

Babbie and Mouton (2005) identify six features of the qualitative approach to research. First, they argue that qualitative research usually occurs within the natural setting of the subjects under study (ibid). Conducting research in such settings allows the qualitative researcher to be as non-intrusive as possible and to study behaviours, attitudes, and so forth as they unfold (ibid). Second, the emphasis on naturalistic settings means that qualitative research is most appropriate to study social phenomena over time (ibid). Third, qualitative researchers adopt an emic/insider perspective in their research (ibid). This refers to the fact that they attempt to see the world from the perspective of those whom they are studying. The behaviours, attitudes, feelings, and so forth of those under study are understood from their own perspective (ibid). A fourth feature of qualitative research is its focus on describing and understanding the phenomena under study from the perspective of the research participants through the generation of so-called thick descriptions (ibid). Coined by Clifford Geertz (1973, in Babbie & Mouton, 2005), the term 'thick' refers to a long and detailed account of phenomena as they unfold. The accounts are usually written in language appropriate to the participants they describe (Babbie & Mouton, 2005). In order to truly understand social phenomena, it is argued that one needs to locate them within the context they occur (Babbie & Mouton, 2005). Therefore, in order to generate a true understanding, qualitative research tends to be context specific (ibid). Finally, qualitative research favours an inductive approach (ibid). Through such an approach, one enters the natural setting and attempts to generate deep and thick descriptions by making use of the research participants' perspective. One then provides an interpretation of the observations one has made and builds a theory to account for these observations (ibid).

The interpretivist paradigm, on which most qualitative research is based, has various ontological and epistemological assumptions. From an ontological perspective, the interpretive approach argues for the importance of the subjective nature of lived reality (Terre Blanche & Kelly, 2002). The epistemological assumptions of this approach argue that interaction with others is essential if we wish to understand their experiences (ibid). An empathic reliving, whereby data is interpreted and understood in context, is a key tool of this approach (ibid). With the principles and assumptions of the interpretive, qualitative paradigm in mind, the researcher designed the study which complied with the demands of the approach.

3.4. Design Coherence and Validity

Designing sound research involves making a number of decisions (Durrheim, 2002). Four linked domains of design, identified by Durrheim (2002), and which should guide the various decisions made are the purpose of the research; the theoretical paradigm which informs the research; the context of the research; and the research techniques to be used to collect and analyze the data. The purpose and theoretical paradigm informing the research have already been discussed and decisions related to context and research techniques will be discussed in later sections of the chapter.

Durrheim (2002) argues that in order for a design to be judged sound, it must satisfy the criteria of coherence and validity. To satisfy the criterion of design validity, a research design must identify and incorporate possible alternative explanations for the results obtained (ibid). Designs which fail to consider the possible alternative explanations may result in the drawing of invalid conclusions (ibid). With regard to the current research, the researcher was aware that certain factors could be present and that these might influence the conclusions drawn. One possible factor was the possibility that the participants would respond in a defensive manner. The topic of interest required participants to be willing to reveal vulnerabilities and sensitivities and the participants may have found this difficult to do. Furthermore, the participants may not yet have reached a stage of development where they were able to give adequate voice to their experience. Thus, the topics of discussion were designed to elicit material in as nonthreatening a manner as possible, and in accordance with the participants' level of development.

The concept of design coherence emerged in response to the development of paradigms which were non-positivist in nature (Durrheim, 2002). In order for a design to achieve design coherence, the research purposes and techniques must fit together in a logical manner (ibid). As previously discussed, the study aimed to gain an understanding of the experiences of visually impaired adolescents. The research adopted a qualitative focus, employing focus groups as the means of data collection. Participants were selected for the focus groups based on the presence of visual impairment and level of education. The analysis conducted utilized an interpretive thematic approach (Terre Blanche & Kelly, 2002). A more detailed discussion of sampling and analysis will be conducted later in the chapter. Issues of reliability and validity as they applied to the study will also be considered.

3.5. Ethical Considerations

While the aim of the researcher was to gather rich data which would assist in answering the research questions, careful consideration of the ethical implications of the research was required at every stage. Given the focus of the research, it was difficult to anticipate the experiences which would be shared. The researcher needed to guard against causing distress to the participants by evoking in them memories of painful issues which they had experienced. The researcher and supervisor together developed methods of safeguarding the participants and plans for dealing with any difficulties which arose.

A second concern which required careful consideration was the fact that the research participants were all under 18, so particular care had to be taken to ensure that their participation was gained and maintained in an ethical manner.

While many ethical codes and guidelines are available to guide ethical research, Durrheim and Wassenaar (2002) identify three principles which underpin the various codes. The first is the principle of autonomy (ibid). In order to satisfy this principle, researchers must ensure that consent is informed and voluntary, participant withdrawal is permitted, and anonymity is guaranteed when the research findings are published (ibid). The principle of nonmaleficence is the second of the three broad principles which need to be taken into account (ibid). Nonmaleficence requires that the research should inflict no harm on the participants and, if harm may occur, that the researcher determines whether the benefit of the research will outweigh the harm (ibid). The third principle is referred to as the principle of beneficence (ibid). This principle requires that the research yield benefits which, if not directly benefiting the research participants, should benefit other researchers and/or society in some way (Durrheim & Wassenaar, 2002).

In an article considering the ethics of research in developing countries, Emanuel, Wendler, Killin and Grady (2004) provide guidelines one may use to ensure that research is conducted in an ethical manner. These guidelines are social value, scientific validity, the fair selection of participants, favourable risk/benefit ratio, independent review, informed consent, an ongoing respect for dignity and community participation and feedback (ibid).

It was with these principles and guidelines in mind that the researcher began to design and execute the research. The most challenging ethical issues in the study centered round the involvement of

adolescents under the age of 18 in the research. According to Santelli *et al.*, (2003) due to the complex nature of the ethical challenges of involving adolescents in research, many studies exclude this population from participation in research. However, it is argued that research with adolescents is needed to further the understanding of adolescent health and development (*ibid*). Thus, despite the ethical challenges inherent in involving adolescents in research, the researcher felt that if carefully handled, the successful participation of adolescents in the current research could be achieved.

In order to address issues of consent, confidentiality and anonymity, the researcher adopted various strategies. Firstly a full proposal was sent to the Faculty Ethics Review Board for consideration and subsequently approval was granted (Appendix A). As the participants were to be drawn from a school, it was necessary to obtain the informed consent of the Department of Education. A letter outlining the aims and rationale of the research was sent to the Department of Education and is provided in Appendix B. The researcher also met with the principal of the school and provided a written request to conduct research with selected learners. This request contained an outline of the aims and rationale of the proposed research and provided information with regard to the voluntary nature of consent as well as highlighting the proposed steps to ensure that participants participated voluntarily and with the consent of their parents. Finally, the request addressed issues relating to the confidential nature of the research. The anonymity of the school and participants was guaranteed. This request also outlined the dissemination of results. A copy of this request is included in Appendix C.

The guidelines for the ethical involvement of adolescents in research (SAM, 2003) require that one obtain the assent of adolescents to participate in research. In order to gain assent, the researcher met with potential participants at the school with the consent of the principal. The aims, rationale and potential benefits of the study were carefully explained and all questions were answered. Those willing to participate were provided with an assent form to read. This form emphasized the voluntary nature of participation, the freedom of the participants to withdraw at any time and the planned dissemination of results. Braille copies of the assent form were made available to learners with more severe visual impairments. A copy of the assent form is provided in Appendix D. Each participant was then provided a copy of an informed consent form which was to be given to their parents/guardians to read and sign. While the researcher would have preferred to meet with parents/guardians in person, this proved impossible as many participants lived far away from the school and parents did not often come to the school. The consent form contained similar information to the assent form. It was translated into isiZulu and the translation was checked independently to

ensure accuracy. Brailled copies of the consent form were also made available for parents who were themselves severely visually impaired. Provision of Braille consent forms also allowed blind participants to read the forms to parents/guardians who were illiterate (See Appendix E).

A further concern in this study was the fact that the participants all attended the same school and so confidentiality was not assured within the group and between participants once the focus group had been concluded. It was thus necessary to warn participants of this potential risk and to request that they respect the confidential nature of much of the discussed issues.

As the researcher was unsure whether discussion of their experiences would evoke painful memories and events, steps were taken to ensure that participants could be assisted to deal with these difficulties. It was decided that adolescents who suffered distress as a result of the research would be referred to the Child and Family Centre to receive counseling. In this way, the researcher hoped to minimize potential harm to participants.

Finally, the researcher agreed to make copies of the results obtained available to any interested stakeholders and to the participants in particular.

3.6. Sampling

In order to ensure that sound conclusions are reached in research, the people, settings, behaviours, processes, etc one chooses to study need to be selected carefully. The process of selection is referred to as the sampling process (Durrheim, 2002). As the researcher wished to develop an understanding of the ways in which visually impaired adolescents think and feel about their disability, the sample group needed to possess the necessary attributes to provide the relevant information. Thus, the method of sampling was purposive in nature. Purposive sampling is a non-random method of sampling and allows participants to be chosen because they possess an attribute in which we are interested (Silverman, 2004). However, Silverman (2004) cautions that purposive sampling does not involve simply choosing any case which possesses a particular attribute. The parameters of a population need to be carefully and critically considered and utilized when one selects research participants (*ibid*).

Durrheim (2002) argues that sample size and representativeness are two issues which need to be given careful consideration during the sampling process. While these issues are more easily dealt with in quantitative designs, they also need to guide the sampling process in qualitative research (ibid). With regard to sample size, the researcher aimed to study a small sample of information-rich cases, an approach often employed in qualitative research. Initially, a sample of nine learners was drawn. However, as the research progressed, the researcher realized that the participants' level of impairment was less severe than other members of the population. The researcher was concerned that failure to include adolescents with more severe visual impairments would result in the development of an incomplete picture of the experience of visual impairment. Therefore, the researcher drew another sample of seven learners with more severe visual impairments.

Representativeness refers to whether or not one can generalize findings from a sample to the broader population (Durrheim, 2002). The researcher aimed to develop an understanding of how the visually impaired adolescents in the study experienced their disability. Therefore, the generalisability of the findings is somewhat limited, a problem often encountered in qualitative research.

As the sampling process was purposive in nature, the researcher decided to select participants from a school for the visually impaired. The researcher held a meeting with the principal of the school to determine whether he would be willing to allow research to be conducted with the learners. Once his permission was obtained, the researcher was instructed to liaise with the deputy principal of the school to set up a meeting with pupils from Grades 8 to 12. A meeting with these learners was arranged and attended by the researcher and her supervisor. The learners were provided with a description, the aims and rationale as well as the means of data collection to be employed in the study. Learners were also given assurance as to the voluntary nature of participation, the option to withdraw at any stage, and the guarantee of anonymity. The researcher also explained that their parents/guardians would need to provide consent for them to participate in the study. After being provided the opportunity to raise any concerns and to ask questions, learners were then asked to raise their hands if they were willing to participate. This yielded a response from thirty learners. A further meeting was arranged at which the researcher would distribute copies of the informed consent form. At this meeting, attended by only 12 learners, the researcher again emphasized the voluntary nature of participation and the option to withdraw. The importance of obtaining parental consent was also emphasized and consent forms were distributed. Nine learners returned with signed consent forms and formed the first sample of learners.

As the study progressed, the researcher realized that all the participants were in fact partially sighted and became concerned that the sample did not contain any blind learners. It was felt that learners with more severe visual impairments ought to be given the opportunity to participate and share their experiences of their impairments. The researcher therefore met with blind learners from Grades 8 to 12 to propose that some of them join the study. Once more, the voluntary nature of participation was clarified and emphasized. Seven learners volunteered and obtained the required consent of their parents/guardians. These seven learners formed the second sample of learners who participated in the research.

3.6.1. Criteria for Inclusion

The criteria employed in the selection of participants into the study are as follows:

- ❖ Adolescents must be in Grade 9 to Grade 11 so as to avoid any difficulties caused by the learners entering high school or any disruption for final year matriculants;
- ❖ Adolescents must have been visually impaired from birth, lost their sight before 5 years of age or be placed in a school for the visually impaired due to a severe visual impairment.

The choice to focus on adolescents as opposed to children was based on an understanding of children's cognitive development. During adolescence, one possesses a wider vocabulary and is more able to express feelings and opinions than younger children. It was therefore reasoned that adolescents would be able to provide more detailed, rich information than younger children. As the research focused on issues such as growing up with a visual impairment, it was felt that only those who were born with a visual impairment or developed one before commencing formal schooling would provide information in this regard.

3.6.2. Description of the Research Participants

The main difficulty encountered was gaining the informed consent of the parents/guardians. This difficulty arose as many parents do not come to the school and those who do, come only on special occasions such as prize-giving's, sports gatherings and at the beginning and end of the year. As many parents live far away from the school, the researcher could not go to their homes to inform them

about the nature of the research. It was thus decided that the learners would be asked to take copies of the consent form home at the end of the school term and to provide their parents with a description of the study. This approach yielded 16 participants. Of these, 9 were partially sighted and 7 were blind. Two learners in the first group attended the group intermittently, resulting in a stable sample of 7 learners. As described earlier, the samples were drawn at different stages of the research and thus formed 2 groups. One comprised learners with less severe visual impairments and the second comprised those with more severe visual impairments. The group of learners with less severe visual impairments comprised 4 boys and 5 girls while the group of severely visually impaired learners comprised 3 girls and 4 boys. As stipulated in the criteria for inclusion, the learners came from Grades 9 to 11.

3.7. Focus Groups

By definition, a focus group involves a group of eight to twelve participants who discuss a particular topic, known as the focus of conversation (Stuart & Shamdasani, 1998). Focus groups have the potential to yield rich data and as such are frequently employed as a technique of data collection in qualitative research (ibid). Stuart and Shamdasani (1998) advocate the use of focus groups for research where little is known about the phenomenon of interest. Given that the experience of visual impairment is still being researched and developed, focus groups provided a means of investigating this area.

Stuart and Shamdasani (1998) identify several advantages and limitations pertaining to the use of focus groups. Those relevant to the current research will be highlighted below.

One advantage of focus group research is that it allows one to adopt a more emic approach (Stuart & Shamdasani, 1998). This involves conducting the group in such a way that the researcher does not impose their own conclusions and perspectives on to those expressed by the group. While questions and themes guide the discussion, the data yielded is determined by the participants (ibid). An emic approach is in keeping with the insider perspective required in qualitative research. Another advantage associated with the use of focus groups is the direct interaction which occurs between researcher and participants. During this interaction, a researcher can seek clarification and probe responses to obtain deeper meanings (ibid). Data may emerge which would not have emerged in individual interviews as the group is able to respond to and build upon the responses of individual

members (ibid). Finally, focus groups provide a more cost-effective means of data collection than individual interviews (ibid).

Two potential disadvantages form part of focus group research. First, interaction within the group may be determined by the presence of dominant members and those more reserved may be hesitant to speak (Stuart & Shamdasani, 1998). There is also the possibility that the researcher can bias the findings by providing cues to the participants regarding appropriate answers (ibid). In order to counteract these limitations, the researcher took two steps. The first involved ensuring that each person in the group was given a chance to speak. Second, the researcher conducted the groups with the aid of her supervisor to serve as a monitor and to guard against the introduction of leading questions or cues.

3.7.1. Setting up the Focus Groups

Arrangements for conducting the focus groups were made with key stakeholders. It was negotiated that the groups would be conducted outside school hours as this would allow participants to participate without being absent from class. As the participants are visually impaired and dependent on others for assistance in terms of transport, it was decided that it would be best to conduct the research at the school. This also meant that the participants would be in a familiar setting. The groups were conducted over a period of nine months from July 2008 to March 2009, with each participant participating in three focus group discussions which were conducted about two to three weeks apart.

3.7.2. Development of the Focus Group Schedules

It was decided that the focus groups would address three areas of interest:

- ❖ The experience of growing up with a disability;
- ❖ The perceived impact that the disability has had on the participants' relationships with others;
- ❖ Dreams and aspirations for the future.

The schedule of topics for the three focus group discussions is to be found in Appendix F.

3.7.3. The First Group

The focus of interest of the first group revolved around growing up with a visual impairment. In order to guide the group, this focus was further divided into 2 areas. The first area focused on exploring the age at which the participants became aware of their visual impairments. The second area of interest focused on what had led to the development of this awareness and feelings around this awareness.

At the beginning of the group, the participants were provided with an explanation of the aims and rationale underlying the research. The participants were reminded of the voluntary nature of the research and confidentiality and anonymity were also highlighted. The group was also asked to develop norms for the smooth running of the group. These norms included respect for one another and confidentiality about what was discussed. At the end of the group, the participants were asked to highlight any upsetting aspects of the discussion and encouraged to remain behind to discuss them with the researcher if they wished to do so. Participants were also provided refreshments during the focus group. The first group session lasted for 2 hours.

3.7.4. The Second Group

The second area of interest concerned the participants' perceptions of how their impairments had impacted upon relationships with family, peers, teachers and the general public. This area was divided into the various groups of people mentioned above. At the beginning of the group, the group was asked to reaffirm the group norms and to sum up the previous discussion. The voluntary nature of the research was highlighted and the aims of the discussion introduced. At the end of the discussion, the participants were again asked to highlight more upsetting aspects of the discussion and to remain behind to discuss them with the researcher if they so wished. Refreshments were again provided. The second group took 1 ½ hours to complete.

3.7.5. The Third Group

This group focused on the dreams and aspirations for the future of the participants. While this was run as a separate group for the partially sighted participants, time constraints meant that it had to be included as part of the second focus group discussion for the severely visually impaired students. The focus in this group was aimed at exploring the participants' plans for the future and whether their

disability had influenced their choice of future career. Once more the norms of the group were re-established at the beginning of the group. The participants were reminded of the voluntary nature of the research and of the option to withdraw. At the end, the researchers asked for feedback about the participants' experience of the group and said that if anyone had been upset by any aspect of the research to remain and discuss it with the researcher. Participants were also encouraged to inform teachers at the school should they become negatively affected by the research and request that the teachers contact the researcher. Refreshments were also provided during this group. The group took 2 hours to complete.

3.8. Data Analysis

An interpretive thematic analysis was utilized during the analysis of the data. A key assumption of this approach requires that one must immerse oneself in the data (Terre Blanche, Durrheim & Kelly, 2006). As discussed earlier in the chapter, another principle which is essential to this approach is empathic reliving whereby data are interpreted in a context specific manner (ibid). Terre Blanche, Durrheim and Kelly (2006) argue that a context specific analysis is essential as it allows others who are embedded in, or close to, that context to recognize the interpretation as true. Yet, it is also argued that the interpretation must be far away enough so that the phenomenon may be viewed from a new perspective by those involved in the context in which the phenomenon emerges (ibid). The process of data analysis is described below.

3.8.1. Transcribing the Focus Group Data

Transcription involves transforming oral interviews into written records (Kvale, 1996). Transcription is an essential part of analysis using an interpretive thematic approach as one is required to read and reread the transcripts in order to immerse oneself in and remain close to the data (Terre Blanche, Durrheim & Kelly, 2006).

The data was transcribed by the researcher. Though it was the intension of the researcher to record the focus groups and to transcribe later, an experience whereby the recording equipment malfunctioned resulting in the loss of some data led to the development of a different method of recording. The researcher took a laptop computer to the focus groups and, with the group's permission, typed up the discussion as it unfolded. In order to keep up with the discussion, these

records were done in shorthand. Later, the researcher went over and edited the text, removing the shorthand and adding in parts of the discussion which had not been captured during the course of the focus group. While this method was time consuming, it meant that the researcher became fully immersed in the data, which is an essential necessity of qualitative research (Babbie & Mouton, 2005).

3.8.2. The Process of Data Analysis

The analysis followed five steps as proposed by Terre Blanche, Durrheim and Kelly (2006). These steps are described below.

A. Familiarisation and Immersion

It is argued that by the time analysis begins, a researcher has already developed ideas about what the data will reveal and which interpretations will prove useful and which will not (Terre Blanche, Durrheim & Kelly, 2006). Commencement of analysis signifies a move away from focusing on the actual lived realities of the participants and on to the texts generated during data collection and transcription (ibid). In accordance with this step, the researcher focused the analysis on the transcripts generated from data collection. Multiple readings of these texts were necessary to ensure thorough immersion in the data.

B. Inducing Themes

The next step involves developing a set of organizing principles which underlie the data (Terre Blanche, Durrheim & Kelly, 2006). This requires the utilization of a bottom-up approach whereby one uses the data to determine the organizing themes rather than applying preconceived themes to the data (Terre Blanche, Durrheim & Kelly, 2002). It is advised that the themes incorporate the language used by participants and it is also noted that the number of themes generated will depend on the nature of the study (ibid). Terre Blanche, Durrheim and Kelly (2006) caution that too few themes will restrict interpretation but too many themes will do likewise. They suggest developing a few main themes with various subthemes embedded in them (ibid).

C. Coding

Coding occurs during the induction of themes (Terre Blanche, Durrheim & Kelly, 2006). It involves identifying parts of the data which are instances of, or relevant to, a particular theme (ibid). Codes are flexible and may represent instances of more than one theme (ibid).

D. Elaboration

Elaborating involves refining and altering the themes and codes one has developed (Terre Blanche, Durrheim & Kelly, 2006). This is essential if one is to develop an accurate interpretation of the phenomenon of interest (ibid).

E. Interpretation and checking

This stage involves the development of a written account of the interpretation of the phenomenon of interest (Terre Blanche, Durrheim & Kelly, 2006). During this stage, one examines the interpretation, checking the relevance of the various themes and codes (ibid). It is also advised that the researcher reflects on their role in collecting and analyzing the data in order to determine how this may have influenced the collection and analysis processes (ibid). Given that the researcher is herself visually impaired, this process of reflection was essential to ensuring that the data was not contaminated by the researcher's biases and experience.

3.9. Reliability and Validity

3.9.1. The Concepts of Reliability and Validity Applied to Qualitative Research.

While the concepts of reliability and validity operate differently in qualitative research as opposed to quantitative research, they are nevertheless of crucial importance (Silverman, 2004). Silverman (2004, p. 274) goes on to state that "Short of reliable methods and valid conclusions, research descends into a bedlam where the only battles that are won are by those who shout the loudest." With this in mind, the concepts of reliability and validity, as they applied to the current research, are described in the following sections.

3.9.2. Reliability

Hammersley (1992, in Silverman, 2004) defines reliability as the extent to which instances of a particular phenomenon are assigned to the same category by the researcher and others on different occasions. In order to achieve reliability, one needs to accurately document the procedures followed and the observations made (Silverman, 2004). One can also seek assistance from other researchers to determine whether they would assign instances of a phenomenon to the same categories used by the original researcher. This method is referred to as inter-rater reliability (ibid). Furthermore, by engaging in a constant process of reflection, one can attempt to uphold reliability by ensuring that bias on the part of the researcher is excluded as far as possible from the study (Babbie & Mouton, 2005).

In order to ensure reliability, the researcher attempted to keep careful and accurate records of the procedures followed as the study unfolded. Transcription was completed in as accurate a manner as possible. Furthermore, the researcher engaged in a process of constant reflection and conscious self awareness. This process was aided by discussion with the researcher's supervisor and other colleagues.

3.9.3. Validity

Hammersley (1990, in Silverman, 2004) defines validity in terms of the extent to which an interpretation accurately reflects the phenomenon it is meant to. One engages in a continuous process of questioning the truth and accuracy of one's findings (Silverman, 2004). Silverman (2004) identifies different methods of maximizing validity. One such method involves testing hypotheses with different cases of a phenomenon (ibid). This method is referred to by Silverman (2004) as the constant comparative method. One can also employ a method of deviant case analysis, in which one seeks out a deviant case and attempts to explain it in terms of one's original hypotheses (ibid).

With regard to validity, the researcher submitted her findings for independent review. The review was carried out by her supervisor and two other colleagues working in the field of psychology. The researcher participated in parts of the review process and was absent during others. This process afforded a consideration of alternative explanations of the findings and an opportunity to broaden the interpretation of the findings.

3.10. Conclusion

This chapter has presented a consideration of the methodological approach employed in this research. The design, sampling techniques, method of data collection and analysis were also discussed. A discussion of ethical issues most relevant to the study was provided. Finally, issues of reliability and validity applied in qualitative research were highlighted. The next chapter presents the results and interpretation of t

4. Results and Discussion

This chapter presents the results obtained from the focus group discussions. Elaboration and interpretation of these results will also be provided within this chapter. Themes which emerged with the two sampled groups; that is, those with different degrees of visual impairment and disability, will be analyzed. Where dissension occurred in the group discussions, this is noted and explored.

Various extracts are used to support and demonstrate the analysis. The extracts taken from discussion with the less severely visually impaired students are marked with an A; whilst those taken from discussions held with the more severely visually impaired group will be marked with a B.

Participants are simply identified by number; i.e. P1, P2, and so forth, with the first 9 referring to participants with less severe visual impairments and the second 7 coming from the more severely visually impaired group.

Many themes emerged during the process of analysis. These include negative social responses to disability from many different stakeholders in the participants' lives, the socially constructed nature of disability, frequent violations of personal boundaries and concerns for the future. These and other themes are discussed below. However, before the analysis is presented, a note on the researcher's response to the participants and their discussion about visual impairment is provided.

4.1. Awareness and Concerns of the Researcher

From the outset, I was very aware that having a visual impairment would be both advantageous and disadvantageous to the study. On one hand, I was able to locate and gain access to participants more easily as I knew where suitable participants could be found and whom to speak to, to gain access.

The staff at the school was accommodating and trusted that I would ensure the safety of their learners. Furthermore, I was able to establish rapport and to gain the trust of the participants quickly as I was very open about my own experiences and they began to identify and relate to me more willingly than they did to my supervisor, who was present during the focus group discussion as well as at the meeting to explain the study and to ask people to volunteer to participate in the research.

My visual impairment allowed me to develop a deeper insight and empathy toward the participants as it became apparent that we faced similar difficulties and employed similar coping strategies.

Nevertheless, it was also clear that there were aspects of each person's experience which were unique to them. While we encountered similar difficulties, our understanding, interpretation and feelings about what we encountered differed. It also became apparent that though different experiences were reported by both groups, challenges faced were not more or less difficult depending on how much sight a person had but were determined more by the particular experiences they had in their lives. It seems that considering experiences by placing them along a dimension of impairment would be unwise and problematic as it would create an artificial divide, and minimise the personal experiences of visually impaired individuals.

An important part of qualitative research is the researcher's ability to immerse herself in the context of her participants (Babbie & Mouton, 2005). While my visual impairment allowed me to achieve this immersion more easily, it also proved hazardous as there was more potential for my narrative and perspective to contaminate those of the participants. In order to guard against this, a critical reflection was engaged in at different stages of the analysis. These reflections served two important functions. The first purpose was to provide me with a space where I could reflect upon my own (and the participants') feelings and thoughts which the participants' narratives evoked in me and how these paralleled or contrasted with my own experience. Bracketing one's own experiences is essential if one is to gain an understanding of the participants' perspectives (Babbie & Mouton, 2005). At times, it was a simple and uncomplicated procedure to bracket my own experiences; however, at other times, it was complex and required an analysis similar to what one would use in identifying counter-transference issues in psychodynamic psychotherapy. Counter-transference is described by Weiner (1998, p. 237) as "displacements by the therapist on to a patient of thoughts, feelings, and impulses that are not justified in reality by anything the patient has said or done." In similar fashion to the manner in which I approach counter-transference issues arising in psychotherapy, I engaged in an analysis that required me to reflect upon and tease out the emotions and responses which were being evoked in me. The purpose was to determine which of the responses pertained to my personal experience and which belonged to that of my participants. This process was aided and guided by my supervisor who encouraged me to engage in open discussion and debate with her about the content and process of the research.

Having reflected upon my narrative and the way my impairment impacted upon the study, the remainder of the chapter provides a discussion of the various findings which emerged in the data. The focus group began with an icebreaker and a discussion about the nature of the research, group norms and the ethics of the research. The open and participatory approach used encouraged all to feel

comfortable with the researcher and her supervisor who was present to help with some of the logistics.

4.2. *“Finding out” About Disability*

The topics introduced during this first focus group were exploring the age at which the participants became aware of their visual impairments; followed by discussion on their awareness and feelings around this awareness. When asked to talk about how they first realized that they were different or had an impairment, it emerged that many of them were unaware of the terms visually impaired or disabled until they were told about them. While many of them began to realize that they could not do things that their playmates could, they seemed to have accepted this as part of who they were. It was only when they began to question, or when parents were sending them to different schools than those of their siblings, that they were introduced to the idea that others regarded them as fundamentally different from their counterparts.

Extract 4.1. (Focus Group 1B, page 1, lines 32-42)

- P13:** It wasn't a problem for me as I played normally with other kids, rough games and every thing; I wasn't excluded. The first time I realized was when we couldn't find a school. Social workers helped us. I realized I couldn't go to a school like my brothers and sisters, I had to come to special school. People often don't know I can't see so I tell them. I tell them the progress of my eyes if something is wrong. I have laser treatment and I tell them about the pain I went through and stuff.
- P15:** I've never had anyone explain to me I'm blind. I discovered myself at primary school because whenever I moved class my teachers always told me my desk had to be at the front of the class. My parents had spoken to them without telling me. I asked one day and teacher said I was one of the brightest students. As I grew older, I wanted to be a big dude and sit at the back with the other dudes and I couldn't see the writing, so I went home and asked and they told me. It wouldn't have made a difference if they'd told me as well as the teachers. I didn't go to a doctor till I got to school.
- P11:** No one told me I was blind. The doctor told my mother, not me, and told her they need to find a school for the blind so I went to (the name of the school) and I realized I'm not the only one who is blind. There are others. I asked what it's like to be blind and no one had an answer. In my opinion,

it's good to be blind. You don't get involved in different problems and you can read at night and do your homework without disturbing anyone.

Writers such as Marks (1999) have begun to argue that disability is a socially constructed phenomenon and is entrenched by social structures. The evidence, presented above, seems to lend support to this argument. Participants became aware of the fact that they were different through the actions of others. Further support for this argument is provided by the finding that participants often received negative messages from others about their capabilities. Extracts 4.6 and 4.7, presented later in the analysis, will provide an illustration of such messages.

Had there been no social labeling and categorizing of them, one wonders how development would have been different. This is, however, a rhetorical question since no answer could be provided in the face of the degree of social labeling and discrimination that attends the visual impairment. Certainly the participants expressed a strong view that they felt freer at school, when the label of being impaired and different no longer applied. In the school context, the participants felt “more themselves” and more accepted as individuals.

4.3. Social Responses to Disability

The second aspect discussed in the focus groups covered responses which family, friends and society experienced when faced with the participants' impairment. Social responses to disability were described differently by both groups of participants. While both groups acknowledged that these responses were predominantly negative, participants in the second group seemed to make allowances for what they viewed as ignorance.

Participants in the first group gave a contradictory account of their relationships with their families. They were in agreement that their parents responded to them in exactly the same manner as they did with their siblings. However, at a later stage, they described instances of how they were treated differently to their siblings. These will be discussed shortly.

Some participants felt that their relationships with their siblings were negatively influenced by their visual impairment. For example, one participant felt that her siblings treated her differently than they would if she did not have a disability. Of interest is that this respondent felt that the sibling who tended to treat her differently did so as he was himself visually impaired. The extract which follows

presents participant P03's description of her difficulties with her brother and illustrates the attempts of participants P01 and P02 to develop an understanding of the possible cause of these difficulties:

Extract 4.2. (Focus Group 1A, page 1, lines 18-24)

I: Do your siblings treat you the same as they do everyone else?

P03: Not all of them, I have two brothers and a sister. One of my brothers is an albino and we are always fighting. We fight for no reason. Because we are both albinos, we are always fighting.

P02: Maybe they are jealous of each other. Maybe they can't take it that they are not the only albino. Perhaps the brother who is older may feel uncomfortable because he was there first. Perhaps as "A" is a girl and is treated differently, maybe she feels she is not getting enough attention.

P01: Maybe you are jealous because he can see, because he's in mainstream and you're not.

P03: I feel I'm getting enough attention, maybe he isn't. Maybe we are both jealous.

A further difficulty highlighted by some participants reflected the fact that they were sometimes given more attention by other family members, and that this resulted in increased sibling rivalry and resentment on the part of their siblings. This led to participants experiencing feelings of frustration, sadness, and anger, as well as dreading the extra attention. Other participants reported that though their siblings treated them differently, it was in a positive manner. For example, a participant reported that his younger sibling saved him a space close to the television and became very angry and protective of him when other children teased him. He felt good that she cared very much about him but was concerned that she needed to make her own friends and not follow him around with his friends.

Negative responses encountered by some participants in the first group included being called names by others. The extract which follows provides an illustration:

Extract 4.3. (Focus Group 1A, page 2, lines 46-54)

P03: I'm not comfortable in my community, I'm comfortable in my uncle's community. In my community they tease me, they know I'm not going to hit them but they scared of my brother. My brother is older than me, he can fight. A big man came to me and he threatened me to take me to the bush because I'm a monkey. I felt that ok, I'm different from them. I told my mother, she said I mustn't stress, I mustn't worry about them.

P02: I don't have much experience. One morning early, I was walking to the taxi rank. Two huge women were coming down the road and I was going up the road. They said wow, 'umlungu' (white person). I said at least the city has come to the townships. They told my mother I was being rude and she chased them out of my house.

In contrast to the abovementioned account, participants in the second group reported experiencing less negative social responses to their disability. They reported that their visual impairment did not negatively influence their various relationships and, in some cases, enhanced them. This point is illustrated by the following extract.

Extract 4.4. (Focus Group 1B, page 2, lines 28-38)

I: Do you have people who protect you?

P15: Yes.

I: Who are they?

P10: Friends I grew up with. They think that as I'm from this school, I'm intelligent and they like it.

P12: My family and friends protect me. I'm not the kind of person who sits at home so I like to associate with people at home.

P14: My family and friends.

I: Do many people find that they are respected because they think you are intelligent?

P15: Most of the people in my community never knew about the capabilities of people with disabilities. It's like they need to spend time with me and learn what I can do. For me I feel they should accept me and know that I'm just like them.

Extract 4.5. (Focus Group 2B, page 3, lines 10-19)

P15: One common question is, do blind people dream. I tell them we do dream. My eyes are the only body part that don't work properly. Dreams have to do with the mind/brain and that functions properly. People don't understand that because they see things then they dream; so they wonder if we see when we dream.

P12: They don't understand the concept of being blind.

P10: I've told them what happens in my dream is the same as what goes on in their dreams.

P15: They should understand the functioning of a blind person's mind and a sighted person's mind. I've had friends ask if I can feel colour. It's because they don't understand how a blind person's mind functions. I'm the type of person who will say anything to get over something. I told my friend that I cannot feel colour.

Extract 4.5 suggests that while participants in the second group were able to identify the challenges posed by others' response to their visual impairment, they tended to make allowances for the ignorance of others. The issue of being asked inappropriate questions emerged in their narrative as it had done in that of the other group. They felt that many of the questions stemmed from ignorance and tended to adopt the role of educators, but also fobbed people off to get peace and avoid dealing with what they perceived to be prying questions.

A consideration of the different accounts, provided above, revealed that participants in the first group experienced more negative social responses to their impairments while those in the second group experienced more positive aspects. Two possible explanations are presented to explain these differences. First, it may be that participants in the second group were more defensive and less inclined to admit they experienced negative social responses.

Another explanation for these differences is provided by Watermeyer (2000). He argues that partially sighted people often evoke a wide range of responses which vary from suspicion to anger (ibid). It is suggested that the reason for this is that some partially sighted people do not appear to have visual impairments (ibid). Therefore, the difficulties they face may be less visible and understood by society (ibid). Furthermore, many participants in the first group were visually impaired as a result of the condition Albinism. Authors such as Wana (2003) note that Albinism is a condition which is often accompanied by stigma. Evidence of the presence of stigma was provided in extract 4.3. The difficulty associated with Albinism is that while it is highly visible, the fact that an individual who has this condition is visually impaired may be less apparent. Thus it may be that, in keeping with the argument of Watermeyer (2000), the difficulties experienced by these participants as a result of their visual impairment may not be understood by other members of society. This possible lack of understanding, coupled with the stigma which accompanies Albinism may have led to these participants experiencing more negative responses than their counterparts in the second group.

4.4. Normality in Spite of Others

The participants' narratives reflected a view of themselves as 'normal' and that they were largely unaffected by their visual impairment. While they were prepared to discuss the challenges that visual impairment posed, many were reluctant to admit that these had any impact on their lives. However, it became apparent that they faced many challenges. The nature and impact of these challenges will be examined in later sections. Two possible explanations for their reluctance to own difficulties are provided below.

Firstly, from Erikson's (1950) psychosocial developmental perspective, this presentation would not be regarded as surprising. This is because adolescents are attempting to build a cohesive and unified identity and are trying to conform in order to gain greater acceptance from their peers. Therefore, it could be that the participants were reluctant to divulge their personal difficulties with their visual impairments as this would make them different from their sighted counterparts.

In addition to this, a further explanation emerges in keeping with the accounts provided by French (1993b) and Kuusisto (1998), as well as the findings of Watermeyer (2000, 2009). In all the abovementioned accounts, it emerged that there were layers of the experience of disability which impaired persons felt unable to share. The silence surrounding aspects of the experience of disability stems from socialized messages which require that impaired persons protect others from the difficulties they encounter as nondisabled people experience unmanageable levels of anxiety and discomfort when faced with the true nature of the disabled experience. It is possible that the participants are choosing to minimalise the impact of their visual impairments in an attempt to fend off their own and others' anxiety. Therefore, while it was acknowledged that difficulties were encountered, they were often portrayed as things one had to deal with and grow accustomed to. As shall be discussed later, one of the most frequently adopted methods of achieving this aim involved the use of humour and it was felt that any other response was pointless. Participant D in the second group made this point very clear when she stated that becoming upset in the face of others' inappropriate comments, responses and questions would be pointless as they occur so often that a visually impaired person would be distressed every day.

4.5. Barriers 'Out There'

In keeping with the emphasis on normality, described in the previous section, most participants felt that challenges related to their visual impairment arose from others' responses to them and the ill adapted physical environment. This line of argument is in accordance with the social model perspective of disability (Marks, 1999). It was felt that if others would accept the participants for who they were and simply interacted with them as they did with their sighted counterparts, there would be fewer difficulties to negotiate. This also lends support to the constructed nature of disability whereby one is made to feel different because others respond to you as such. This finding is similar to that reported by Watermeyer (2000) in which his participants felt that the world was ill prepared to deal with visually impaired people.

As noted earlier, participants were often very reluctant to own any of the difficulties they described. However, participants from both groups freely admitted that they experienced feelings of frustration in response to the manner in which they were sometimes treated. The frustration stemmed from the fact that others tended to overprotect and act for them, ignoring their capabilities. One participant recounted an incident where she had been asked to serve food to a lady. The lady was reprimanded by another who pointed out that the participant was blind and could not do it. This irritated the participant as dishing up and serving food was well within her capabilities. In the extract which follows participants 08 and 09 provide further examples of how limits are placed upon them by others:

Extract 4.6 (Focus Group 2A, page 1, lines 32-40)

P09: Sometimes when we have those traditional things and we are told to do something, and the old people keep you away from the others, because they can't understand that you can do what they do. Or when we have to go out at night, they will say leave me behind because I can't see. It makes me angry, they take me lightly. They must ask me if I can cope, instead of them telling me that I can do this or do that.

P08: For me I'm quite a sporty person and I play cricket. We play with a tennis ball and if it falls in the sand, it gets a dark colour and when someone hits the ball, I'll be looking for it to catch it and it will just fall in front of me and my friends will laugh. I don't play cricket so much now because it embarrasses me. Sympathy also affects me. I do sit in front of the TV but when I sit in the back because I don't want to sit in front and they tell me to move (closer to the TV set). I just go out of the room.

Having reported that their relationships with family members were positive ones, it began to emerge that these were less positive than had been indicated. Some participants admitted that family members frequently disrespected their privacy, by telling others their life story and describing their visual impairment and medical history as if they were not present. This seemed to be a common experience as when these two participants described their experience, all tried to recite their own similar incidents. An illustration is provided below:

Extract 4.7. (Focus Group 2A, page 2, lines 7-10)

I: What are some of the difficulties you deal with?

P06: Not knowing my relatives. When my parents meet someone, they tell your whole story and you have to stay here and listen.

P04: They ask why you had to come to school in PMB and my mother starts again.

As was noted above, other participants experienced violation of their autonomy. Furthermore, in earlier discussions, it was noted that all participants experienced inappropriate social responses to their disability by strangers. While participants in the second group made allowances for such responses, the fact remains that their boundaries, autonomy and privacy were violated on a regular basis.

These findings are in accordance with the work of Watermeyer and Swartz (2008) who argue that the personal and psychic boundaries of impaired persons are subject to frequent violation and distortion. The findings also indicate that participants were beginning to lower their defenses and allow themselves to explore the difficulties they experienced. Yet, this lowering of defenses did not happen very frequently. It is possible that with time and experience in the focus group, they realized that the researcher and their fellow participants were worthy of trust, and unlike so many others, were able to hold and respond appropriately to their experiences.

Of interest is the fact that some participants identified older women as presenting the most difficulty to them. They reported that older women often asked personal questions or underestimated their capabilities. An illustration is provided in the following extract (FG2B, page 3, lines 48-55):

Extract 4.8

I: Are there particular types of people who talk?

P10: Old women. Usually you draw their attention and they say shame or curious about why they different.

P13: I've heard that women have said blind children should marry their sons because they in a boarding school and taking care of yourself and not wild like others.

I: Black, white Indian?

P13: All.

I: How about young people?

P13: They more kind to you except those they rude. Others are kind.

Other participants felt that women of all ages demonstrated more discrimination than men. This is evidenced by p02's account, provided in Extract 4.3, of his experience with some women in the community. Further evidence is provided in the following extract, (FG2B, page 4, lines 4-24):

Extract 4.9

I: Is there a difference between men and women?

P10: Young people don't talk as much, they accept the image you portray.

P13: I went to a camp with my cousins and I was the only one who was disabled. The person noticed I couldn't see so when we lined up for food she told me to sit down she'd bring it. Women tend to do more talking, men just ask where we go to school. Our school is widely known. They just want to understand. When I told them I didn't need help they left me alone.

P15: To me it's the males who seem not to discriminate. I sometimes walk from my house to my grandfather's place. Whichever guy who knows me if we meet they will assist me. If I walk past a group of girls they will start whispering and laughing and turn around to watch. I find the males to be friendly. They won't ask, they'll just ask one another.

P11: The males are better than the females. I went to the mall and I met one female and I bashed her accidentally and she was so rude to me! She was swearing at me! I was worried because why is she talking to me like that.

P10: The girls only get the right perception if you give them the right perception. We must give the image of being normal and independent.

P16: Sometimes the females discriminate the blind people. When they passing somewhere they asking what made you blind and where you going and if you don't tell them they laugh. Men are alright. All race groups are the same, the males and females are different.

P12: Females talk too much. When let's say you sitting in the car on the way to something one day I was going home with my brother and we were sitting in the car and I phoned somebody. This lady said this lady can't see but she can use your phone. They think you can't use a phone or a computer.

P11: I came with a woman to PMB. She just hit me and said pay me!

Participants reported that young people were more tolerant and accepting than older people. The question of why women are perceived to hold most negative assumptions, and to be less tolerant of impairment, is a question which could lead to interesting future research. Perhaps no-one can explain the responses of members of society in terms of the messages they have received about difference. Perhaps older women are more aware and critical of impairment because they were most likely raised in the Apartheid era where differences were highlighted or before human rights ideologies highlighted equity. Following this argument, it is possible that young people are more accepting of difference as they are growing up in a more integrated context where differences are no longer highlighted.

4.6. Relationships with Peers

Differences in experience were evident in the participants' accounts of relationships with peers. The partially sighted group reported experiencing difficulty with making friends in their home communities. Participants felt that their visual impairment impacted negatively on their ability to make friends. Many participants reported that they tended to withdraw from others in their home communities and preferred to be alone. Some felt that choosing to be alone, reflected their personality and not their disability. Some conflict emerged in the group while this was being discussed as members felt that the experience of disability interfered with the ability to make friends, and others did not. An extract is presented below to highlight the disagreement which arose between participants P02 and P01:

Extract 4.10 (Focus Group 1A, page 2, lines 28-35)

P01: It's strange that all albinos like being alone. They just assume that people are not going to accept me.

P02: It's because of your experience of disability. It's because of the experience you have at home that makes you into the shy person.

P01: It's not because you are a shy person, it's because you are an albino. At school, you are so happy and talkative but at home you are shy - it's because of being an albino.

P02: It's because here there are people surrounding you and supporting you, at home you are alone.

P01: You should not describe yourself as a shy person. It is because of the experience of being an albino. It's about being honest.

Participants in the second group reported no difficulties. However, their heightened defenses may have prevented their speaking openly about the topic. When they discussed friends, they reassured that their friends treated them 'normally'. An illustration was provided in Extract 4.4, presented earlier, in which participants described the manner in which their family and friends protected them. Furthermore, friends with visual impairments were frequently made use of as a means of distancing i.e. participants would describe challenges faced by visually impaired persons but would argue that such things did not happen to them and that they knew about such difficulties because other friends had told of them. For an illustration see Extract 4.11 which is presented in section 4.7.1 of this chapter.

As has been noted, it is the tendency of impaired persons to minimalise the impact that disability has on their lives (French, 1993; Watermeyer, 2000, 2009). Furthermore, it may be that these participants felt more vulnerable and more impaired than the partially sighted participants. This question will be examined in subsequent sections.

The finding that some participants (especially those with the more visible form of disability; i.e. albinism) experience difficulties when making friends supports the findings of other studies. Firstly, it lends support to the findings of Huurre and Aro (1998) that visually impaired adolescents tend to experience difficulty when making friends. Furthermore, Watermeyer (2000) noted that participants in his study reported experiencing difficulties making friends and, following a loss of sight, lost friends who had been regarded as significant members of the participants' lives.

Based on the reports of the participants, and the work of writers in the field of disability studies, the following explanation is offered to account for these difficulties. On the one hand, participants reported withdrawing from others in their home communities. It is suggested that disability evokes intense anxiety and discomfort in nondisabled people (Marks, 1999; Shakespeare, 1994, 2006; Watermeyer, 2000, 2002, 2006, 2009; Watermeyer & Swartz, 2008) such that the disabled respond by withdrawing. Perhaps, this withdrawal, coupled with the possible anxiety experienced by potential friends, adds to increased difficulty on the part of the visually impaired adolescents.

Despite this hypothesis, a question remains as to why the withdrawal occurred in the first place. The extract, presented above, in which a discussion of why disabled people don't have friends suggests that participants have negative experiences at home which result in their withdrawal. Given that many of those who reported difficulties in making friends were Albinos, the withdrawal may have occurred as a result of stigmatization and discrimination against them. Perhaps they have attempted to make friends and been rejected. This is only speculation, however, as the participants did not mention such occurrences. Yet, given that they were unwilling to discuss many difficulties which they experienced, the lack of elaboration could represent a further attempt to minimise difficult experiences of disability.

It must be noted that despite experiencing difficulties in establishing friendships, participants reported that the relationships they had with both sighted and visually impaired friends were very positive. They reported that their friends served as a vital source of social support. This is indeed a positive finding as good peer relationships form an essential part of healthy development and are particularly salient during adolescence. However, if this report is a part of denial and the conspiracy of silence in which they share the imperative of reassuring able-bodied people that all is well, then they remain caught in a web of social isolation.

4.7. Defensive Strategies

As has been noted throughout this analysis, participants were reluctant to own identified difficulties resulting from impairment. They employed three main strategies in warding off anxiety i.e. distancing, manipulating the system, and humour.

4.7.1. Othering or distancing from personal experiences

It became evident that participants in the second group made use of othering on a regular basis. An instance of othering is provided by the following extracts.

Extract 4.11 (Focus Group 2B, page 1, lines 17-21)

P12: You can tell you are not different. People think that because we are blind everything is black, we can't think, we can't smell. You can tell people, that you are blind.

I: Have you been treated like that?

P12: No, but in reality it happens. My friends have told me that people have asked them that. People think we don't have feelings.

Extract 4.12 (Focus Group 2B, page 2, lines 19-21)

P15: Sometimes it happens that people treats you as if you are useless, you can't do anything on your own. They take you to your room, to the dining room, pull out a chair and if they could they'd chew your food for you. But I haven't experienced that. I'm the eldest of the children at home, so the adults feel that they treat me like an adult and they treat me as an independent person and I do many things on my own.

In both of the above extracts the participants state that they are describing the experience of other blind people and not their own experience. Nevertheless the conviction with which they offer the description, leads one to wonder if this is not a personal account. Shakespeare (1994) argues that nondisabled people distance themselves from disabled people through a form of distancing whereby the disabled person is created as "other." Watermeyer (2009) further notes that when disabled persons feel particularly vulnerable, a means of dealing with this is to split off and project these feelings into other disabled persons.

The above accounts indicate that participants were engaging in othering. They freely acknowledged that visually impaired persons encountered particular difficulties and offered examples of these. However, they maintained that such things happened to others and that they knew about these difficulties from listening to the experiences of other visually impaired friends. Two possible reasons present as possible explanations for the tendency to engage in this form of defense. Perhaps the discussion took place at a time when inadequate rapport and trust had been established between participants and researcher. Another explanation might be that the topics being discussed evoked a great deal of anxiety in the participants and required them to engage at a deeper level than they would normally do.

4.7.2. *Humour*

A further recurrent theme was the tendency of the participants to make use of humour. This took two forms. Many participants recalled that if they encountered difficulty in the physical environment, such as tripping over objects or walking into glass doors, they would laugh with the bystanders. It seems as though humour served to relieve some of the anxiety and shame experienced in the situation.

Humour was also demonstrated in the focus groups where accounts of difficult encounters with sighted people would result in all the participants laughing together. The extracts presented below provide an illustration of the use of humour and the attempts which the researcher made to explore the role it played (FG2A, page 1, lines 49-54) and (FG2B, page 3, lines 34-40):

Extract 4.13

P04: With my family, they treat me differently because they think I can't do things. I can't make fire, I'm blind, I must come back early. Sometimes, I can't go to town. The other thing, one day I went to the café and I was so embarrassed, I couldn't see the sliding door and I couldn't see it was open and I knocked myself.

(All participants laugh)

I: Do you laugh because it's funny or because this is something that has happened to you.

P02: It's hard to imagine that it happens to you and others.

Extract 4.14

I: You use a lot of laughter A?

P10: Yes.

I: Who'd be upset?

P13: You'd be wasting your tears.

I: Why?

P13: Because you'd be crying every day. At the hospital they say you can't see, in the bus they say something. At the bank they'd say something.

The use of humour has been documented by Watermeyer (2000). In agreement with the argument of Watermeyer (2000), the researcher felt that the humour relieved the anxiety which was experienced by reliving and recounting the experiences to others. The researcher often experienced anxiety while listening to the stories which the participants related and found that laughing alleviated this anxiety

as well. This suggests that apart from minimizing anxiety experienced by the narrator, humour also serves to alleviate the anxiety of others such as bystanders and friends.

The comment made by participant 11, presented in extract 4.7 lends support to the presence of a tendency to minimalise or deny the more painful aspects of disability. It seemed that it was felt that being upset by inappropriate comments would be pointless as they occur so frequently.

4.7.3. Manipulating the system

It also became apparent that many of the participants successfully manipulated the system and used their impairments for secondary gain. Davis and Watson (2002) reported that participants in their study also learned to manipulate the system to their advantage. This did not mean that they accepted the exclusion and marginalization they experienced from others, but made the system work for them. In keeping with these findings it seems likely that rather than continuing to oppose the limitations imposed on them by others, they learned to bend the system to their advantage. It is interesting that they did not attempt to employ this strategy at school and this was accounted for by the fact that their teachers were well aware of their capabilities and encouraged, rather than discouraged them, to engage in as many activities as they could.

4.8. School as a key Support Structure

The participants were asked to identify sources of support. One of the most significant supportive structures identified was the school. The school in this instance was a special needs school which catered for children with visual impairments. The extracts which follow provide a clear illustration of the significance of the school in the lives of the participants:

Extract 4.15 (Focus Group 1A, page 2, lines 38-45)

P04: I'm more shy when I'm not at school. In school I like making lots of friends. In school I'm an open person. It's because of people out of school treating me differently. Out of school, it's like I have pride. They ask why I'm not visiting.

P06: When I'm at school, you feel free not like at home where you not so free. At school you are free, people are the same, you don't expect questions, sometimes stupid questions. Sometimes when you at home you just feel like

staying at home and not getting exposed. I'm less open at home than when I'm at school.

P07: The same. I'm more free at school than at home. Most of them ask stupid questions.

Extract 4.16(Focus Group 1B, page 1, lines 37-45)

I: Was there a time where it was difficult?

P13: Well I struggled to find a school but it didn't matter because they didn't treat me any different. School is great. Even when we do pick on each other it's ok.

I: Why?

P13: We can pick on each other and we don't get angry because we know they won't get angry and they don't get angry and we don't get angry.

I: How do others feel?

P13: Children find it ok but adults feel we hate each other which isn't true.

P11: We feel we understand each other. We can guide each other.

Extract 4.17(Focus Group 2B, page 4, lines 44-46)

I: Do you laugh with each other about the comments?

P10: A lot.

P13: We tell each other what to do.

While participants bemoaned the fact that they had to board at the school, they nevertheless regarded themselves as fortunate to be attending it. Many reported that they felt able to be themselves in an environment where their differences were not highlighted. Furthermore, a sense of camaraderie and fellowship existed between the learners who often shared experiences, accidents and responses from sighted people with one another. They reported that they felt understood by their peers as everyone could relate to the story they were recounting. Apart from social support, they also reported that the school had provided them with many academic and sporting opportunities which they believed would not have come about away from the school environment.

These findings give rise to concerns related to the government's intention to introduce inclusive education. The introduction of inclusive education, proposed and described in Education White Paper 6 (2001) would mean that many of the participants would be placed in mainstream schools. While this might be received positively as it would mean that learners no longer had to board and miss out on family life, it would also mean the loss of the specialized, nurturing environment which the school seems to provide. While inclusive education seems to have the potential to generate

positive results, the possible psychological, social and academic consequences need to be considered carefully.

4.9. Future Plans

All participants acknowledged that they felt their visual impairment had negatively impacted on their career choices. They felt that having a visual impairment limited their career choice, which is indeed the case.

Many of the participants in the first group reported that their career choices had altered as a result of others telling them that they could not do what they wanted to do initially. While this was true of some participants' choices, it was not true of others. It seemed that while they did not feel unable to do the jobs concerned, others placed limitations on them. Furthermore, some were concerned that the career options open to them would not meet their parents' expectations. Others felt that it would be better to come to terms with their difficulties and choose in accordance with their visual impairments. In response to this, the concern was raised that if one did this, one would not be happy or content. The following extract illustrates the debate which took place between participants B and C:

Extract 4.18 (Focus Group 2A, page 3, lines 32-41)

P01: To please my parents, I have to aim higher. My sisters say doctor or engineer and I can't please them by being a switchboard operator. For them being successful means that you need to be a doctor.

I: Should they say you can do anything? Or stop you because you're disabled?

P02: Be straightforward with me.

P01: If they say you must be a lawyer and you don't want to, you will do it because you want to please them; and you struggle and stress to become someone you didn't want to be.

P02: If they told you you could be a scientist, they would be lying to you and you come to grade 10 and you base your subject choices on science, you pass matric and find that you can't do what you want to do. Maybe you can do anything, according to your sight, given your options.

The above extract seemed to suggest that the participants were in conflict with one another and within themselves. On the one hand, they held certain aspirations for the future which they felt could

not be reached. On the other hand, they seemed to feel limited by the career options open to them. It was also interesting that the participants accepted what they were told by others and did not try for themselves. It seemed that some participants felt they needed to be high achievers in order to out-do their siblings and to please them. P03's comment in the extract above is an illustration of this point. P01's desire to please her parents could represent a form of compensation whereby she is trying to make up for the fact that she is visually impaired.

As in the case of their counterparts in the first group, participants in the second group reported that many of their career aspirations had altered as a result of being told by others what they could and could not do. In some cases, this led to the participants choosing an alternative career option; but in the case of others, they had found solutions to these limitations. In the following extract, participants P10, P13 and P15 discuss their career decisions:

Extract 4.19 (Focus Group 2B, page 4, lines 47-59)

P15: Before I came to school for the blind, I had an ambition of driving racing cars. This was what I wanted to do when I grew up. When I came here, I realized I wouldn't be able to drive any car, let alone a racing car, so now I'm going to do law. It really affected me because I enjoyed fast cars but now it doesn't affect me so much. I'm happy doing law.

P10: I'm a guy who likes getting physical. My dream is to one day become a private investigator. That dream for me is impossible because I can't shoot and stuff. Then I read this magazine about a blind Sherlock Holmes in America so now I feel it is possible again. I'm going to study criminology or psychology. I got the idea from my own qualities and watching movies and the fact that I was exposed to people who liked playing mind games and taking advantage of people.

P13: If my sight was better I love being a soldier. I love chicks, girls in the army. Because I can't see I wouldn't enjoy sitting at the desk, I told (participant's friend) I want to be a PI and I spoke to someone and she said I can't see so I can't be an investigator. I read and saw about someone who's blind and a detective. I'd be the person who analyses things, not going out to find things. But, I hate things like office jobs.

It seems that while visual impairment had influenced their choice of career, negative messages from others about participants' capabilities were more powerful in shaping the course of career decision making. While some career choices were unrealistic and could not be pursued, others had been discarded because other people did not believe the participants capable of fulfilling them. It seems

that the participants were once more influenced and limited by negative messages received from friends and family.

One must be cautious in assuming that only those who are disabled receive negative social messages regarding their career choices. Negative messages about career choice are not limited to those with disabilities. Indeed, Mkhize (2005) noted that the expectations and messages a person receives from family and other important institutions plays a powerful role in shaping the career choices of each individual. Furthermore, participants noted that their career choices also depended upon financial resources and academic performance as these would determine acceptance to various institutions. These concerns are faced by many individuals, whether they are impaired or not (Mkhize, 2005). These negative messages were rated by participants as having more of an impact on their choices than their visual impairment.

4.10. A Commonality of Experience

In chapter 2, it was argued that while impairments vary, the experience of discrimination and difference are common to all disabled persons (Watermeyer, 2009). Evidence to support this argument emerged throughout the narratives of the participants; however, a common thread through much of what was disclosed was also that they were “fine”.

Participants’ accounts seemed to resonate with attempts to minimise the impact which disability has on impairment. Examples of such attempts may be found in Extract 4.5, 4.11, 4.12 and 4.14. As was highlighted, attempts to minimise the impact of impairment occurred more frequently with the more severely visually impaired participants than with those in the other group. It seems, that like participants in other studies (see Watermeyer, 2000, 2009), these participants were bound by an imperative to silence. Extracts 4.3, 4.5, 4.6 and 4.7 provided illustrations of the manner in which participants’ personal boundaries, privacy and autonomy were violated by others. As the extracts indicate, violations tended to take the form of inappropriate questions and responses by others.

They experienced the social and physical environments as inadequately adapted to meet their needs. Defenses employed mirrored those used by other impaired persons. These included distancing, humour and manipulation of the system. All these findings are in keeping with and lend support to the work of Watermeyer (2000, 2009). It is likely that as participants grow and enter new environments, they will encounter similar difficulties to those reported by Watermeyer (2000, 2009).

4.11. Social construction of disability

A fairly strongly supported theoretical theme that emerged was that disability was socially constructed. As the participants became more socially engaged as they grew older, they became more aware of how to behave and be with various social contexts. Evidence supporting this theme is to be found at various points throughout the analysis. For example, it was noted in section 4.2 that participants only became aware of the fact that they were regarded as different when others told them about it. Further evidence was provided in sections 4.3 and 4.5 where social responses to disability were explored. Once more, difference was highlighted and entrenched through the actions of others, i.e., inappropriate responses to impairment, frequent violations of the participants' personal boundaries and an undermining of their autonomy. Finally, the tendency to minimalise experiences also points to a constructed reality in which difference creates discomfort. Participants seemed to minimalise the challenges and experiences they had encountered. This minimalisation served to defend themselves and others from the anxiety which is evoked by disability. Defensive minimalisation is said to emerge as a response to the realization that nondisabled people cannot cope with the level of discomfort and anxiety they encounter when confronted with the true nature of the disabled experience (French, 1993a, 1993b; Watermeyer, 2000, 2009). It seems that a strong argument exists in favour of the socially constructed nature of disability.

4.12. Summary

This chapter presented the results obtained from the study. Discussion of these findings and their implications was also provided. Various interesting findings emerged. Evidence emerged to support the argument that disability is a socially constructed phenomenon. Differences in the narratives of both groups were highlighted and explored. Differences which emerged included the fact that participants in the first group seemed to encounter more negative social responses to impairment than their counterparts in the second group. It also emerged that participants in the second group attempted to minimalise their experiences more frequently than those in the first group. Consideration of these and other differences led to an exploration of whether participants in the first group experienced more negative responses to them as a result of the visibility of their impairments. Another line of argument considered whether participants in the second group felt more vulnerable than their counterparts in the first group. The defensive strategies employed by participants were also examined. Links were drawn between the emerging findings and those produced by other studies.

Evidence supporting the argument for a commonality of experience regardless of impairment was also noted. The school and peers were identified as essential sources of support. Finally, the extent to which visual impairment impacted upon the participants' career choices was considered. The discussion now turns to a critique of the current study and proposes lines of future research.

5. A Critique of the Current Research

This chapter presents a critique of the current study. Strengths and weaknesses will be highlighted and future lines of research will be identified.

5.1. Weaknesses of the Current Research

There were three major weaknesses in the current study: the method of data collection; the format and sequence of topics covered in the focus groups; and the researcher became aware of highly relevant literature after the data had been collected.

The method of data recording employed during data collection involved the researcher taking written notes and resulted in her being less active in the discussion than she could have been. While this method was not chosen as the original means of recording the data, a fault in the recording equipment was encountered in the early stages of the research. The researcher learned a valuable lesson about recording and testing recording equipment. Some precautionary measures had been taken in this regard but clearly these were insufficient as an equipment failure was experienced in terms of the clarity of the taped material. There were therefore missing sections of the transcribed data, which was however supplemented by the notes taken during the focus group discussions.

The format and sequence of topics covered in the focus groups is open to criticism. For example, it might have proved advantageous to the research if the researcher had devoted more time to getting to know the participants and allowing rapport to develop more slowly. This might have led to the participants being more open and willing to explore more deeply throughout the process. This anticipated difficulty was incorporated in the design in that three focus groups were conducted with each group of participants to allow for the rapport and trust to develop over time. However, with hindsight, perhaps more time on an informal basis would have helped in the development of a deeper level of trust.

Finally, the researcher became aware of highly relevant literature after the completion of data collection. Had she been aware of this literature prior to data collection, other interesting avenues could have been explored with the participants. However, this literature proved highly useful in the interpretation of the gathered data.

5.2. Strengths of the Current Study

The researcher aimed to safeguard the participants from harm and distress and it seemed that this aim was achieved. Evidence for this was provided by the participants themselves when they reported that they had thoroughly enjoyed the discussions and had made new friends with other participants to whom they had never spoken. In addition, several of the participants expressed the view that they had never before engaged in a discussion about the nature of their visual impairment and the ways in which the impairment may have shaped who they are now and how they interact with others.

The study yielded findings which lent support to the work of writers such as Davis & Watson (2002; French, 1993a, 1993b; Kuusisto, 1998; Marks, 1999; Shakespeare, 1994, 1996, 2006; Watermeyer, 2000, 2002, 2006, 2009; Watermeyer & Swartz, 2008). It is hoped that these findings will help to expand the understanding of the experience of disability. The study also generated many questions which may prove useful as possible lines of future research. These questions will be considered next.

5.3. Suggestions for Future Research

One area of future research might investigate the extent to which the participants' experiences of disability change over time. Such research may assist in determining whether the participants were attempting to minimise their experiences of difference or if their description represented well-developed coping styles. Both French (1993B) and Kuusisto (1998) reported that as they grew older, they found it easier to explore aspects of their experiences they had previously denied. It may be that the participants may follow a similar trend.

A further line of research might attempt to gain a clear understanding of why participants in the second group seemed to report less negative experiences. Various hypotheses have been explored during the course of the research. Is it that they genuinely encounter fewer negative experiences or do they feel more vulnerable than the other group of participants? Furthermore, to what extent does the visibility of an impairment mediate the experience of disability? Given that those in the first group reported difficulties making friends and many of them had Albinism, it may prove useful to explore whether the visible and unusual nature of their impairment may negatively influence these difficulties,.

Another area of interest relates to why women and older women in particular, were perceived by the participants to be more critical and less tolerant toward them. Is this indeed a result of some being raised in the apartheid era where differences were highlighted or perhaps women experience more anxiety when confronted with disability?

Over the course of the study, it became apparent that discourse plays a crucial role in the perpetuation of negative assumptions about disabled persons. Furthermore, language seems to be employed by disabled and nondisabled persons alike to distance themselves from the effects of disability. Further investigation of the discourse which surrounds disability as well as the functions it serves for disabled and nondisabled people may produce interesting findings.

Finally, it may prove beneficial to explore the possible positive and negative consequences which may follow the implementation of inclusive education from the perspectives of those whom it is most likely to affect. Research might also seek a way of ensuring that positive aspects of the nurturing, specialized environment can be transferred to the mainstream school systems. This research may produce findings which are influential in determining recommendations for future policy development with regard to inclusive education.

6. Conclusion

Greater recognition of the needs of disabled people seems to be developing. Both in South Africa and internationally, policy is being developed to address the needs and issues which pertain to disability. Advocacy organizations and movements which represent disabled people have been arguing against the ongoing marginalization of people with disabilities. The discipline of disability studies is generating research and sparking academic debates. Current research, such as that undertaken by Watermeyer (2009), is focused on interrogating the social, psychological and political aspects of disability. The aim is to develop an understanding of how these aspects interact to create ongoing exclusion and marginalization of those who are impaired.

This study was undertaken with the principal aim being to explore the experiences of visually impaired, school-aged adolescents. Consideration of the literature led to a second aim being incorporated into the study. This aim was concerned with exploring the extent to which the experiences of the current participants mirrored those reported in the literature. The study aimed to employ an approach which moved away from the discourse of difference and emphasized the phenomenological day-to-day experiences of the participants.

The study employed a qualitative design, using a series of focus groups to collect data and a thematic approach to analyzing the collected material. In order to assist in the bracketing of her own assumptions and experiences, the researcher adopted a reflective approach to the data and emerging findings. Reflections were aided and guided by the supervisor of the study. Bracketing proved difficult at times as many of the participants' experiences closely resembled the researcher's own narrative. However, the researcher feels that engaging with the literature and listening to the participants' narratives have created a deeper understanding within her of disability and the various challenges faced by many impaired people.

Sixteen school-aged, visually impaired adolescents volunteered to participate in the study. One of the most important ethical considerations centred on the inclusion of adolescents under the age of 18 in the study. A further crucial ethical consideration concerned the protection of participants from potential physical, social and emotional harm. Each participant participated in three focus group discussions. The first focus group explored the experience of growing up with a disability. The second explored the extent to which disability impacted upon the participants' relationships with

parents, siblings, peers, teachers and the general population. The final focus group explored the participants' dreams and aspirations for the future.

The data was analysed by means of an interpretive, thematic approach. This approach required the researcher to follow five steps: familiarization and immersion, inducing themes, coding, elaboration and interpretation, and checking (Terre Blanche, Durrheim & Kelly, 2006).

Many interesting findings emerged from the analysis. Results indicated that there is strong evidence to support the argument that disability is a socially constructed phenomenon. Negative messages about those who are regarded as disabled are socially entrenched and reflected by the manner in which participants' families, and those in the general population, relate to them. Frequently encountered difficulties included an ill adapted physical environment, having one's autonomy undermined, and one's privacy invaded, making friends with sighted peers, and dealing with negative assumptions by many members of the public.

Evidence to support the argument proposed by Watermeyer (2009) that a commonality of experience exists among impaired persons was also found to be present. Many of the difficulties encountered were similar to those identified by participants in other studies undertaken by writers such as Davis and Watson (2002; Watermeyer, 2000; 2009). Identified sources of support included family, friends, and the school. Participants seemed to find it difficult to acknowledge that the identified difficulties impacted upon them. These and other findings were discussed in Chapter 4 of the dissertation.

A critique of the study was provided. Possible areas for future research were identified and elaborated upon. One of the most important of these involves evaluating the negative and positive consequences of inclusive education.

The study has provided the researcher with useful insight into both the participants' and her own manner of understanding and managing disability. It is hoped that the findings generated by this study will be carried forward and used to improve the lives of those who live with a visual impairment.

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Appendix A: Letter of Ethical Clearance



RESEARCH OFFICE (GOVAN MBEKI CENTRE)
WESTVILLE CAMPUS
TELEPHONE NO.: 031 – 2603587
EMAIL: ximbap@ukzn.ac.za

28 JULY 2008

MS. KA GREENER (204510341)
PSYCHOLOGY

Dear Ms. Greener

ETHICAL CLEARANCE APPROVAL NUMBER: HSS/0316/08M

I wish to confirm that ethical clearance has been approved for the following project:

“The lived experience of blindness as described by blind adolescents”

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years

Yours faithfully


.....
MS. PHUMELELE XIMBA

cc. Supervisor (Dr. BJ Killian)
cc. Mrs. B Jacobsen

Appendix B: Letter of request to the Department of Education

School of Psychology
P/Bag X01 Scottsville
PIETERMARITZBURG, 3209
South Africa
Phone: +27 33 2605371
Fax: +27 33 2605809
Cell: 082 447 9092



17 January 2008

The Director,
Department of Education,
Pietermaritzburg
3201

Dear (director of education)

Request to conduct research with schools for the visually impaired.

I am registered as a Masters Clinical Psychology student at the University of KwaZulu Natal. I am writing to request your permission to involve some learners who attend schools for the visually impaired in my research. As a past pupil at one such school, I feel that I have some insight and sensitivity into the issues that may be raised and will welcome the opportunity to explore these issues systematically, impartially and to give voice to the adolescents own experience of their disability.

The aim of the project is to try and develop an understanding of how blind school aged children think and feel about their disability. I would need to firstly obtain your consent and then the permission of the principals and School Governing Bodies of the schools to conduct my research. Once these levels of consent have been obtained, I would like to identify learners willing to participate in focus group discussions about their disability.

In each school, I would like to conduct three focus groups with learners from Grade 9 to 11. Each group will consist of about 8 to 12 learners. I would like to use class registers to randomly identify the individuals to participate in the focus groups. The criteria for selection would include severe visual impairment, being at a school for the visually impaired for at least four years and that they fall within the age range for my study. Once I have identified twelve learners, the consent of each learner's parent/guardian will be obtained. The learners will also be asked to provide their own written assent before being involved in the project. I assure you that no learner shall be forced to participate against his/her will. All information obtained during the focus groups will be regarded as confidential and each participant will be assigned a pseudonym to ensure that they cannot be identified. Furthermore, names of the schools involved will be withheld to ensure anonymity.

The results of this project will be presented as a thesis and submitted to the School of Psychology for marking. A copy of the findings will be made available to you, the principals and staff of the schools concerned and any parents who may be interested in the results. If you have any further queries, please feel free to contact me on 0829286462. Alternatively, please contact Dr Bev Killian, the supervisor of this project on 0824479092.

Yours sincerely

Kristy Greener
Master student in Clinical Psychology

Dr B J Killian
Supervisor

Appendix C: Letter of request to the principal of the school

xxxxxxxxxx

.....

Street,

Pietermaritzburg

3201

23 January 2008

Dear xxxxxxxx

I am registered as a Masters Clinical Psychology student at the University of KwaZulu Natal. I am writing to request your permission to involve some of your learners in my research.

The aim of the project is to try and develop an understanding of how blind, primary school aged children think and feel about their disability. I would like to hold a maximum of four focus groups with learners from Grade 9 to 11. Two groups of six learners will be involved in the project. The first group will be comprised of congenitally blind learners and the second will comprise six partially sighted learners. I would like to hold a meeting with all learners from Grade 9 to 11 where I will explain my research and call for volunteers. Once twelve learners have volunteered, the consent of each learner's parent/guardian will be obtained. The learners will also be asked to provide their own written assent before being involved in the project. I assure you that no learner shall be forced to participate against his/her will. All information obtained during the focus groups will be regarded as confidential and each participant will be assigned a pseudonym to ensure that they cannot be identified. Furthermore, the name of your school will be withheld to ensure anonymity.

The results of this project will be presented as a thesis and submitted to the School of Psychology for marking. A copy of the findings will be made available to you and your school staff and any parents who may be interested in the results. If you have any further queries, please feel free to contact me on 0829286462. Alternatively, please contact Dr Bev Killian, the supervisor of this project on 0824479092.

Yours sincerely

Kristy Greener

Appendix D: Participant Assent Form

Dear Learner

My name is Kristy and I am a clinical psychology masters student at the university of KwaZulu Natal. I am writing to you to ask if you would be interested in participating in my research. Being blind myself since birth, I am very interested in how other people, especially children experience this disability. The aim of my research is to try to learn about how visually impaired children think and feel about their disability.

I would like you to participate in three focus group discussions. All that we discuss during this time will be kept confidential. To ensure that you cannot be identified when the results are published, you will be allowed to choose another name which will be used instead of yours. If you would not like to participate in the project, you will not be forced to do so. You will not be punished if you choose not to participate. If you would like to stop participating at any time, you will be allowed to do so. I shall make an audio recording of the focus group discussions for the purpose of accurate transcription. If you become anxious or upset during the discussion or because of the discussion, I have arranged for intern psychologists from the Child and Family Centre to offer you counseling.

The results of this project will be presented as a thesis and submitted to the School of Psychology for marking. We will have a session where I show you my results and we discuss them as a group. If you have any further questions or feel unsure about anything, please feel free to contact me on 0829286462. Alternatively, please contact Dr. Bev Killian, the supervisor of the project. Dr Killian is also the head of the Child and Family Centre on campus and will ensure that your welfare is protected. She may be contacted on 033 2605371 or 033 260 5166.

If you would like to participate, please speak the following message into this tape-recorder:

I (your full name) have read and understood the information provided to me and would like to participate in this project.

Appendix E: Parent/Guardian Consent form

22 March 2008

Dear Parent/primary caregiver/legal guardian,

My name is Kristy Greener and I am studying towards my masters' degree at the University of KwaZulu Natal. I am writing to ask for your permission for your child to participate in my research. Being blind myself since birth, I am very interested in how other people, especially adolescents, experience this disability. The aim of my research is to try to learn about how blind adolescents think and feel about being blind.

I would like your child to participate in three focus group discussions. The information collected during these focus groups will be kept confidential. To ensure that your child cannot be identified he/she will be asked to select a pseudonym both during the collection of information and when the results are printed. Your child will also be asked if s/he is willing to participate and if s/he chooses not to participate, then s/he will not be forced to do so. If your child does not wish to participate, they will not be punished or experience any negative consequence. If your child wishes to stop participating in my research, he/she will be allowed to withdraw. I shall make an audio recording of the process for the purpose of accurate transcription of the discussion. In the unlikely event of your child becoming distressed at any time during the discussions, or as a result of the discussion, I have arranged for intern psychologists from the Child and Family Centre to be available to offer counselling.

The results of this project will be presented as a thesis and submitted to the School of Psychology for marking. A copy of the results will be made available to you if you want them.

If you have any further questions or feel unsure about anything, please feel free to contact me on 0829286462. Alternatively, please contact Dr. Bev Killian, the supervisor of the project. Dr Killian is also the head of the Child and Family Centre on campus and will ensure that the welfare of your child is protected. She may be contacted on 033 2605371 or 033 260 5166.

If you are willing to allow your child to participate in the project, please read and sign the attached reply slip.

Thank you very much.

Kristy Greener
Masters' Student in Clinical Psychology

Dr B J Killian
Supervisor

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Research Project: The lived experience of blindness as described by blind adolescents
Consent Form

I have understood the information I have been given and am willing to allow my child to participate in this research project.

Name of child:

Age of child: Grade:

Date of birth of child:

I understand that s/he will participate in three focus groups of a maximum of two duration each, will be free to participate or withdraw at any time, and his/her identity will remain confidential. I agree to the focus groups being audio recorded for the purpose of obtaining an accurate transcription of the group discussion.

Signature of parent/guardian:

Date:

Please return this form to the school by 14th July 2008.

Appendix F: Themes covered in focus groups

Focus group 1

- ❖ Getting to know you;
- ❖ Establishing ground rules;
- ❖ Exploring the experience of growing up blind.
- ❖ Exploring the feelings that the discussion has evoked;
- ❖ Reaffirming the rule of confidentiality;
- ❖ Closure and refreshments.

Focus group 2

- ❖ Reminder of the ground rules;
- ❖ Ensure that participants are still willing to continue;
- ❖ Explore responses by others;
- ❖ Discuss experiences of stigmatization and discrimination.
- ❖ Explore the group's experience of the discussion;
- ❖ Reminder of confidentiality between group members and by the researchers;
- ❖ Closure and refreshments.

Focus group 3

- ❖ Ensure that participants are still willing to participate and reassure them of the voluntary nature of the study;
- ❖ Explore personal aspirations for the future;
- ❖ Explore fears for the future.
- ❖ Thank participants for their participation;
- ❖ Allow time for questions and concerns;
- ❖ Closure and refreshments.