

**Knowledge, attitudes and practices of parents/guardians of children with disabilities on abuse of children with disabilities, in the Willowvale area, Eastern Cape Province, South Africa.**

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## **DECLARATION**

I, M.N. Wogqoyi, hereby declare that the entirety of the work contained in this thesis is my own original work (except where acknowledgments indicate otherwise) and that I have not previously in its entirety or in part submitted it for obtaining any qualification at this or other institution or tertiary education or examining body.

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**O ctej '4234**

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## ABSTRACT

Child abuse is a problem worldwide and also a serious problem in South Africa. Recent statistics revealed an increase in reported cases. Incidence of abuse is difficult to determine accurately but there might be a million children involved annually (Berkow 1977: 1040). Available research indicates that disabled children across all types of disabilities are at a greater risk of all forms of abuse than non-disabled children. The causes of child abuse are complex and involve social factors. The general effect of poverty, unemployment, alcohol and drug abuse are likely to be associated with child abuse. In addition the disability and its effects on the child and family as well as wider societal views of disability exacerbates the risk for disabled children and make apprehending and bringing perpetrators to justice more difficult. But, the topic requires further exploration. Thus the study evolved with the aim to explore parents' and caregiver's knowledge, attitudes and practices towards the abuse of children with disabilities in the Willowvale area of the Eastern Cape of South Africa.

A qualitative, descriptive study with a small quantitative component was done. The sample consisted of 24 participants, identified through snowball sampling, in five purposively sampled study areas in the Eastern Cape. Data was collected in March 2009 through a self-designed questionnaire that focused on knowledge of abuse and a focus group discussion in each site. Content analysis of data according to pre-determined themes was done.

Results indicated low levels of knowledge on abuse as well as difficulties defining the concepts of disability and abuse. However, participants had a general awareness of the presence of abuse of children with disabilities and could provide many an example from personal experience. In addition participants indicated challenges with reporting of abuse such as being unsure what constitutes a criminal offence, what the lines and procedures of reporting are, being scared of the perpetrator and his or her family, being scared of losing social support and poor support from the police and legal system.

It is recommended that customized education programs on disability and child abuse are developed and implemented for both parents of children with disabilities in the study communities as well as the communities at large. Developing and implementing these educational packages can be structured along community based rehabilitation guidelines. The current study participants can form the core group to represent children with disabilities. Implementation, monitoring and evaluation can be linked to local rehabilitation projects. In addition various local and provincial departments such as social

services, health, education and safety and security must collaborate to develop and assist with implementing the education programs and materials.

**KEY TERMS**

Child abuse, disability, knowledge, attitudes, practices

## ABSTRAK

Statistiek dui op 'n toename in kindermishandeling. Die probleem kom wêreldwyd voor en neem ook in Suid Afrika ernstige afmetings aan. Spesifieke insidensiesyfers is moeilik bepaalbaar, maar dit wil voorkom asof 'n miljoen gestremde kinders jaarliks mishandel word. Die risiko van mishandeling is groter vir gestremde kinders as vir nie-gestremde kinders. 'n Komplekse interaksie tussen sosio-ekonomiese faktore soos armoede, werkloosheid, alkohol- en dwelmmisbruik kan dikwels met kindermishandeling geassosieer word. In die geval van gestremde kinders dra die effek van die gestremtheid op die kind en familie, sowel as gemeenskappe se negatiewe houding teenoor gestremde kinders, by tot die risiko vir mishandeling en vergroot die uitdaging om die oortreder op te spoor en suksesvol te verhoor. Daar is egter steeds verskeie onduidelikhede oor die onderwerp en verder studie is nodig. Die huidige studie het beoog om ondersoek in te stel na die kennis, houdings en optrede van ouers en voogde van gestremde kinders in die Willowvale area van die Oos-Kaap, Suid-Afrika, ten opsigte van mishandeling van gestremde kinders.

'n Kwalitatiewe beskrywende studie met 'n klein kwantitatiewe komponent is gedoen. Vier en twintig ouers of voogde van gestremde kinders uit vyf plekke in die Willowvale-gebied het aan die studie deelgeneem. Die studieplekke is doelbewus geselekteer en die deelnemers is deur middel van sneeubalseleksie geïdentifiseer. Data-insameling is deur middel van fokusgroepbesprekings en 'n vraelys oor kennis van kindermishandeling in Maart 2009 gedoen. Die inhoud van die fokusgroepbesprekings is volgens voorafbepaalde temas geanaliseer.

Die resultate dui daarop dat die deelnemers beperkte kennis van kindermishandeling het. Hulle het ook gesukkel om begrippe soos gestremtheid en kindermishandeling te definieer. Hulle was egter bewus daarvan dat mishandeling van gestremde kinders voorkom en kon vele voorbeelde uit eie ervaring opnoem. Volgens die data het deelnemers verskeie probleme met betrekking tot die aanmelding van kindermishandeling ervaar. Die probleme sluit onsekerheid oor wanneer mishandeling 'n kriminele oortreding is, watter prosedure om te volg om mishandeling aan te meld, vrees vir die mishandelaar en sy/haar familie, vrees dat die gemeenskap hulle sal verwerp, asook onvoldoende ondersteuning van polisie en regstelsels in.

Na aanleiding van die bevindinge word aanbeveel dat 'n opvoedingsprogram oor gestremtheid en kindermishandeling saamgestel en in die studiegemeenskappe geïmplimenter word. Die program behoort op ouers en voogde van gestremde kinders sowel as op die breër gemeenskap te fokus.

Deelnemers aan hierdie studie en bestaande gemeenskapsrehabilitasieprojekte kan genader word om die proses te bestuur. Voorts moet plaaslike en provinsiale regeringsverteenwoordigers van Gesondheid, Gemeenskaspontwikkeling, Opvoeding sowel as Veiligheid en Sekuriteit betrokke wees by die ontwikkeling, implementering en monitoring van die opleiding.

### **SLEUTELWOORDE**

Kindermishandeling, gestremdheid, kennis, houdings, optredes

## **DEDICATION**

I dedicate this thesis to

- the Hlangana family who has instilled a sense of love in me and educated me at an early age;
- the Makaluza and Wogqoyi families who have given me support throughout my studies;
- all the institutions I attended namely Colosa High School, Dutywa, Umtata General Hospital in Umtata, St Barnabas Hospital in Libode, Komani Hospital in Queenstown, the University of South Africa in Pretoria and University of Bellville in Cape Town.

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## **DEFINITION OF TERMS**

### **Abuse**

Abuse refers to physical, emotional or sexual injury to a child resulting from acts of commission or omission by the child's parent or guardian (Berkow, 1977).

### **Attitude**

Attitude refers to "the way a person views something or tends to behave towards it, often in an evaluative way" (Collins English Dictionary, 2003).

### **Community**

A community is a group of people sharing same interests and a common set of objectives (Soanes & Hawker, 2006).

### **Disability**

Disability refers to the outcome or result of a complex relationship between an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives (WHO, 2000: 17)

### **Empowerment**

Empowerment refers to liberation and not to pacifying and domesticating communities (Soanes & Hawker, 2006).

### **Knowledge**

Knowledge refers to the sum of what a person has learned or discovered on a specific subject. It includes facts, information and feelings as well as a person's understanding of a subject based on his/her experience regarding the subject (Collins English Dictionary 2003; The American Heritage® Dictionary of the English Language 2009).

### **Practice**

Practice is the habitual way in which a person acts or behaves in a given situation (WordNet 2008).

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## LIST OF ACRONYMS

ARV	Anti-retroviral treatment
CBO	Community-based organisation
CHW	Community health workers
CLO	Community liaison officer
CP	Cerebral Palsy
CRW	Community rehabilitation worker
DPO	Disabled People Organization
DOE	Department of Education
DOH	Department of Health
HIV/AIDS	Human Immune Virus / Acquired Immune Deficiency Syndrome
ICF	International Classification of Function, Disability and Health
NGO	Non-governmental Organization
SAPS	South African Police Services
UN	United Nations
USA	United States of America

## EXPLANATION OF XHOSA TERMS

*Isidenge:* Fool/someone with diminished mental capacity.

*Marewu:* mealy – meal sour solids made with porridge.

*Ukuthwala:* Forced marriage.

*Ukuzunywa:* The tradition of boys attempting to have sexual intercourse with a girl, without her permission, while she is asleep, during circumcision into womanhood.

*Usidzubha:* Mentally disturbed.

*Uzunyiwe:* A successful attempt to practice *Ukuzunywa* that brings admiration to the boy by his peer group.

## CHAPTER 1: BACKGROUND

### 1.1 Introduction

David Werner stated that able-bodied people sometimes view disabled people as those who are being punished or have sinned (Werner, 2000). They are viewed as people who are inferior or who do not deserve the same rights and privileges in society as others. Otherwise, people with disabilities are seen as sick and helpless and treated like children. They are called by nicknames such as *isidenge* (fool) in the Xhosa culture as it is believed that their mental capacity is diminished by the disability. This happens even to people with only physical and no intellectual impairments. Such prejudiced and discriminatory attitudes can result in abuse (Disabled People of South Africa, 2001).

People in the community perceive children with disabilities as less valuable and without feelings; thus people might feel that such children can be treated with impunity. For instance, although individuals with disabilities are at an increased risk of being raped, officials often dismiss the allegations of sexual abuse made by them, assuming that they are confused or lack insight (Rohleder, 2010). Furthermore, limited knowledge on the side of the police service, legal professionals and rape crises councillors on assisting a person with disability that has been abused might lead to a lack of legal protection (Hibbard & Desch, 2007). In addition to attitudinal barriers, physical barriers that vary from staring to no sign language used by interpreters make clinics, courts and police stations frequently inaccessible. These barriers result in underreporting of abuse in general, and sexual abuse specifically, by individuals with disabilities hence perpetrators may go unpunished (Washington, 2009; Rohleder, 2010; Handicap International, 2011).

The science of medicine often overlooks violence against people with disabilities (Rohleder, 2010). Some doctors exhibit misconceptions and negative attitudes towards people with disabilities. Therefore, signs and symptoms of abuse may not be explored in people with disabilities in the same way these might be explored in able-bodied persons. Communication barriers may also cloud proper diagnosis (Selbst, 2007). An American study found that in 40% of cases professionals did not report sexual abuse of disabled children. The reason for this might be related to either poor recognition of signs and symptoms of sexual abuse or due to the frustration they experience in dealing with the complicated requirements of families and guardians of abused children with disabilities (Reiter, Bryen & Shachar, 2007).

Children with disabilities are particularly vulnerable to abuse (Handicap International, 2011). Research has shown that for every non-disabled child who is abused there are three children with disabilities who are abused. Children with disabilities are at a higher risk of abuse because of availability, opportunity and secrecy (Johnson & Drum, 2006; Sullivan, 2009). They are considered “at high risk” since they may be unable to disclose their abuse, can be more easily manipulated by abusers and are sometimes hidden from the public eye (Berkow, 1977; Handicap International, 2011). Mobility problems also contribute to the abuse of disabled children because the child may be confined to one area and will not be able to flee the abuser. Some parents hide their disabled children from the community, thus they are more vulnerable to perpetrators such as family members or neighbours who know they are being hidden from the public eye (Sullivan, 2009). Many children who are not raised by their biological mothers become vulnerable to abuse and neglect as a result of their particular family lifestyle (Kati, 2004). The child can be exposed to abuse because he/she is isolated and has lost attachment with the immediate parent or caregiver. There is nobody to advocate for her or him. The child is forced to obey and be submissive to the carer who might abuse the child (Johnson & Drum, 2006).

Children with disabilities may be abused for long periods of time because they are afraid or unable to report the incidents (Reiter, Bryen & Shachar, 2007). They hesitate to report the abuse to anyone for fear of retribution. Sometimes they are also unsure of the channels that they should use to report the abuse (Johnson & Drum, 2006). Many parents and guardians will provide feeble explanations out of embarrassment or fear when asked about the signs of abuse in children with disabilities (Miller, 2002). When asked about injuries, they maintain that their children had bumped into something or had fallen. Furthermore, children with disabilities display a pronounced inability to trust, which contributes to the sense of secrecy and non – disclosure (Miller, 2002).

In addition, poverty and the deprivation trap increase the vulnerability of children with disabilities as a result of the isolation, physical weakness and the perception of not being heard (Office on the rights of child - The Presidency 2001). The effects of social problems such as drug abuse, alcohol abuse and unemployment become intertwined with abuse making effective intervention more complex and challenging (Seedat, Van Niekerk, Jewkes, Suffla & Ratelle 2009). In the Eastern Cape Province of South Africa, where the study was conducted, poverty levels amongst families with disabilities remain unacceptably high compared to the average population (Seedat et al 2009). Even where people with disabilities have been targeted in terms of poverty alleviation, they still face tremendous challenges

with regard to being recognised as a group with entitlements whose needs should be addressed on their own terms rather than on terms dictated by others (Disabled People of South Africa, 2001).

Abuse is generally caused by the breakdown of impulse control in the abuser. An abuser can be any person, a stranger or someone familiar to the child who is being abused. However, it is usually someone well known to the child and often an adult in a position of trust (Waterhouse & Stevenson, 1993, Sullivan, 2009).

The prevention of the abuse of children with disabilities is a very broad field which cuts across all sectors. It is therefore imperative that various government departments and other stakeholders such as parents, community health workers (CHW), the police services, non-governmental organizations (NGO`s), community-based organisations (CBO) and disabled peoples organizations (DPO`s) all collaborate to successfully curb the scourge of child abuse (Waterhouse & Stevenson 1993).

In conclusion: the abuse and neglect of children is a complicated and serious problem. It is estimated that in South Africa, a child is abused every eight minutes and every twenty four minutes a child is the victim of rape or attempted rape (Berkow, 1977). This paints a very gloomy picture and shows that we are not giving the necessary attention and providing resources to protect children from abuse in this country. In addition, the number of children being victimised is rising and the extent of the problem is much greater than reported. The public is aware of only those cases that come to the attention of the media, the Child Protection Units of the South African Police Services (SAPS), and service providers. The actual number of children who may in fact be suffering in silence may be more than expected (Dawes et al, 2007). Child abuse has long life consequences for physical and mental wellbeing. In serious cases it may lead to increased mortality (Rees, 2010).

## **1.2 Research Problem**

Children with disabilities are at greater risk of abuse than their non-disabled counterparts. Research on child abuse focused on children with disabilities specifically is limited (Handicap International, 2011). Related to this, parents have a lack of knowledge or power to identify and stand up against the abuse of their children (Johnson & Drum, 2006).

### 1.3 Motivation

If one looks at any newspaper, a day scarcely goes by without reports of dangerous acts of violence against children with disabilities. When listening to the radio or watching television, there are numerous reports of child abuse (Peterson, Bhana & McKay, 2005). The researcher, who is a Rehabilitation Manager in the Mbhashe Health sub-district of Willowvale in the Eastern Cape of South Africa, has noticed the escalation of abuse of disabled children in this particular community. It came to her attention that disabled children are found killed and dumped in rivers and in the forest. Forensic investigations regarding the cause of their deaths have revealed that they had been sexually abused prior to being killed and dumped. The researcher has witnessed the abuse in one family where two children aged 8 and 10 respectively were abused by their father. Their mother left the family to escape this abusive relationship.

The researcher has further noticed that parents and guardians have insufficient knowledge and skills to manage conditions emanating from abuse of these children. Most parents and guardians were not clear about the procedures of reporting abuse, and are afraid of the perpetrator. Another aspect which has drawn the attention of the researcher is that parents and guardians are abused by the relatives of the perpetrators.

Child sexual abuse is often unreported in South Africa (Collings, 2009). In addition, the researcher has noted that there is no follow up of cases by the South African Police Services and sometimes the parents and guardians have lost the evidence before the matter goes to court. Furthermore, the erratic referral of abused children with disabilities raised concern with the researcher. It was noted that though they sometimes reported and then referred the abuse to several government departments, none of the cases had produced successful evidence whereby perpetrators were punished for their misconduct. This observation of the researcher is supported by Collings (2009) who indicates that less than 10% of child sexual abuse cases that are reported leads to criminal conviction and sentencing. Washington (2009) connected a lack of knowledge to delays in reporting of abuse which in its turn resulted in poorly coordinated intervention.

While it is well known that the abuse of disabled children occurs frequently, there is a lack of appreciation of the extent and severity of the problem (Johnson & Drum, 2006). Furthermore, parents and guardians of children with disabilities lack the proper knowledge, attitudes and behavioural skills to be able to deal with these problems. Parents and guardians are sometimes unsure about what abuse

really involves, how to prevent it from happening and what to do if it does happen (Johnson & Drum, 2006). By conducting this study the researcher has aimed to describe parental behaviour, attitudes and knowledge on the subject as well as identifying related shortcomings which can be addressed.

#### **1.4 Outline of the study**

The aim of the study was to explore parents' and guardian's knowledge, attitudes and practices towards the abuse of children with disabilities in the Willowvale area of the Eastern Cape of South Africa.

Chapter 1 discusses the reasons for embarking upon this study and provides background information on parents and guardian's knowledge about the abuse of disabled children. The significance of the study is explained and finally the contribution that the study might make to the participants and the community as well as academically is discussed.

Chapter 2 covers background knowledge on child abuse in general, and the abuse of children with disabilities specifically, based on a literature review. In chapter 3 the study methodology is presented. A mixed methods design was implemented. Qualitative data was collected through focus group discussions, and quantitative data through questionnaires, from 24 participants in five study sites.

The study results as presented in chapter 4 indicate that participants showed a lack of theoretical understanding and knowledge about the abuse of children with disabilities, but practically they could relate to it through their knowledge of the experiences of abuse of children with disabilities known to them. Lack of knowledge of participants caused the abuse of children with disabilities to go unreported in some instances. There was lack of moral support and nurturing of the abused child. It is concluded that there is a need for education of parents and guardians on abuse of children with disabilities.

#### **1.5 Significance of the study**

In South Africa, children with disabilities face a struggle, which is often characterised by poverty and abuse. This study was an attempt to begin to address the challenge of the abuse of disabled children by putting the subject on the public agenda through assessing parent and guardian's knowledge about it, as well as determining attitudes and practices in this regard. The intention was to raise their awareness and provide some empowerment solutions to be in a position to stand up and fight for what is right for their children (Hibbard & Desch, 2007). The researcher embarked upon this journey in the belief that empowering parents and guardians would contribute to reducing the abuse of children with disabilities

within the selected research population and communities. Empowerment would give them power to act and cascade the information to others. In that way, through a snowball effect, other parents and guardians in similar situations will be empowered.

As a further motivation, literature indicate a lack of research on abuse of children with disabilities and a lack of knowledge and experience on this subject amongst parents and educators (Johnson & Drum, 2006, Handicap International, 2011). This research would thus in a small way add to the increase in knowledge on this particular subject.

## **1.6 Summary**

Children with disabilities are often perceived by communities as of lesser value and without rights. These attitudes can cause abuse of children with disabilities. In addition, children with disabilities are vulnerable due to immobility, communication difficulties, invisibility and availability. The poverty and deprivation trap increases their vulnerability to abuse and limit their parent's ability to fight for their rights. Professionals and legal systems often fail them.

Abuse can be physical, sexual, emotional, financial verbal or in the form of neglect or child labour.

Few research studies focus on the abuse of disabled children. Literature indicates that endeavours to root out the abuse of children with disability can be initiated by providing parents or guardians with the necessary knowledge and skills to recognise, prevent and deal with the abuse of disabled children. In order to do that, a baseline understanding of what knowledge parents have and what their attitudes and current behaviour in this regard is, are vital.



## CHAPTER 2: LITERATURE REVIEW

### 2.1 Introduction

In this chapter the findings of the reviewed literature on child abuse will be presented. With introductory perspectives on child abuse as a logical starting point, the attention will focus specifically on the abuse of disabled children and will therefore also touch on disability and definitions thereof. Causes, risk factors, signs and symptoms of abuse as well as the effect of abuse on the child together with family, management and preventative strategies will be deliberated. This chapter will also discuss the social factors which are related to the abuse of children with disabilities. Finally the methodology used in four studies which focus on parental experience and coping with child abuse will be discussed in relation to the methodology used in the current study.

### 2.2 The basic needs and rights of a child

Childhood is regarded as a period of special protection and human rights. Children have a right to grow up healthily and be happy. Aligning with the Constitution of South Africa, children have a right to be treated with dignity and respect irrespective of race, gender and disability (Constitution of the Republic of South Africa, 1995). The term “childhood” is centred on safety and discipline. Initially the child inside its mother’s uterus is safe from all the elements such as coldness and excessive heat. Once born, the child should be kept safe, fed, sheltered and nurtured so that he or she can grow normally (Renvoize, 1975). In other words, children have a right to basic needs such as shelter, food, drink and clothing as well as a right to be loved and treated with respect. Refusal by an adult to recognise these rights can be categorised as child abuse (Constitution of the Republic of South Africa, 1995).

### 2.3 Child abuse

Child abuse is any ill treatment of a child by an adult or other children with the purpose of inflicting injury or harm and can be categorised into seven types as follows:

- **Physical abuse** occurs when an adult inflicts intentional injury on a child. Such actions take place when there is slapping, pinching, beating, strangulation, burning or fracturing of bones (Selbst, 2007; Dawes, Bray & Van der Merwe, 2007). Shaken baby syndrome causes brain or neck injuries. It occurs to infants under six months old (Joyner, 2010; Dawes et al, 2007).

- **Sexual abuse** occurs when an adult or older child shows a child his or her private parts (Miller, 2002; Department of Health, 2005; Dawes et al, 2007). It constitutes touching of a child by an adult in a way that gives the adult pleasure but distresses the child. A child has the right to be in charge of his or her own body, hence sexual abuse is a violation of this right. Sexual abuse includes any non- contact abuse like flashing and exposure to pornographic materials. There is contact abuse which can involve fondling, finger penetration, masturbation or oral sex (Dawes 2007). In South Africa sexual crimes are prosecuted under both Common Law and Statutory Law. Sexual crimes prosecuted under Common Law include rape and incest, while sexual intercourse with a minor is prosecuted in terms of the Sexual Offences Act 23 of 1957 as amended by National Assault Policy of January 2005 (Joyner, 2010).
- **Emotional abuse** occurs when parents, caregivers or educators humiliate a child by making the child feel unworthy. It is characterized by insulting or withholding love and attention from a child as a form of punishment. This includes saying hurtful things that destroy the self-confidence and self-esteem of a child, for example, “You will never succeed in life” (Berkow, Beers & Fletcher, 1997; Miller, 2002; Dawes et al, 2007; Rees, 2010).
- **Verbal abuse** is apparent when a child is threatened or called unpleasant names that make the child feel dehumanized (Miller, 2002; Dawes et al, 2007)
- **Financial abuse** presents when somebody uses any source of income meant for the disabled child for his own needs without prioritizing the needs of the child (Berkow et al, 1997).
- **Neglect** is represented by parental failure to satisfy a child’s nutritional, emotional and physical needs. It occurs when the child is not offered basic necessities such as food, warmth and clothing although there may be no problem in accessing the resources. It is often seen in families with multiple challenges, where chronic medical conditions or substance abuse might lead to financial problems and lack of attention to the basic needs of a child (Berkow et al, 1997; Dawson & Algozinne, 2006; Dawes et al, 2007). There is often a delay in seeking health care where the child may have unexplained injuries or be exposed to smoke and use of guns. The failure of adults to ensure that their children use car seatbelts may reflect inadequate protection from environmental hazards (Dawson & Algozinne, 2006).
- **Child labour** occurs when a child is made to do work that is inappropriate for a child of that age or work that is detrimental to his or her developmental needs. Some children may be denied schooling opportunities or play because they have to work (Dawes et al, 2007)

Child abuse is a social problem which needs to be addressed by society at large. Many children live under pressure because they are dependent on somebody else and sometimes live within a violent society. Often the parent or the guardian has no power to fight for the rights of the child. However, they have to be empowered to stand up for theirs and their children's rights, for instance by organising support groups for parents whose children are abused. Society has to be involved in this initiative to form community organisations such as "Men as Partners" as well as to revive or establish a community policing forum (Department of Health, 2010). It is important that men be considered partners in the fight against the abuse of children with disabilities because they are the head of families who are the protectors and the providers of care and safety at home (Hershkowitz, Lamb & Horowitz, 2007).

Advocacy groups are of the opinion that the prevention of abuse and injuries should be a national public health priority (Hershkowitz et al, 2007). Just as tobacco adverts have been banned, it is necessary to prohibit adverts for alcoholic substances and to stipulate that taverns have authentic licences with set operational hours. Furthermore, the South African Family Courts where protection orders are obtained ought to improve service standards. Victim empowerment units and police stations should be well equipped and client-friendly. It is necessary to have a smooth collaboration between government departments and non-governmental organisations because the Department of Health cannot function effectively and efficiently in isolation to curb the abuse of children (Seedat et al, 2009).

## **2.4 Incidence and prevalence of child abuse**

Child abuse is a worldwide problem. In 2004, statistics indicated that 872 000 children were abused in the United States of America (USA) and in Israel over 5000 allegations of abuse are under inquiry each year (Hershkowitz et al, 2007). Between 1998 and 2004, 40 430 child abuse-related inquiries were reported in Israel of which 60% involved neglect, 20% physical abuse and 10% sexual abuse (Hershkowitz et al, 2007). According to a United Nations report (UN 2006) approximately 53 000 children in the world died as a result of homicide in 2002. Another study in the USA found that in 20% of cases where children are physically abused they are permanently injured. Approximately 2000 deaths from abuse and neglect occur in the USA annually (Cluver & Gardner 2007). According to the United Nations (UN) report the child homicide rate is two times higher in low income countries than in developing countries - 2.6 versus 1.2 per 100 000 (UN, 2006).

It is estimated that 80% to 98% of children are physically punished in their homes worldwide. A third of these children are subject to harsh punishment involving the use of harmful objects (Miller, 2002). In

South African homes child beatings with sticks, belts or other objects take place regularly and injuries to the children involved are common (Seedat et al, 2009). Beatings are used as a form of discipline in South Africa with the purpose to teach children to obey (Glanz & Spiegel, 1996). From other developing countries it is reported that between 20% and 65% of school-going children experience verbal or physical bullying. It is estimated that 150 million girls and 73 million boys were sexually abused worldwide during 2002.

One of the highest baby- and child-rape rates in the world is found in South Africa (Cluver & Gardner 2007). It is reported that 39% of girls in South Africa undergo some form of sexual violence before they are 18 years old (Seedat et al, 2009). In 2000 more than 67 000 incidents of child sexual assault were reported in South Africa, indicating an increase of nearly 50% from the 37 500 reported incidents in 1998. Estimates suggest that 3 million females undergo genital mutilation in Africa every year (Cluver & Gardner 2006). Although the phenomenon is diminishing, child labour is still a problem. According to estimates in 2004, 218 million children performed some form of child labour with 126 million of these performing hazardous jobs. These dangerous “jobs” included prostitution and pornography (Cluver & Gardner 2006).

Finally, studies have shown that some groups of children are more vulnerable to abuse than the general child population. The vulnerability of children is exacerbated by poor socio-economic circumstances, unhealthy living conditions, being orphaned, living in an institution and having a disability (Cluver & Gardner 2006; Cowen & Reed, 2006).

#### **2.4.1 Incidence and prevalence of abuse of disabled children**

Incidence data on the abuse of disabled children is limited due to the following factors:

- Varying definitions of disability
- The apparent lack of competence on the part of social workers and police officers to identify disability
- The lack of training in terms of assessment and recording of events reported by children with disabilities
- Inconsistent ways of classifying abuse
- The under-reporting of cases of abuse (Hibbard & Desch 2007; Sullivan, 2009).

Because of these factors, the prevalence estimates vary. However, the literature reports that disabled children across all kinds of disabilities are at between 3.4 and 1.7 times more likely to be abused or neglected than their non-disabled counterparts (Miller, 2002; Hibbard & Desch, 2007).

With regard to the various types of abuse, children with disabilities were:

- 1.8 - 3.8 times more likely to be neglected (Miller 2002; Hibbard & Desch 2007; Herschkowitz et al 2007).
- 1.6 - 3.8 times more likely to be physically abused (Miller 2002; Hibbard & Desch 2007; Herschkowitz et al, 2007).
- 1.5 - 3.1 times more likely to be sexually abused (Miller 2002; Hibbard & Desch 2007; Herschkowitz et al, 2007).
- 2.2 to 3.9 times more likely to be emotionally abused (Miller 2002; Hibbard & Desch 2007; Herschkowitz et al, 2007).

Abuse of disabled children covers the entire spectrum of abuse from neglect, bullying, verbal and emotional attack, to physical and sexual abuse and “mercy killings” (Handicap International, 2011). Neglect is the most common form of abuse among children with disabilities (Sullivan, 2009). With regard to gender, physical abuse is again more common amongst boys while sexual abuse is more common among girls (Sullivan, 2009; Glanz & Spiegel, 1996). The Israeli study found that 58.4% of sexual abuse victims were females and 68.7% of physical abuse victims were males (Herschkowitz et al, 2007). Children younger than five years old were more often physically abused while children from the age of seven upwards were more often sexually abused in USA (Berkow, 1977).

The abuse can happen in any setting: at home and in the community, institutions of child care, schools and places used by juvenile justice systems (Handicap International, 2011). Children with disabilities who are orphaned or live away from home are at particular risk. Disabled children not living at home are particularly vulnerable to abuse because there are no parents to defend their rights and these abusive acts often happen at school (Miller 2002). In the United Kingdom, a study conducted at two schools providing special education for children with intellectual disabilities, found that 83% of the children suffered from various forms of abuse including bullying, vulgar language, scorn, intimidation, physical abuse, violating their rights, and sexual molestation (Reiter et al 2007).

Figures from Kenya point to an estimated 15 – 20% of children with disabilities suffering from serious physical and sexual abuse. Intellectually impaired girls were found to be the most vulnerable group. In addition, the majority of disabled children were experiencing neglect in the form of starvation, insanitary living conditions and desertion (Handicap International, 2011).

Figures from South Africa indicate a three to four times higher incidence rate in abuse of children with physical disabilities and a three to eight times higher incidence rate in abuse of children with intellectual disabilities than their able-bodied counterparts (Handicap International, 2011).

There is no available literature on the general abuse of disabled children in the Eastern Cape where the causes of abuse include the practise of ukuthwala (forced marriages) that have resulted in 353 cases of abuse in 2006 and 338 in 2007. According to the practise of ukuthwala in the Eastern Cape the disabled children were pressurised to engage in sex without the permission of their husbands. They were told that negotiations with their parents had been completed). The children involved in ukuthwala were those with minor physical disabilities in Eastern Cape. There were 372 kidnapping offences in 2006 and 397 in 2007 (Thompson, 2009).

## **2.5 Causes and risk factors of child abuse**

Causes and risk factors for child abuse and abuse of children with disabilities are complex and closely related to socio-economic factors as well as alcoholism (Seedat et al, 2009; Cavalcante & Goldson 2009). The general effects of poverty, unemployment, inequality, migration, urbanisation and drug abuse are likely to be associated with abuse of all children (Seedat et al, 2009). In South Africa widespread poverty, inequality, unemployment, patriarchal notions combined with a masculinity that values toughness, risk-taking behaviour and defence of honour, as well as poor parenting, alcohol abuse and limited law enforcement all add to high levels of child abuse (Brown, 1997). This is exacerbated by the myth of virgin cleansing (intercourse with a virgin is a cure for HIV/AIDS) (Rohleder 2010).

Poverty also plays a major role (Cavalcante & Goldson, 2009). It might cause an abusive situation at home where poverty impairs the health and well-being of children with disabilities, resulting in families displacing their anger on to their children (Cavalcante & Goldson, 2009). Since parents are unable to fulfil their responsibilities of feeding and nurturing children, they resort to abuse of their children (Cluver & Gardner 2006; Hershkowitz et al, 2007). Poverty leads to the lack of knowledge and

power and hampers parents' efforts to protect the child against perpetrators from outside which limits disclosure (Cluver & Gardner 2006; Cavalcante & Goldson 2009).

Excessive use of substances by a parent has been associated with family violence, poor parent child communication and a lack of family cohesion (Pierce & Bozalek 2004, Collings, 2005). In a South African study rape were connected to heavy alcohol consumption and drug use (Jewkes et al 2006). Alcoholism is one of the causes of child abuse given that rape and abuse of children might occur when people are under the influence of liquor (Seedat et al, 2009). Within the study setting alcohol consumption is one of the principal forms of recreation and those who are unemployed spend their time in taverns. Interventions aimed at preventing alcohol abuse have not succeeded. Non-implementation of government policy concerning the control of the alcohol industry contributes to the abuse of children with disabilities (Cavalcante & Goldson 2009).

The causes of abuse of disabled children are generally the same as for able-bodied children, but the risk is increased by the fact that the child's needs often increase the emotional, financial and physical burden on the family and by the fact that society disregards the rights of children with disabilities (Hibbard & Desch, 2007; Handicap International, 2011).

## **2.6 Disability and child abuse**

For the purpose of this study the International Classification of Function, Disability and Health (ICF) definition of disability was used. The ICF states that disability is determined by a complex relationship between body structures, function and impairments, activities and participation as well as contextual factors that represent the circumstances in which a person lives (WHO, 2000). Contextual factors are aggravated by society, which does not take into account the varying needs of individuals. Consequently people with disabilities are excluded and prevented from participating fully on equal terms with others (WHO, 2000).

Impairments that results in disabilities might increase the risk of abuse in various ways. Children with disabilities are often isolated in the home environment, since the impairments coupled with inaccessible environments and attitudinal barriers make it very difficult for them to leave their houses. This isolation increases vulnerability to perpetrators who know them and in addition leave them with less contact with people that they might confide in (Handicap International, 2011). The impairments might lead to certain aspects of the child's behaviour that the caretaker finds challenging, embarrassing or frustrating

(Hibbard & Desch 2007; Cavalcante & Goldson, 2007). It might make it impossible for the child to meet the parent's or guardian's expectations – a situation that can create tension, frustration and anger. The physical care of a child with disabilities might be strenuous, time consuming, unremitting and costly. This leads to fatigue, frustration and emotional stress (Cavalcante & Goldson, 2007). The disability might impair their ability to resist the perpetrator (Miller, 2002). Communication problems might increase parental frustrations and lead to physical abuse (Sebald, 2008). In this regard, communication problems and intellectual disability might limit their ability to avoid victimisation, might prevent or hamper disclosure and might cause those in authority not to take the child seriously (Sebald, 2008; Handicap International, 2011).

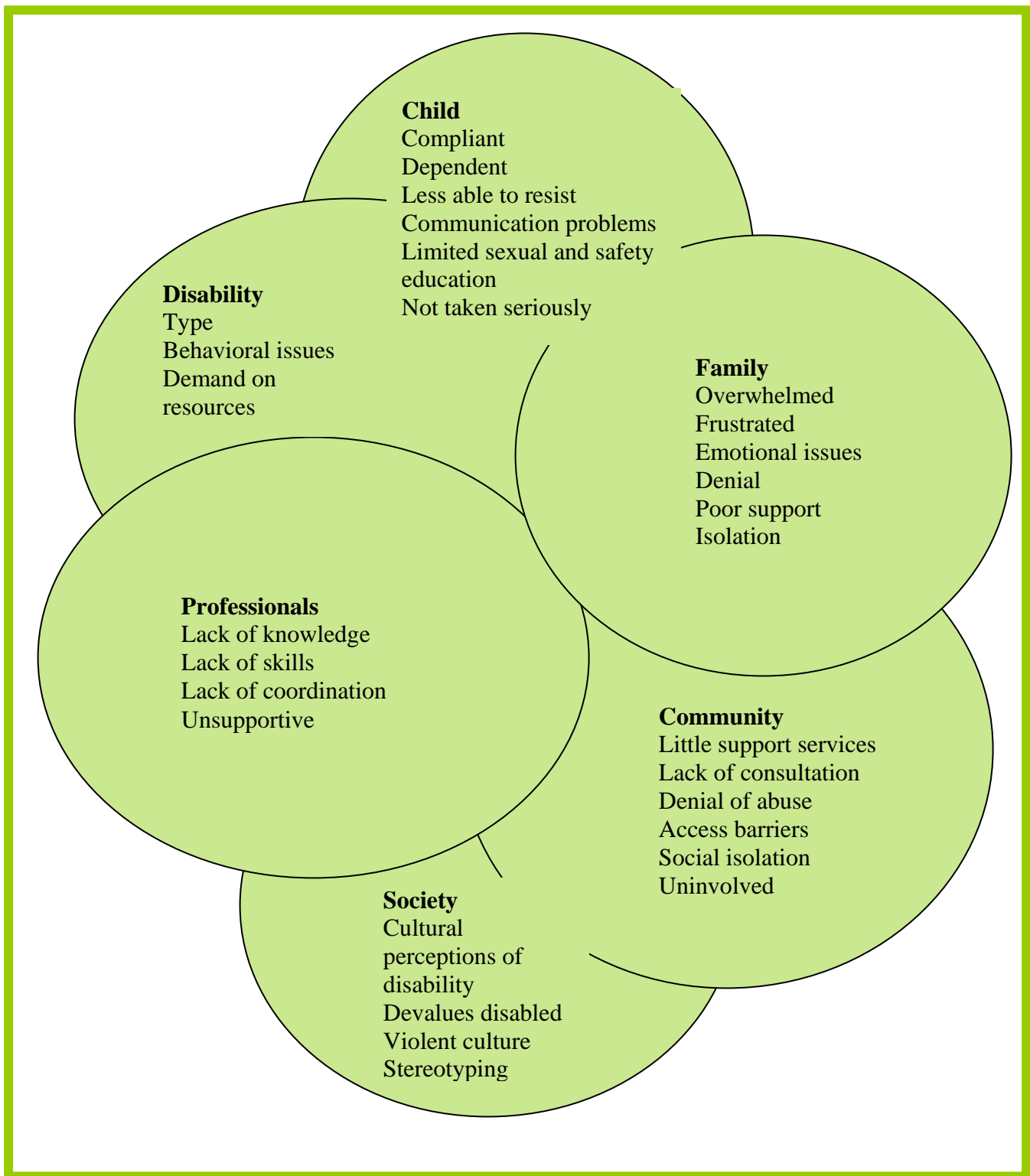
Contextual factors related to the child, the family, community, society and health professionals have both separate and interrelated roles in increasing the risk of abuse as well as the prevention of abuse. These factors are presented in figure 2.1. An increase of preventative factors in one area might trigger high risk in another area, or vice versa (Dawes et al, 2007).

### **2.6.1 The disabled child**

Disabled children are seen as easy targets of abuse for various reasons. They are more dependent, need more assistance and more frequently and usually lack control over their own lives, which leads to an inclination on their part to be compliant and seek approval (Reiter et al, 2007). They might also not have someone to disclose to, especially if the perpetrator is also the guardian (Miller, 2002). The child might have limited access to education on personal safety and sexual counselling since parents might feel they do not need it since the disability will prevent them from encountering risky situations (Miller 2002; Hibbard & Desch 2007; Herschkowitz et al 2007).

Having other people tending to their physical needs might make them accustomed to having their bodies touched in intimate ways (Hibbard & Desch, 2007). They might be used to painful medical interventions which might make it difficult for them to distinguish between acceptable touching and abuse as well as between “good” and “bad” pain (Miller, 2002). When disabled children do lodge complaints of abuse, the management of the complaint is often perfunctory with incomplete police investigations. Prosecution happens rarely because persons with intellectual disability are viewed as unreliable witnesses, characterised by poor memory, vulnerability to suggestion, limited descriptive abilities and poor communication skills (Herschkowitz et al, 2007).





**Figure 2.1: An illustration of the additional risk factors children with disabilities face with regard to abuse**

## 2.6.2 The family

Poor parents with limited social and community support and limited access to health care services are more likely to abuse their children since they might become overwhelmed by the needs of the child and the inability to cope (Waterhouse & Stevenson 1993; Hershkowitz et al 2007; Handicap International, 2011). Social isolation is associated with abuse because parents have no time for socialising with other family members and friends. Travelling is costly when they do not have their own transport. Family roles are stressful and over-demanding resulting in parent or guardian fatigue and frustration. The parent or guardian is exhausted from looking after the child and there is nobody available to offer relief (Berkow, 1977). A minor incident may precipitate a crisis when support is not available (Berkow, 1977). This is likely to occur when parents are isolated and vulnerable in the absence of relatives, neighbours and friends who normally provide physical and psychological support in times of stress such as loss of money or employment (Berkow, 1977; Office on the rights of the child- The Presidency, 2001). In this context single parents especially are at high risk since they have no spouse or partner to support them. The situation is exacerbated by rejection and marginalisation by the communities which parents of disabled children have to face (Disabled People of South Africa, 2001; Cavalcante & Goldson, 2009).

Parental abuse can also be the result of a lack of parental affection and warmth. The parent abuses the child physically because she or he develops hatred and inward anger for no apparent reason. In other cases the parent or guardian may have psychiatric problems such as a personality disorder or low self-esteem (Berkow, 1977; Uys, 1997). Parents who experience emotional health problems such as depression, loneliness, a lack of competency in various life areas, substance abuse, limited intellectual abilities, passive aggression and hostility might be at risk to abuse their children. Similarly, in families where little nurturing occurs and where bonding between parents and children is poor, children are at risk of abuse. In instances where parents deny the disability they might not use support services and resources (Cavalcante & Goldson 2009). In these instances neglect can be caused by a failure to provide in the bigger health care and educational needs of the child (Dawson & Algozinne 2006). Parents might experience guilt and feelings of inadequacy.

Furthermore, parents might not believe the child's allegations and might act in an unsupportive manner (Collings, 2009). For example a parent may seem unconcerned, even when a child comes to her crying. When other people are concerned about the crying of the child the parent may ignore it (Miller, 2002).

Parents might even imply that the child had invited the perpetrator to abuse him or her. The child might know that the parents or guardian cannot protect him or her and might therefore feel guilty about telling the truth. As a result the child finds him/herself in a dilemma (Miller, 2002).

### **2.6.3 Community**

Disabled children and their families are faced with various barriers in the community such as stigmatisation, or attitudinal and informational barriers (Dawes et al, 2007). This might cause the community to ignore or dismiss the rights of the disabled child and condone abuse through silence (Handicap International, 2011). Attitudinal barriers and a lack of access limit their involvement and participation in community services such as education, health care, protection and legal support (Handicap International, 2011). This exclusion and non-acceptance causes social isolation and withdrawal (Miller, 2002; Handicap International, 2011).

Involvement of community members in disability issues can promote the removal of physical and attitudinal barriers and ensure opportunities for children with disability to participate for instance in mainstream education.

Where the community and families see the abuse as a home affair and do not forward it to the next level of law and order the situation remains unresolved (Miller, 2002; Reiter et al, 2007).

### **2.6.4 Society**

Personal attitudes towards and understanding of disability are formed by societal and cultural beliefs. In African culture a disabled person might be seen as a liability since they are perceived as not being able to contribute and disability might be perceived as caused by witchcraft, a curse or punishment. These attitudes lead to devaluation of the disabled person and increase the risk of abuse (Handicap International, 2011). Disability issues are poorly understood. For instance persons with visual or hearing impairments are seen as being unable to learn, children with mental disabilities are seen as naughty or evil.

We live in a society that values self-sufficiency. There is little room and acceptance of those who need assistance (Miller, 2002). Thus, society devalues and disempowers the disabled children, an attitude which increases vulnerability (Miller, 2002; Cavalcante & Goldson, 2009). Vulnerability is further increased as a result of barriers to full participation which limit the ability of disabled persons to make

a meaningful contribution to society and to access resources such as social and preventative health services (Miller, 2002). Stigmatization, stereotypes and prejudices such as the belief that disabled people feel no pain and do not have the same needs, feelings, desires and capacity to love as others, aggravate the situation (Disabled People South Africa, 2001).

Societal beliefs which do not take into account equity in terms of females reinforce powerlessness. The process of socialization which capacitates the females to nurture others before themselves may prevent people from expressing their needs and getting assistance (Miller, 2002). In addition social stereotypes which dictate how males and females should look and act can stop them from asserting themselves and feeling good about the way they really are (Cavalcante & Goldson, 2009).

Finally, there is a culture of violence in our society which allows and even encourages people to resolve conflict, deal with stress as well as unmet expectations via acts of violence.

### **2.6.5 Professionals**

The lack of knowledge and skills amongst professionals has an impact on their advocacy role resulting in many filed cases of children with disabilities being lost. There is no progress in some of the cases reported in respect of the abuse of disabled children (Reiter et al, 2007). When parents are conducting follow-up with the South African Police Services they often receive reports that the case is still under investigation or that the documents have been lost (Reiter et al, 2007). Often professionals are not using the power vested in them to fight for the rights of disabled children. Sometimes abused disabled children are not supported (Collings, 2009) and assessed adequately at health care facilities and police stations (Reiter et al, 2007). They are even chased away from these centres (Sullivan, 2009). Some professionals from the South African Social Security Agency have a negative attitude towards children with disabilities especially when advocating that a child gets a care dependency grant. In addition the bulk of child abuse victims in South Africa do not receive counselling or social work services (Collings, 2009).

### **2.7 The abuser**

The bulk of violent acts against children are performed by people whom they know and often those they know well such as parents, family, friends and teachers (Waterhouse & Stevenson 1993). Often they are a member of the family or community on who the child depends for care and support

(Handicap International, 2011). Generally, the most common abuser is male although there was a significant percentage of approximately ten to thirty eight per cent of abusers who were female (Waterhouse & Stevenson 1993). The majority of the male perpetrators are living in the same home as the victims, some were visitors and others were known to the victim. Perpetrators create opportunities which allow them easy access to children such as at functions at schools and at sports events or by living in locations near playgrounds (Waterhouse & Stevenson 1993).

With regard to all types of abuse it was discovered that in 78% of cases one or both parents could be the abuser while other relatives, foster parents and parent's partners amounted to another 10%, which left only 12% being strangers (Waterhouse & Stevenson, 1993). One study reported that the parent was the perpetrator in 87.2% of cases of physical abuse (Hershkowitz et al, 2007). A Scottish study (Waterhouse & Stevenson, 1993) that gathered data retrospectively from 501 case files found that with regard to sexual abuse of all children, males were the perpetrators in 99% of cases (Waterhouse & Stevenson, 1993). Table 2.1 illustrates the relationship between the child and the perpetrator according to the Scottish study (Waterhouse & Stevenson, 1993).

**Table 2.1: Relationship between perpetrator and abused child**

<b>Perpetrators</b>	<b>Percentage</b>
Friends or acquaintances	18.9%
Child's father	21%
Family brother, grandfather uncle	15,9%
Stranger	9%
Step father	12%
Cohabite	8, 5%
Stepfathers and others known to the child	5, 1%

The Scottish study further found that the age of perpetrators varied from 10 – 81 years, with 29% between 45 and 54. The majority performed unskilled or skilled manual work and three quarters of them were unemployed at time of the offence. Results revealed that 44.7% abused one or other substance, mostly alcohol and 59.8% had previous criminal offences (29% had a record of previous sexual abuse) (Waterhouse & Stevenson, 1993). The profile of perpetrators often includes one or more

of the following: other criminal offences, mental illnesses, exposure to childhood abuse, lower educational levels, poor health and poverty (Sullivan 2009).

## **2.8 Signs and symptoms of child abuse**

Abuse may lead to recognisable behavioural changes as well as physical signs in the child (Berkow 1977). The discussion below explains the behavioural and physical signs which might indicate that a form of abuse is present. These signs can serve as warning that something might be wrong, but does not necessarily indicate child abuse (Miller, 2002; Sullivan, 2009).

### **2.8.1 Physical abuse**

#### **a) Behavioural signs**

The child is unable to recall how observed injuries happened or offers varying explanations. The child is afraid of adults. The child displays fear of physical contact and may flinch or shrink back when touched. Babies may show an “empty” stare or unmoving watchfulness. Aggression towards others is likely (Sullivan, 2009).

#### **b) Physical signs**

In instances where severe force is used abuse can cause cuts, bleeding and even death. Parents should be suspicious of unaccountable bruises, burns, open wounds and bite marks. There are important factors when dealing with physical injuries such as detailed history as well as where and when an injury had occurred. Professionals should observe injuries to make sure that they are consistent with the history given and note any delay in seeking medical assistance (Medline Plus 2008; Joyner, 2010). The child will have new scars and bruises that are not consistent with the explanation offered for example extensive bruises in one area. Numerous injuries in different stages of healing might also be present. The child might wear clothes that are inappropriate for the weather or situation in order to cover signs of injuries (Sullivan, 2009). Ear injuries and twisting of the lobe of the ear is also a physical sign (Miller 2002). Common anatomical sites of injuries caused by physical abuse are the head, face, neck, pelvis and buttocks (Abrahams, Martin, Jewkes, Mathews, Vetten & Lombard, 2008).

## **2.8.2 Emotional abuse**

### **a) Behavioural signs**

The child will display extreme inhibition in play. There may be an apparent lack of concentration and the child could display extreme attention-seeking behaviour for instance crying for minor things. It is also likely that the child may provoke conflict and extreme aggressiveness. In cases of withdrawal the child will isolate her/himself from other children. In some cases children may display an extreme fear of any unfamiliar situation. The child may also demonstrate continual self-criticism for example by saying “I am ugly” (Dawes et al, 2007; Sullivan, 2009). Little children may be wary or superficial in interpersonal relationships. Such children could display passivity and become anxious to please adults. The impact of emotional abuse is usually exposed when the child goes to school and experience difficulties in forming relationships with educators and friends (Dawes et al, 2007; Sullivan, 2009).

## **2.8.3 Sexual abuse**

### **a) Behavioural signs**

There are children who demonstrate visible signs of distress after sexual assault but there are also those who respond to trauma with numbness. In a case of sexual abuse the child might show sexual knowledge, promiscuity and seductive behaviour (Dawes et al, 2007). The child is more advanced in terms of knowledge about sex than the rest of his/her peer group and may choose sexual themes in drawings, poems and stories. They also may engage in promiscuous behaviour and be reluctant to go home after playing with her or his peer group if the problem is at home (Miller, 2002). Observers may notice behaviour expected of younger children such as thumb sucking, nightmares and wetting during the day or night. Changes in eating patterns might occur. The child becomes isolated and introverted developing personality changes such as clinging. Sometimes, the child tries to satisfy adults and overreacts to criticism. There might be distrust or fear of someone the child knows well for instance a babysitter (Miller 2002; Dawes et al, 2007; Sullivan, 2009).

### **b) Physical signs**

The child can have unusual or excessive itching in the tubules (Berkow 1977). Sexually transmitted infections and vaginitis can occur. It is also possible that a child under 16 years of age may become pregnant. Injuries to the vaginal or anal areas, for example bruises and swelling may occur. Torn,

stained or bloody underwear may be observed if the child requires bathroom assistance (Berkow 1977; Sullivan, 2009). Genital injuries accompanied by bites were found amongst sexually molested children (Abrahams et al, 2008).

#### **2.8.4 Neglect**

In toddlers there may be excessive quietness. There is extreme risk- taking behaviour which may reveal a lack of nurturance, affection and supervision. The child lacks proper warm clothing which may result in having flu occasionally. The child may experience constant hunger and poor personal hygiene (Dawson & Algozinne, 2006; Dawes et al 2007).

### **2.9 Effects of child abuse**

#### **2.9.1 Short term effects of abuse**

The short term effect of abuse includes:

- Social withdrawal, poor peer relationships and rejection by peers (Cluver & Gardner, 2007);
- Diminished emotional problems such as sadness and distress;
- Aggressive behaviour (MacDonald, Lambie & Simmonds, 1995; Govindshenoy & Spencer, 2006).
- Depression;
- Anxiety and withdrawn nonverbal communication;
- A sudden drop in school performance due to poor concentration;
- The child is bored and unhappy (Waterhouse & Stevenson 1993);
- Dissociative disorders like hear voices commanding him to harm him or others can occur and are very dangerous.
- Limited resources and poor quality of care lead to poor utilisation of health care services by children who have been sexually molested (Christofides, Muirhead, Jewkes, Penn- Kekana & Conco 2005).

Professionals should ensure that the short term effects of abuse are avoided or minimised by providing the highest quality of service. Aligning with the Batho Pele principles client information is an important part of life after abuse which is often overlooked. The effects of abuse are unlikely to be



serious if the abuse does not involve force or violence, if it is of minimum duration, if there is no penetration and the abuser is not the mother or the father figure. Prognosis is likely to be best for those whose complaints are believed, who are not blamed for being abused, who have a stable family with co-operation between home and the educators and who gets appropriate counselling when needed (MacDonald et al, 1995).

### **2.9.2 Long term effects of abuse**

Later in life, abused children could suffer from a variety of physical, emotional, psychological and social problems such as a negative self-image, anxiety, depression, post-traumatic stress disorder, eating disorders and learning problems (Medline Plus, 2008). Some children may react by displaying regression like bedwetting and crying. Other children may reveal apathetic silences and withdrawal due to fear and flashbacks or a “freeze” look when responding to certain stimuli. Parents and educators may view this reaction as an act of defiance (Weiner & Dulcan, 2004).

The stress experienced as the result of abuse can impact negatively on brain function and development. The brain stem, cortex, limbic system and midbrain are affected and various forms of traumatic memories are generated (Medline Plus, 2008). Anxiety disorders in disabled children include observed sleeping disturbances, nightmares and psychosomatic complaints (Weiner & Dulcan, 2004). Altered cortical homeostasis result in cognitive and narrative memory and altered limbic homeostasis lead in emotional memory (Weiner & Dulcan, 2004). Nightmares and ambivalent feelings are the result of the latter. The former causes persistent fear accompanied by hypersensitivity and reactivity (Weiner & Dulcan, 2004).

In addition, abuse can cause disabilities which in turn can cause further abuse in an escalating cycle (Weiner & Dulcan, 2004; Hibbard & Desch 2007). The duration and frequency of abuse can have an impact on the healing process of the child (MacDonald et al 1995).

### **2.10 Societal attitudes, stereotypes and myths regarding child sexual abuse**

General beliefs on child abuse included myths and untruths such as that children are sexually abuse by unknown people (Collings 2006), or that girls who wear short skirts are enticing adults and that they should be blamed for the abuse. This cause abused girls to hide their injuries and the abuse, because they feel ashamed and guilty (Wood, Lambert &.Jewkes, 2008).

Other social myths and stereotypes include:

- The child had pleasurable feelings
- The incest was not harmful
- Fathers are expressing true and deep love
- Most mothers know at some level
- The effects of incest are minimal (Collings, 2006).

### **2.11 Maternal feelings and responses to child sexual abuse**

Few studies that reported on the attitudes and responses of parents / guardians to child abuse could be found. Bernard (2001) reported on the attitudes and responses of Black British and African Caribbean mothers whose children were abused, often by their husbands. The author found that the discovery of abuse was painful and disruptive to the lives of these mothers. They experienced feelings of ambivalence since they wanted to support their child, but was also scared of losing their husband. While they had to deal with their own confused feelings they also had to assist the child to gain self-confidence and make sense of her relationship with her father (Bernard, 2001).

Mothers and guardians experienced feelings of shame, anger, numbness, denial, withdrawal, avoidance and anxiety. In addition they reported feelings of guilt and felt that they might have been able to prevent the abuse if they took better care of their children. They felt betrayed by their husbands and family. They were ambivalent about whether to believe or not believe their children when they disclosed the abuse (Bernard, 2001; MacDonald et al, 1995; Collings, 2005).

The situation was aggravated by comments from the community which implied that parents and guardians did not care about their children. Some parents and guardians complained that they did not leave the marriage immediately and that adds to their sadness, guilt and shame. Parents were distressed when families interpreted the reporting of the abuse outside the family as a betrayal to their kinship. There were feelings of insecurity and isolation which were caused by the parent's limited support network. Power and control were the leading factors that made these parents and guardians remain silent about the abuse. There was pressure within their community which caused them to cover up and that fuels the secrecy around child abuse. They needed to do something to assist their children but could not believe their children. Some parents did not have space to explore their feelings. Mothers

resorted to informal support rather than accessing the formal support systems such as child protection services to get advice and nurturing (Bernard, 2001).

From South Africa it is reported that notions of good and bad mothering exists and are related to child abuse. Their partners, South African Police Services and child welfare services are blaming parents and guardians and these perceptions have influenced some mothers to be inclined not to involve professional help (Pierce & Bozalek, 2004).

The pillar and cornerstone for these mothers was a strong supportive relationship with their maternal family. This encouraged them a lot (Bernard, 2001) and led them to be able to challenge the abusers. The support system assisted them to make choices about the future and whether to leave the husband or stay in the relationship (Bernard 2001). The family as whole encouraged the mothers to confront their children's abusers. The role of family members in supporting the devastated mothers assisted the mothers to move from denial to acceptance of their situation and they were able to deal with the external destructive criticism about them (Bernard, 2001).

Parents and guardians argued that they were in relationship with men who were not the children's biological fathers and did not have any parental responsibility for their children. These men were not actively involved in children's lives but shared the same household and sometimes became abusers of the children (Bernard 2001).

## **2.12 Reporting and management after abuse**

To assist abused children with a disability the child must be identified. This is a challenge since children with disabilities face various challenges with regard to reporting the abuse. They might not be empowered enough to know the "rights and wrongs" of actions of abuse against them. They often have limited access to medical, social and legal assistance. The system is not geared towards accommodating their specific requirements such as sign language interpreters or physical access to support service providers (Handicap International, 2011). Should the abuse be reported, very few cases reach a court and if they do perpetrators are often acquitted or sentences are lenient, leaving the victim more vulnerable (Handicap International, 2011).

Management strategies should be based on the social model of disability (Miller, 2002). In addition, care must be provided through a holistic approach since the support of an abused child requires input from a multidisciplinary team (Joyner 2010).

A careful assessment of the family situation and parents' challenges and requirements is necessary. A child may need to be admitted to hospital because his or her safety is priority, but it is not always essential. It also depends on the child–parent relationship (Berkow, 1977). In case of hospitalization parents should be consulted before diagnostic tests are conducted on their child and they must be included in all related discussions. The physician should explain to them that any reporting on abuse will involve the South African Police Services. Professionals from all disciplines have an advocacy role as well as the responsibility of preserving the dignity of affected individuals and their families (MacDonald, 1995).

The social worker, parent or police officer should accompany the child to visit the nearest police station to lay a charge. It is compulsory to report any form of child abuse - it is a crime not to report the abuse. Section 15 of the Child Care Amendment Act 96 of 1996 assigns that the above-mentioned professionals and public service providers have to report abuse of a child if there is any suspicion thereof. The child will receive a written notice in the language of her/ his choice. The police assist the child to go to the clinic or hospital if there is an injury (Joyner, 2010). The police officer also conducts inquiry of the criminal case. The case docket is delegated to an investigating officer. If the child wants to move out of the abusive environment, for example to a shelter or to the home of a friend or relative, a protection order is required. The police assist the child to get a protection order by referring the child to the magistrate office. During the final stage of investigation the police present the evidence to the State Prosecutor (Seedat et al 2009; Joyner 2010).

The health care professional plays an important role in the completion of the J88 form and collection of forensic specimens. The healthcare professional should complete the J88 form accurately and concisely and documents should be kept in a safe place. The document will be required for legal purposes (Joyner 2010). In the case of prosecution, the health care professional must act as an expert witness for the client in the court. The confirmation of physical abuse should be a multi-disciplinary process entailing the responses of the social worker, counsellor, health care professional and the radiographer who has physical examined the child and conducted the analysis of the results.

### **2.12.1 Specific management of the sexually abused child**

During the management of the child a detailed clinical assessment must be done as it may be required for legal purposes. Management of the child begins with disclosure and the first point of contact is the health professional. The specific treatment will depend on the child's age, the duration of abuse, the relationship to the perpetrator and the cultural background of the child. The health professional should be able to communicate with the sexually abused child in jargon-free language. Victim empathy is an essential part of the treatment. This includes "getting in touch" with the emotions and feelings of the abused child to enable the counsellor (professional) to plan the session systematically (MacDonald et al, 1995; Department of Health, 2005).

Sex education forms part of this first session which includes the physiology, positive ways of enhancing sexual pleasure and methods of contraception. Education should be given on sexually transmitted infection and HIV/ AIDS. Pre-test counselling before taking any blood for investigation is compulsory. The procedure of blood taking should be explained to the client to allay anxiety and fears (Searle et al, 2004; Joyner 2010).

Discharge must be approved by the social worker as the main goal is to protect the child. After-care is essential as the risk factors may still prevail. Professionals such as therapists, nurses and social workers should continue to work with children either in groups or as individuals. It is also important to follow an integrated approach to therapy which should involve family members and address the needs of all those affected by the abuse. The role of cultural beliefs, norms and values in the healing process should be taken into account (Hibbard & Desch, 2007).

Culturally appropriate services and crisis centres are essential in the healing process. These services should provide education aimed at keeping children safe from sexual harassment. These services involve a critical analysis of power, oppression, gender roles, human rights and social justice. To augment such required services children learn are about attitudes, equality, respect, sensitivity and co-operation. Defaulting parents (in terms of severe neglect associated with physical injuries) should be reported to the Commissioner of Child Welfare (Berkow, 1977).

### 2.12.2 Management of the family

An understanding of the dynamics of the household improves a workable plan especially if the child remains in the parents' care. When the court decides that the child should be removed from the home, a disposition must be arranged and a consent form should be obtained. Family or individual therapy is important to assist the parent to ventilate anger and guilt feelings to be able to assist the child with the possible future effects of abuse. Non-offending parents may experience guilt or depression due to the lack of supervision. The initial family therapy following disclosure of sexual abuse of a child is most difficult. The primary aim of this family therapy is to meet with the family member to obtain the history of the abuse and discuss disclosure (Berkow, 1977). In adhering to the principles of beneficence a prophylaxis treatment is given for pregnancy, sexually transmitted infection and HIV/AIDS. Emergency contraception should be provided for individuals who have been exposed to sexual molestation. Tetanus toxoid is given to victims who have been exposed to assault and if soft tissue injury is observed where the child should be attended to after administration of the injection (Katzenellenbogen, Joubert & Karim, 1997; Joyner, 2010). The child needs to be counselled immediately after trauma. Disabled children who show signs of emotional and behavioural abuse should be referred to a psychiatrist. The family is capacitated in terms of the effects of abuse and how to assist the child after the trauma (MacDonald et al, 1995).

### 2.12.3 Supporting abused children at home

The family need to be assured about how they have coped and also be empowered with more coping skills if needed. As abuse is very painful parent need to be clear about how to respond in the most helpful way to support the child. Some of the behaviours that develop as the result of abuse need to be attended to by the parents as soon as possible. The following are important guidelines for parents:

**Believe the child:** tell the child that you believe him or her. Children do not lie about abuse (MacDonald et al, 1995). Bernard (2001) found that in some instances children received negative responses or were treated with disbelief from their guardians when they reported that they have been abused by an immediate family member.

**Explore the child's feelings:** try to alleviate any guilt feelings the child may express by explaining that it was not his or her fault (Sullivan, 2009).

**Provide support:** tell the child that you are sorry that the incident occurred. Affirm his or her courage for telling you about the abuse and explain to the child that he or she is not alone - there are others who have had similar experiences. Tell the child that together you will try to solve the problem (MacDonald et al, 1995).

**Listen** to the child and try to build a relationship of trust by displaying empathy, warmth and acceptance. Also stress the confidentiality of the disclosure (MacDonald et al, 1995).

**Consult with the child.** If you feel you need to involve other professionals explain the extent of their involvement, the advantages as well as consequences (MacDonald et al, 1995).

**Be aware of your own feelings:** remain calm, do not shout at the child when telling you about his or her history/experience. Do not be judgemental. Get in touch with your own feelings so that you may be able to relate better to how the child may be feeling (MacDonald et al, 1995).

### **2.13 Prevention of abuse of children with disabilities**

Prevention of abuse of disabled children can only be successful in a supportive and safe environment that empowers disabled children. This includes:

- safe, accessible leisure activities and community services that will assist the child to feel comfortable and secured (Govindshenoy & Spencer, 2006).
- effective networks and support systems that will help the child to feel that he or she belongs to a trustworthy system (Govindshenoy & Spencer, 2006).
- the parent or the carer must be able to liaise with other structures such as the community nurse, community liaison officer, therapist and social worker (Govindshenoy & Spencer, 2006).
- support must be flexible, value the opinions of the child and be receptive to each child's individual requirements (Govindshenoy & Spencer, 2006).
- policy and practices in schools and similar establishments must include respect and empowerment of children with disabilities. They must include clear guidelines on procedures such as intimate care, discipline as well as staff recruitment and screening (Miller, 2002).

It is important to encourage support groups of mothers whose children have been abused to share and learn from others about their experiences. Empowering parents and guardians in coping skills, parental management and anger management is vital.

Influential leaders in the community should be involved in marketing prevention and management of child abuse in the community. The community leaders are people who are respected and who have power (authority) to assign duties to certain people in the community. Generally, it is easier for them to implement strategies at grassroots level than for professionals.

Awareness campaigns should be conducted in crèches, schools, and churches and in the community emphasising the vulnerability of disabled children, signs of abuse and how abuse can be prevented. Campaigns should include the topics that concern what abuse is, the causes, the signs and symptoms, the consequences of abuse, as well as procedures of collaboration between the South African Police Services and the local health facility as well as the management of disclosure (Miller, 2002).

Parents and guardians should be capacitated on stress management at home. They should be assisted to develop listening and communication skills to create a therapeutic environment. Sex education should be done by parents at home. Children should be empowered through listening to their views and wishes; thus building on what they have (Miller, 2002). This means that they should be on the same level of understanding as the child. For example, children must know that they should not accept any sweets or money from strangers. The counsellor should re-enforce the existing knowledge and understanding of the child.

### **2.13.1 Primary prevention**

In primary prevention the focus is on health promotion measures. It is important to take measures to raise awareness amongst the public, public service providers and decision makers. Examples of promotional measures include:

- home visitation of parents and care givers who are looking after children with disabilities (Miller, 2002; Hibbard & Desch, 2007; Sullivan, 2009);
- parental support groups where parents of children with disabilities can meet and discuss their problems (Miller, 2002; Hibbard & Desch, 2007; Sullivan, 2009);
- respite care (Miller, 2002; Hibbard & Desch, 2007; Sullivan, 2009);
- the establishment of family resource centres where parents can access information especially in poverty stricken areas (Miller, 2002; Hibbard & Desch, 2007; Sullivan, 2009);
- encourage health seeking behaviour (Cavalcante & Goldson, 2009);



- involve the community and influential leaders such as the headman/chief, counsellors, businessmen, community based organisations and non-governmental organisations (Cavalcante & Goldson, 2009);
- awareness campaigns during National Child Protection week in schools;
- safety programs for children (Berkow, 1977);
- education on proper nutrition and food supply (Berkow, 1977);
- provision of quality schooling as well as affordable and accessible health services (Berkow, 1977);
- in-service education to midwives, doctors and traditional birth attendants on new developments in maternity and child health services and management of bad obstetric conditions (Berkow, 1977);
- educate parents on temper regulation, behaviour management disability and its management and promote effective attachment (Berkow, 1977).

It is necessary to provide children with knowledge and skills so that they can prevent their victimisation. Educate them on factors of suicide and promoting a healthy life style at the household as well as capacitate them on coping mechanisms and stressors related to transition from primary to high/secondary school.

It is also necessary that adults are assisted to strengthen protective factors and skills such as stress management, self-esteem, emotional resilience, positive thinking and problem solving skills. Home visits should be conducted during pregnancy and early infancy addressing risk factors such as smoking and the use of other substances during pregnancy, poor social support and parental skills. Early booking and proper antenatal care are very important and should be emphasized during primary prevention. The community liaison officer (CLO) should run anti-verbal abuse campaigns in schools, churches and to the general public and collaborate with the Social Welfare Department to embark on extensive counselling pertaining to early marriage, school dropout, delinquent behaviour and unhappy relationship (Miller, 2002; Hibbard & Desch, 2007).

### **2.13.2 Secondary prevention**

Secondary prevention is aiming at preventing the complications of abuse through home visiting programs and providing support and assistance after abuse had occurred. Early diagnosis, prompt treatment and referral are important secondary measures.

### **2.13.3 Tertiary prevention**

Tertiary prevention aims to enable abused children to remain in their homes and communities and to prevent the recurrence of abuse. It is recommended that family centres facilitate rehabilitation, reunification of families and parent mentor programs. In mentor programmes stable families can be a role model and offer support to families in crisis. Mental health services could focus on enhancing communication and functioning within the family (Miller, 2002).

## **2.14 Literature underscoring the study methodology**

The literature search regarding research methodology on child abuse and parental/guardian knowledge, attitudes and behaviour yielded the following:

- all identified studies were descriptive in nature while both qualitative (Carvalho et al, 2009; Handicap International, 2011) and quantitative (Hiebert-Murphy 1998; Plummer 2006) designs were utilised in these studies. This variance made the researcher to choose a mixed methods design for the current study.
- the number of participants in studies varied from 125 to 10 with lower numbers of participants participating in the qualitative studies. This is in accordance with literature on study methodology (Domholt, 2005). The same strategy was implemented in the current study, i.e. a smaller group of participants were identified since the study was predominantly qualitative in nature.
- All the studies recruited participants from organisations that provided support services to abused children and employ no or convenient sampling methods. In the current study setting there were no such organisations existing; therefore this avenue was not open for identifying participants.

- Questionnaires or semi structured interviews were used to collect data in the studies identified in the literature (Hiebert-Murphy, 1998; Plummer 2006; Carvalho et al, 2009). A similar approach was followed in the current study.

### **2.13 Summary**

The statistics of abuse of children in South Africa remain high. There are various social factors that play a role, which need to be dealt with in a multi-disciplinary approach. Disabled children are at higher risk of abuse than their non-disabled peers as a result of the interaction between the impairment and various contextual factors related to the family, the community, society and different professionals. The incidence of abuse of children with disabilities is difficult to determine accurately because of a variety of reasons related to disability definitions, knowledge of professionals and under-reporting.

The consequences of child abuse are devastating and affect both the child and the parent or guardian psychologically, physically, socially and academically and can persist through adulthood. Capacitating these parents and guardians should be done as part of a larger effort whose objective is to achieve good outcomes for their children; therefore prevention is of utmost importance. Capacitating these parents and guardians should be done as part of a larger effort whose objective is to achieve good outcomes for their children.

## **CHAPTER 3: METHODOLOGY**

### **3.1 Introduction**

This chapter outlines the aim and objectives of the research, the research design, setting and sites, population, sample size, and sampling methods. Data collection strategies consisting of the instruments used for data collection such as the questionnaires and focus group discussions are also discussed together with the pilot study and analysis of data. The chapter concludes with a presentation of the ethical considerations that were crucial to the research.

### **3.2 Aim of the study**

The study aim was to explore the knowledge, attitudes and practices of parents and guardians of children with disabilities in respect of the abuse of children with disabilities in the Willowvale area, Eastern Cape Province, South Africa.

### **3.3 Objectives of the study**

- To describe the demographic details of the study participants;
- To determine the knowledge of the study participants on the subject;
- To determine the attitudes and practices of the study participants regarding abuse of children with disabilities;
- To analyse the above information and identify shortcomings in the knowledge, attitudes and practices of participants on abuse of children with disabilities;
- To make recommendations to address the identified shortcomings.

### **3.4 Research design**

This was a qualitative, descriptive study with a small quantitative component. The qualitative approach was chosen since it allows researchers to understand how the participants perceive their situation and their role within the bigger context. It is out of these perceptions that behaviour, including health-related behaviour, is born. Qualitative research can help us to find out why these behaviours occur or why people hold particular views. Qualitative research investigates phenomena in their natural settings where these are interpreted in terms of the meanings people attribute to them. This is the method used when the aim is to obtain a comprehensive knowledge of what people think of a particular issue in a

given context. The descriptive approach allows the researcher to develop a detailed picture of the situation under study. It focuses on “how and who” questions such as “How did it happen?” and “Who assisted you?” The purpose of the quantitative component was to gather data on participants’ knowledge of abuse or disabled children (Domholt, 2005). Quantitative research is especially important in quantifying and documenting the extent of the problem. It provides figures to convince authorities that a significant problem exists that require policy and pragmatic solutions. In the quantitative approach data are in the form of numbers and it is analysed with statistical procedures (Domholt, 2005).

### **3.5 Study setting**

The study was conducted in Mbhashe, a new local health service area in the Eastern Cape Province. It is a rural, underdeveloped, under-resourced and very remote area. Ninety five percent of the population of Mbhashe live in deep rural areas. There are high levels of unemployment and poverty in the Mbhashe sub–district. The unemployment rate is 70% and the income levels are low (80% of households earn less than R1 100-00 per month). The population has high dependency ratios with large households dependent on a single income. In some instances families are dependent on social grants such as care dependency grants, child care grants or disability grants; varying between R250-00 to R1100.00 per month. Infrastructure is poorly developed and people living in the area struggle to access clean water, sanitation services and electricity (Kati, 2004). They are also faced with challenges such as disability emanating from HIV/AIDS, tuberculosis, and malnutrition and these reflect the extent of poverty in the area as these diseases are related to poverty (Kati, 2004). There are 31 clinics and one hospital in the area. The Mbhashe sub-district consists of three magisterial areas, namely Willowvale, Dutywa and Elliotdale.

The study was conducted at five sites in the Willowvale magisterial area. According to registers of community-based organisations there are about 210 disabled children in the Willowvale area. However, these numbers are likely to be low since some children are hidden from the community by their parents - it is possible that a number of up to 350 disabled children might be a more realistic figure according to census 2002 statistics.

### 3.6 Study sites, population, sampling and participants

#### 3.6.1 Study sites

The five sites in the Willowvale area were selected through purposive sampling. All five areas were located in deep rural areas with distances from the Willowvale health centre varying between 20 and 50 km. These areas are difficult to access due to the geographic terrain and location. Of relevance to this study is the fact that reports of child abuse were received from these areas. For instance, preliminary investigations indicated that an eight-year-old child with disability was sexually abused, killed and dumped in a river at Ebende Location.

The five research sites were:

- Fort Malan (site A)
- Qhakazana location (site B)
- Ebende location (site C)
- Gxara location (site D), and
- Nqabeni location (site E).

Further information on the study sites are provided in the table below.

**Table 3.1: Information on study sites and number of participants**

Sites	Name	Distance from and type of road to Willowvale health centre	Health care	Type of settlement	Other	Initial contact point from where sampling started	No of participants	Data collection venue
A	Fort Malan clinic	30 km gravel road	Renovated buildings with a nursing home	Rural	Office of the rehabilitation manager is wheelchair inaccessible	Community health worker	6	Local clinic
B	Qhakazana location	35 km Gravel road	Mobile clinic	Deep rural village	Majority of the people are dependent on grants	Amajwara community-based rehabilitation project	4	Parent or guardian's home

C	Ebende	25 km Gravel road	Health facility	Rural village	Majority of the people are dependent on grants and stipend from the social development funders	Amajwara community-based rehabilitation project	6	Parent or guardian's home
D	Gxara location	20 km gravel road	Mobile clinic	Rural village	People are still wearing red blankets and head scarves. Most people are illiterate and unemployed.	Hleke community-based rehabilitation project	4	Parent or guardian's home
E	Nqabeni clinic	50 km gravel road	Clinic with nurses home	Deep rural Village	Forests and wide rivers. When it rains it is a challenge to cross the rivers which make it difficult to access services. There is a tribal authority next to the clinic where minor cases are attended to administratively.	Community health worker	5	Local clinic

### 3.6.2 Study population

The study population included all parents and guardians of children with disabilities, aged 0–18 years.

#### 3.6.2.1 Inclusion and exclusion criteria

All parents or guardians of disabled children, whether they had a child who experienced abuse or not, were eligible for the research as they are the people who give care and nurture the children with disabilities. Parents not willing to participate were excluded from the study

### 3.6.3 Sampling procedure

Since child abuse is a very sensitive topic and no formal register of either disabled children or abused children existed in the study area the researcher depended on snowball sampling to identify participants (Katzenellenbogen et al, 1997; Neuman, 1997). This sampling method was also used in another similar African study where data on study participants were not available (Handicap International, 2011). With snowball sampling study participants are identified through networking. From a small beginning it grows as the information spread in the community and ever more participants are identified and 'picked up' like a rolling snowball gathering snowflakes. The researcher realised that in instances where potential participants were not connected to any of the networks they would not have been identified.

Specific networking starting points included wheelchair seating and positioning workshops in the study setting, rehabilitation and community health workers in the study setting, community based rehabilitation projects such as Amajwara Community Based Rehabilitation and Hleke Community Based Rehabilitation projects, the Mbhashe district office and community based organisation. The leaders of these projects were informed about the study and asked to provide names of possible participants. They were also asked to spread the information in the community. In addition, the researcher identified participants through her knowledge of the study sites and people living there. These parents as well as those identified by the project leaders were invited to participate in the study. They were also asked to spread the word and inform further possible participants about the study. In this way participants mobilised other parents with disabled children which they knew. Their names were given to the researcher. She contacted them and invited them to participate in the study, while other parents of disabled children phoned her and asked to be a part of the study.

There were 24 participants in total in the five sites. This number of participants was seen as adequate for the study since it was mainly a qualitative study where the richness of the information as opposed to the number of participants is the focus of the study.



## **3.7 Instrumentation**

### **3.7.1 Data collection strategies**

#### **3.7.1.1 Quantitative data**

Quantitative data was collected by means of self-compiled, structured questionnaires (Appendix A and B) which consisted of closed and open ended questions. The questionnaire on demographic details (Appendix A) had two sections. Section A dealt with the demographic details of participants and included questions on their age, level of education and employment status. Section B covered the demographic details of the disabled child. The second questionnaire (Appendix B) determined the participants' knowledge of the abuse of children with disabilities and included questions on type of abuse and signs of abuse. This questionnaire was developed by the researcher in conjunction with her study leaders.

#### **3.7.1.2 Qualitative data**

Qualitative data was collected through focus group discussions. Focus group discussions provide a unique opportunity for participants to make a positive contribution to their community because their input and ideas assist in formulating an intervention to the challenges discussed. In addition, focus group discussions assisted the researcher to explore her or his motivation, biases and subjective interest in doing the research. An important consideration for the current study was that in focus group discussions there is no discrimination against illiterate persons. Also, focus group discussions develop confidence in participants who might believe they have no contribution to make or who are hesitant to be interviewed individually (Katzenellenbogen et al, 1997). It was realised, though, that in research as sensitive as the current study some participants might be hesitant to reveal sensitive and private information in a group (Katzenellenbogen et al, 1997). This did in fact happen when one of the participants became too distraught and requested to share her story in private. The researcher accompanied her to an office where she could speak freely in privacy.

A focus group discussion schedule was developed (Appendix C) that provided broad guidelines for discussion in the form of questions such as:

- What is disability?
- What is the general attitude in the community towards children with disabilities?

- What is child abuse?
- Is there a need to talk about abuse?
- Do you think children with disability are at risk of abuse in your community?
- Do you think there is a difference between the abuses of an able-bodied child versus that of a disabled child? How do you think abuse will affect the child?

The above guide was formulated with the assistance of study leaders.

### **3.7.2 Research assistant**

The researcher used a Xhosa speaking research assistant to assist her during the data collection process. The specific roles of the research assistant were to assist illiterate participants with completion of the consent forms and questionnaire. She also operated the voice recorder during focus group discussions. The research assistant was trained on the performance of these duties as well as on confidentiality requirements.

### **3.8 Pilot study**

The researcher performed a pilot study in February 2009 in Sinqumeni. Permission to conduct the pilot study was obtained from the local councillor. Nine persons participated in the pilot study.

The researcher tested the draft questionnaire. No ambiguities were identified. No changes were thus required except for the demographic details of the child with disability where unnecessary questions were deleted. The name of the school and headman were omitted from the final questionnaire. It took the participants 60 – 90 minutes to complete the questionnaire and focus group discussion. On analysis the data were found to be sufficient to address the study aim and objectives; thus no further changes were made to the questionnaire and planned methodology.

### **3.9 Data collection procedure**

Data was collected during January 2009. The researcher obtained provisional consent from participants and made appointments with them to attend the focus group discussion on a specific date. On arrival to each study site the researcher introduced herself. The researcher greeted the clinic staff and the participants. Participants were introduced to one another and requested to take a seat around a table.

Then the researcher explained the study to them in detail and asked them to sign the informed consent forms.

After written informed consent was obtained from all of them the data collection process started. The questionnaire on demographic data and knowledge of abuse were read to participants and explained step-by-step. These forms were then completed. During completion of forms participants were not sitting around the table but in the way of personal choice. When the participants could not read or write answers, the questions were read aloud by the researcher or research assistant who filled in the responses/answers as given by the participants. The questionnaires were collected after completion of the demographic details of the parents/guardian and child with disability. The participants took 25–25 minutes to complete the questionnaire.

During the focus group discussion participants sat around the table and talked to one another under the guidance of the researcher who facilitated the discussion to generate relevant opinions, ideas and information around the abuse of children with disabilities.

Before commencing with the focus group discussions the researcher requested permission for notes to be taken to allay anxiety and frustration in participants about what was actually reported. The researcher requested to use a tape recorder and their permission was granted. Once they understood that a tape recorder and camera could be used and were happy to participate in this research they were asked to start the focus group discussion. The interview schedule was read to them and the participants were told that the questions will be asked one by one and they will be given time to discuss it in the same sequence. The researcher asked probing questions during the focus group discussion. The focus group discussions took 60–90 minutes to complete.

After they had completed the discussion the researcher thanked the group for their time and contributions. Participants were reimbursed for transport costs. They enjoyed refreshments provided free of charge.

All participants were Xhosa first language speakers. Informed consent was obtained in Xhosa. All data was collected by the researcher and a research assistant who are both fluent in Xhosa.

### **3.9.1 Ethical considerations**

The following measures were taken to ensure an ethically sound study:

- the research proposal was approved and registered with the Committee for Human Research at the University of Stellenbosch (N08/03/067);
- permission was obtained from headmen and ward members in the study sites to perform the research;
- participation was voluntary and all participants signed an informed consent form (Appendix D) which was translated and presented to them in Xhosa – their home language;
- all information was kept confidential in a locked cupboard in the researcher’s office or on computer;
- the researcher and her supervisors were the only people who had access to the data;
- the responses during the focus group discussions were generally quite emotional in nature. Participants were hurt and angry. Some cried a lot during the discussions. The telling of stories of abuse generated anger, frustration and hurt. Where needed, participants were referred to social workers for counselling. In instances where participants voiced other concerns such as a need to send their children to school or for hearing assessments, referral to the relevant professionals were arranged.
- the researcher was aware that, by law, child abuse must be reported to the SAPS.

### **3.10 Data analysis**

#### **3.10.1 Quantitative data**

Responses to the questionnaire on demographic details and knowledge of abuse were captured on an Excel spreadsheet. The assistance of a statistician was sought for the analysis of data gathered by means of the questionnaire. Minimum, maximum, mean, median and standard deviation scores were calculated and are presented in graphs, bar graphs and frequency tables.

#### **3.10.2 Qualitative data**

Thematic analysis of qualitative data was done. The data from the interviews and field notes were transcribed by the researcher, read thoroughly, reread and manually coded. Codes were organised into themes. Existing themes from the focus group discussion schedule were used to provide initial classification categories. These were enhanced with emerging themes from the data.

The researcher conducted member checks with the participants. The researcher asked the participants whether the information appeared to be accurate and indeed reflected what they intended to report. The participants agreed that the information was an accurate reflection of their views and ideas.

Participants who were too far from the researcher were contacted via telephone to query issues regarding the data especially the field notes collected during focus group discussions. Otherwise, those who were nearer the researcher were visited and the information was reread to them. The participants commented whether it was a true copy of what they had said, or not.

### **3.11 Rigor**

Two aspects related to the researcher impacted strongly on the credibility of the data, namely the level of trust the researcher could establish with the participants and the impact of the way questions were phrased.

Building a relationship of trust during this research was important. The seriousness of child abuse can be illustrated by the fact that some of the participants hide their involvement in the research because they were afraid of their neighbours. Trust was achieved in varying ways and to varying degrees. After the researcher has lead the group through a discussion on the confidential nature of the information and they had reached commitment with each other to keep all that was said in the groups confidential everyone became more relaxed.

However, other fears still persisted and had to be allayed. Parents with children with disabilities might have fears that they are under investigation and withhold information (Waterhouse & Stevenson, 1993). The issue of the social grants has an impact too because they might assume that the grant could be withdrawn due to their participation in the study. In some families the grant is the only source of income and they are dependent on it for survival. The researcher tried to allay fears in this regard by stating clearly that she was not investigating grants and how the money is being used.

In one instance the participant became severely emotional and did not want to share any information in the group further. However, she was willing to share her experiences with the researcher privately in an office where she was sure of confidentiality.

Though the researcher tried to build rapport with the participants the sensitive nature of the study rendered it more complicated to collect a wealth of information through appropriately phrased

questions and obtaining information on real examples. Regardless of the data generated, posing the question itself established parameters of the problem. For example one question was: “Which other factors can increase the risk for child abuse, for example an illegitimate child?” It creates a milieu for blaming the victim.

### **3.12 Summary**

A qualitative study design was chosen to explore parents’ and guardians’ knowledge, attitudes and behaviour regarding abuse of children with disabilities. The study was performed in five locations of the Mbhashe local district. Snowball sampling was used and 24 participants were identified for the data collection. Data was collected through focus group discussions and a questionnaire on knowledge.

## CHAPTER 4: RESULTS

### 4.1 Introduction

In order to achieve the primary aim of the study namely to investigate the knowledge, attitudes, practices and behaviour of parents and guardians towards the abuse of children with disabilities in Willowvale area of the Eastern Cape the researcher set clear objectives as stated in Chapter 3.

In this Chapter the results are presented according to the study objectives. Quantitative results are illustrated by tables and graphs. Qualitative results are presented according themes and illustrated by narrative results. For easy reference, the study sites will be called site A, B, C, D and E. Participants will be referred to anonymously as person E1, E2, E3 and children with disabilities will be referred to as child EC1 and EC3 according to their residences. Five study sites were identified within the boundaries of the Willowvale area and 24 people in total participated across the study sites.

### 4.2 Demographic details of the study participants

As indicated in table 4.1 all the participants were females and the majority were older than 41 years. The mean age of study participants were 49.5 years and the oldest participant were 69 years old (table 4.2). The majority of the participants (15) had some schooling (formal education) while seven had no schooling. Fifteen of the participants were married and 16 were housewives.

**Table 4.1: Demographic details of the study participants**

<b>Gender</b>		
Male	0	0%
Female	24	100%
<b>Age</b>		
< 20	1	4%
20 – 30	1	4%
31 – 40	3	13%
41 -50	8	33%
51 - 60	6	25%

60+	5	21%
<b>Schooling</b>		
None	7	30%
Grade 1 – 8	15	62%
Grade 12	2	8%
<b>Marital status</b>		
Married	15	62%
Single	5	21%
Widow	4	17%
<b>Employment status</b>		
Unemployed	5	21%
Student	1	4%
Housewife	16	67%
Community Health Worker	2	8%
<b>Household income (per month)</b>		
0 – R1 000	2	8%
R1 001 – R 2 000	11	46%
R2 001 – R 3 000	5	21%
R3 001 – R 4 000	2	8%
R4 000	4	17%
<b>Relationship to child</b>		
Mother	14	58
Grandmother	9	38
Aunt	1	4%
<b>Number of dependents</b>		
1 – 2	8	33%
3 – 4	6	25%
5 – 6	5	21%
More than 6	4	17%
Not answered	1	4%



The majority of participants (14) were the mother of the disabled child, while nine were the grandmother of the child. Except for four participants all had other dependents as well as the disabled child. The number of dependents ranged from two to eight, with a median of four (table 4.2).

**Table 4.2: Descriptive statistics on age, dependents and income of the study participants**

Variable	Valid number	Mean	Median	Minimum	Maximum	Lower Quartile	Upper Quartile	Std. Dev.
Age	24	49.17	49.500	19.0	69.0	42.5	59.5	12.67
Dependents	23	3.91	4.000	1.0	8.0	2.0	6.0	2.21
Income	24	2165.46	1600.000	860.0	5000.0	1010.0	3250.0	1432.64

As indicated by table 4.1 thirteen of the households had an income of R2000 or less per month and the mean household income per month was R2165.46. The only source of income in some families were old age pensions, disability grants, foster care and dependency care grants while some of them were dependent on subsistence farming and agriculture. Table 4.3 shows that seven participants received child support grants of R250 per month and five receive care dependency grants. Even though ten children are cared for by grandmothers or an aunt none received foster care grants.

**Table 4.3: Grants related to the child with the disability received by participants**

Category	Count	Cumulative count	Percent	Cumulative percent
0	12	12	50.00000	50.0000
250	7	19	29.16667	79.1667
1080	5	24	20.83333	100.0000

In addition, 12 participants indicated that they have a support system, five indicated no support system and seven did not answer the question.

### 4.3 Demographic details of the children with disabilities

Table 4.4 shows an equal gender distribution in the children involved. With regards to age the majority were between 5 and 10 years old.

**Table 4.4: Demographic details of the children with disabilities**

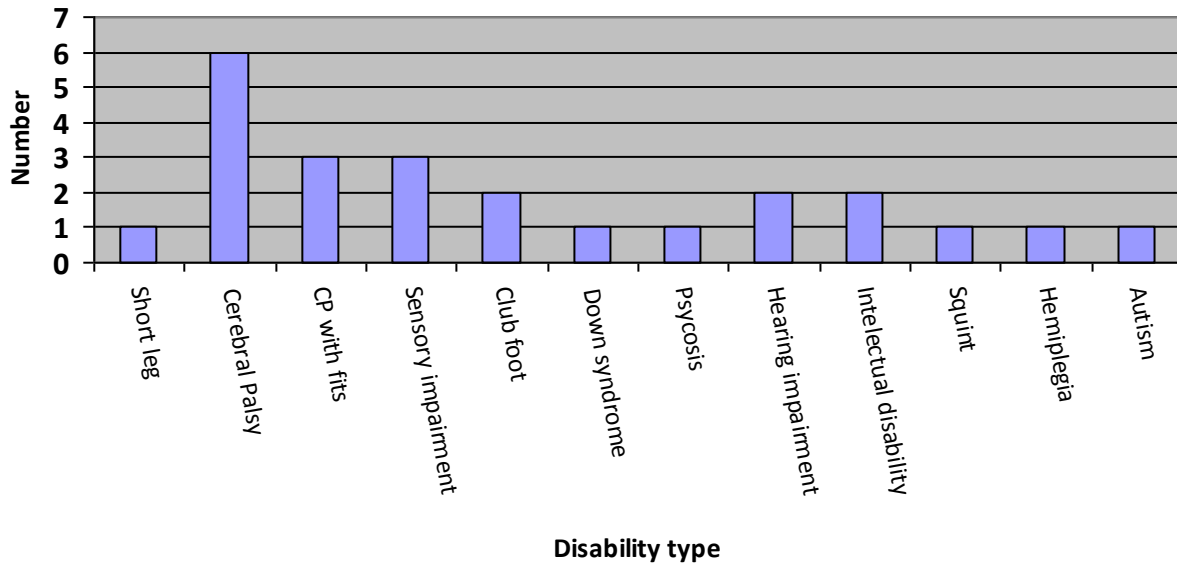
<b>Gender</b>		
Male	13	54%
Female	11	46%
<b>Age</b>		
<5	3	13%
5 – 10	15	62%
10 – 18	6	25%
<b>Schooling</b>		
No schooling	17	72%
Grade 1 – 11	7	28%

As indicated by table 4.5 seventeen of the children received no schooling. The parents/guardians ascribed this lack of school attendance to the children's level of understanding abilities that are very low.

**Table 4.5: Frequency data on schooling of the child with the disability**

<b>Category</b>	<b>Count</b>	<b>Cumulative count</b>	<b>Percent</b>	<b>Cumulative percent</b>
<b>Yes</b>	7	7	29.16667	29.16667
<b>No</b>	17	24	70.83333	100.0000

Figure 4.1 illustrates the impairments that the children involved suffered from. The most common condition were cerebral palsy (6) followed by with cerebral palsy with fits (3) and sensory impairments (3).

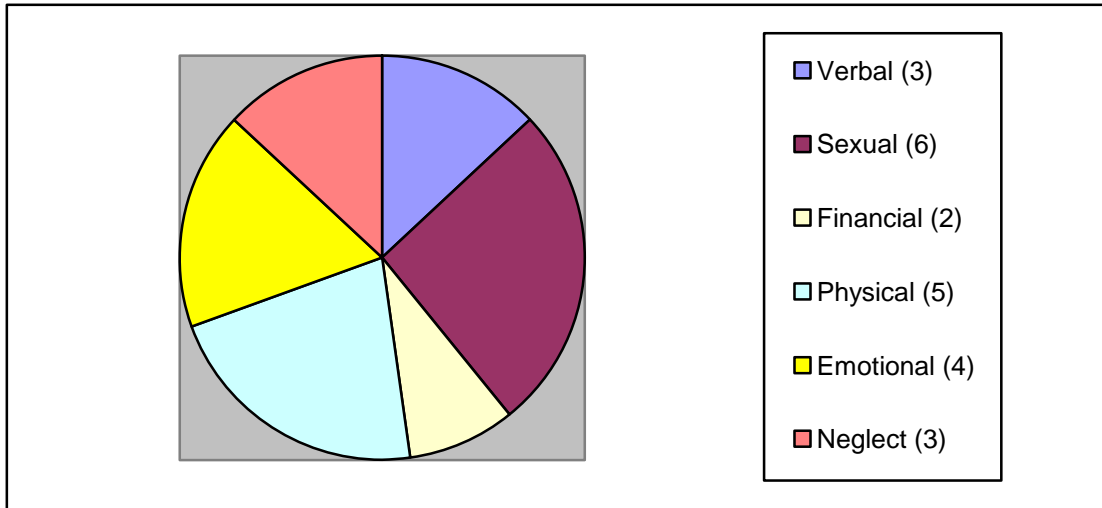


**Figure 4.1: Conditions that children suffered from**

#### **4.4 Knowledge of the study participants on child abuse**

##### **4.4.1 Types of abuse**

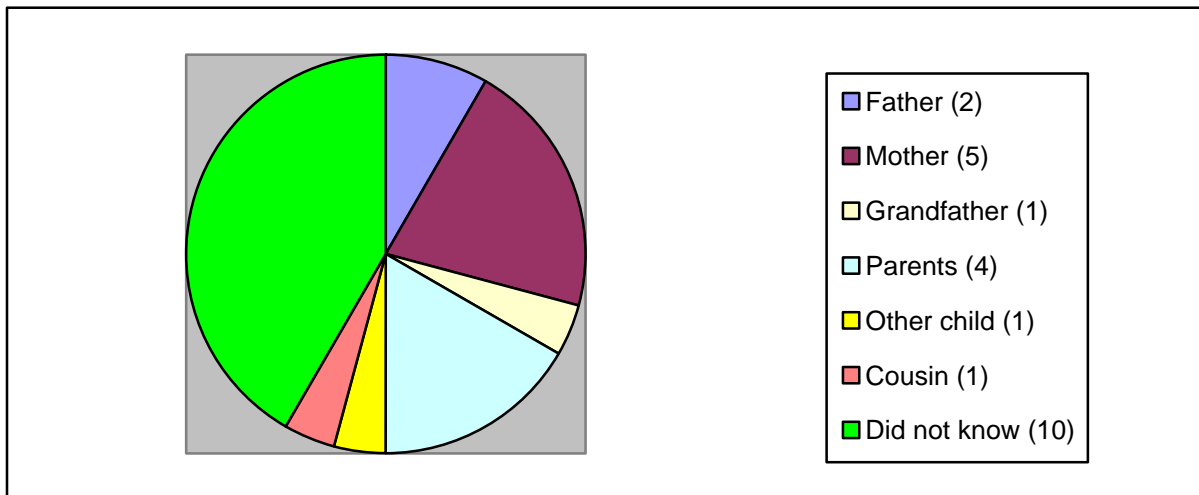
Between them the 24 participants gave 23 correct responses on types of abuse. Sexual (6) and physical (5) abuse were mentioned most often while child labour was not mentioned at all (figure 4.2).



**Figure 4.2: Types of abuse listed by participants**

#### 4.4.2 Likely abusers

Participants felt that the mother (5) or parents (4) were the most likely perpetrator (figure 4.3). Each participant gave only one option and 10 did not know or did not respond to the question.

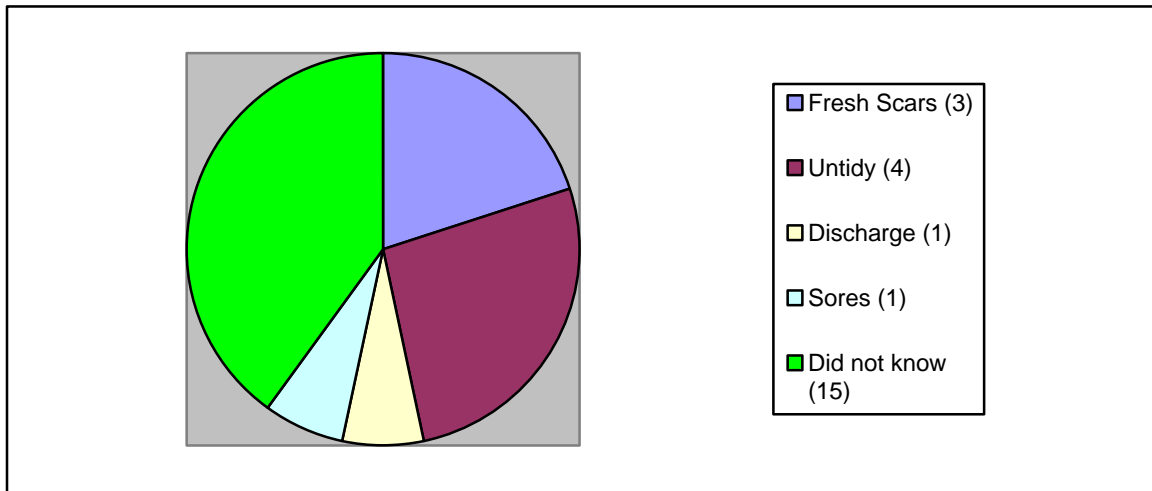


**Figure 4.3: Possible abusers according to participants**

#### 4.4.3 Physical signs of abuse according to participants

Participants identified various physical signs of abuse as presented in figure 4.4. The sign most often mentioned was untidiness (4) followed by fresh scars (3). Again, every participant mentioned only one

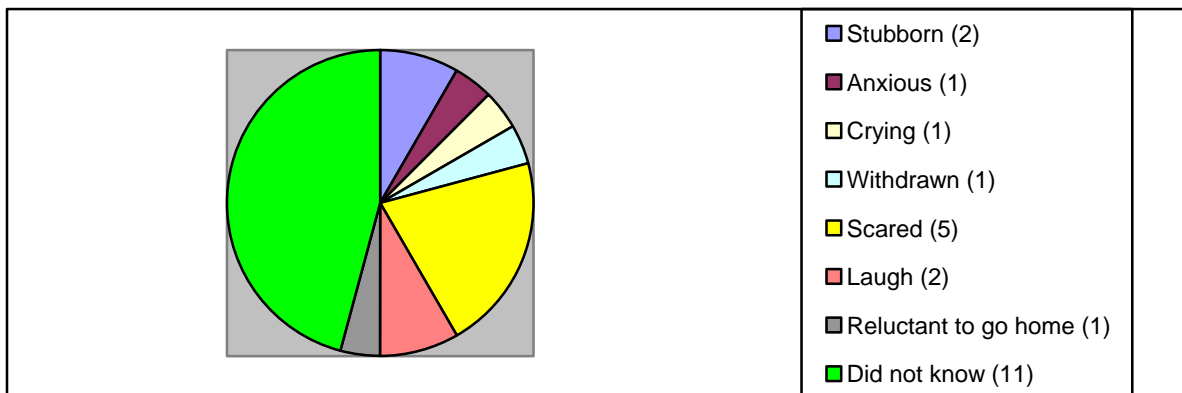
sign. The majority (15) of participants either indicated that they did not know the answer to the question or left the question unanswered.



**Figure 4.4: Presentation of physical signs of abuse according to participants**

#### 4.4.4 Behavioural signs of abuse according to participants

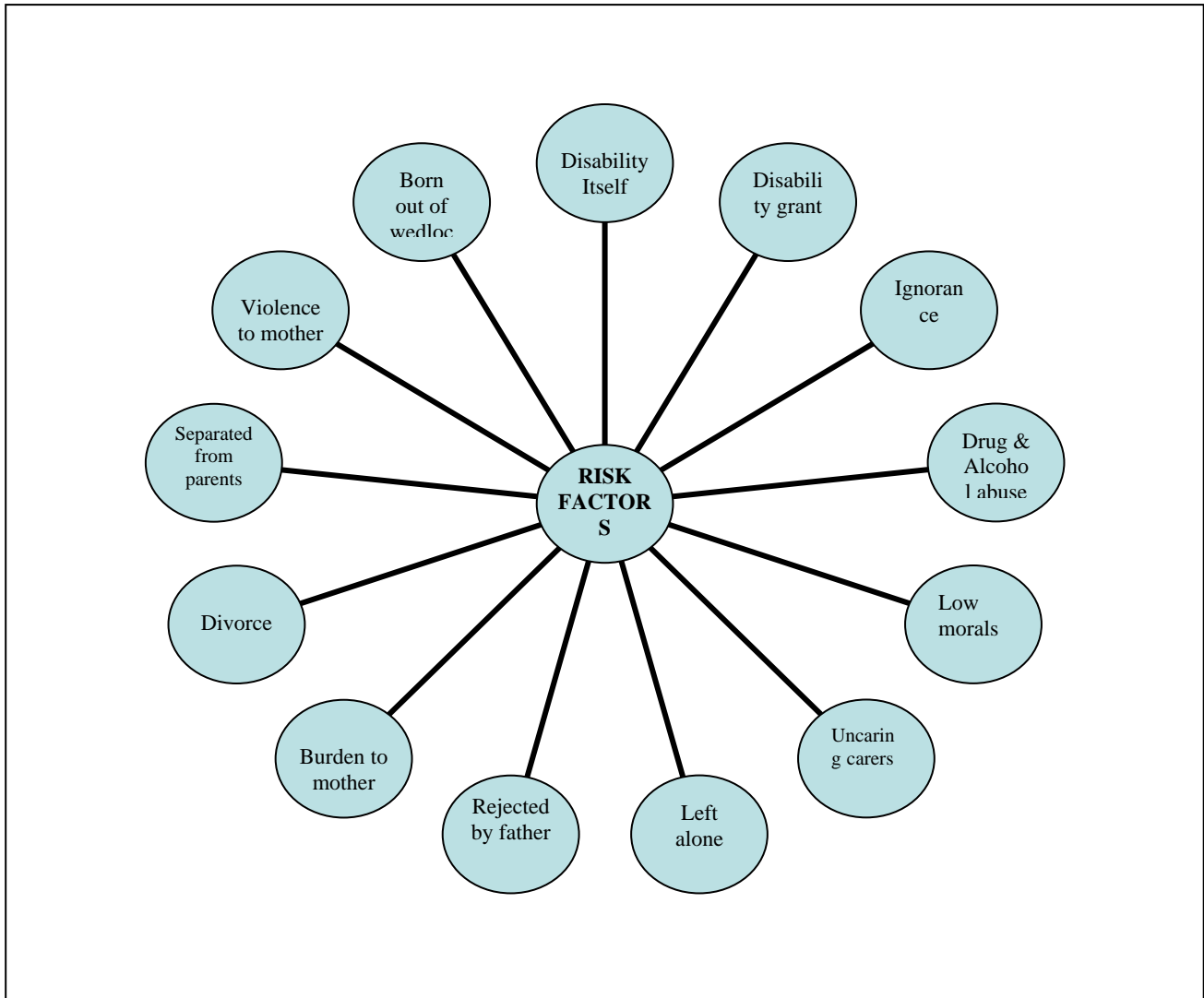
The behavioural sign most often mentioned was that of the child being scared (5). Participants again experienced challenges with this question and 13 signs were mentioned. Eleven participants either did not know or did not answer the question.



**Figure 4.5: Presentation of behavioural signs of abuse according to participants**

#### 4.4.5 Circumstances that increase the risk for abuse

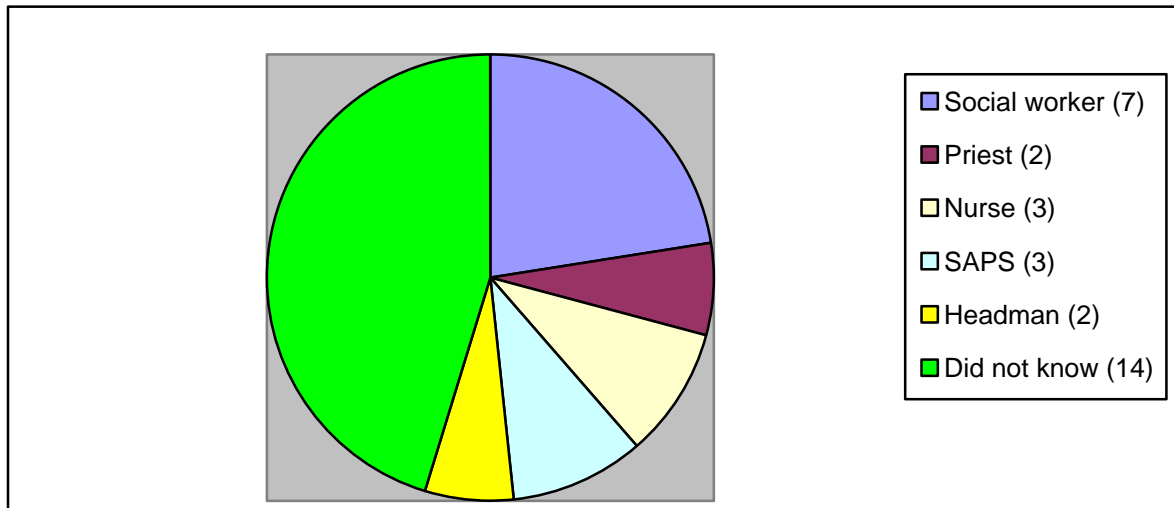
Circumstances that could increase the risk of abuse, according to participants, are presented in figure 4.6. The circumstances are related to the child and the disability, the situation at home, the presence, involvement and knowledge of parents and substance abuse. Factors that were mentioned by more than one participant included the child being born out of wedlock (2), divorce (2) and ignorance (2). Eight participants were not able to provide any information on this question.



**Figure 4.6: Circumstances that can increase the risk for abuse**

#### 4.4.6 Possible sources of assistance

The possible sources of assistance when abuse is present or suspected, according to participants, are presented in figure 4.7. The source of assistance most often indicated was the social worker (7). Fourteen participants did not know where to go for assistance in the instance of abuse or suspected abuse. The ten participants who did show knowledge of this mentioned 17 sources between them.



**Figure 4.7: Sources of support according to participants**

#### 4.5 The impact of demographic details on occurrence of abuse according to qualitative data

The following opinions were voiced by participants on the role demographic details might play in the occurrence of abuse in children with disabilities during the focus group discussion.

##### Age

Participants felt that children younger than 10 years were abused more often than teenagers.

##### Gender

According to participants girls are abused more than boys: “Yeey! The abuse is more to girl children” (C6). In addition, they felt that the types of abuse occurring most often with girls were sexual molestation. Both boys and girls were likely to be abused emotionally, verbally and physically.

## Socio economic status and educational status

According to the participants there is a relationship between the socioeconomic status of the parent or guardian and the abuse of the child with disability. In instances where families were poor and not well educated they experience abuse over and above the abuse of their children with disabilities by the community. In one instance the mother of the perpetrator shouted to the parent of a child with disability: "The mother of the perpetrator shouted at me in the streets saying go and report again, we have applied for a bail for our son. As parents we end up being abused for the sake of our children" (C2). The perpetrator's mother is acting this way, since having money empowers her to pay for bail and a lawyer to protect her son, while the destitute parent of the abused child has no money to pay for a lawyer.

### 4.6 Perceptions, attitudes and behaviour of participants with regards to abuse of children with disabilities

Data will be presented under the themes and sub themes as presented in table 4.6.

**Table 4.6 Core concepts, themes and sub themes as identified during interviews**

Core concept	Themes	Sub themes
Disability	Participants understanding of disability	<ul style="list-style-type: none"> <li>- Defining disability</li> <li>- Need to talk about it</li> <li>- Community perceptions of it</li> </ul>
	Attitudes of parents towards disabled children	<ul style="list-style-type: none"> <li>- Disappointment</li> <li>- Abandonment</li> </ul>
	Impact of disability on abuse	<ul style="list-style-type: none"> <li>- Increase risk</li> <li>- Reasons why</li> </ul>
Abuse	Participants understanding of abuse	
	Experiences of abuse	<ul style="list-style-type: none"> <li>- Sexual</li> <li>- Other</li> </ul>
	Abuse risk factors	
	Support at disclosure	



	Impact of abuse	
	Reporting and management of abuse	
	System responsiveness	
Support systems		<ul style="list-style-type: none"> <li>- Formal</li> <li>- Informal</li> </ul>
Non disclosure		

#### 4.6.1 Participants' understanding of disability

Participants struggle to define disability and in three of the focus group discussions this question was met with silence. In the other two the responses were virtually the same and disability was equalled to dependency and an inability to perform tasks for yourself: *"It is when somebody cannot do things for himself"* (C1) and *"It is when she or he is dependent to other people"* (B2).

Participants felt that there was a need to talk about disability but could not voice the reasons why: *"Yes but we cannot explain what it is"* (C3).

With regards to the attitude of the community towards disabilities participants were more vocal and could relate experiences of their children which points towards derogatory treatment, exclusion and stigmatisation: *"Sometimes they called her "usidzubha", meaning mentally disturbed. Morning "sidzubha" (B1).*

*"Humiliating her for being unable to talk. The community is not accepting our children especially those who are unable to communicate"* (B4).

*"The community disempowers and look down for our children with disabilities"* (C1).

*"People in the community are calling our children by bad names"* (C2).

*"Teachers and parents insult our children. Shut up! The disabled child will feel belittle. The in – laws are saying that there were no disability in this family this disability comes from your side. The child will isolate herself from others and sometimes cries"* (D2).

*"They are treated as if they are mentally ill"* (A1).

#### **4.6.2 Attitudes of parents towards disabled children**

Participants related disability and parental disappointment with the fact that the child is disabled to neglect and abandonment:

*“A girl in this area left the child in the taxi and requests the owner of the taxi and the neighbour to take the child to her mother. These are the words from this girl “I have gone to Cape Town with my dependency grant for my child.” She paid the taxi both for her child and the neighbour” (C5).*

*“CCI was abandoned by his father...The father did not accept him and went to Johannesburg. He stayed there with no communication between him and his family until the child went to initiation school. Patriarchal domination has led to breakdown of traditional culture and humanity whereby a biological father could neglect his offspring even during critical periods of initiation school of a child. The procedure (circumcision) he knew it very well that it needs the biological father and the immediate family members to support the child especially the one with disabilities. The father did not care when the son has to undergo initiation school the mother struggled to organise for the initiation ceremony. Even when the child had to go and visit his father after the ceremony the father shows no interest and this led the mother to seek help from the Magistrate court in order for the child to get his rights” (C2).*

One 22 year old mother said that she decided to have another child because the child with the disability did not meet her expectations. However, now she is neglecting the child with the disability.

*“My daughter left her 4 year old child with me now I am struggling to get a disability grant for her because she is neither phoning nor sending money for her child” (C6).*

#### **4.6.3 Impact of disability on abuse incidence**

Participants argued that physical, verbal and emotional abuse occurred more often in children with disabilities:

*“Disabled children are abused more than able bodied children” (B1).*

*“Both are abused but it is more to those who are disabled” (C3).*

Reasons for this were related to societal attitudes as well as constraints placed by the impairments on the children. Society devalues children with disabilities:

*“...the able bodied children are not a shame to the public and are not abused as the disabled” (A4).*

In addition, children with disabilities are unable to move from one place to another to escape easily from environmental hazards:

*“Yes because they are confined to one place” (B2).*

Their disabilities might make it difficult for them to identify perpetrators:

*“My child reported to me that the boys in the community slept with her (They had sex with her). When I asked who they are she cannot point out who slept with her because she is mentally ill” (B1).*

#### **4.6.3 Participants’ understanding of abuse**

Participants could not give a general explanation of what child abuse is, but they were able to give examples of various forms of abuse which usually could be related to things their children experience or things that they observe.

#### **4.6.4 Experiences of abuse**

While participants often struggled with the abstract concepts such as disability and abuse they were able to relate well to the concrete experience of abuse and many could share personal experiences where their own child with a disability was abused. The most common type of abuse talked about in the focus group discussions were sexual abuse:

*“My grandchild was raped” (C3).*

*“A 17 year old girl was raped by a drunken man. The perpetrator molested the child under knife point and he kicked the door to get entrance to the house.” (C6).*

*“Sub – A girl child was raped while her mother has gone to town” (A1).*

*“Yes my child was sexually abuse by four men when she was 16 years old” (C2).*

*“Child under my care was sexually abused by a known perpetrator” (C5).*

*“My daughter was sexually molested and he poured soil on her vagina after he has done. He also pricks her with a stick in her vagina” (A4).*

Examples of murder / sexual abuse as well as neglect were also given:

*“A 7 year old child was kidnapped by a relative during the evening when the mother was busy assisting her neighbour in making marewu. There was an initiation ceremony into womanhood to their neighbour. When she comes back she found that the child is not there with her wheelchair. Her father was chatting outside at their neighbour’s house. They searched for the whole night. The child was discovered in the morning dead and dumped in the river with her wheelchair lying next to the river” (C6).*

*“I think child abuse is when a child is not cared for” (B1).*

*“It is to starve a child” (B2)*

Participants reported that in some families children with disabilities are a source of income. Parents/guardians use their social grant money for their own needs.

*“She [child’s mother] disappeared with the grant of her child” (E2).*

*“The young man is not getting food and his grant is utilised by his aunt for her own needs” (A6).*

*“Parents and guardians pay their debts with dependency grant of the child ignoring the needs of the child” (C4).*

*“...the child minder is stealing the food for my child for her own children and is not feeding her properly” (B3).*

It seems as if the community and even fathers in some instances do not acknowledge the seriousness of child abuse and explain it as being tradition:

*“Her husband said the child has not been sexually molested it was “ukuzunywa”. Normally “ukuzunywa” (attempted rape) occurs in circumcision into womanhood and it occurs without permission to the girl child. The boys crawl during the night and they will look for a girl whom he has*

*admires her for a long time and try to have sex with her while the girl is asleep. If he succeeded to do that then it is termed “uzunyiwe” and that gives praise to the boy when they are chatting with his group mate. Even to the parents and care givers, they are aware of this issue they took as normal development of children to adolescent stage. In this context attempted rape “ukuzunywa” did not apply because this occurred while the child has attended a church during the evening. The environment and the procedure where this incidence occur are not proper” (C2).*

Participants felt there was a need to talk about child abuse and to allow an abused child the opportunity to talk about his or her experiences:

*“Yes if somebody is abused she can ventilate out. It is also important to be always helpful so that that she can trust and have confidence in me” (C1).*

#### **4.6.6 Abuse risk factors**

Participants voiced being an orphan, being a child of a single parent and family conflict as risk factors for abuse:

*“I am worried of children who have no parents because they are abused in all forms, an example is that their money is used for the carer’s needs, they are not cared for, not given food and they are abused physical” (A3).*

*“The family disputes put the child at risk of abuse” (C5).*

*“The illegitimate child is also at risk because the mother has nobody to assist her” (C6).*

*“Single parents displace their anger to the child and they did not accept them” (C2).*

#### **4.6.7 Impact of abuse**

Various participants were afraid that the children might contract HIV through sexual abuse:

*“I am scared that she will contract HIV/AIDS” (B1).*

This is a realistic fear since at least three children in the study did contract HIV in this manner.

*“I cried in despair now my child has contacted HIV/AIDS” (C4).*

*“My grandchild also has contracted HIV and is taking antiretroviral treatment” (C3).*

Other side effects mentioned relates to the emotional impact of abuse:

*“She has failed the same class twice and is wetting herself” (C3).*

*“The child will not progress well at school” (C1).*

*“I am praying for the child to recover but she will not progress at school” (A3).*

*“Children who are abused are always scared and anxious” (C4).*

#### **4.6.8 Lack of support for abused children**

In some instances abused children with disabilities did not get support from family members and care givers.

*“...the child said her grandmother was angry during her disclosure of this incidence [sexual abuse]. The grandmother said if your continue having sex with the boys your will get pregnant. The child bled after having raped and now she said she is afraid to have a baby” (C5).*

#### **4.6.9 Reporting**

Some participants indicated that they did not know what to do should they become aware that a child is being abused and responded with silence or said they did not know:

*“We do not know what to do” (A4)*

*“...it is difficult to report the abuse though we are talking about it because they are abused by the known person.” (C2)*

This level of uncertainty about where and how to report the abuse was further exposed by the fact that in some instances participants saw the research as an opportunity to disclose and came to report the incidences of abuse to their children with disabilities. The researcher conducted an orientation session on the relationship between the South African Police Services and the health facility (see addendum). On the spot training was done to equip the parents and guardians on how to manage an abused child.

Other indicated various routes of reporting:

*“We can report the incidence to the clinic and the headman” (A5).*

*“I reported to my neighbour and at school because my child was abused at school and while playing with other boys” (C1).*

*“I report to SAPS” (C2).*

Another way of dealing, or rather not dealing, with the abuse was non-disclosure because of fear of retribution or social isolation/discrimination:

*“We keep quiet because we are scared of the perpetrator” (C1).*

*“I decided to forgive him when the mother of the perpetrator harassed me in the streets” (C2)*

*“I recruited the perpetrator to the community based rehabilitation project purposively to reconcile when he listened to the life stories of the parent /guardian about their children with disabilities who have been abused in their community” (C2).*

#### **4.6.10 Responsiveness of the system**

While quite a few incidents of abuse were reported to the police it seems as if the system responded poorly and many obstacles had to be dealt with:

*“I reported to the South African Police Services (SAPS) but there was no follow up by the police. “ I am worried by the report from the police which is so slow. The police said to me the case is still under the investigation. There rumours that the perpetrator fled from that area to another relative and he was successful because he was not caught.” (C6)*

*“When the child was sexually abused I phoned to the South African Police Services and they said they do not have transport to visit her” (D4).*

*“Yes my child was sexually abuse – I report this incidence to the SAPS and to the district surgeon who said there is no evidence” (C2).*

*“The incident was reported but there was no follow up by the SAPS” (A3).*

In addition, cases of little or no progress in processing valuable documents like birth certificates due to displacement leading to other troubles were reported:

*“...my birth certificate of my child got lost during the investigation of the case now I cannot apply for a child’s grant for my child because there is no proof that this is my child. When I am going to the police to check the progress of the case, they will say we are still investigating” (C4).*

Wealthier perpetrators can afford expensive defence counselling:

*“I decided to forgive the perpetrator who abused my child because his father hired a lawyer for the case. The mother of the perpetrator shouted at me in the streets saying go and report again we have applied for a bail for our son. As parents we end up being abused for the sake of our children. I do not have money to pay for a lawyer and I am powerless” (C2).*

*“I just stopped following the case due to neglect by the police officers and the power of the relatives [of the perpetrator]” (C5).*

Adults in positions of power that should protect children did not provide support:

*“Teachers are ignoring the abuse of these children; they are not taken into consideration” (C6).*

Others followed the unofficial route and involved the headman or the community in the case:

*“The matter was reported to the headman and the perpetrator paid the damage with a goat” (C6). “I am the grandmother of the child. I am accepting the fine though the fine will not replace my child’s virginity and I am hurt” (C5).*

*“My child was sexually abused twice by a neighbour and the neighbour was chased away from that area” (D4).*

However this route did not always result in acceptable outcomes:

*“This was discussed administratively with no proper solution. One of the perpetrators was related to the headman” (C2)*



#### 4.6.11 Support systems

Participants identified both informal and formal support systems. Informal support came from other parents, neighbours, their parents and partners. Formal support came from community health workers, clinic staff and community-based rehabilitation projects:

*“I am getting moral support from the rehabilitation team members” (C1).*

*“I am assisted by the project team members and the clinic manager of Nqabara clinic” (C3).*

*“My neighbours, social development and the clinic nurses are assisting me lot” (C4).*

#### 4.6.12 Non-disclosure

The researcher observed the non-verbal and verbal communication behaviour of participants and assumed that they were using certain defence mechanisms. The first client responded as if she was talking about somebody else whereas she was actually explaining her own feelings about non-disclosure.

*“Other parents are afraid to tell that her child was abused by her father because she thought the abuse will continue.” (A4).*

Non-disclosure occurred due to fear of retaliation and sometimes due to the lack of knowledge. Some of them did not report the abuse because they think it is a home/family matter. Other participants did not report financial and verbal abuse. They thought that only sexual abuse need to be reported.

*“The parent did not report the first incidence she only reports the second episode via telephone”. (D4)*

#### 4.7 Summary

Participants were all females with a mean age of 49.5 years. They were mostly housewives with limited schooling and coming from households with a low average income. The disabled children were equally distributed in terms of gender and mostly younger than 10 years old. The majority of them were not attending school. The most common cause of the disability was Cerebral Palsy (CP).

Findings indicated a lack of knowledge and awareness on both abuse and disability. Participants stuck to concrete examples of abuse that happened and how they dealt with that. They struggle to define abstract terms and describe their attitudes towards these. The narratives showed that abuse of children with disabilities were a serious issue in the study communities. Furthermore, findings indicated a lack of knowledge of what to do once abuse did occur and how to report it. In addition, the police and legal system often failed those who did report the abuse.

## **CHAPTER 5: DISCUSSION, CONCLUSION AND RECOMMENDATIONS**

### **5.1 Introduction**

In this chapter the results of the study will be discussed in an integrated fashion in line with the study objectives.

### **5.2 Demographic details of the study participants**

In general the demographic details of parents and guardians such as high levels of poverty, low levels of education, unemployment, little involvement of a father figure, high levels of single parenthood and generally high ages amongst care givers paint a picture of high risk for child abuse when compared to risk factors in the literature (Cluver & Gardner, 2006; Cowen & Reed, 2006; Seedat et al, 2009; Cavalcante & Goldson, 2009).

#### **Age, gender and relationship to the child**

With regards to gender the study participants were a homogeneous group though the researcher's interest was to have a heterogeneous group with male representation included. However, the male spouses and partners said that their wives and girlfriends will attend the meeting, because they are busy with other chores. When the researcher enquired about their non-attendance some were at part-time jobs while others were in the tavern or attending other social gatherings. Seemingly children are seen as a women's responsibility and meetings about children with disabilities are meant for mothers. This is a concern since literature indicates the need for the involvement of fathers in successfully preventing child abuse (Hershkowitz et al, 2007).

Fifty percent of the participants were 50 or older, while five were younger than 40. Thus the children were being cared for by the middle aged people who might not be active and vibrant enough to manage the demands and responsibilities of caring for a child with a disability.

When compared to literature and ages of mothers in similar studies the current group were much older. Various comparisons are used since studies reported age in different ways. For instance, one study mentions a mean age of 33.67 (Hiebert-Murphy, 1998) compared to the mean age of 49.5 in the current study. In another study, ages ranged from 21 – 53 (Carvalho, 2009) compared to 19 – 69 in the current

study. Finally, the ages of the majority of the group were 31- 40 (Plummer, 2006) compared to 40 – 59 in the current study.

The results have indicated that nine children were cared for by grandmothers. This can in part explain the high mean age of study participants. The reasons why grandmothers are caring for the children instead of mothers and fathers might be related to abandonment by mothers as described in the study. Sometimes children were abandoned under the pretext of going to find a job, but the grandmothers of children with disabilities reported that their daughters did not have love and passion for their children since they are not writing to explain whether they have found the jobs or not. Another explanation might be the HIV/AIDS epidemic which mainly affects young adults and leave children orphaned. Often grandmothers step into the void and take over care responsibilities.

### **Marital status and support systems**

The children cared for by the nine participants who were either single or widowed might have been at a greater risk of abuse since literature indicates that a lack of support, which more often occurs in single parent households, can lead to the mother abusing the child (Waterhouse & Stevenson, 1993; Hershkowitz et al, 2007). Nurturing and caring for a child with disability takes an excessive amount of time and energy and places more responsibility on a parent.

In addition, current boyfriends might not be the father of the child and might not care for the child or protect the child. In fact, the boyfriend might even be the abuser of the child. The participants mentioned that the single parents are abused by their boyfriends and that it is related to dependency. Most of the parents or guardians are unemployed and they depend to their husband and boyfriends for an income.

Twelve (70.6%) participants indicated that they have the support system in the form of partners, spouses, in-laws and other community structures. Basically those who have support system are less prone to be abused than the one with no support because they are able to discuss their feelings and fears about their children with disabilities. The abusers are always anxious that parents and guardians will be equipped when his partner socialises with others then decided to refrain his partner from socialising with others. Patriarchal domination causes fear in the partner of equipping the spouse with more information and therefore a reason for no longer being submissive to him. Other partners did support their spouses. In this study it was found that they are getting the moral support from their families. This

has resulted in a decrease in the level of distress experienced by the parents when the child has been abused. Parents who reported lack of support from their spouse experienced more distress as revealed by their anger towards the child. Participants who did not get the support punished their children after the disclosure. Some parents chased away their children due to anger and disrespect from the child after disclosure.

### **Income**

Considering the low income levels it is unsure why 12 participants did not receive child support grants and why none of the grandmothers caring for their grand children received foster care grants. The causes might be related to a lack of access to these services and lack of support from professionals, or a lack of knowledge on grants and their eligibility to apply for it.

### **Demographic details of the children**

The children were equally distributed with regards to gender. Nine of them suffered from Cerebral Palsy with or without epilepsy. Another six of them had conditions of the central nervous system. These conditions often implies mental and intellectual challenges as well and increase the strain experienced by guardians and parents and might make abuse easier/justified (Kilonzo, 2004). Of serious concern are the 17 children who were not receiving any schooling. The reason might be connected to the severity of the disability and the fact that many of them suffered from disabilities that might have a negative impact on their intellect and ability to progress at school. However, mainstreaming is propagated in South Africa through government policy and in instances where children's challenges are too severe to be accommodated in mainstream schools they must be supported in specially equipped schools (DoE, 2001). To a large extent neither option was implemented for the current study population. Since this was a qualitative study with non-representative sampling findings cannot be extrapolated to the bigger community, but if this trend is an indication of what is happening to children with disabilities regarding schooling aimed at children with disabilities in these areas there is a serious need for support and change. Without schooling the cycle of poverty and possibly abuse is perpetuated from one generation to the next (Mechanic & Tanner, 2007). A lack of education increases the vulnerability of the disabled child to abuse since they are isolated from the community and their peers. They have less exposure to information on their rights and how to report abuse. If they remain alone at home they are more accessible to perpetrators (Handicap International, 2011).

Participants felt that girls were at higher risk of sexual abuse than boys. This perception was supported by a study from Burundi, Madagascar, Mozambique and Tanzania (Handicap International, 2011). However, the authors (Handicap International, 2011) warn that it might be even more difficult for boys than girls to report sexual abuse and that they might be more reluctant to report sexual abuse since boys might associate it with homosexuality - a taboo in African communities, or they might see the abuse as an insult to their masculinity.

### **5.3 Knowledge on child abuse**

The findings on knowledge of abuse raised serious concerns. There were three irrelevant answers to question 1 which asked the participants to name the different forms of abuse. Another participant mentioned that stubbornness is a form of abuse. Stubbornness is not a form of abuse, but a behavioural indicator of abuse. Three participants did not respond to question 2 inquiring about the different groups of persons likely to be abusers of children. Question 3, which asked what physical signs can be an indication of child abuse, produced four irrelevant answers. With regard to question 6, participants said that they did not know other risk factors for abuse. Thus all aspects pertaining to child abuse knowledge showed a lack of knowledge on the part of participants.

This lack of knowledge can possibly be attributed to participants' socio-economic circumstances such as poverty and the lack of education. The study site is a poverty stricken area and participants had low income levels. There is a relationship between poverty and disability as well as between poverty and child abuse. The poor often lacks information, power, access and knowledge. They often live in circumstances and communities that perpetuate poverty and in which risk factors for child abuse are exacerbated (Mechanic & Tanner, 2007).

The rather low levels of education might have played a negative role in both the prevention and management of abuse. Education increases knowledge and the ability to fight injustice (Mechanic & Tanner, 2007). A lack of education can cause under-reporting of abuse. For instance, some crimes went unreported since participants did not have sufficient knowledge of the various types of abuse or how to identify a child that has been abused. Knowledge on signs and symptoms of abuse were very scant and something like laughing can hardly be credited as a sign of abuse. Fourteen participants did not know where to seek support in instances of child abuse. Often child abuse is not reported to higher authorities, but instead handled administratively at local level as was the case in some instances in the current study. The lack of education could leave parents without the knowledge and empowerment to

deal with often daunting criminal procedures and cases might be thrown out of court or impossible to pursue because of late reporting or destruction of evidence as was the case in the current study.

While there is suspected little male involvement in day to day care of the child, as discussed above, patriarchal domination was strong in the study community. Husbands or partners tended to make decisions about the lives of their spouses. For example, a participant reported that her husband decided to come to an agreement with the perpetrator and told her to close the case. The perpetrator escaped unpunished.

In conclusion, a person's judgment cannot exceed the knowledge on which the judgement is based. Thus limited knowledge will have a negative impact on attitudes and behaviour. (American Heritage® Dictionary of the English Language, 2009).

#### **5.4 Attitude and behaviour regarding abuse of disabled children**

From the limited responses made on the question about what disability is it seems as if participants perceived disability as related to dependency. They see children as disabled when they have problems performing activities for themselves. This limited understanding of disability and of what constitutes disability might lead to negative and incorrect perceptions about disability such as that idea/myth that all disabled children are intellectually challenged or that the disability is a form of punishment, especially if these perceptions are predominant in the family's culture (Handicap International, 2011). Education of both parents and the wider community about abuse of disabled children is essential.

Participants perceived the community to be negative and hurtful in their interaction with children with disabilities. The quotes on this aspect present communal perceptions about disability that has been identified by literature as risk factors for abuse of disabled children (Handicap International, 2011). It indicated a need for community education and desensitisation with regards to disability.

Participants' understandings of abuse were concrete and related to instances of abuse that they have knowledge of like personal experiences. While this study did not attempt to determine the incidence of abuse of children with disabilities it seems as if this might be high in the study community since every participant had a personal story to tell in this regard, or at least knew a disabled child that was abused.

In accordance with literature findings (Handicap International, 2011) participants felt that children with disabilities are at greater risk of abuse than their "normal" counterparts in the study community. The

reasons were multifaceted and some, such as mobility problems which make them easy targets, and communication problems which make it difficult for them to disclose and even more difficult to be believed by authorities, are shared with other disabled children all over the world (Hibbard & Desch 2007; Rohleder, 2010; Handicap International, 2011).

Study findings point towards a certain tolerance towards sexual abuse of disabled children which was also described in another African study. Handicap International (2011) presents findings that point towards sexual abuse of disabled children not being regarded as a serious offence, some participants going as far as describing the abused girl as being fortunate or that she could see it as a sign of being wanted. Other reasons such as accepting sexual molestation as *ukuzunywa* were related directly to the cultural norms of the study community. While attitudes like these persist, it will be impossible to eradicate abuse against children with disabilities completely.

The strong patriarchal system still in operation in the study communities often left women powerless. The lack of support from husbands/boyfriends can cause a situation where the mother does not report the abuse or withdraw her report because of pressure from the husband.

Incidences of serious neglect which might have been caused by parental non-acceptance of the disabled child were also mentioned. Some of the parents have relocated to Johannesburg and Cape Town and left the disabled child with a grandmother. Other mothers expressed the desire that a disabled child should die and therefore did not provide the necessary nurturing and care to the child. These feelings and behaviour from parents might be related to the value or rather lack of value that the community in particular and society in general puts on disabled children (Handicap International, 2011). They are often seen as a burden without the ability to add anything of value to their families and communities. In the study community concerned children with disabilities are stigmatised, viewed as those who are punished by God or as a source of shame. They are seen as people who do not deserve the same rights as others.

These communities are relatively closed and community members have knowledge of each other's movements. Thus, perpetrators might be well orientated about the movements of the parent or guardian and the whereabouts of the child, creating opportunities for him or her to perform mischief. This closeness of communities also had an effect on participants' behaviour once abuse had occurred. In some instances they decided to ignore the abuse in order to maintain peaceful social cohesion.



Social cohesion is of big importance in small rural communities, especially those who are poor. In times of hardship such as illness or natural disasters the people depend on each other for support and survival. Thus no one can afford to be excluded from the community and lose your social capital (Department for International Development, 1999). Linked to social capital is the actual fear of the perpetrator and fear that they might be harmed physically.

Limited knowledge on the possible signs of abuse may cause missed cases of abuse and thus under-reporting. Some of the participants did not know how to go about reporting the abuse. Often reporting was attended too late and valuable evidence has been destroyed.

Support from the SAPS seems insufficient. Lost documents and cases dragging on with no or too slow progress can destroy all trust in the system and lead to future non-reporting. From literature it seems as if the lack of trust in the system is well founded - other studies have found that there is poor or no follow up by medical and justice systems (Handicap International, 2011). It seems as if professionals are either unwilling or unable to act. This lethargy is identified by literature to increase boldness in perpetrators (Handicap International, 2011). This was also found in the current study.

Poverty shaped reporting behaviour and left parents powerless to defend their children when dealing with the legal system. Wealthier perpetrators could afford expensive counselling and poor parents were left with no defence against the expertise that money could pay for.

Reporting to the headman might fit within the social structure of the community, but is not a long term solution. In some cases the issue was not dealt with because of suspected nepotism. In other cases it was dealt with and restitution reached. However, this did not remove the perpetrator from the community or rehabilitate the perpetrator, leaving all children in the community still at risk.

The abused child will receive no emotional support and counselling. This lack can leave an abused child with scars for life and impacts negatively on his or her intellectual, emotional and social pursuits (Weiner & Dulcan, 2004; Medline Plus 2008). The impact of abuse was touched on superficially during the focus group discussions. The physical risk of HIV is a real concern, understandably so in a community where the belief of virgin cleansing still persists (Rohleder, 2010). Negative affects on school performance and behavioural issues were also identified. No mention was made by participants on how or if these issues were addressed.

Where cases of abuse were reported the system often failed the child. This might be due to the lack of relevant knowledge of the parent and the child and thus reporting not adhering to the standards of the judicial system, or the lack of knowledge and proficiency on the part of professionals. Be that as it may a disabled child faces severe barriers in terms of reporting the crime of abuse and receiving restitution by means of the judicial system (Handicap International, 2011). They are victims and often disempowered members of the community, thus professionals should make all effort to support and assist them in pursuing the legal route instead of protecting the perpetrator as seems to be the case currently.

Instead, little support was forthcoming and valuable documents loss. In the face of these challenges one can understand that disempowered persons with little education decided to forgive the perpetrator and continue with their daily lives. However, this lack of action and protection from both parents and professionals leave the child extremely vulnerable because the perpetrators now know that they would not even have to face any consequences for their actions. Therefore a combination of isolation of the child, a lack of reporting and even less perpetrators facing a court hearing or being sentenced lead to perpetrators becoming arrogant and further victimisation of the disabled child and his or her family might occur.

Factors that might increase the risk of abuse was not explored in depth during the focus group discussions and participants need to be made aware of these to be able to recognise and be aware of situations that might increase risk in their own lives.

With regards to support systems participants referred to their own support, but no mention of support or counselling of the child was made in instances where abuse did occur.

The results showed several gaps in participants' knowledge, attitudes and practices with regards to child abuse. The results showed certain perceived community and professional attitudes and practices which suggest challenges regarding these two groups as well.

## **5.5 Shortcomings in knowledge, attitudes and practices regarding the abuse of children with disabilities**

Firstly, parents and guardians can be empowered through increasing their knowledge on this particular subject. Knowing what constitutes abuse, how it might manifest in the child, which risk factors to look

for and how to preserve evidence and follow the correct lines of reporting timeously will empower them to deal with abuse after it has happened. On the other hand, increased knowledge on risk factors will increase awareness and thus vigilance which might assist them to create a safer environment for the child and at the same time make it easier to control the circumstances where the child might be at risk in that way decrease the incidence of abuse.

Secondly, parents, guardians and seemingly the wider community suffered from a lack of knowledge on disability. Education that focuses on the causes and consequences of disability must be provided as essential “must” information on the rights of disabled children and their abilities. Only through awareness and education can attitudes and beliefs be changed, which in turn could change stereotyping of and discrimination against the abuse child.

From certain findings it seems as if abuse of disabled children is not considered a serious offence by all parents and guardians. This might be related to less value (emphasis) some people seem to put on the life of a disabled child and the fact that the rights of disabled children are not acknowledged, or respected. Be that as it may parents, guardians and the wider community must be educated and empowered to a point where they value disabled children and protect them from harm, or if harm does come, to make the perpetrator fully accountable.

In instances where the crime has been dealt with in the community itself and restitution paid, additional support to the child and perpetrator alike was not forthcoming. The perpetrator needs rehabilitation to understand the wrongness of the deed, or if this fails, must be removed from the community since he or she will remain a risk to that particular child and all other children.

It has been reported through the literature review that the act of abuse has serious long term consequences for the abused child. These consequences can be addressed through effective intervention such as rehabilitation – a key support service that none of the children in this study seemed to receive and could count on. This means that there is another gap that must be addressed in the future.

Another area where education is needed is on HIV/AIDS and the fact that it cannot be cured through sexual intercourse with a virgin.

Finally, experiences of parents and guardians leave the researcher with several questions over the responsiveness of professionals, police and the legal system in dealing with the matter of abuse of children with disabilities.

## **5.6 Recommendations**

The present findings suggest the importance of raising awareness of the harm being done by any act of child abuse.

Education through workshops on child abuse in the study communities is essential. It is further recommended that on the spot education is done on child development, parenting skills, health issues, nutrition and coping skills to equip parents for the task of raising their children in a nurturing environment.

It is essential that fathers are included in these education endeavours and that they are acknowledged and strengthened in their role as head of the household who should take an active part in nurturing and protecting their children.

Communities must be educated and desensitised with regards to disability, its causes and the abilities people who are classified by them as disabled might have. They should be encouraged to include these children in their midst and protect them as one of their own instead of ostracizing them.

Future research in this field might build on the current findings and should, for example, investigate the strategies to fill the gaps identified. It would be of prime importance to explore the notions of parents' anger resulting in assaulting the child after disclosure. Some of the parents have not believed their children and they have assaulted them physically due to uncontrollable anger and frustration.

It is recommended that customized education programs, including resources such as information packs, on disability and child abuse are developed and implemented for both parents of children with disabilities in the study communities as well as the communities at large. The development and implementation of these programs and materials could be structured along community-based rehabilitation guidelines. The participants in this study should form the core target group, but community members can also be involved. Local rehabilitation projects are already partially sensitised due to their involvement in the sampling process. Thus implementation, monitoring and evaluation can be linked to their current practices. Various local and provincial departments such as Social Services,

Health, Education as well as Safety and Security must collaborate to develop and assist with the implementing of these programs.

### **5.7 Areas for further study**

- Studies on education and school attendance of children with disabilities in the study area
- Developing, implementing and assessing outcomes of education according to the above recommendations.
- Incidence studies on abuse of disabled children in the Eastern Cape and South Africa as a whole.

### **5.8 Limitations**

- The findings lack depth, because of a lack of exploration during focus group discussions

### **5.9 Conclusion**

The study found that abuse of children with disabilities in the study communities continue to remain largely invisible and cases often goes unreported or when reported it tends to be disregarded. As indicated in literature, poverty and low levels of education seemed to keep participants in bonds and they had little knowledge on the subject under study. This lack of knowledge impacted negatively on their attitudes and practices in that they were unsure how to protect children from abuse, how to identify whether it actually happened and how to go about reporting it. Patriarchal practices and societal pressure lead to attitudes of fear and submission which allows perpetrators to remain in the communities un-rehabilitated. Proper follow up and feedback by the South African Police Services and other stakeholders involved in disability was also lacking.

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**APPENDIX A**

**DEMOGRAPHIC DETAILS**

**Demographic details for parent or caregiver**

**Participant Research number:**

- 1. Age
- 2. Gender
- 3. Marital status:

1.	Married	
2.	Never married	
3.	Divorced	
4.	Widow/er	
5.	Separated	
6.	Cohabitation	
7.	Other	

If other please specify:

- 4. How many children/ dependents do you have?
- 5. Is there anybody who assists you with caring for child /children /dependents?

1.	Yes	
2.	No	

- 6. Is there anybody to take care of the child /children/ dependents if you want to go somewhere e.g. shopping?

1.	Yes	
2.	No	

7. Educational status

1.	Below grade 7	
2.	Grade 8-11	
3.	Grade 12	
4.	1-3 years tertiary education	
5.	Above 3 years tertiary education	

8. Occupation:

9. Monthly household income

1.	R0 – R100.00	
2.	R101 – R500.00	
3.	R501 – R1000.00	
4.	R1001.00 – R2000.00	
5.	R2001.00 - R5000.00	
6.	R5001.00 – R10 000.00	
7.	R10.001.00 –R15 000.00	
8.	Above R15 000.00	

10. List the available resources for children with disabilities in your community e.g. crèches

11. How many times per week do you spend away from you child/ children/ dependents?

1.	No time	
2.	< than an hour per week	
3.	1 – 7 hours per week	

4	8 - 14 hours per week	
5.	15 - 23 hours per week	
6.	1 day per week	
7.	>than a day per week	

12. Do you have any support system?

1.	Yes	
2.	No	

If yes specify:

13. If no how do they cope in a crisis situation?

**Demographic details related to your child with a disability**

1. Gender:

1.	Male	
2.	Female	

4. Do you receive a care dependency grant for the child?

1.	Yes	
2.	No	

5. Is the child attending school?

1.	Yes	
2.	No	

6. If no why not?

7. What is wrong with the child?

8. Parent's or caregivers comments

## APPENDIX B

### Questionnaire on knowledge of abuse

**Participant research number:**

Please answer the following questions.

1. There are various forms of abuse. Can you name the different forms?  
E.g. Verbal abuse can be the calling of names that make the child feel inhuman.  
\_\_\_\_\_  
\_\_\_\_\_
2. Name different groups of persons that are likely to be the abusers of a child. E.g. Uncle  
\_\_\_\_\_  
\_\_\_\_\_
3. What physical signs can be an indication that a child is abused? E.g. old scars  
\_\_\_\_\_  
\_\_\_\_\_
4. What behavioural signs can be an indication that a child is abused? E.g. Having lies  
\_\_\_\_\_  
\_\_\_\_\_
5. What circumstances can increase the risk for child abuse? E.g. Single parent household  
\_\_\_\_\_  
\_\_\_\_\_
6. Which other factors can increase the risk for child abuse? E. g. illegitimate child  
\_\_\_\_\_  
\_\_\_\_\_
7. Where should one go for assistance if one suspects that a child is being abused?  
\_\_\_\_\_

Thank you

## **APPENDIX C**

### **FOCUS GROUP INTERVIEW SCHEDULE**

#### **Disability:**

What is disability?

How do you see disability?

What is the general attitude in the community towards children with disabilities?

#### **Abuse:**

What is child abuse?

Is there a need to talk about child abuse?

Do you think children with disability are at risk of abuse in your community?

Do you think there is a difference between abuse of able-bodied child versus disabled child?

What would you do should you become aware that a child with/without disability is being abused?

How do you think abuse will affect the child?

#### **Experiences of abuse:**

Have you ever dealt with somebody that has been abused?

Can you tell me about it?

#### **Support systems:**

Tell me about your support system or lack thereof.



## APPENDIX D

### PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

**Title of the research project:** A participatory study on the knowledge, attitudes, behaviour and practices of parents/guardians on abuse of children with disabilities, in the Willowvale area, Eastern Cape Province, South Africa.

**Reference number:**

**Principal investigator:** Mirriam Ntombesoka Wogqoyi

**Address:** 5935 Vullivalley, Extension 15, Butterworth.

**Contact number:** 047 492 1020 / 0883782176/ 0738078013.

You are invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the researcher about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part. This study has been approved by the **Committee for Human Research at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

#### **What is the research study all about?**

The study will be conducted at Willowvale district to the following sites:, Nqabeni and Fort Malan clinics, Ebende, Qhakazana and Gxara locations. The total number of participants recruited will depend on the number of participants who will be willing to participate, but will not be less than twelve or more than thirty, with a minimum of four and a maximum of 10 per site.

#### **Aim of the study**

The study aims to explore the knowledge, attitudes, beliefs and practices of parents/guardians of children with disabilities regarding the abuse of children with disabilities.

### **Reasons for doing this research**

In my work as a rehabilitation manager I have seen instances where children with disabilities have been maltreated or abused. It has also come to my attention that parents do not know how to deal with abuse e.g. how to report to the South African Police etc. Parents are sometimes unsure what abuse is and how to prevent it from happening. I want to determine how you feel about abuse of children with disabilities and whether you want to know more about the subject. This information will be used to develop a training package on the subject and to assist in planning for health promotion strategies in the area. Part of the research will be to provide information and education to you should you want it.

### **Procedures**

Should you decide to take part in the study you will be asked to sign this document stating that you fully understand the nature of the study and that you freely agreed to participate in the study. You will be asked to participate in a focus group discussion with the researcher and other parents/guardians of children with disabilities where you will be invited to share opinions on knowledge, attitudes, behaviours and practices on abuse of children with disabilities. The discussion will last approximately one hour and will take place at a time and venue convenient to you. The researcher will make use of a tape recorder to record the discussion and an assistant to take notes, assists with changing tapes etc.

This discussion will be followed by an educational workshop on the subject approximately 6 weeks after the discussion. During this workshop needs and shortcomings as identified by you and the researcher during the first discussion will be addressed and you should gain further knowledge and a better understanding of abuse of children with disabilities.

This will be followed two months later by another focus group discussion to determine the impact of the workshop and see whether there has been a change in knowledge, attitude, beliefs and practices and if any further needs must be addressed. All discussions and workshops will be done in Xhosa.

### **Reasons for being invited**

You as parents of children with disabilities will be asked to come forward and to participate in the study. You are invited because by providing you with a better understanding of the subject you can protect your own children better as well as teach people in the community how to protect all children against abuse.

### **Your responsibilities**

Should you decide to participate in the study the researcher and other participants will expect you to be truthful in your dealings with them and maintain complete confidentiality. Nothing that is said in the focus group discussions should be discussed outside the group.

### **Possible benefits**

By participating in the study you will assist the investigator to determine the extent of knowledge, attitudes, behaviour and practices regarding the abuse of children with disabilities in the Willowvale district. In this way you will not only gain a better understanding of the problem and how to prevent and manage it, but you will also assist in the development of training packages for your community and other communities. Eventually this should lead to a decrease of abuse and strategies will be devised to reduce the complications associated with child abuse like unplanned pregnancies, mental illness, depression, suicide and drug abuse.

### **Possible risks**

There are no risks involved with the study.

### **Indemnity**

The investigator will take care during the research project but will not be held responsible for any damages or lost which may occur during the research project.

### **Remuneration**

The participants will not receive any remuneration for participating in the study but transport and meal costs will be covered for each study visit.

### **Information on support for abuse victims and their families**

The investigator will explain to the abuse victims and their families that child abuse is a team effort involving health workers, social workers and other role players such as the child protection unit and South African Police Services. If there are signs of sexual abuse or previous scars the families should take the abuse victims to the South African Police Services to get J88 form and then to the District surgeon for examination and filling out of form. They are also referred to the health facility for further management for example examination and prompt treatment. The South African Police Services will assign a delegate to accompany the abuse victims and the families to the health facility and to the social worker for continuous counselling and support. Emergency contraceptive pills are used to prevent pregnancy from unprotected sex before 72 hours.

Management of non sexual abuse and other forms of abuse. A careful review of the family and setting and parents needs is essential and is the first step in treatment. Hospitalisation may be indicated but it is not always essential. When hospitalisation occur parents or guardian should be told that the studies to be undertaken will include discussions with them as well as the diagnostic tests on their child.

Adequate understanding of the parents backgrounds usually requires considerable review of medical records and of prior contacts with social development department

By law, abuse cases should be reported in all states. When a report is made, a face to face conference should be held with a social development representative. This assures clear understanding and helps in planning management. Many communities have a multidisciplinary team consisting of a social worker, psychiatrist and others to provide valuable diagnostic assistance and guidance. Psychiatrist assistance in understanding personality disorders and in dealing with specific conditions such as depression is often indicated. Day care centres for small children can relieve a mother stressed by home responsibilities, allowing her a few hours for herself. Community based services can give direct household assistance. If the home setting may be a danger to the child's health temporary removal may be indicated. Removal requires a court petition, presented by the legal counsel of the appropriate social development. When the courts decide to remove a child from the home, a disposition is arranged. The physician for the family should participate in this planning.

You can contact the Committee for Human Research at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher. You will receive a copy of this information and consent form for your own records

