

AN INVESTIGATION INTO THE REALIZATION OF CHILDREN'S RIGHTS IN SOUTH AFRICA: PERCEPTIONS OF AFRIKAANS-SPEAKING PRIMARY CAREGIVERS OF CHILDREN WITH INTELLECTUAL DISABILITIES

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An investigation into the realization of Children's Rights in South Africa: Perceptions of Afrikaans-speaking primary caregivers of children with intellectual disabilities¹

Abstract

There has been a growing awareness of human rights, specifically children rights, over the past 20 years. Children with intellectual disabilities are often described as a vulnerable group, with limited opportunities to fully participate in society and act as meaningful contributors. Primary caregivers are responsible to act in their child's best interest and hence their perception of children's rights is important. The role that they play in their child with disabilities' life and how they promote their child's rights, can never be ignored. The main aim of this study was to describe the extent to which Afrikaans-speaking primary caregivers perceive that the basic needs of their children between 8;0 and 14;11 (years;months) with intellectual disabilities are being met, in an attempt to describe their rights as set out by the United Nations Convention on the Rights of the Child (UNCRC). The UNCRC is a widely accepted body of which South Africa is a signatory. Forty-nine participants who met the selection criteria were asked to complete a questionnaire, consisting of biographical information, the Ten Questions Questionnaire (TQQ), and questions related to needs and rights of children with disabilities as set out by the UNCRC. Participants were mostly older, married mothers who had only a Grade 10 or lower qualification. Either themselves or their spouses were in full-time employment, and they were part of the low to middle socio-economic group. Results revealed that the majority of primary caregivers believed that their children with intellectual disabilities understood them when they told their children to do something and could speak and say recognizable words, whilst less than half of the primary caregivers reported that their children's speech was different from normal. More than half of the primary caregivers indicated that their children learn to do things in the same way as typically developing peers. With regard to different assistive devices, the majority of primary caregivers felt that their children's needs were met in respect to different assistive devices. This study revealed that primary caregivers most frequently mentioned intangible rights such as self-esteem rights (which included attitudes, acceptance, respect and equality. The study contributed to an improved understanding of

Afrikaans-speaking primary caregivers' perception of their children with intellectual disabilities' needs as a starting point for claiming their human rights.

Keywords: Hierarchy of Needs, human rights, intellectual disability, perceptions, primary caregivers, The International Classification of Functioning Disability and Health, Children and Youth (ICF-CY), United Nations Convention on the Rights of the Child (UNCRC)

Opsomming

Oor die afgelope 20 jaar was daar 'n groeiende bewustheid van menseregte, met spesifiek die klem op kinderegte. Kinders met intellektuele gestremdhede word dikwels as 'n kwesbare groep persone beskryf, waar beperkte geleentheid bestaan om ten volle deel te wees van die gemeenskap en om 'n betekenisvolle bydrae te lewer. Primêre versorgers is verantwoordelik om in hul kind se beste belang op te tree en gevolglik is hulle persepsies ten opsigte van kinderegte belangrik. Die rol wat hulle speel in die lewe van hul kind met gestremdheid en hoe hulle die regte van hul kinders kan bevorder, kan nooit geïgnoreer word nie. Die hoofdoel van die studie was om die omvang waartoe Afrikaanssprekende primêre versorgers die basiese behoeftes van hulle kinders tussen 8;0 en 14;11 (jaar;maande) met intellektuele gestremdheid waarneem te beskryf, in 'n poging om vas te stel of daar in hulle regte soos uiteengesit deur die *United Nations Convention on the Rights of the Child (UNCRC)* voldoen word. Die *UNCRC* is 'n algemeen aanvaarde liggaam, waarvan Suid Afrika 'n ondertekenaar is. Nege-en-veertig primêre versorgers wat aan die seleksiekriteria voldoen het, is gevra om die vraelys in te vul wat op biografiese inligting, die *Ten Questions Questionnaire (TQQ)*, en vrae wat verwant is aan behoeftes en regte van kinders met gestremdheid soos uiteengesit deur die *UNCRC*, gebaseer is. Primêre versorgers het hoofsaaklik uit ouer, getroude moeders wat slegs 'n Graad 10 of laer kwalifikasie het, bestaan. Óf hulle óf hul eggenote het 'n voltydse beroep beoefen en hulle was deel van die lae tot middelklas inkomstegroep. Resultate toon dat die meerderheid van primêre versorgers glo dat hulle kinders met intellektuele gestremdheid verstaan wanneer hulle gevra word om iets te doen, kan praat en verstaanbare woorde kan sê, terwyl minder as die helfte van die primêre versorgers gerapporteer het dat hulle kinders se spraak van die normale verskil. Meer as die helfte van die primêre versorgers het getoon dat hulle kinders dinge op dieselfde manier as hul tipies-ontwikkelde portuurgroep leer. Met verwysing na verskillende ondersteunende hulpmiddels, het die meeste van die primêre versorgers gevoel dat daar aan hul kinders se behoeftes voldoen word. Hierdie studie het getoon dat primêre versorgers nie-tasbare regte, soos ego-motiewe, die meeste benoem het; dit sluit gesindheid, aanvaarding, respek en gelykheid in. Hierdie studie het aan die lig gebring dat Afrikaanssprekende primêre versorgers verstaan dat hulle jong kinders met intellektuele gestremdhede

basiese behoeftes het soos uiteengesit deur die *UNCRC*, en dat die meerderheid van hierdie basiese behoeftes bevredig word. Die studie het 'n bydrae gelewer om 'n beter begrip van Afrikaanssprekende primêre versorgers se siening van hulle kinders met intellektuele gestremtheid se menseregte te bekom.

Sleutel terme: Hierargie van Behoeftes, intellektuele gestremtheid, menseregte, persepsies, primêre versorgers, *The International Classification of Functioning, Disability and Health, for Children and Youth (ICF-CY)*, *United Nations Convention of the Rights of the Child (UNCRC)*

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CHAPTER 1

INTRODUCTION TO THE STUDY

A mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

*(United Nations Convention
on the Rights of the Child,
Article 23)*

1.1 ORIENTATION AND PROBLEM STATEMENT

All over the world, children with disabilities and their primary caregivers are challenged with significant barriers to their human rights and the way they are treated. According to the United Nations Educational, Scientific and Cultural Organization (UNESCO, 2006), about 10% of the world's population are estimated to have some form of disability and of these 650 million individuals, one-third are children. There were approximately 18,500 million children under the age of 18 years in South Africa in mid-2010 (Statistics South Africa, 2011) and 6.3% of South Africans aged 5 years and older were classified as disabled. In South Africa, the prevalence of intellectual disabilities (ID) is estimated at 3.6% (Christianson, et al., 2002).

Intellectual disability (ID) is a pervasive and lifelong condition that not only affects the individual, but also places a burden on families and the community at large. Primary caregivers play a crucial role in the lives of their children with disabilities. They are typically the one constant person in the life of a child with disabilities. Furthermore, they have an added role to play in ensuring that the rights mandated to their children with disabilities by various laws and policies are made available to them (Austin, 2000). Primary caregivers can empower their children with ID to know and understand their rights. They should also know how to use these rights to their child's benefit in order for their children to have the best possible opportunity for the best school education, health services and treatment; such knowledge will assist them in promoting positive attitudes in their child with ID towards the services mentioned above. The earlier this can begin in the life of a child with ID, the more capable that child will be in making decisions about the future and the more comfortable primary caregivers will be in advocating for their child's

rights (Austin, 2000).

Caring for a child with disability brings challenges to primary caregivers, such as an additional financial burden related to the disability, looking for appropriate educational options and dealing with social stigma associated with disabilities. Families of children with disabilities often have limited available resources and therefore it is important to consider availability against rights, for example special schools that are too far from homes, implying that children with special needs have to travel far to attend the special school. Primary caregivers should also be treated as individuals and the role of primary caregivers as the guardians of their children's rights must be recognized. The law does not grant a child complete control over all of his or her rights. According to the law, the primary caregivers may decide how to guard—and advocate for—many of a child's rights. Primary caregivers may decide how to utilize these rights in order for the child to have the best opportunity for gaining positive support in the health and educational domains. Primary caregivers have the primary responsibility for the care and welfare of their children with ID.

Helping children with disabilities to understand their rights does not mean pushing them to make choices with consequences that they are too young to handle. Primary caregivers must be encouraged to deal with rights issues in order to make informed choices and decisions about their child's life. Children's rights flow from their needs; therefore, by listening to the voices of their children, primary caregivers should try to understand their own adult ambivalence and conflicts of interest regarding children rights (Woodhouse, 1994). Abraham Maslow (1970) believed that people are motivated by their needs. Maslow developed the Hierarchy of Needs Model to explain how needs motivate people.

Despite progressive legislation, the current situation in many countries is that children with ID and their families remain one of the most vulnerable population groups. Too many children with ID continue to face barriers that prevent them from participating as equal members of society and thereby from full enjoyment of their human rights. It seems that often the life of a person with ID is viewed as less valuable than the life of a non-disabled person, lacking in significant fundamental equality and moral status (Stratford, 1991). Historically, children with ID had been denied their rights or severe restrictions were imposed on their rights. Recent studies show an increasing concern for the way in which children with ID have been treated and the awareness of children's rights have become paramount during the

past two decades. As a result, many international initiatives highlight the challenges that exist in the world of children with disabilities. The key authoritative international body governing children's rights is the United Nations Convention on the Rights of a Child (UNCRC). It was first published in 1959 and thirty years later, in 1990, the second edition was accepted. This convention was ratified by South Africa in 1995 (Van Bueren, 1998). Although the rights of children with disabilities have gained recognition in international and local law in the past two decades, more progress towards the realization of the rights of children with intellectual disabilities is necessary. Children with intellectual disabilities are especially vulnerable and therefore at risk for abuse and discrimination. This risk is increased by a lack of facilities that would grant these children equal access to services by and resources in the child protection system (Berry, 2007).

In 2001, the World Health Organization (WHO) adopted a new approach that recognized disability within a broad continuum of human functioning (WHO, 2001). The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) marks a shift in attitudes and approaches concerning people with disabilities away from viewing them as objects of charity, health care and social protection towards viewing them as individuals with rights. The ICF-CY makes a common language available that can be used by professionals in allied health, rehabilitation, social work, and education to describe the functioning of children and adults with disabilities across settings and disciplines (R.J. Simeonsson, Simeonsson, & Hollenweger, 2008). Therefore, it may function as a standard for documenting the nature and severity of a child's disability and thereby formalize the child's rights and protection from discrimination, abuse, neglect and denial of access.

The current study aims to establish whether Afrikaans-speaking primary caregivers have the perception that the rights of their children with disabilities, as set out in the UNCRC, are met.

1.2 DEFINITION OF KEY TERMS

Intellectual disability

For the purpose of this study the definition of *intellectual disability* according to the American Association on Intellectual and Developmental Disabilities (AAIDD) is used (Luckasson, Borthwick-Duffy, Buntinx, Coulter, Craig, Reeve et al., 2002). ID is characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills

which originates before the age of 18 years (Schalock, Luckasson, Shogren, Borthwick-Duffy, Bradley, Buntinx et al., 2007). An intellectual impairment is characterised by a number of specific features, including:

- That the child's intellectual functioning is significantly sub-average, which will lead to difficulties in the classroom regarding attention, perception, thought processing, memory and generalisation;
- That limitations related to the intellectual functioning will be seen in any two or more of the following adaptive skill areas: communication, self-care, social skills, community skills, health and safety skills, functional academics, leisure and work;
- The importance of inclusive community settings such as schools, churches and libraries where these children can learn, live, work and play together (Luckasson, Coulter, Polloway, Reiss, Schalock, Shell et.al., 1992). This implies the right of everyone to be socially included in their communities, including children with intellectual disabilities (Westling & Fox, 2004).

Hierarchy of Needs

Abraham Maslow developed the well-known Hierarchy of Needs in 1970. It is a motivation theory which suggests five interdependent levels of basic human needs, namely a) biological and physiological needs, which include aspects such as breathing, food, water, shelter, clothing and sleep, b) safety needs, which include health, employment, property, family and social stability, c) love and belonging needs, which include friendship, family, intimacy, sense of connection, d) self-esteem needs, which include achievement, confidence, respect for others, the need to be a unique individual and, finally, e) self-actualization needs, which include morality, creativity, spontaneity, acceptance, experience and purpose (Maslow, 1970; Prince & Howard, 2002). A human need is something that is essential for survival; hence, Maslow's Hierarchy of Needs provides a valuable framework for thinking about human rights, since each of the five levels mentioned above has rights implicit in it. This hierarchy is presented schematically in Chapter 2, Figure 1.

Human rights

The term *human rights* refer to those rights that are considered universal to humanity, regardless of citizenship, residency status, ethnicity, gender or other considerations (Sen, 2004). Although human rights are traditionally divided into two

main groups, namely civil and political rights on the one hand and economic, social and cultural rights on the other, this distinction will not be used in this study. Rather, it will refer to nurturance and self-determination rights. For the purpose of this study, nurturance rights refer to society's responsibilities to make decisions in the best interest of children, to protect them from harm (Rogers & Wrightsman, 1978), while self-determination rights refer to the importance of allowing children to exercise control over several facets of their lives (Cherney & Perry, 1996).

Perceptions

Perception can be defined as the conscious awareness of the objects and events in the perceiver's environment (Norman, 2002). For the purpose of this study, *perception* refers to how primary caregivers perceive the fact that their children with intellectual disabilities have rights. Adults' perception of children's rights is important for the implementation and success of the rights specified in the UNCRC, because primary caregivers act as the first line in implementation of children's rights (Cherney, Greteman, & Travers, 2008).

Primary caregiver

In a country with a high incidence of HIV/AIDS, traditional family structures are adversely influenced, and therefore *primary caregiver* was selected over *parent* (Commission on HIV/AIDS and Governance in Africa, 2004). In this study, *primary caregiver* refers to any individual who serves as a parent figure for children with ID. Primary caregivers are responsible for the day-to-day care and maintenance of these children and could include mothers/fathers/grandparents/guardians or even house mothers in orphanages (Freeman & Komo, 2006).

The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) (WHO, 2007)

The ICF-CY made a common language available that can be used across disciplines, government sectors and national boundaries to define and document the health, functioning and development of children and youth (Raghavendra, Bornman, Granlund, Björck-Åkesson, 2007). All content in the ICF-CY was developed to conform to international conventions and declarations on behalf of the rights of children (WHO, 2007). The ICF-CY can document the child's limitations and environmental barriers, providing evidence for the rights to protection, care and

access (Simeonsson, 2006), thereby making it a suitable framework for use in this study.

United Nations Convention on the Rights of the Child (UNCRC) (1990)

The key authoritative international instrument governing children's rights is the United Nations Convention on the Rights of a Child (Berry, 2007). The UNCRC is a universally agreed upon set of obligations and standards that recognize that children, independent of adults, are born with and entitled to the fundamental freedoms and rights that are inherent to all human beings (Coppins, Casey & Campbell, 2011). (See Appendix B)

1.3 ABBREVIATIONS AND ACRONYMS

AAIDD	American Association on Intellectual and Developmental Disabilities
CRPD	The Convention on the Rights of Persons with Disabilities
d	Activities and participation (according to the ICF-CY)
e	Environmental factors (according to the ICF-CY)
ICF-CY	International Classification of Functioning, Disability and Health for Children and Youth
ID	Intellectual disability
SES	Socioeconomic Status
TQQ	Ten Question Questionnaire
WHO	World Health Organization
UNCRC	United Nations Convention on the Rights of the Child
UNESCO	United Nations Educational, Scientific and Cultural Organization

1.4 OUTLINE OF CHAPTERS

Chapter 1 presents the justification for the study, the definition of the key terms, abbreviations and acronyms as well as the outline of the chapters.

Chapter 2 provides a comprehensive literature review with discussions on the theoretical constructs that guided the study. It also investigates primary caregivers' rights, the rights and needs of children as well as rights linked to specific articles of the UNCRC, ICF-CY and Maslow's Hierarchy of Needs. This is followed by a discussion on primary caregivers' perception of the rights of children with ID. It concludes by discussing cultural influences on children's rights.

Chapter 3 describes the methodology used in the study. It includes a layout

of the main aim and the sub-aims followed by the research design, the pilot study, the participants in the study, the development of the survey instrument, data collection procedures and finally the data analysis. Validity and reliability aspects are included as well.

Chapter 4 presents a description of the results in accordance with the aims of the study, as well as a discussion of the results. First the reliability of the data is described. This is followed by a discussion of the results of participants' responses to the disability-specific questions and to questions on assistive technology. Thereafter, a discussion of the questions on human rights presented. Finally, the results of children's human rights with regard to the ICF-CY Environmental Codes, the UNCRC and Maslow's Hierarchy of Needs are discussed.

Chapter 5 contains the conclusions drawn from the study. The critical evaluation of the study in conjunction with the clinical implications is presented. Finally, the recommendations for future research are discussed.

1.5 SUMMARY

This chapter provides the rationale for the study by providing background information regarding the extent to which primary caregivers perceive the basic needs of their children with intellectual disabilities to be met, in an attempt to describe their rights as set out by the UNCRC. This is followed by a discussion of the terminology used in the study. In conclusion, an outline of all the chapters of this dissertation is provided.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

In this chapter, the literature review is presented. It provides a review of human rights, more specifically the rights of caregivers, as well as the rights and needs of children. Subsequently, caregivers' perceptions of the rights of children with intellectual disabilities are addressed by focussing on nurturance rights and self-determination rights. Finally, the influences of culture and the impact it may have on how caregivers and children perceive their rights are discussed. Studies investigating children's rights are described and discussed. The chapter ends with a summary.

2.2 HUMAN RIGHTS

The concept of human rights is an ethical ideal, a way of reaching across the divisions of country, ethnicity, class, and conduct in a search for what is common to all people of the world (Wart & Stewart, 2008). Human rights are seen to be basic requirements for the maintenance of human dignity and individual freedom (Ruck, Keating, Abramovitch, & Koegl, 1998).

Rights is a term that implies entitlement to such things as food, shelter, a non-threatening physical environment, security, health, knowledge, work, freedom of conscience, freedom of expression, freedom of association and self-determination (Bayles, 1981). Wart and Stewart (2008) noted that if there is one group which has historically been denied the dignity and value attached to the status of being human it would be people with intellectual disabilities. It seems as if the lives of people with intellectual disability have been traditionally viewed as less valuable than the lives of their non-disabled peers (Wart & Stewart, 2008). Despite this, Griffiths et al. (2003) argued that people with intellectual disabilities have been denied the rights to live in the community, marry, procreate, work, receive an education, and, in some cases, to receive life-saving medical treatment. In some countries, this still holds true. Wart and Stewart (2008) believed that human rights create a protective zone around persons and allow them the opportunity to further their own valued personal developments. They also believed that, from a human rights viewpoint, the key is

that the level and period of support needed by individuals with disabilities ought to be based on their ability to act in service of their goals. Freedon (1991) argued that human rights are intended to function as protective capsules that form a defensive zone around individuals so that they can lead meaningful lives. Furthermore, human rights should protect what are considered important characteristics of human beings. In the seventies, the status of children as human beings and not as objects of concern started to emerge, signalling a significant new movement (Rogers & Wrightsman, 1978). This movement continued to gain momentum and over the last half of the 20th century, the human rights approach to disability has developed (Rioux & Carbert, 2003). These authors were of the opinion that human rights were an international issue, practiced at the local level.

The growing awareness of human rights has led to an increase in the degree to which children with disability are considered ‘persons’ (Melton, 1983b)—beings who have beliefs and desires, and who act on their desires in the light of their beliefs (Lindley, 1986). Freeman (1992) is of the opinion that children differ, meaning that many of them have lesser abilities and capacities and are more vulnerable. Therefore, they need protection. Children are often described as the world’s most valuable resource but, unfortunately, they keep on being neglected and abused and due to their subordinate status in society, children are often unable to exercise their own rights (Glotzer, 2005).

2.3 THE RIGHTS OF PRIMARY CAREGIVERS

It seems impossible to separate children’s and caregivers’ rights. In this study, *parent* refers to primary caregiver. To strengthen children’s rights, it is essential to strengthen responsibilities, rights and duties of caregivers (Woodhouse, 2006). Peens and Louw (2000) stated that the rights of children should never be considered separately from the rights of their caregivers. Furthermore, they stated that children’s rights have a place and that they should be respected; likewise, adults have rights that should be respected by children. Woodhead (2005) also believes that recognizing the inter-dependencies between children and caregivers sets a challenge, because realizing children’s rights requires close attention. In this regard, it is important to understand that the UNCRC is not a charter for children’s rights to be free of parental authority (Woodhouse, 2006). Woodhouse (2006) is also of the

opinion that children are not adults, but are entitled to basic human rights that must be held 'in trust' by their caregivers. The UNCRC recognizes caregivers' role as the guardians of their children's rights and advocates that caregivers should understand that the UNCRC encourages governments to take positive steps in supporting children and families. Woodhouse (2006) noted that the intent of the UNCRC was not to affect or take rights away from caregivers, but rather to retain the balance between the rights of children and the rights of families. The idea that children have rights does not mean that the responsibility of caregivers is weakened, but rather the contrary. The responsibility and need for care and protection is increased by speaking about rights (Dillen, 2006). During the period when children are developing from infants to adults, they require and have a right to nurturing, discipline and care from their caregivers (Woodhouse, 2006). The rights as set out in the UNCRC also form a valuable base for caregivers from which to act and each right serves as a guideline that can be used in their raising of children (Peens & Louw, 2002). Caregivers, like their children, should be treated as individuals, each caregiver with his/her unique view of his/her child (Henley, Ramsey, & Algozzine, 2006).

2.4 THE RIGHTS AND NEEDS OF CHILDREN

Realising the basic needs of children and the importance of providing them with comprehensive care are among the ethical principles that are called *human rights* (Van Bueren, 1998). For children with disability the expression of a need is often the beginning of a problem solving process. A need defined by the family is something that is observed as necessary in order to solve a problem (Carlhed, Björck-Åkesson, & Granlund, 2003). The most widely accepted human rights convention in history, and the key authoritative international instrument governing children's rights, the UNCRC, indicated that needs become rights when they are recognized as being absolutely necessary for protection and quality of life (United Nations General Assembly, 1989). The United Nations (UN), in 1959, published the first Convention on the Rights of the Child (World Health Organization, 2001). Thirty years later, in 1990, the second UNCRC was implemented. Van Beuren (1998) is of the opinion that the UNCRC is primarily concerned with four aspects of children's rights: participation by children in decisions affecting them; protection of children against discrimination and all forms of neglect and exploitation; prevention of harm to

children; and provision to children for their basic needs. However, according to Alderson (2002) the UNCRC's 54 articles concerning the treatment of children and these can be divided into three categories: protection rights, participation rights and provision rights (Alderson, 2000). Each of the substantive articles, i.e. Articles 1 - 41, details a different type of right for children (Alderson, 2000). Despite the use of different categories, the convention itself makes no distinction between the different rights and establishes no hierarchy of rights (Lurie & Tjelflaat, 2012).

The UNCRC was ratified by the South African government in 1995 (Berry, 2007). The post-apartheid South African Constitution that was adopted in 1996 gives full recognition to children's rights at the highest level (Moses, 2008). Children's rights feature strongly in the Constitution's Bill of Rights and form the foundation of South Africa's legal responsibility towards children (Berry, 2007). Section 28 of the Constitution lists additional rights relating specifically to children (Government Gazette, 2008). These include the right to: a name and nationality; family or alternative care; basic nutrition, shelter and social services; protection from maltreatment, neglect, abuse, degradation and exploitative labour; to be detained only as a last resort and then with special rights; and to legal representation (Moses, 2008). Moses (2008) is furthermore of the opinion that according to international agreements, the responsible government must ensure that children have the opportunity to be heard in matters that affect their lives.

Governing bodies such as the UN and the World Health Organization (WHO) have advocated for universal human rights. The International Classification of Functioning, Disability and Health (ICF) developed by the WHO, is a classification of health and health related domains (WHO, 2001). The ICF and its extension for children and youth, the ICF-CY (WHO, 2007), were formulated to provide a universal framework for classifying and documenting disability. The UNCRC and the ICF-CY complement each other. The UNCRC defines the rights of children, whereas the ICF-CY provides the framework for documenting deprivation of rights and the conditions under which those rights can be realized (Simeonsson, 2009). The ICF-CY is the WHO's framework for measuring health and disability at the level of the individual and of populations (Simeonsson et al., 2003). It constitutes an overarching conceptual framework for discussions about how children participate in everyday life situations (WHO, 2007). In addition to participation, the ICF-CY

framework includes three individual dimensions: body functions and structures, activities and participation. It also includes the two contextual dimensions namely, personal factors and environmental factors (WHO, 2007). Environmental factors include physical, social, and attitudinal factors (WHO, 2007).

Usually, children with disabilities interact less with peers in everyday life situations than typically developing peers interact and therefore they may need adult support to take part in activities outside home or at school (Cowart, Saylor, Dingle, & Mainor, 2004). It is well known that young children with special needs usually experience difficulties with peer relationships that might lead to problems in understanding the social tasks of gaining entry into peer groups, maintaining interaction and resolving conflicts (Guralnick, 2010). The impact of the social environment plays an important role in overcoming these difficulties, because children are influenced by interactions and activities in their micro-environments (Bronfenbrenner & Ceci, 1994). Unfortunately, adults around children with disabilities may have low expectations regarding children's skills and may have a tendency to do everything for the child, especially in situations that call for creativity on the part of the child which might cause learned helplessness (Bornman & Rose, 2010).

Because the ICF-CY provides a structure for organizing information about children's life situations from various sources, it may serve as a screening tool to identify individual needs and potential development areas as a basis for more comprehensive assessment of children with disabilities (Adolfsson, 2011). The ICF-CY can document the child's limitations and environmental barriers providing evidence for the rights to protection, care and access (Simeonsson, 2006). Environmental factors add information about how the context affects a child's functioning (WHO, 2007). To describe the impact of environmental factors on children's functioning there are two available qualifiers that are applied to indicate facilitating factors and/or barriers (Adolfsson, 2011). Simeonsson (2006) pointed out that the availability of the ICF may therefore function as a standard for documenting the nature and severity of the child's disability and thereby formalize the child's rights and protection from discrimination, abuse, neglect and denial of access. Disability is the outcome or result of a complex relationship between an individual's health condition and personal factors and the external factors that represent the

circumstances in which the individual lives (UNESCO, 2006). The ICF-CY emphasizes key issues such as the role of the developing child in the context of the family, developmental delay, nature of cognition, language, play and behaviour. The ICF-CY also describes the situation of each individual within the context of environmental and personal factors, rather than classifying the individual according to his/her health or health-related conditions only (UNESCO, 2006). The ICF-CY covers the age range from birth through 17 years of age, paralleling the age range covered by various United Nations conventions, for example the UNCRC (Carlhed et al., 2003). These authors are of the opinion that, although such rights are often implicit in legislation of Western countries, the ICF-CY may provide the basis for explicit documentation of rights. The ICF-CY may thus serve as a source of evidence to identify, in particular, the lack of rights at the level of the individual child or a population (Simeonsson, 2006). Woodhouse (1994) believes that children's rights flow from their needs; therefore, by listening to children's voices and experiences as evidence of their needs, caregivers can confront their conflicts of interest regarding children's rights. A human need is something that seems important for survival.

Abraham Maslow (1970) believed that people are motivated by their needs. Their basic needs are inborn and must be satisfied in order to fulfil the higher order of needs that influences personal development. Human beings are motivated by unsatisfied needs; certain lower factors need to be satisfied before higher needs can be satisfied. Consequently, Maslow developed the Hierarchy of Needs model to help understand how needs motivate people. Maslow's Hierarchy of Needs is described as a theory of human motivation where individuals strive to reach the highest level of consciousness and wisdom through a sequence of stages (Simons, Irwin, & Drinnien, 1987). Maslow identified five levels of needs that a human being wishes to satisfy, starting with the lowest and most important. These needs include biological and physiological needs, safety needs, love and belonging needs, self-esteem needs and needs for self-actualization, and are schematically displayed in Figure 1.

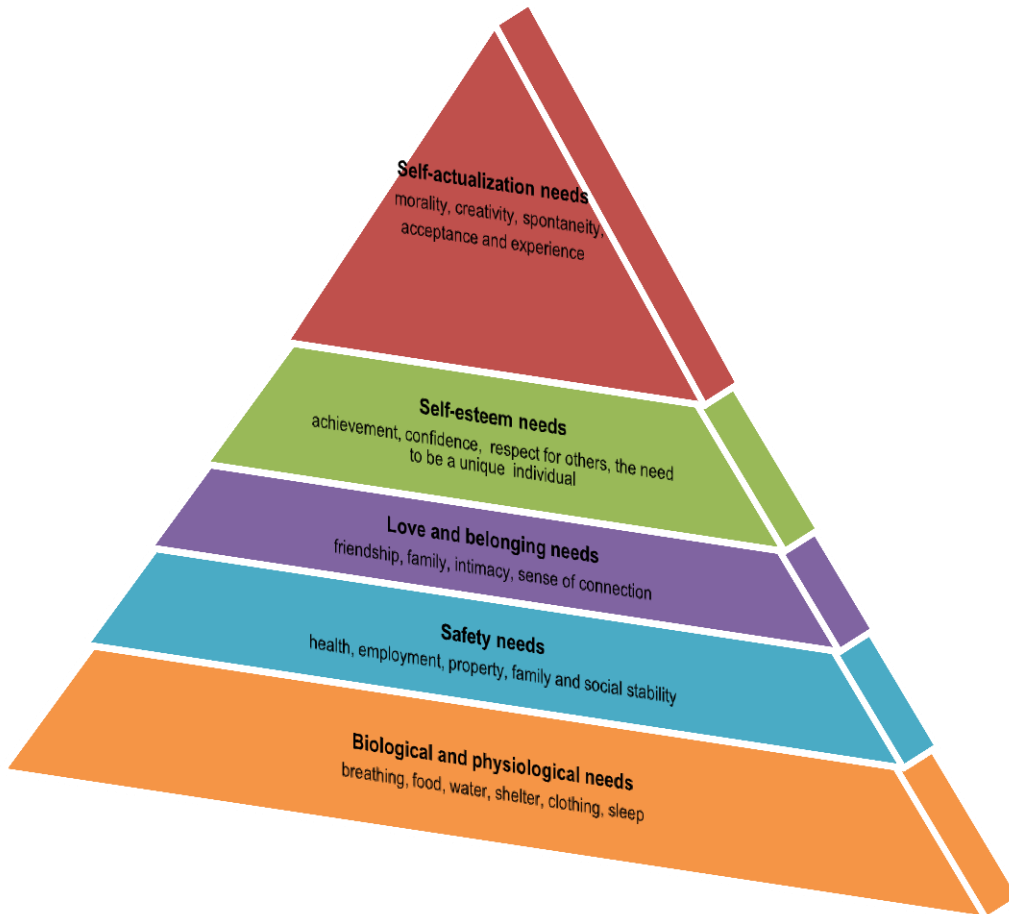


Figure 1 Maslow's Hierarchy of Needs (adapted from Maslow, 1970)

Once one need is satisfied, the person will seek to satisfy the next immediate level and the process continues until he/she reaches self-actualization. Research showed that, in children reared in poverty, the attainment of each level of need is jeopardized by the many difficulties presented by poverty (Prince & Howard, 2002). They are also more likely to have serious physical and mental disabilities and ill health (Duncan, Brooks-Gunn, & Klebanov, 1994). Being poor is associated with poor nutrition, living in substandard housing and dangerous neighbourhoods, receiving substandard child care, teen pregnancy, juvenile delinquencies, child abuse, and death in childhood (Children's Defense Fund [CDF], 2010). Poor families cannot afford health care and many caregivers who have found employment are often not aware of the fact that they may still be eligible for food stamps in the United States (Prince & Howard, 2002). Therefore, there is no doubt that unless the above-mentioned needs are met, the child will be destroyed (Prince & Howard, 2002). The

five basic needs identified by Maslow form the basis of the International Rights of the Child (Van Bueren, 1998).

The differentiation between human rights and needs that is sometimes advocated is not required according to Wart and Stewart (2008), as it fails to appreciate the fact that human rights function to protect the interests and needs of individuals. Implementation of the rights of children with disabilities has taken the form of legislative and societal initiatives on behalf of children with disabilities in most of the developed world (Simeonsson, 2006). Simeonsson (2006) is furthermore of the opinion that the dimension of environmental factors provides the opportunity to document those aspects of the environment, whether physical, social or psychological, that create barriers to or denial of access. Saleh (1999) mentioned an endless diversity among children and the different environments in which they live and learn. Saleh (1999) is furthermore of the opinion that, the more accommodating the environment is to the needs of children, the fewer barriers there will be to children's development and learning. Decisions about how to best respect and support the expressions of competence of young children's as rights-bearing citizens place new responsibilities on adults to structure children's environment and to guide their learning, interest and ways of communicating, especially about issues that directly affect their lives (Woodhead, 2005). Therefore, environmental factors as well as personal factors are important in understanding disabling conditions.

There is a shortfall in action to ensure the satisfaction of the rights guaranteed by international conventions and agreements, especially regarding children with special needs (Saleh, 1999). Saleh (1999) is also of the opinion that nobody is against the rights of the child, as was evidenced by the record speed with which governments adopted the UNCRC. This convention, in brief, insists that children must be seen as individuals with rights, views and feelings of their own. Every child has a right to respect, dignity and consideration of his/her views and best interests (Saleh, 1999). Burke (2005) argues that families of children with disabilities have limited resources available to them; therefore, it is essential to consider availability against that which is a right. The Children's Act No 38 of 2005 (as amended by the Children's Amendment Act No 41 of 2007) (Government Gazette, 2008), stipulates that barriers must be removed and that the necessary support services should be provided to facilitate equal opportunities and access to protect

children with disabilities. The rights of children with disabilities have gained recognition in international and South African law in the past two decades (Boezaart & Skelton, 2010). The Convention on the Rights of Persons with Disabilities (CRPD) (adopted in December 2006 and opened for signature in March 2007), is a complement to existing international human rights treaties. As far as children with disabilities are concerned, the CRPD builds upon and elaborates on the provisions of Article 23 of the UNCRC (Boezaart & Skelton, 2010). The rights and protection of children with disabilities are underlined in various parts of the CRPD. The Children's Act recognises the rights of children with disabilities and provides the primary framework for the realization of every child's rights (Boezaart & Skelton, 2010). Therefore, caregivers of children with disabilities need to know what their children's rights are and need to know that laws are in place to assist them in obtaining support for their disabled child.

Woodhead (2005) noted that the UNCRC has become a powerful catalyst for action on behalf of young children, since it requires all children to be respected as persons in their own right. Article 14 (UNCRC, 1989), refers to the rights and duties of caregivers and others to provide direction to the child in exercising their rights to freedom of thought, conscience and religion. This balance between respecting the competent child and acknowledge children's need for guidance in the realization of their rights is very important for the practical implementation of participatory principles (Woodhead, 2005).

Burke (2005) believes that the UNCRC reminds us that children have the right to an opinion based on information they have received and that such opinion should be considered according to their age, maturity and capabilities (United Nations, 1989, Articles 12 and 13). It is part of the child's right to be heard; it is fundamental to the child's rights to be treated as an independent player (Burke & Montgomery, 2003). Feshbach and Feshbach (1978) are of the opinion that rights are related to the specific legal and social structure of a society, for example the right to privacy. On the other hand, needs are more general and less negotiable, for example the need for food, shelter and caring. However, few researchers who have asked children what they think about their rights, found that both developmental factors and socioeconomic status influence their perception of their rights (Melton, 1980).

The increasing awareness of children's needs and rights has led to an overall change toward giving children a greater degree of autonomy in the choices affecting their own development and lives (Ruck & Horn, 2008). Autonomy is defined as a person's ability to make self-determining choices and involves independence and decision making (Edwards 1996). Woodhouse (1994) argued that out the nature of children their needs arise and that out of children's needs their rights arise. Children have special developmental needs that turn into collective positive rights such as rights to recreation, to education, and to parental care (Woodhouse, 1994).

2.5 PRIMARY CAREGIVERS' PERCEPTION OF THE RIGHTS OF THEIR CHILDREN

Caregivers of children with intellectual disabilities need to know what their children's rights are. It is up to caregivers to provide appropriate direction and guidance in children's exercising their rights as recognized in the UNCRC (Woodhouse, 2006). Schoeman (1980) argued that the needs of children and the preferences of the caregivers go some way toward showing that it is the caregivers and not someone else that should be allowed rights over their children. For caregivers of children with special needs, the obligation to be well informed in the decisions they make concerning their children, is important (Saleh, 1999). Caregivers' perspective on children's rights insists that children need special care and are unable to implement their own rights (Dillen, 2006). It would be asking too much of children in terms of choosing for themselves, because such choices could not guarantee children's proper protection (Dillen, 2006). Renaut (2002) noted that caregivers are afraid of giving children rights, since this would imply power and power, in turn, may imply a challenge to the parent-child relationship. Some authors are of the opinion that expressing children's rights are damaging to the relationship of trust between caregiver and child and that rights could be seen as a threat to caregivers' authority (Dillen, 2006). She argued that there were other arguments that recognised the criticism from caregivers' perspective on children's participation rights. On the contrary, it is just the opposite; the responsibility and the need for care is increased (Dillen, 2006). The role that caregivers play in the lives of their children can never be ignored.

Two different orientations toward children’s rights exist—nurturance rights and self-determination rights (Rogers & Wrightsman, 1978). Hart (1991) is of the opinion that, when the UNCRC was adopted by the UN Assembly, it was an indicator of the increased emphasis being given to self-determination rights for children, in balance with nurturance rights. Nurturance deals with issues of care and protection, hence nurturance rights refer to society’s responsibilities to make decisions in the best interest of children, to protect them from harm, and to guide their development (Rogers & Wrightsman, 1978). This is basically, a ‘parentalistic’ view (Rogers & Wrightsman, 1978), where ‘parentalism’ suggests that there is a hierarchy of power and those with authority can limit the personal freedoms of those without authority to improve society in such a manner that the greatest good for the greatest number of people is achieved (Worsfold, 1974). Worsfold (1974) is furthermore of the opinion that, in the children’s rights debate, parentalism refers to caregivers’ abilities to make decisions for children to protect what caregivers perceive as in the children’s best interests.

On the other hand, the self-determination orientation stresses the importance of allowing children to have control over several facets of their lives, including making autonomous decisions about what they want and need, even if those decisions might differ from the views of the caregivers (Cherney & Perry, 1996). Cherney and Perry (1996) indicated that adults were willing to express their preferences regarding children’s rights. In a study on children’s knowledge of human rights, self-determination rights were very prominent (Wade, 1994). It was also reported that, by 10 years of age, the participants in the study regarded self-determination as an important reason for young people to have rights. In contrast, nurturance rights in the form of protection from harm (category of care and safety) and certain other rights (category of education) were mentioned less frequently by this age group. These findings corresponded closely with previous research done by Melton, (1980; 1983a) and Melton and Limber (1992).

The UNCRC’s highlighting of children’s nurturance and self-determination brings increased attention to the issue of children’s rights (Ruck, Tenenbaum, & Willenberg, 2011). The balance between nurturance and self-determination rights is captured in the two tenets that are emphasized in the CRC, i.e. *the best interests of the child* (Article 3) and *the evolving capacities of the child* (Article 5) (Ruck et al.,

2011). A concern in extending further rights to children is the degree to which young people are capable of understanding their rights in a meaningful manner (Ruck et al., 2011). To extend children's rights on paper without investigating how they feel and think about their rights may be problematic if children do not understand these extended rights (Day, Peterson-Badali, & Ruck, 2006; Peterson-Badali, Morine, Ruck, & Slonim, 2004).

The views of caregivers are also important in the understanding of children's rights since caregivers are in a favourable position to either fulfil or restrict children's nurturance or self-determination rights (Cherney et al., 2008; Day et al., 2006; Ruck, Peterson-Baldali, & Day, 2002). The results of a large-scale survey investigating adult attitudes toward children's nurturance and self-determination rights showed that adults are more likely to advocate children's nurturance rights over their rights of self-determination (Borhnstedt, Freeman, & Smith, 1981; Morton, Dubanoski, & Blaine, 1982; Peterson-Badali, Ruck, & Ridley, 2003; Rogers & Wrightsman, 1978). However, both nurturance and self-determination rights are extended to children depending on the type of right involved and the age of the child. Adult perceptions of children's rights are important for the implementation and success of the rights specified in the UNCRC because adults, especially caregivers, act as the first line in implementation of children's rights (Cherney et al., 2008). Caregivers are often the best advocates for their children to ensure that children's rights are recognized (Ruck et al., 2002).

Lowden (2002) argued that adult beliefs about children's rights influence children's opportunities for self-determination. As some researchers noted, for young children who experience economic, psychological as well as physical dependence on their caregivers, children's rights are provided by their caregivers on behalf of the child rather than through the child's own intervention (Cherney et al., 2008; Peterson-Badali et al., 2004). Research showed that caregivers were more likely to respect children's rights to freedom of choice, but that they felt that they also had to take responsibility for their children regarding freedom of choice issues related to education, restrictions on media exposure, sexual conduct, appearance and religious behaviour (Borhnstedt et al., 1981). Furthermore, these authors noted that biographical factors such as age, marital status, religious affiliation, ethnicity and education of the caregivers made a difference in the type of responses in their study.

2.6 CHILDREN'S PERCEPTION OF THEIR RIGHTS

The way in which children perceive their rights along with the type of rights they feel should be afforded, is affected by various factors (Peens & Louw, 2000). These findings correspond closely to previous research done by Melton (1980;1983b). In this study a three-level progression of children's concepts of their rights to principled reasoning was proposed. It was hypothesized that children in higher school grades and of high SES backgrounds would be more likely to give high-level responses and to advocate rights for children than would younger children and children of lower SES. The stated hypotheses were tested in semi-structured interviews of 80 first, third, fifth, and seventh graders. Half of the sample came from pupils in a lower-and working-class neighbourhood in a poor area of Boston (Low SES), and the other half were drawn from schools in a wealthy area of Boston (High SES). In one instance, children who were out of the regular classroom for bilingual or special education more than 25% of the time were dropped from the sample. Occupations of the participants' caregivers were recorded from the town censuses.

Children in the study were informed by the interviewer that he was interested in what they think about things that happen to them, and their opinions about some stories. Their replies would be kept confidential. The interviews, each about 30 minutes in duration, consisted of two parts and were administered in school by the researcher, a white male. The first part consisted of determining what the child thinks a *right* is. The data were scored according to a Wechsler-type three-point scale in order to establish norms. The second part of the interview comprised of 12 vignettes designed for the research to test the children's judgments in various conflict situations in which they might assert a right.

Both developmental factors and socio-economic status influenced children's perception of their rights. The findings also suggested that children reared in low SES group may grow up to see themselves as having fewer rights, less access to self-actualization and less opportunity for self-determination. At Level I Melton found that children were unable to differentiate between what happened to them and what they should be entitled to. They believed that adults had more rights than they did, because of physical and authoritarian qualities. At Level II, Melton found that children perceived rights as being directly related to fairness or competence to act in

a self-determined manner, rather than on authority figure's permission. Therefore, children's attitudes towards their self-determination rights become more positive. Children at Level III justified the attribution of rights by means of abstract values such as the right to privacy, independent decision-making, freedom of speech and equality.

Melton and Limber (1992) examined an overview of children's views of their rights, their attitudes towards rights and the meaning of rights in their daily lives. Four studies were conducted in Massachusetts, Nebraska, Washington State and Norway. The Massachusetts study comprised 90 children in the Boston area, which included children from affluent, working class and poor homes. The sample was further divided into Italian, Portuguese, African and white American learners aged 6, 8, 10 and 12 years. The Nebraska study included a sample of 300 children aged 4 to 14 years. Half of the sample lived in an urban area while the other half were from various rural areas. The Washington State sample included 200 children aged 4 to 13 years, while the Norway sample consisted of a representative sample of 192 children aged 7 to 16 years, from several schools of diverse social classes. A representative sample of children from the four studies was interviewed. A similar stage-like progression in thinking and knowledge about rights was evident in Norwegian children. A major difference between the four groups focused on self-determination versus nurturance rights. American children viewed self-determination rights as more salient than Norwegian children, whereas Norwegian children placed greater emphasis on special entitlements and protection for children than their American counterparts.

In a study on children's knowledge of human rights, self-determination rights were very prominent (Wade, 1994). The aim of the study was to focus on understanding the conceptual changes in children as they attempted to make sense of the abstract concept of human rights. The research was conducted in a fourth-grade classroom of a public school in rural New Hampshire, USA, from October of 1990 through June of 1991. There were nine girls and eight boys in the class, ranging in age from 9 - 11 years. All children were white and came from single-parent families. The teacher was a white, 38-year-old woman and it was her first year teaching fourth grade and her first year in this particular school. The data set for this study consisted of field notes of classroom and school observations;

conversational interviews with the classroom teacher, special subject teachers and the children; audiotaped classroom events; and the researcher's logs. The findings of this study support a comprehensive view of conceptual change in the elementary social studies classroom. Children's understanding of human rights was influenced by their personal agendas, interests, cognitive engagement and motivation as well as related aspects of the curriculum.

An investigation of Canadian children's reasoning about nurturance and self-determination issues, indicated that these children tended to have positive understandings about both types of rights (Ruck et al, 1998). In the findings of studies by Ruck et al. (2002), it is striking that children may be more sensitive to the negative aspects of not having their nurturance rights fully met. Ruck et al. (2002) provided an example revealing a nine-year-old boy's comments regarding his right to have someone at home upon returning from school.

His response was that maybe somebody would kidnap him because they knew that he was home alone and they might have wanted money. Younger children may see nurturance rights as more prominent because they have little experience in autonomous decision-making, but they are familiar with being cared for and protected (Ruck et.al., 1998). In order for children's rights to be genuinely considered, it is imperative that adults are genuine about nurturance and self-determination constructs (Freeman, 1992). Adults should therefore adopt policies, practices and laws that protect children and their rights (Freeman, 1992). Hence, it seems important to consider moving beyond the focus on *balancing* (for example balancing children's and caregivers' rights, balancing self-determination and nurturance, balancing rights and responsibilities) and work on strategies that will allow children to take part in community life in the society (Melton, 2008).

2.7 CULTURAL INFLUENCES ON CHILDREN'S RIGHTS

A question has arisen in the literature as to whether the rights of children are universal or culturally bound (Murphy-Berman, Levesque, & Berman, 1996). Only a few published studies have addressed whether there are differences in thinking about children's rights between children and their caregivers in different cultures. Families differ in terms of makeup or structure, roles, cultural and linguistic backgrounds, faith backgrounds, values and belief systems, resources, priorities and

concerns for their children (Hanson, 2003). Family systems interact within a broader ecological system of neighbourhoods, communities, service structures and systems and the broader culture is highly influential on the family and the child's development (Bronfenbrenner, 1999). In countries with much diversity, a range of cultural values underlies relationships that exist between children and caregivers (Bronfenbrenner, 1979; Odom, Peck, Hanson, Beckman, Kaiser, Lieber, Brown, Horn, & Schwartz, 1996). One may expect that cultural differences affect how the expression *children's rights* is understood (Cherney & Shing, 2008). Peterson-Badali et al. (2003) found that perceptions of children's rights differ, thereby suggesting that cultural values may influence thinking about children's rights. Melton (1980) argued that both developmental factors and socioeconomic status influence same-aged children's perceptions of their rights. Cherney and Perry (1996) believe that Melton's socioeconomic explanation is too simplistic; they offered a cultural explanation, which suggests that cultural values might play a central role in influencing children's perception of their rights. For example, in some cultures autonomy of the individual, whether child or caregiver is very important, whilst others value collectivism and interdependence.

Cherney and Shing (2008) are also of the opinion that the understanding of these differences would enhance the success with which the UNCRC could use them to guide children's strategies in different countries. In some cultures, individuals may find it difficult to understand that children could have rights apart from their caregivers (Murphy-Berman et al., 1996). In societies that are more traditional, for example, African cultures, the links to family and the local community are important and the principle of *best interest of the child* (Article 3 of the UNCRC) will therefore be understood as requiring the sublimation of the individual child's preferences to the interests of the family (Murphy-Berman et al., 1996). These traditional cultures have a strong belief in a structure of an authoritarian, patriarchal society, which is also carried down into the home (Peens & Louw, 2000). In Western cultures, there is a greater emphasis on individual rights while other cultures place greater value on collective rights, emphasising the rights of all. It might be argued that despite the diversity of African cultures, one feature shared by all of these cultures is that life is organised around the family and the home.

Westernised cultures in general are more aware of and intent on human rights in general (Peens & Louw, 2000). Research done in three Western countries, namely Britain, Sweden and the United States indicated that adults differed in their perception of typical children's rights (Cherney et al., 2008). Western cultures are usually described as individualistic, with an emphasis on individual rights, personal choice and autonomy (Markus & Kitayama, 1991; Triandis, 1989). European cultures (which would include the Western cultures) place a high priority on the nurturance orientation (Cherney & Perry, 1996). Cherney and Perry (1996), furthermore, expressed the opinion that in European culture it might be reasonable to assume that children tend to favour the nurturance orientation over the self-determination orientation. Ruck and Horn (2008) argued that recent studies suggested that children from diverse cultures endorse both nurturance and self-determination rights, rather than preferring one or the other. Cherney et al. (2008) proposed that the degree of parentalism in a specific culture might be a good predictor of adults' perceptions of children's rights. The most common Western philosophical approach to the parent-child relationship has been parentalism (Worsfold, 1974). Worsfold (1974) also noted that in the debate of children's rights, parentalism refers to caregivers' abilities to make decisions for children to protect what caregivers perceive as in the children's best interest. Thus, parentalism suggests that children do have natural rights, but may be too vulnerable or dependent to make decisions about rights themselves. A parentalistic culture would support nurturance rights rather than self-determination rights (Cherney et al., 2008).

2.8 A SOUTH AFRICAN PERSPECTIVE

There is limited published research investigating the perception of children's rights in South Africa. However, a study aimed at determining the degree to which children's awareness of their rights was promoted by the school system was conducted by Venter, Kok, and Myburgh (1996). Results from this study showed that more Afrikaans- than English-speaking participants felt that children had been made more aware of their rights by their final school year. Furthermore Peens and Louw (2000) showed that different perceptions existed between English-, Afrikaans- and Sotho-speaking children about legal rights, autonomy rights, entitlement, choice and abuse rights. Intense social and political transformation in South Africa may

influence people's conceptions of rights (Ruck et al., 2011). Although there are indeed sociocultural differences in terms of reasoning about children's rights, the home is nevertheless one of the first contexts in which children's rights are respected or restricted (Cherney & Shing, 2008; Helwig, 2006).

The two South African studies that investigated typical children's perception of their rights are discussed in Table 1.

Table 1
 South African studies that investigated typical children's perception of their rights

Author/s	Venter, Kok, & Myburgh, (1996)	Peens & Louw (2000)
Aims	These authors conducted a study to determine the degree to which children's awareness of their rights was encouraged by the school system.	In this study the authors focused specifically on children's perceptions of their rights.
Design	A sample of 640 teachers and 713 matriculants of the Witwatersrand (South Africa) were included in the study.	The sample comprised 312 children residing in Bloemfontein (South African). The sample consisted of children between the ages of 6 and 18 years, with equal numbers of Afrikaans, English and Sotho-speaking males and females
Procedures	All respondents were asked to specify to what extent they felt children were informed of certain rights via the school by their final year, for example rights to self-identity, the right to protection against child labour, physical and psychological abuse and the right of every child to attend a state school, be taught in their mother tongue to at least primary education level in a state school and the rights to state-funded medical care.	The Children's Rights Interview (Melton, 1983) and Moral Judgement Interview (Blatt & Kohlberg, 1975) were used to describe the rights and problems to evaluate perceptions of rights and level of moral-ethical development respectively.
Findings	Results showed that more Afrikaans- than English-speaking participants felt that children had been made more aware of their rights by their final year in school. Teachers related to the Christian religion were more supportive of children's rights than those of other religions or non-religious teachers. The matriculants indicated that the school system had made them less aware of their rights than the teachers had indicated. Differences in awareness perceptions of rights to protection against child labour and abuse and to the right to medical care existed between male and female matriculants. Females felt that they had been made more aware of the first right while males felt this about the latter right. Participants who watched the news at least seven times a week felt they had been made more aware of their rights, especially their rights to protection against abuse and the right to a primary education and to be taught in one's mother tongue.	Differences in perceptions existed between male and female, English-, Afrikaans- and Sotho-speaking children. Significant differences are that male and female participants felt differently about certain rights pertaining to freedom of choice and legal rights.

Table 1 summarises two South African studies that investigated children's perception and understanding of their rights. The aim of the two studies was to focus on children's own perception of how they understand their rights. In both the studies typically developing children were interviewed. The participants comprised boys and girls between the ages of six and 18 years from diverse social classes. The results of these studies showed that the way in which children perceived their rights along with the type of rights they felt they should have, was affected by a variety of factors such as level of development, culture, socioeconomic status, age, gender, environment, religious affiliation and contextualisation. Since children are largely governed by adults, the perception of how adults perceived children's rights were also investigated in one study summarised in Table 1 (Kok et al., 1996). Results of the reviewed studies indicated that various factors played a role in the adults' perceptions. Results also indicated that most adults preferred granting children nurturance rights rather than rights to freedom. Although there has been an increase in research and literature on human rights and on children's rights in particular, little research was done (both locally and internationally) on caregivers' perception on the rights of their children with disabilities. Therefore, further investigation of caregivers' perception of the rights of their children with disabilities is required.

This study will differ from those in Table 1 in that the sample in the current study will consist of Afrikaans-speaking primary caregivers of children between the ages of 8;0 and 14;11 (months;years) with intellectual disabilities. Although children's perception of their rights is highlighted in this study, the focus of this study is to investigate how primary caregivers perceive the fact that their children with disabilities have rights and caregivers need to advocate for their children's rights.

2.9 SUMMARY

The role that caregivers play in the lives of the children with disabilities in ensuring that their rights are protected is vital. Children, specifically children with intellectual disabilities, are individuals in their own right and as such should be recognized as having rights. Implementing the UNCRC does not just alter the status of children, but also alters the status of caregivers. Children with intellectual disabilities are entitled to enjoy all human rights. Respecting the rights of children

changes the way society provides for, and protects these children. As much as children's rights have their place, so too do caregivers have rights. Caregivers should continue to insist on a human rights perceptive and demand recourse for violations of the human rights of children with intellectual disabilities. Children's rights need not be at odds with parental authority and responsibility. Caregivers should work towards developing a structure that will ensure that children with disabilities are provided with care and protection. Community and family involvement play a large role to enhance the development of the child with disability and to provide the child with optimal opportunities for an independent life. Therefore, cultural values play a central role in influencing children's perception of their rights. An African proverb claims, "It takes a village to raise a child" (Clinton, 1996).

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

This chapter describes the research methodology that was followed in this the study. It contains a description of the aims, including the main aim and four sub-aims, followed by a discussion of the research design. The pilot study is subsequently presented in terms of aims, procedures, results and recommendations. Thereafter, the main study is discussed. This discussion starts by describing the context, followed by a discussion of the participants in terms of criteria set for participant selection and a description of the selected participants. Next, the development of the measuring instrument and the procedures are explained. This explanation is followed by a discussion of the procedures for data collection and analysis and a discussion of reliability and validity, as they pertain to this study. Finally, a summary is provided.

3.2 AIM OF THE STUDY

3.2.1 MAIN AIM

The main aim of the study is to describe the extent to which Afrikaans-speaking primary caregivers perceive that the human rights of their young children 8;0 to 14;11 with intellectual disabilities are being met by using basic needs as a proxy for rights, as set out by the UNCRC.

3.2.2 SUB-AIMS

Four sub-aims, by which the realisation of the main aim of the study could be attained, were formulated:

- (i) To develop and translate a measuring instrument that will capture the perceptions of primary caregivers of the human rights of children with intellectual disabilities, as set out by the UNCRC;
- (ii) To describe the extent to which participants regard the human rights of their children with intellectual disabilities are met in terms of the ICF-CY codes that measure environmental factors;

- (iii) To describe the extent to which participants regard the human rights of their children with intellectual disabilities are met in terms of selected codes of the UNCRC;
- (iv) To describe the extent to which participants regard the human rights of their children with intellectual disabilities are met in terms of Maslow's five stage Hierarchy of Needs, i.e. biological and physiological needs, safety needs, love and belonging needs, self-esteem needs and finally self-actualization needs.

3.3 RESEARCH DESIGN

A quantitative non-experimental descriptive survey design was used, since it best addresses the aim of the research (McMillan & Schumacher, 2006). Non-experimental research was used, because it involves variables of interests that cannot be manipulated (Johnson, 2001). These variables include attribute variables such as age, gender and other personal characteristics or traits. Data was collected by means of a questionnaire, which is a suitable survey instrument for determining perceptions; furthermore, questionnaires are versatile, since they can be used to investigate almost any problem or question, such as human rights issues. A disadvantage of a survey design is that the return rate of completed questionnaires might be low (Leedy & Ormrod, 2005).

3.4 PILOT STUDY

A pilot study was conducted to identify any potential factors that could have a negative influence on the main study (Brink, 2003). It also served to refine the survey instrument and the methods for data collection.

3.4.1 PARTICIPANTS

Ten Afrikaans-speaking primary caregivers of children with intellectual disabilities were included in the pilot study. The participants were similar to those selected for the main study (see Section 3.5.2); they resided in an area different from, but comparable to the geographical area in the same province in which the main study was conducted. All granted informed consent to participate in the pilot study. The possibility of participants in the pilot study discussing the contents of the test material with participants of the main study was considered. However, this

concern was dismissed, because the participants did not know each other and lived far apart. It was therefore not likely that they would come into contact. All participants were literate, Afrikaans-speaking married mothers of a child with intellectual disabilities between the ages 8;0 and 14;11.

3.4.2 RESULTS AND RECOMMENDATIONS OBTAINED FROM THE PILOT STUDY

The aims, as well as the procedures, results and recommendations from the pilot study are presented in Table 2.

Table 2

Aim, procedures, results and recommendations of the pilot study

Aim	Procedures	Results of the pilot study	Recommendations for the main study
1. To determine whether the survey instrument was user friendly	Children who met the selection criteria were provided with the questionnaires by their teachers to take home for their primary caregivers to complete.	Participants completed all the questions in the survey, except for one participant who wrote <i>uncertain</i> next to Question 36. Question 35 was left unanswered by the same participant. There was no other indication that participants experienced problems in answering the questions.	The questionnaire seemed to be user friendly. Questions that are related to each other were grouped together. No major changes were recommended for the main study, although the different options for the Likert scale questions were highlighted to make the options more visible.
2. To determine whether the questions were clearly formulated and well-understood	Participants were encouraged to contact either the researcher or the class teacher if anything was unclear.	From the answers, it was clear that most participants understood the questions and were at ease when completing the. One participant wrote <i>none</i> next to Question 10, because no provision was made for the option <i>none</i> . Question 10: <i>Please indicate how many other children between the following ages are staying in your house:</i> 1 year and 2 years 3 year and 4 years Older than 5 years	No major changes were recommended, but provision was made for the option <i>none</i> under Question 10 to allow participants to indicate that there were no other children in the house apart from the one included in the study.
3. To determine the relevance of the questions in terms of the research aims	The aims of the study were briefly explained in the letter requesting informed consent that was sent to the participants. Participants had to complete the questionnaire. The researcher as well as an expert panel evaluated the questionnaires to determine whether it addressed the main aim and sub-aims of the current study before the pilot.	The participants completed the questionnaire and all the questions that were asked addressed the main aim and the sub-aims. The fact that an expert panel commented on the content before the pilot study facilitated the process.	The questionnaire seemed to have been effective in answering the research aims. No changes were recommended for the main study.
4. To test for misleading questions	Primary caregivers had to complete the questionnaires to determine if there were any ambiguous and/or misleading questions.	No misleading questions were found, as participants interpreted all questions correctly.	The questions will remain the same for the main study. No changes were recommended.
5. To test the clarity and preciseness of the instructions	Primary caregivers had to read the instructions carefully to answer them with precision.	Instructions on the questionnaire were clear. The participants answered the questions carefully, since the one open-ended question that was added to avoid generalization was	Instructions were not altered and no changes for the main study were recommended.

Aim	Procedures	Results of the pilot study	Recommendations for the main study
		<p>interpreted correctly. None of the participants answered “yes” to Question 30—the acquiescence question. Question 30: <i>Does your child like it when people get angry at him/her?</i></p>	
6. To evaluate the comprehensibility of the terminology used in the survey instrument	Primary caregivers completed the questionnaires at home.	Participants completed the questionnaire without any difficulties in understanding the terminology. This statement was confirmed by the correct way in which the questions were interpreted and answered by the participants.	No need to rephrase or change the terminology in the questionnaire.
7. To determine the feasibility of the proposed data collection procedure	The classroom teacher gave the letters requesting informed consent and the questionnaires to 10 children whose primary caregivers met the selection criteria. Children were asked to take the survey home and ask their primary caregivers to complete and return it.	The classroom teacher received six questionnaires back from the participants within two weeks. Five participants returned the consent forms and completed questionnaires. One participant returned the questionnaire, but preferred not to participate in the study. The class teacher had to write a reminder note to the participants. The researcher collected the surveys from the teacher. A response rate of 60% was achieved. This average to high response rate could be ascribed to the small sample and the fact that the researcher was able to follow up on questionnaires by keeping close contact with the participating school. Babbie (2004) stated that return rates of 60% are good.	To achieve a higher response rate, an incentive should be given to each child who returns the survey instrument. Both children whose primary caregivers grant consent and those whose do not will receive the same incentive (small packet of sweets). A reminder note will be sent out by the classroom teacher. More questionnaires will be handed out if a low response rate is noted.
8. To test the adequacy of coding and the intended analysis of the data	All data was coded and entered onto a Microsoft Excel spreadsheet. Results were coded and basic descriptive statistical procedures were performed, e.g. frequency distributions and standard deviation.	Participants could not answer Question 1 with a cross (x), because the option for “Yes” or “No” was not given. The numerical order of the questions was incorrect.	Provision was made for a “Yes” and “No” option for Question 1. The numerical order of the questionnaire was corrected.

3.4.3 CONCLUSION OF THE PILOT STUDY

After the completion of the pilot study, the recommendations were implemented to refine the survey instrument and the methods for data collection. These changes increased the reliability of the data and contributed positively to the quality of the main study.

3.5 MAIN STUDY

3.5.1 CONTEXT

In the main study, primary caregivers of children with intellectual disabilities, from a school for children with special needs participated in the study. The school is a government school for learners with intellectual disability in the Tshwane South District, Gauteng province. The school caters mainly for children with severe intellectual disabilities from junior phase up to senior phase. Currently, the school has over 460 learners of whom 120 stay in a hostel. There is an average of 15 learners per classroom. In each of the phases, two assistants work in the classrooms once a week. This part of the Tshwane Metropolitan is characterized by middle- to low- income households (Statistics South Africa, 2011). The researcher contacted the principal of the targeted school to obtain permission to conduct the study at the school and to identify potential participants. This was done with assistance from staff members of the school. The principal of the participating school signed a letter granting permission.

3.5.2 PARTICIPANTS

The participant selection criteria are stated first, followed by a description of the participants. Results obtained from the biographical section of the survey instrument were used to describe the participants according to the selection criteria.

3.5.2.1 Criteria for the selection of participants

Table 3 outlines the four criteria that were used for the process of participant selection. It also provides a justification for the criteria as well as the measures that were used to determine the criteria. The presence of the intellectual disability was mentioned in the school records of the children, as all attended a government school for learners with intellectual disability.

Table 3

Criteria for the selection of participants

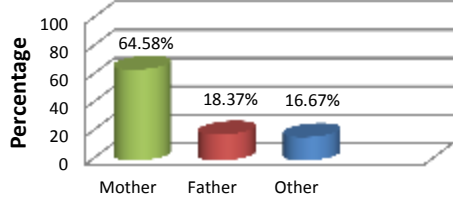
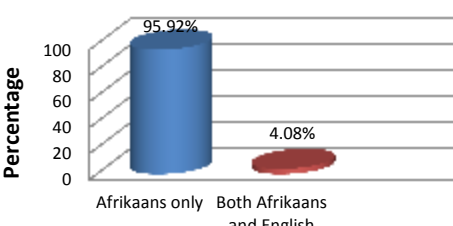
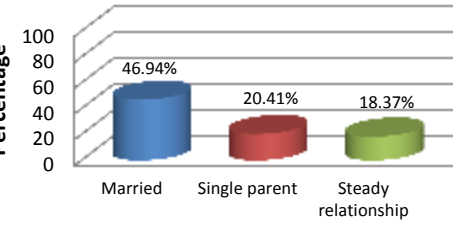
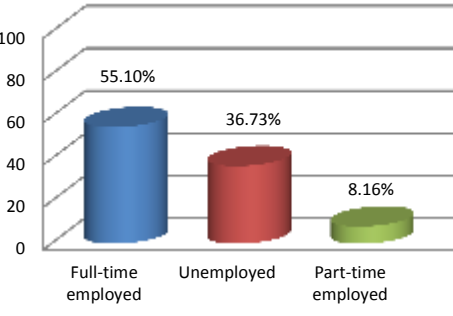
NO	CRITERIA	JUSTIFICATION	MEASURE
1	Afrikaans as home language	The participants' home language had to be Afrikaans. Different language groups could influence the overall results of the study, possibly caused by cultural and social differences. Afrikaans is one of the predominant languages in the South African urban context (Hirson, 1981; Gonzales & Yawkey, 1994).	Please see Appendix C1, Question 3: <i>In watter taal voed u u kinders op?</i> In which language do you raise your child?
2	Literate	All participants had to be literate to enable them to independently understand and read questions, since the survey instrument was sent home to be completed.	Please see Appendix C1, Question 7: <i>Wat is die hoogste opvoedkundige kwalifikasie wat u voltooi het?</i> What is the highest educational qualification that you completed?
3	Must be a primary caregiver of a child with intellectual disability between the ages of 8;0 to 14;11	Primary caregivers had to be mothers/fathers/grandparents/guardians of children with intellectual disability who served as parental figures for these children and were responsible for the day-to-day care and maintenance of these children, because this group was expected to have homogeneous experiences.	Please see Appendix C1, Question 2: <i>Wat is u verwantskap met die gestremde kind?</i> What is your relationship with the child with disability? Question 12: <i>Hoe oud is u gestremde kind?</i> How old is your child with a disability?
4	Primary caregiver must be willing to participate in the research	Participants had to provide all the information requested in the questionnaire, some of a personal nature.	Participants must sign a letter of informed consent indicating their willingness to participate.

3.5.2.2 Description of participants

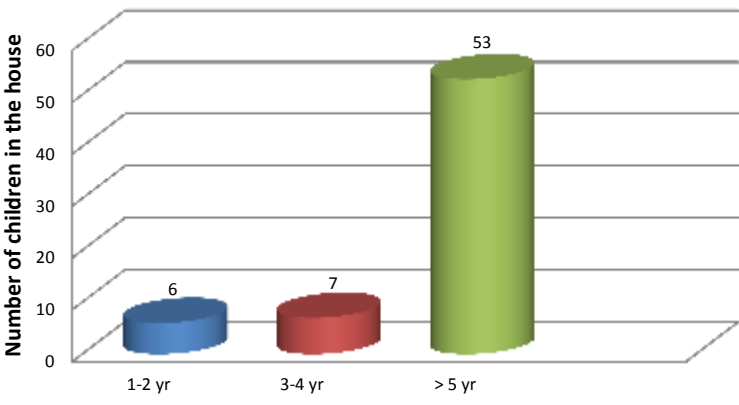
Forty-nine primary caregivers of children with intellectual disabilities met the selection criteria described above, and provided informed consent to participate in the study. Only one primary caregiver per child participated in the study. Participants are described according to nine different variables as described in Table 4.

Table 4

Description of Participants (N = 49)

DESCRIPTION	RESULTS										
<p>Mostly mothers completed the questionnaires (64.58%), followed by fathers (18.37%) and others (16.67%). The category <i>Other</i> comprised housemothers, guardians and foster-care parents. One participant did not answer the question.</p>	<p>Relation to the child (1 = missing data)</p>  <table border="1"> <thead> <tr> <th>Relation to the child</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Mother</td> <td>64.58%</td> </tr> <tr> <td>Father</td> <td>18.37%</td> </tr> <tr> <td>Other</td> <td>16.67%</td> </tr> </tbody> </table>	Relation to the child	Percentage	Mother	64.58%	Father	18.37%	Other	16.67%		
Relation to the child	Percentage										
Mother	64.58%										
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<p>As expected, Afrikaans is the most common language spoken at home, in line with the selection criteria (95.92%). However, 4.08% of the families speak both Afrikaans and English at home.</p>	<p>Languages spoken at home</p>  <table border="1"> <thead> <tr> <th>Languages spoken at home</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Afrikaans only</td> <td>95.92%</td> </tr> <tr> <td>Both Afrikaans and English</td> <td>4.08%</td> </tr> </tbody> </table>	Languages spoken at home	Percentage	Afrikaans only	95.92%	Both Afrikaans and English	4.08%				
Languages spoken at home	Percentage										
Afrikaans only	95.92%										
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<p>The majority of the participants were married (46.94%). This was followed by single parents (20.41%), those in a steady relationship (18.37%) and 14.29% indicated <i>Other</i> without any specification. This could possibly include widows, stepmothers or stepfathers.</p>	<p>Current relationship status</p>  <table border="1"> <thead> <tr> <th>Current relationship status</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Married</td> <td>46.94%</td> </tr> <tr> <td>Single parent</td> <td>20.41%</td> </tr> <tr> <td>Steady relationship</td> <td>18.37%</td> </tr> <tr> <td>Other</td> <td>14.29%</td> </tr> </tbody> </table>	Current relationship status	Percentage	Married	46.94%	Single parent	20.41%	Steady relationship	18.37%	Other	14.29%
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Married	46.94%										
Single parent	20.41%										
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Other	14.29%										
<p>By far the largest group of parents were full time employed (55.10%), followed by 36.73% who were unemployed. Because the questionnaires were mostly completed by mothers, the high incidence of unemployment (36.73%) could reflect stay-at-home mothers. Only 8.16% of the participants indicated that they had a part time job.</p>	<p>Current employment status</p>  <table border="1"> <thead> <tr> <th>Current employment status</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Full-time employed</td> <td>55.10%</td> </tr> <tr> <td>Unemployed</td> <td>36.73%</td> </tr> <tr> <td>Part-time employed</td> <td>8.16%</td> </tr> </tbody> </table>	Current employment status	Percentage	Full-time employed	55.10%	Unemployed	36.73%	Part-time employed	8.16%		
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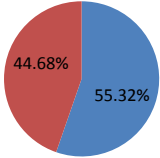
DESCRIPTION	RESULTS														
<p>The ages of the participants ranged between 21 and 51+ years. The majority (54.17%) were between 31 and 40 years of age, followed by 25% between 41 and 50 years. Given the ages of the children (8;0-14;11), the high number of 50 year- olds was unexpected (14.58%), but this refers to the housemothers (accepted as <i>Others</i> in relationship). The young parents (21 to 30 years) were also unexpected (10.20%).</p>	<p style="text-align: center;">Current ages of participants (1 = missing data)</p> <table border="1"> <caption>Current ages of participants</caption> <thead> <tr> <th>Age Group</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>21-30 yr</td> <td>10.20%</td> </tr> <tr> <td>31-40 yr</td> <td>54.17%</td> </tr> <tr> <td>41-50 yr</td> <td>25%</td> </tr> <tr> <td>50+ yr</td> <td>14.58%</td> </tr> </tbody> </table>	Age Group	Percentage	21-30 yr	10.20%	31-40 yr	54.17%	41-50 yr	25%	50+ yr	14.58%				
Age Group	Percentage														
21-30 yr	10.20%														
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<p>The majority of participants (53.06%) had a grade 10 or less qualification, and 22.45% had passed grade 12. This was followed by 10.20% of the participants who had obtained a 1 to 4 year qualification after school and 10.20% a 8 to 10 year qualification after school. Of the participants, 4.08% marked the category <i>Other</i>. Although participants were requested to specify, no one did, so this cannot be interpreted with any degree of certainty. One participant did not answer the question. None of the participants had obtained a 5 to 7 year qualification after school.</p>	<p style="text-align: center;">Level of Education (1= missing data)</p> <table border="1"> <caption>Level of Education</caption> <thead> <tr> <th>Level of Education</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Grade 10 or less</td> <td>53.06%</td> </tr> <tr> <td>Grade 12</td> <td>22.45%</td> </tr> <tr> <td>1-4 years after school</td> <td>10.20%</td> </tr> <tr> <td>5-7 years after school</td> <td>0%</td> </tr> <tr> <td>8-10 years after school</td> <td>10.20%</td> </tr> <tr> <td>Other qualifications</td> <td>4.08%</td> </tr> </tbody> </table>	Level of Education	Percentage	Grade 10 or less	53.06%	Grade 12	22.45%	1-4 years after school	10.20%	5-7 years after school	0%	8-10 years after school	10.20%	Other qualifications	4.08%
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5-7 years after school	0%														
8-10 years after school	10.20%														
Other qualifications	4.08%														
<p>Regarding the total household income per annum, the majority (57.78%) of the participants earned less than R60 000 per annum. The cut-off point of R60 000 per annum was selected because families earning less than this amount are exempt from paying personal income tax. They are therefore classified as being low-income earners (SA Income Tax Act no 58 of 1962, 4th schedule par 28(c) and read with Article 6 (2)(9).</p>	<p style="text-align: center;">Total annual household income</p> <table border="1"> <caption>Total annual household income</caption> <thead> <tr> <th>Income Category</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>R60 000 and less</td> <td>57.78%</td> </tr> <tr> <td>R60 000 and more</td> <td>42.22%</td> </tr> </tbody> </table>	Income Category	Percentage	R60 000 and less	57.78%	R60 000 and more	42.22%								
Income Category	Percentage														
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<p>People living together in a household ranged between two and 66 persons. Two of the participants were house mothers at an orphanage, hence the numbers 66 and 13. If these outliers are ignored, results showed that in two households there were two people and another two households there were eight people. In six of the households there were seven people and in another six households there were six people per household. Six participants indicated that five people were living in the house, followed by 12 households with four people each. Results showed furthermore that in 11 households were three people per household. One participant did not answer the question.</p>	<p style="text-align: center;">Number of people living in a house</p> <table border="1"> <caption>Number of people living in a house</caption> <thead> <tr> <th>Number of households</th> <th>Number of people</th> </tr> </thead> <tbody> <tr> <td>2</td> <td>2</td> </tr> <tr> <td>6</td> <td>5</td> </tr> <tr> <td>11</td> <td>3</td> </tr> <tr> <td>12</td> <td>4</td> </tr> </tbody> </table>	Number of households	Number of people	2	2	6	5	11	3	12	4				
Number of households	Number of people														
2	2														
6	5														
11	3														
12	4														

DESCRIPTION	RESULTS								
<p>One participant indicated 60 children older than 5 years living in one household (orphanage hostel) and one participant had 12 children living in the household (orphanage house unit). If these outliers are ignored, results showed that one participant had six children and five participants had three children each, older than 5 years, in one household. Eight participants had two children each and 16 participants had one child living in each household older than 5 years. Four participants each had one child aged 3 to 4 years and one participant had three children aged 3 to 4 years. Six participants had one child between the ages of 1 to 2 years living in the household.</p>	<p style="text-align: center;">Age groups of children in the house</p>  <table border="1" style="margin-left: auto; margin-right: auto;"> <caption>Age groups of children in the house</caption> <thead> <tr> <th>Age Group</th> <th>Number of children</th> </tr> </thead> <tbody> <tr> <td>1-2 yr</td> <td>6</td> </tr> <tr> <td>3-4 yr</td> <td>7</td> </tr> <tr> <td>> 5 yr</td> <td>53</td> </tr> </tbody> </table>	Age Group	Number of children	1-2 yr	6	3-4 yr	7	> 5 yr	53
Age Group	Number of children								
1-2 yr	6								
3-4 yr	7								
> 5 yr	53								

From Table 4, it is clear that the majority of participants were older, married mothers who only had a Grade 10 or a lower qualification. Either they or their spouses were in full time employment in half of the cases, earning less than R60,000 per annum—an indication that they were part of the low to middle socio-economic group. Results show an almost equal split between families earning less than R60,000 and more than R60,000 per annum. From Table 4 it is also clear that (only when the outliers are ignored) the average number of people living in a house was 6. According to Table 4 the average age of children, calculated for the children in the orphanage and house unit, was 5 years and older. Descriptive information about the participants’ children with ID is presented in Table 5.

Table 5

Descriptive information about the participants’ children with intellectual disabilities

DESCRIPTION	RESULTS						
<p>The majority of the children were boys (55,32%). In a study done by Einfeld et al., (2006), they found that more boys were affected by intellectual disability than girls.</p>	<p style="text-align: center;">Gender of the child (2 = missing data)</p>  <table border="1" style="margin-left: auto; margin-right: auto;"> <caption>Gender of the child (2 = missing data)</caption> <thead> <tr> <th>Gender</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Male</td> <td>55.32%</td> </tr> <tr> <td>Female</td> <td>44.68%</td> </tr> </tbody> </table>	Gender	Percentage	Male	55.32%	Female	44.68%
Gender	Percentage						
Male	55.32%						
Female	44.68%						

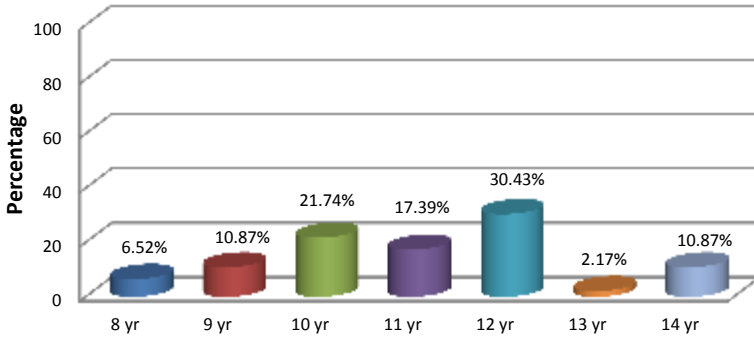
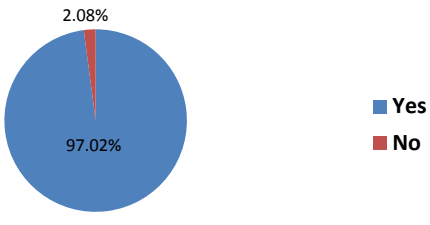
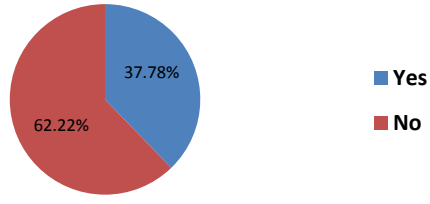
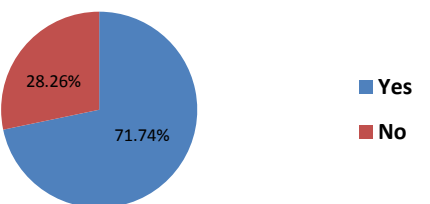
DESCRIPTION	RESULTS																
<p>Most (30.43%) of the children were between the ages of 12;0 and 12;11, 21.74% between 10;0 and 10;11, 17.39% between 11;0 and 11;11 years, 10.87% were between 14;0 and 14;11 and the same percentage between 9;0 and 9;11 and 6.52% of the children were between 8;0 and 8;11 old. The age group with the least children (2.17%) was 13;0-13;11. In summary, children were split relatively evenly around the median (11;0 and 11;11) with 39.13% being between 8 to 10 years and 43.47% between 12 to 14 years.</p>	<p style="text-align: center;">Ages</p>  <table border="1"> <caption>Ages</caption> <thead> <tr> <th>Age</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>8 yr</td> <td>6.52%</td> </tr> <tr> <td>9 yr</td> <td>10.87%</td> </tr> <tr> <td>10 yr</td> <td>21.74%</td> </tr> <tr> <td>11 yr</td> <td>17.39%</td> </tr> <tr> <td>12 yr</td> <td>30.43%</td> </tr> <tr> <td>13 yr</td> <td>2.17%</td> </tr> <tr> <td>14 yr</td> <td>10.87%</td> </tr> </tbody> </table>	Age	Percentage	8 yr	6.52%	9 yr	10.87%	10 yr	21.74%	11 yr	17.39%	12 yr	30.43%	13 yr	2.17%	14 yr	10.87%
Age	Percentage																
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13 yr	2.17%																
14 yr	10.87%																
<p>Most of the children (97.02%) had a birth certificate, with only 2.08% not having a birth certificate. One participant did not answer the question.</p>	<p style="text-align: center;">Birth certificate (1= missing data)</p>  <table border="1"> <caption>Birth certificate</caption> <thead> <tr> <th>Response</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Yes</td> <td>97.02%</td> </tr> <tr> <td>No</td> <td>2.08%</td> </tr> </tbody> </table>	Response	Percentage	Yes	97.02%	No	2.08%										
Response	Percentage																
Yes	97.02%																
No	2.08%																
<p>The majority of participants indicated that their child was not born with a disability (62.22%), while 37.78% indicated that the disability had been present from birth, indicating a congenital condition. Four participants did not answer the question.</p>	<p style="text-align: center;">Born with disability</p>  <table border="1"> <caption>Born with disability</caption> <thead> <tr> <th>Response</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Yes</td> <td>37.78%</td> </tr> <tr> <td>No</td> <td>62.22%</td> </tr> </tbody> </table>	Response	Percentage	Yes	37.78%	No	62.22%										
Response	Percentage																
Yes	37.78%																
No	62.22%																
<p>More than two thirds of the participants (71.74%) indicated that their child had access to medical services, while 28.26% of the children did not have access to medical services. Given the fact that free primary health care is available, this is surprising (Goudge, Gilson, Russell, Gumede, & Mills, 2009).</p>	<p style="text-align: center;">Medical services</p>  <table border="1"> <caption>Medical services</caption> <thead> <tr> <th>Response</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Yes</td> <td>71.74%</td> </tr> <tr> <td>No</td> <td>28.26%</td> </tr> </tbody> </table>	Response	Percentage	Yes	71.74%	No	28.26%										
Response	Percentage																
Yes	71.74%																
No	28.26%																

Table 5 shows that the majority of the participants' children were boys (55.32%) and that the age category with the most children (30.43%) was the 12;0 to 12;11 age group. The smallest number of children (2.17%) was 13 years old. The majority (97.02%) of the children had a birth certificate. Table 5 also shows that more than

half (62.22%) of the participant's children were not born with a disability. Primary caregivers indicated that 71.74% of their children had access to medical services.

3.6 DEVELOPMENT OF THE SURVEY INSTRUMENT

The survey instrument was developed in order to answer the research question. It is based on biographical information about the primary caregivers' information about their children, which was obtained through the Ten Questions Questionnaire (TQQ) (Durkin, 2001) and through questions related to the needs and rights of children with disabilities, as set out by the UNCRC.

3.6.1 BIOGRAPHICAL INFORMATION

Biographical information about the primary caregiver, the family structure and the child with intellectual disability was included in the first part of the questionnaire. Descriptive information also included the caregiver's relation to the child, home language, current relationship status, current employment status, age, highest level of education completed, annual household income, number of persons living in the same house and number of children in a specific age group living in the same household. Participants also provided information pertaining to the age, gender, birth certificate, medical services and origin of disability of their child with intellectual disabilities.

3.6.2 THE TEN QUESTION QUESTIONNAIRE (DURKIN, 2001)

The TQQ is a standardized descriptive questionnaire that collects information about the nature of the children's disabilities (Durkin, 2001) and was developed as a rapid, low-cost screening method to assist in the identification of children aged 2-9 years with serious disabilities in diverse cultures where professional resources were extremely scarce (Durkin, Hasan & Hasan, 1995). Although not standardized for older children, the TQQ can be used. Studies have been reported in many countries, among others Jamaica, Pakistan, Saudi Arabia and Bangladesh (Mung'ala-Odera, Meehan, Njuguna, Mturi, Alcock, Carter, & Newton, 2004). The TQQ was translated from English into Bangla for use in Bangladesh and into Urdu for use in Pakistan, including back-translations, pre-testing of the forms and revising them before arriving at the final versions (Mung'ala-Odera et.al, 2004). These translations did not affect its reliability. In the current study, the TQQ was translated blind-back from English to Afrikaans as part of the translation of the complete questionnaire and pilot tested as discussed in Table 2.

3.6.3 QUESTIONS RELATED TO THE NEEDS AND RIGHTS OF CHILDREN WITH INTELLECTUAL DISABILITY

The questionnaire items suggested by Simeonsson and Granlund (2011), based on the UNCRC, were adapted and refined to obtain specific information from the primary caregivers of children with intellectual disabilities. To ensure face validity, the proposed questions were given to several panels of experts. De Jong and Schellens (1995) suggested an informal, minimally structured approach to an expert panel review. The following procedure was followed:

- The researcher provided the experts with sufficient background information, particularly regarding the aims of the study and the description of the participants who were targeted for the study.
- The proposed questions were given to a panel of experts consisting of four professionals (three speech therapists and a psychologist) to read, refine and develop the questions in such a way that they correlate with the ICF-CY codes that measure environmental factors, Maslow's Hierarchy of Needs and selected articles from the UNCRC.
- A different expert panel consisting of 25 PhD and master's students who studied in the field of disability, independently considered the questions suggested by the first expert panel. The second expert panel grouped the different items together and linked them to Maslow's Hierarchy of Needs.
- Meetings were scheduled with the appointed experts to discuss their recommendations.

Originally, Simeonsson and Granlund (2011) suggested 14 Likert scale questions. After the experts developed, refined and ranked the original questions to correlate with the ICF-CY codes, Maslow's Hierarchy and selected articles from the UNRCR, 13 Likert scale questions were proposed. Seven of these questions focussed specifically on human rights related aspects (Questions 26, 27, 28, 29, 31, 32, and 33), while six questions were focussed on the availability of assistive technology (Questions 17a, 18a, 19a, 20a, 21a, and 22a), which also form part of human rights. The experts recommended that the question, *Does your child have water to drink at home?*, be changed to, *Does your child have clean water to drink at home?* The experts also recommended that the question, *Does your child have a place to sleep at home?*, be changed to *Does your child has his/her own bed to sleep in at home?* The experts also recommended that one Likert scale acquiescence question should

be added to determine whether participants considered each option or merely marked their choices in a specific pattern. Hence a question was added, i.e. *Does your child like it when people get angry at him/her?* Two questions were developed to determine what primary caregivers' beliefs about the rights of their children with intellectual disabilities were. The first question was a Yes/No question namely, *Are you of the opinion that your child has rights?*, with a follow-up open-ended question, *If you answered 'Yes' to Question 34, please list in order of importance the child's rights that you can think of.*

The 13 developed questions in this section of the survey instrument were rated on a 4-point Likert type scale, allowing the participants to indicate agreement or disagreement with the statement (McMillan & Schumacher, 2006). There were two positive options, namely *Always* and *Sometimes*, and two negative options, *Seldom* and *Never* for each statement. Designing a Likert scale with balanced keying (an equal number of positive and negative statements) will prevent the problem of participant biases, since agreement on positively keyed statements will balance agreement on negatively keyed statements (Babbie, 2005).

3.6.4 SURVEY INSTRUMENT

Table 6 presents a breakdown of the survey instrument design. It provides an explanation of the criteria, the number and type of questions included to obtain the needed information as well as the justification for questions included in the survey instrument (see Appendix C).

Table 6

Survey instrument

Criteria	Type of questions	Question number	Topic	Justification
Background information of the participants	Nine close-ended Questions	1	One question related to the type of primary caregiver was included. Since many different types of primary caregivers are possible, the broad category "other" was included, with an instruction to please specify.	According to Article 5 (UNCRC, 2006), the responsibility vested in primary caregivers is linked to the requirement that they act in their children's best interest and that this relationship offer children physical and emotional security, as well as consistent care and attention. Primary caregivers are typically the channel through which young children are able to realize their rights.

Criteria	Type of questions	Question number	Topic	Justification
	One open-ended question	2,3,4,5,6,7, 8,10 9	Eight questions relating to the relation to the child, home language, current relationship status, current employment status, age, highest level of education completed, annual household income, number of persons living in the same house and number of other children living in the same house were included. One question related to the number of people living in the household was included. It was felt that an open-ended question was more relevant than a close-ended question to determine the family size of the household.	Three documented studies done by Bohrnstedt et al., (1981), Rogers and Wrightsman (1978) and Yankelovich and White (1977) found that certain biographical variables could influence adults' perceptions regarding children's rights. Bohrnstedt, et al., (1981) also noted that certain biographical factors made a difference in the type of responses given by parents. The size of the family influences its socioeconomic status (SES). Families of low SES and larger families may have fewer resources to meet all the caretaking and medical needs of the child with disability (Hannah & Midlarsky, 1999).
Background information from the participants about their child with a disability	Fifteen close-ended questions	11,12,13, 14,15,16, 17,18,19, 20,21,22, 23,24,25	Five questions dealing with the age, gender, birth certificate, medical services, and origin of disability of the child and ten disability specific questions from the TQQ (Durkin, 2001).	Research indicated that factors such as age and gender could play an important role in children's correct reasoning (Peens & Louw, 2000). The TQQ (Durkin, 2001) is a standardized screening questionnaire for obtaining information about the nature of the child's disability.
Information on the rights of the participant's child with disability	Thirteen Likert-type questions	17a,18a, 19a, 20a, 21a ,22a, 26,27,28, 29,31,32, 33	Thirteen questions based on the questions developed by Simeonsson and Granlund (2011) were presented on a 4-point Likert scale. There were two positive options i.e. 1= <i>Always</i> and 2= <i>Sometimes</i> , and two negative options, i.e. 3= <i>Seldom</i> and 4= <i>Never</i> . A Likert scale with an equal number of positive and negative statements will prevent the problem of participant bias, since agreement on positively keyed statements will balance agreement on negatively keyed statements. Six questions (17a, 18a, 19a, 20a, 21a, and 22a) dealt with the availability of assistive technology, while seven other focussed on other types of human rights.	The questions were developed and refined to correlate with the ICF-CY codes that measure environmental factors, Maslow's five level Hierarchy of Needs, as well as selected articles from the UNCRC. The UNCRC defines the rights of children whereas the ICF-CY provides the framework for documenting the deprivation of rights and the conditions under which those rights can be realized (Simeonsson, 2009). According to Woodhouse (2006), caregivers of children with intellectual disabilities need to know what their children's rights are. Therefore, it is up to the parents to provide appropriate direction and guidance in the exercise by the child of the rights recognized in the UNCRC.
Acquiescence	One Likert-type questions	30	One question on acquiescence was added, namely: <i>Does your child like it when people get angry at him/her?</i> .	To determine whether the participants considered each option or merely marked their choices in a specific pattern.
Information on perceptions of the participants regarding their child with a disability	One close-ended question and one ordinal question	34, 35	One question probed participants' perception about the rights of their children with disabilities, namely: <i>Are you of the opinion that your child has rights?</i> One question asked participants to rank order their answers to the question, from most to least important. Participants were requested to list the rights in order of importance that they could think of. Six spaces were provided.	To determine if primary caregivers perceive that their children with intellectual disabilities have rights. Studies reviewed showed that generally adults felt more comfortable affording children nurturance and protections rights rather than rights to freedom and choice (Peens & Louw, 2000). By asking participants to rank order their perceptions, it can be observed if a similar response would be seen.

3.6.5 TRANSLATION OF THE MEASURING INSTRUMENT

Every culture has unique values, organizational systems and environments; therefore, cultural sensitivity, deep understanding and respect for other cultures are required for valid translation (Beauford, Nagashima, & Wu, 2009). An adapted or translated questionnaire does not ensure that the resulting questionnaire measures the exact same constructs as the original one, because of the cultural and lingual differences (Lin, Chen, & Chiu, 2005). Therefore, researchers who attempt to adapt or translate questionnaires from the source language into a different target language should be aware of such potential problems (Lin, Chen, & Chiu, 2005). Pena (2007) points out that the linguistic equivalence of the questions and instructions must be demonstrated by translating them by using methods such as blind-back translation or expert review. Translation strives to achieve conceptual equivalence (Schmieding & Kokuyama, 1995; Mason, 2005). Conceptual equivalence implies that an item may be translated into different words, but the original meaning or conceptual framework remains intact (Mason, 2005). In the present study the survey instrument was translated from English (the source language) to Afrikaans (the target language), using a blind-back translation procedure, based on Brislin's (1980) suggested translation methods. The translation procedure is discussed in more detail in Table 8. Two translators were identified for the blind-back procedure who were familiar with both the source and the target language. Translators must be familiar with the target language and culture to avoid translation errors and minimize problems (Hambleton & Kanjee, 1993). The translators are described in Table 7.

Table 7

Description of translators

Translator's attributes	Translator 1	Translator 2
Qualification	BA Languages Specialization in Afrikaans	BA Languages Higher Diploma in Education- specialization in English
Occupation	Administrator and translator	English teacher for 10 years
First language Second language	English Afrikaans	Afrikaans English
Experience in translation	Frequently for work-related purposes for two years	Frequently for work-related purposes for eleven years

From Table 7 it is clear that the translators were skilled to perform this activity and that they had the necessary translations experience. The translation process they followed is described in Table 8.

Table 8

Description of the translation procedure

STEP 1: First translation into Afrikaans		
<p>Translators involved The researcher and Translator 1 were involved.</p>	<p>Procedure The measuring instrument was independently translated from the source language (English) into the target language (Afrikaans) by both the researcher and Translator 1. They compared the two Afrikaans translations.</p>	<p>Results Minor differences were found between the two Afrikaans translations. The following adjustments were made and a provisional Afrikaans version of the questionnaire was accepted. Question 17: Source question <i>If yes, does your child have something like glasses at home to help him/her see?</i> Translation (Target language) <i>“Indien ja, het u kind by die huis iets soos ‘n bril om hom/haar beter te laat sien?”</i> According to the Bilingual Dictionary (Bosman, Van der Merwe, & Hiemstra, 1984), “beter” means <i>better</i> and not <i>help</i>. The researcher and Translator 1 agreed that the Afrikaans word “help” should replace the Afrikaans word “beter”. Question 23: Source question <i>Does your child learn to do things like other children his/her age?</i> Translation (Target language) <i>“Leer u kind om dinge soos ander kinders van sy/haar ouderdom te doen?”</i> The researcher and Translator 1 agreed that the word “dinge” should be replaced with a more descriptive word and the Afrikaans word “vaardighede” replaced the Afrikaans word “dinge”. The word ‘fit has different correct Afrikaans translations (e.g. “stuipe, konvulsies, epileptiese aanvalle”). The researcher and Translator 1 decided to use the Afrikaans words “epileptiese aanvalle”, because it is the term commonly used in the field to describe this medical condition.</p>
<p>STEP 2: First consensus. The researcher and Translator 1 reached consensus on the Afrikaans translation</p>		
STEP 3: Blind-back translation		
<p>Translators involved Translator 2 was involved</p>	<p>Procedure Translator 2 who had not seen the questionnaire in the source language performed a blind-back translation from the target to the source language.</p>	<p>Results No major challenges and differences were encountered with the blind-back translation of the questionnaire into English. It was found that the Afrikaans word “aanvalle” had more than one English translation (e.g. <i>fit, convulsion, seizure</i>). It was decided that the word “fit” is commonly used and therefore may be kept.</p>
STEP 4: Review by translators		
<p>Translators involved The researcher and Translators 1 and 2</p>	<p>Procedure The researcher and Translators 1 and 2 compared the blind-back English translation to the original English questionnaire to determine if there were questions and response options in the Afrikaans version that differed in meaning from the original source.</p>	<p>Results After comparing the blind-back English translation with the original English source, no differences were found. The researcher was satisfied that the translation was valid and no further modifications were made</p>
<p>STEP 5: Final consensus. The final version of the Afrikaans (target language) questionnaire was accepted, and was edited for spelling and grammatical errors (see Appendix C1).</p>		
<p>STEP 6: Pilot study. A pilot study was conducted to test the acceptability, validity, and reliability of the translated measuring instrument.</p>		

3.7 DATA COLLECTION PROCEDURES

The procedures that were followed during this are provided in Table 9 below.

Table 9

Procedural steps

Steps	Description of procedure
Step 1	Permission was obtained from the Gauteng Department of Education (see Appendix D).
Step 2	The necessary documentation was compiled and submitted to the Ethical Committee of the Faculty of Humanities at the University of Pretoria. Ethical clearance was obtained from this body (see Appendix E).
Step 3	The pilot study, following the same steps suggested for the main study was conducted.
Step 4	The principal of the school was contacted to request that the study might be conducted at the school. A written description of the nature and importance of the research was provided (see Appendix F) and he signed the informed consent letter, thereby granting permission (see Appendix G).
Step 5	The principal introduced the researcher to the teachers who taught children in the specified age range. The teachers identified possible participants' children.
Step 6	The survey instrument were compiled and copied. Each survey instrument was coded with a unique respondent code to ensure confidentiality.
Step 7	Possible dates were discussed as to when the survey instrument and letters requesting consent by the participants would be hand-delivered at the school and sent home; these letters stated the purpose of the research and requested primary caregivers to consent to participate in the study (see Appendix H).
Step 8	The survey instrument and letters requesting consent were sent to all possible participants via their children. They had to complete the survey instrument and a letter of informed consent and return it to the classroom teacher. Primary caregivers were asked to complete the survey instrument in their own time and return it with the informed consent letter to the classroom teacher a week later.
Step 9	The classroom teacher wrote a letter in the child's homework book to ensure that the primary caregivers acknowledged the receipt of the questionnaire.
Step 10	The researcher asked the classroom teacher to send a reminder to all participants via their children to return the completed survey instrument and letter requesting informed consent in a week's time. As motivation, all children who returned a survey instrument received a small packet of sweets, irrespectively of whether they consented to participate or not.
Step 11	The researcher collected all the completed survey instruments (3 weeks after distribution) from the classroom teacher. The questionnaires were immediately checked by the researcher to ensure that all data were present. Incomplete answers were captured as missing data.
Step 12	The participants and the school who participated in the research were thanked for their co-operation.

3.8 ANALYSIS OF DATA

All data were coded on the questionnaires in the pre-designed column marked *For official use*. In order to meet the aim of the present study, data obtained through the questionnaires was analysed with the assistance of a statistician from the Department of Statistics at the University of Pretoria and is presented in the form of descriptive statistics. Data were summarized by using simple descriptive statistics and graphs. Primary caregivers' perception of positively worded statements were tallied from 4 "*Altyd*" (meaning *always*) to 1 "*Nooit*" (meaning *never*). Negatively

worded statements were tallied from 1 “*Nooit*” to 4 “*Altyd*”. The total number of words within each column was calculated and presented in the form of figures. This means that a high score represented a positive perception and a low score a negative perception. The data obtained from the questionnaires was coded according to the categories presented in the questionnaires into a Microsoft Excel data file. A spreadsheet for each participant was created, with columns for all categories, as described earlier. To determine how participants answered individual questions, frequency counts were used. To interpret the data, all scores were listed from high to low creating a rank-order distribution (McMillan & Schumacher, 2006). In this study the rank-order distribution was transformed to a frequency distribution by indicating the number of times each score was attained. Along with the frequency of scores, results were summarized by percentage of responses for each score (McMillan & Schumacher, 2006).

For the open-ended question, a registered physiotherapist with long-term experience of working with children and youth with disabilities and with a PhD in Disability Research, independently considered the participants’ responses to the open-ended question. This expert grouped the different items together and linked them to the ICF-CY codes. An expert with a postgraduate degree in Augmentative and Alternative Communication (AAC) and 20 years of experience in the field of disability, independently looked at the participants’ responses to the open-ended question. This expert also grouped the different items together and linked them to Maslow’s Hierarchy of Needs and selected articles from the UNCRRC.

3.9 VALIDITY AND RELIABILITY

Two basic principles of measurement that are common for all methods are validity and reliability (McMillan & Schumacher, 2006).

3.9.1 VALIDITY

Face validity of the survey instrument was obtained through input from the expert panel, and selected experts in the field. Face validity and the understanding of the instructions were addressed during the pilot study. For this study, blind-back translation (English to Afrikaans and Afrikaans to English) of the questionnaire was used as a method to ensure a valid translation procedure. Back-translation into the source language is a well-established approach (Brislin, 1970). The translation of

the instrument was checked in the pilot study to make sure that the each message was equivalent in both languages.

3.9.2 RELIABILITY

Reliability refers to the accuracy or precision of the measuring instrument (Norland-Tilburg, 1990). In this study, the reliability of data was assessed using inter-rater reliability as a measure (McMillan & Schumacher, 2010). The reliability of the data is described in Chapter 4, Section 4.2.

3.10 SUMMARY

This chapter described the methodology used in this study. The aims and sub-aims were presented, followed by a description of the research design. The pilot study and its results were discussed. The criteria for participant selection and material used in the research process were presented. The biographical information of the participants was visually presented and discussed. This was followed by a description of procedures for the collection of data. The procedures for data analysis were outlined to form a basis for the presentation and interpretation of the results. Finally, the validity and reliability of the study were addressed.

CHAPTER 4

RESULTS AND DISCUSSION

4.1 INTRODUCTION

This chapter describes and discusses the results of the study. The results are discussed against the background of the sub-aims as stated in Chapter 3. Under each sub-heading, the pertaining results are mentioned, followed by the relevant discussion. Figure 2 provides a schematic outline for the presentation and discussion of the results.

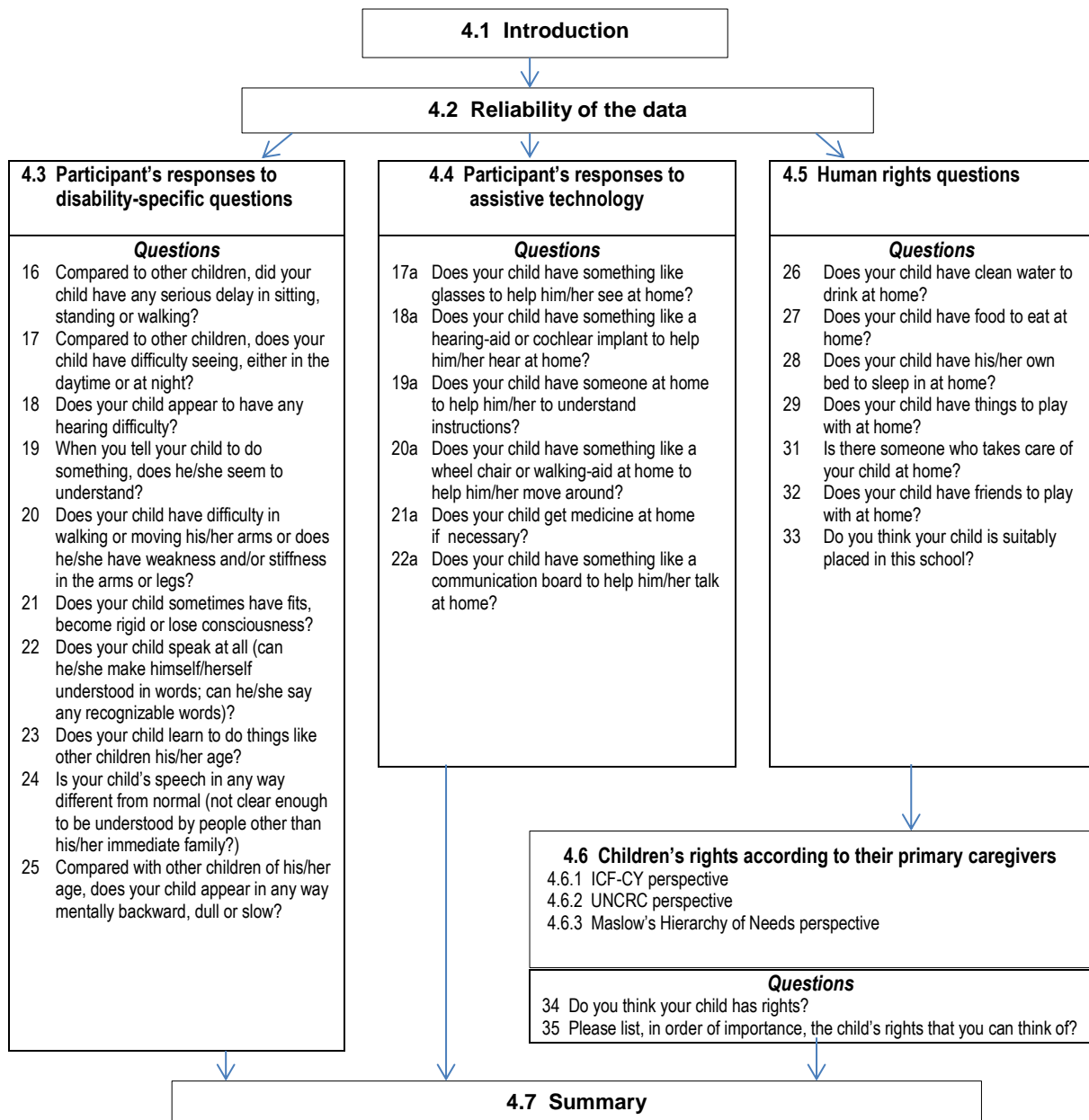


Figure 2. Schematic outline of Chapter 4

The results discussed and described in this chapter reflect the perception of Afrikaans-speaking primary caregivers of children with intellectual disabilities regarding the extent to which their children's basic needs are met. Of the 80 survey instruments that were distributed, 49 were received back. A high response rate of 61.25% was achieved (Babbie, 2004). Firstly, primary caregiver's responses to disability-specific questions based on the TQQ (Section 4.3) are provided and then discussed, followed by their perception regarding assistive technology (Section 4.4), a part of human rights (Article 23), as well as selected other articles from the UNCRC (Section 4.5). In the last instance, primary caregivers' ideas regarding human rights are presented and explained from three different theoretical perspectives. In all cases, the results are presented first and are subsequently discussed.

4.2 RELIABILITY OF THE DATA

In this study, the reliability of data was assessed using inter-rater reliability (McMillan & Schumacher, 2010) as a measure. A second rater with a postgraduate degree in Commerce independently checked the capturing, coding and analysis of all the data. Furthermore, she independently scored a randomly selected 40% of the survey instruments. Inter-rater reliability is expressed as a percentage. The formula for the calculation of inter-rater reliability percentage is as follows (McMillan & Schumacher, 2010):

$$\frac{\text{(Number of correctly scored items) 775}}{\text{(Scored items) 780}} \times \frac{100}{1}$$

For this study, the inter-rater reliability was calculated to be 99.3%, which shows excellent inter-rater reliability.

The reliability of the data was also strengthened by adding one Likert-scale acquiescence question (Question 30) to determine whether participants considered every option or merely marked their choices in a specific pattern. This question read: *Does your child like it when people get angry with him/her?* As expected, most of the participants answered *Never* (65.96%), showing that response set bias was not effectively eliminated. However, 19.15% participants answered *Sometimes*, 8.51% answered *Always*, and 6.38% *seldom*. This could possibly be attributed to the fact that primary caregivers may incorrectly have regarded this question as a request for attention on the children's side, which is a phenomenon that is often

observed in children with ID who show challenging behaviour (Bornman & Rose, 2010).

4.3 PARTICIPANTS' RESPONSE TO THE DISABILITY-SPECIFIC QUESTIONS

Table 10 indicates the participant's response to the disability-specific questions based on the TQQ. These 10 questions were integrated into the questionnaire as Questions 16 to 25. Results show that all the participants (N=49) answered Questions 18, 19, 20, 21 and 22. Questions 16, 17, 23, 24 and 25 were not answered by all the participants, resulting in some missing data for these items, as shown in Table 10.

Table 10

Participants' response to the TQQ (N=49)

Question No	Questions	Yes		No		Missing Data
		Freq.	%	Freq.	%	
16	Compared to other children, did your child have any serious delay in sitting, standing or walking?	23	54.76	19	45.24	7
17	Compared to other children, does your child have difficulty seeing, either in the daytime or at night?	3	6.38	44	93.62	2
18	Does your child appear to have any hearing difficulty?	4	8.16	45	91.84	-
19	When you tell your child to do something, does he/she seem to understand what you are saying?	45	91.84	4	8.16	-
20	Does your child have difficulty in walking or moving his/her arms, or does he/she have weakness and/or stiffness in the arms or legs?	1	2.04	48	97.98	-
21	Does your child sometimes have fits, become rigid or lose consciousness?	3	6.12	46	93.88	-
22	Does your child speak at all (can he/she make himself/herself understood in words; can he/she say any recognizable words)?	44	89.80	5	10.20	-
23	Does your child learn to do things like other children his/her age?	27	57.45	20	42.55	2
24	Is your child's speech in any way different from normal (not clear enough to be understood by people other than his/her immediate family?)	19	39.58	29	60.42	1
25	Compared with other children of his/her age, does your child appear in any way mentally backward, dull or slow?	16	33.33	32	66.67	1

It is evident from Table 10 that the majority of primary caregivers (91.84%) thought that their children understood them when they told them to do something (Question 19). This is confirmed by the fact that more than half of the primary caregivers (57.45%) indicated that their children learn to do things like other children their age (Question 23). Results show that only a small percentage of the children (2.04%) had difficulty with motor function (Question 20), although 54.76% reported that their children had serious delays in sitting, standing or walking (Question 16). This could possibly be part of a profile indicative of a general delay in early motor skills, which is often seen in children with intellectual disabilities (Wuang, Wang, Huang, & Su, 2008). Furthermore, it is clear from the results that 89.80% of primary caregivers believed that their children could speak and say recognizable words (Question 22), although 39.58% of primary caregivers also reported that their children's speech was different from normal (Question 24) and not clear enough to be understood by members outside the immediate family. The exact nature of this difference is unknown. In an earlier large-scale study by Bornman and Alant (1997) in the same geographical area, it was reported that non-speaking children in special schools for children with intellectual impairments were a heterogeneous group regarding communication and literacy skills, with a prevalence rate of 38.3%.

Regarding Question 21, 6.12% primary caregivers indicated their children *Sometimes* had fits, became rigid or lost consciousness. Likewise, Memisevic and Sinanovic (2009) reported an occurrence of epilepsy in children with ID in their study conducted in two special education schools in Sarajevo, Bosnia and Herzegovina. Shephard and Hosking (1989) also found that the occurrence of epilepsy in all children between the ages of 5 and 16 years of age in the City of Sheffield with mild, moderate or severe intellectual disability was higher than in their typically developing peers. These authors reported an overall percentage of 18%, with a range from 7% for those with mild to moderate intellectual impairments, to 67% for those with severe intellectual impairments and a physical disability. In this study, the 6.12% primary caregivers who reported that their children *Sometimes* had fits, one mother responded that her child did not have fits, become rigid or lose consciousness, but indicated that the child received medication for epilepsy, namely Epilim® (*Sodium Valproate*). Epilim® is used in the treatment of epilepsy (Vajda, McNeil, Morris, Drummer, & Bladin, 1978). This could possibly be why, according to the mother, the child did not get fits at the time this study was conducted.

As shown in Table 10, primary caregivers reported that their children had slight difficulties with sensory functions (Question 17). Results show that only a small percentage (6.38%) of the children had difficulty seeing, either in the daytime or at night, and slightly more (8.16%) of the children had difficulty hearing. However, children with intellectual disabilities are characterized by delay or impairment of sensory motor functions (Hogan, Rogers & Msall, 2002). A possible reason why primary caregivers reported these low percentages of sensory deficits can possibly be attributed to the high frequencies of undiagnosed early childhood sensory impairment in children with ID. Early detection, diagnosis and treatment of hearing and visual impairment in children with ID should be a responsibility of paediatricians and youth health physicians (Evenhuis, Mul, Lemaire, & de Wijs, 1997).

4.4 PARTICIPANTS' RESPONSE TO ASSISTIVE TECHNOLOGY

Items related to Article 23 of the UNCRC were developed as follow-up questions to the disability-specific questions, since they deal with the provision of specific assistive technology. Participants were instructed to complete these questions if they had answered Yes to Questions 17, 18, 20, 21, and No to Questions 19 and 22. Six questions, namely Questions 17a, 18a, 19a, 20a, 21a and 22a explored participants' response to different assistive technologies their children with ID probably needed. Therefore the N-value in Table 11 shows only the follow-up answers, and not the frequencies for the whole group.

Table 11

Participants' responses regarding assistive technology

Nr	N	Questions	Likert-scale questions			
			Always	Sometimes	Seldom	Never
17a	3	Does your child have something like glasses to help him/her see at home?	100%	-	-	-
18a	4	Does your child have something like a hearing aid or cochlear implant to help him/her hear at home?	50.00%	-	-	50.00%
19a	4	Does your child have someone to help him/her understand instructions at home?	100%	-	-	-
20a	1	Does your child have something like a wheel chair or walking-aid to help him/her move around at home?	-	-	-	100%

Nr	N	Questions	Likert-scale questions			
21a	3	Does your child get medicine when needed at home?	66.67%	-	-	33.33%
22a	5	Does your child have something like a communication board to help him/her talk at home?	25.00%	-	25.00%	50.00%

It is clear from participants' responses in Table 11 that primary caregivers (100%) felt that their children *Always* had glasses to help them see at home (Question 17a). Participants (100%) also indicated that their children *Always* had someone to help them understand instructions at home (Question 19a). On the other hand, primary caregivers (100%) indicated that their children with motor disabilities *Never* had something like a wheel chair or walking-aid to help them move around at home (Question 20a). The 100% response rate can be attributed to the fact that participants believe that their child does not need a wheelchair or walking-aid to help them move around at home. Two thirds of participants (66.67%) responded that their children *Always* received medicine at home when needed, while the other third (33.33%) stated that their children *Never* received medication (Question 21a). As this question directly followed on the question related to epilepsy, primary caregivers could have interpreted this to mean medication to treat epilepsy or fits, although the intention of the question was determine medication in general. According to the four participants whose children had hearing difficulties, their children only *Always* had something like a hearing aid or cochlear implant to help them hear at home in 50.00% of the time. The other 50.00% *Never* had something to help with hearing at home. This could possibly refer to children who have conductive hearing loss associated with ear infections. This type of hearing loss is commonly associated with Down syndrome (Roizen & Patterson, 2003). On the other hand, primary caregivers might have confused hearing and listening skills. In cases where children do not listen or pay attention, primary caregivers might have incorrectly confused this with hearing skills. Participants (25.00%) also indicated that their children *Always* had something like a communication board to help them talk at home; 25% *Seldom* had such a device; and 50.00% of the children have *Never* had such a device (Question 22a). One participant did not respond to this question.

In summary, it is clear from Table 11 that primary caregivers had varying opinions regarding assistive technology. Assistive technology related to vision and

cognition (helping children understand) were available, while mobility advices were not. More than half of the primary caregivers indicated that their children *Always* received medication at home when needed. The same percentage felt that their children's needs were not met in terms of a communication board to help them talk at home.

4.5 HUMAN RIGHTS QUESTIONS

Questions 26, 27, 28, 29, 31, 32 and 33 relate to various articles of the UNCRC and were aimed exploring participants' response to different human rights. The results are presented in Table 12.

Table 12

Participants' response with regard to human rights (N=49)

Nr	Questions	Likert-scale questions				Missing Data
		Always	Sometimes	Seldom	Never	
26	Does your child have clean water to drink at home?	100%	-	-	-	
27	Does your child have food to eat at home?	91.67%	6.25%	2.08%	-	1
28	Does your child have his/her own bed to sleep in at home?	93.88%	-	-	6.12%	
29	Does your child have things to play with at home?	91.84%	6.12%	2.04%	-	
31	Is there someone who takes care of your child at home?	100%	-	-	-	
32	Does your child have friends to play with at home?	53.06%	36.73%	4.08%	6.12%	
33	Do you think your child is suitably placed in this school?	78.72%	36.38%	48.51%	36.38%	2

Table 12 shows that 2 of the 7 questions yielded a 100% positive rating. It is clear that primary caregivers (100%) felt that their children *Always* had clean water to drink at home (question 26) and that there was *Always* (100%) someone to take care of their children at home (Question 31). According to the Constitution of South Africa (1996) every person has the right to clean water. The Department of Water Affairs and Forestry's community Water Supply and Sanitation Programme (CWSS) were established in 1994 to achieve this (Department Water Affairs and Forestry, 1996). Primary caregivers indicated that the majority of the children (93.88%) *Always* had

their own bed to sleep in, although 6.12% did not (Question 28). It is interesting to note that according to the participants (91.67%), their children *Always* had food to eat at home, 6.25% *Sometimes* had food to eat at home, and 2.08% *Seldom* (Question 27). One participant did not answer this question. From the results obtained (Question 33), it is evident that participants (78.72%) thought that their children were *Always* suitably placed in the specific school they attended, 36.38% indicated *Sometimes*, 48.51% *Seldom*, and 36.38% *Never*. Primary caregivers had varying opinions regarding suitable placement in school (Question 33). A possible reason for this variation could be that primary caregivers felt that resources to accommodate their children are limited and that the support is not effective. One of the greatest challenges that face many schools today is that the resources to accommodate children with ID are not in place (Bornman & Rose, 2010). Two participants did not respond to Question 33. The question regarding friends (Question 32) yielded the smallest number of *Always* responses. Participants (53.06%) indicated that their children *Always* had friends to play with at home, 36.73% indicated *Sometimes*, 4.08% *Seldom*, and 6.12% *Never*. Despite the above, 91.84% of the participants indicated that their children *Always* had toys to play with at home, 6.12% indicated *Sometimes*, and 2.04% indicated *Seldom* (Question 29). Based on these findings, similar to typically develop peers, children had more access to toys than to friends to play with at home.

4.6 CHILDREN'S HUMAN RIGHTS ACCORDING THEIR PRIMARY CAREGIVERS' PERSPECTIVES

As described in Chapter 3, an open-ended question, followed the *Yes/No* question *Do you think your child has rights?* (Question 34). Results showed that 93.02% of the participants answered *Yes* to Question 34 and 6.98% of the participants answered *No* to this question. Six participants did not answer the question.

The *No* responses might reflect the perceptions described in the literature that expressing children's rights are damaging to the relationship of trust between parent and child and that rights could be seen as a threat to parent's authority (Dillen, 2006). This question was followed by a follow-up question in which primary caregivers were asked to list, in order of importance, children's rights that they might think of if they had answered *Yes*. Overall, they mentioned 186 rights (see Appendix I for raw data). The Highest number of rights mentioned by a participant was 6 and

the lowest was 1, with an average of 3. All participants' responses were first listed under the participant number. Thereafter, a theme analysis was done and similar items were grouped together, resulting in 28 themes.

As mentioned in Section 3.8, a second rater with a postgraduate degree in Augmentative and Alternative Communication (AAC) and 20 years of experience in the field of disability, independently studied the raw data and grouped the data according to themes and the researcher subsequently compared the two lists. The second rater recommended that responses that related to a school theme should be grouped together, for example *the right to learn and the right to get support with school work*. The second rater also recommended that responses related to love should be grouped together, for example *the right to charity and the right to be treated as the caregiver's own child*. Discussions continued until consensus was reached between the two coders. All recommendations were considered and the necessary adjustments were made. These 28 themes were first be analysed using the ICF-CY Environmental codes, then according to Maslow's Hierarchy and finally according to selected articles from the UNCRC.

4.6.1 CHILDREN'S HUMAN RIGHTS: AN ICF-CY ENVIRONMENTAL CODES PERSPECTIVE

The ICF-CY Environmental Factors includes physical, social and attitudinal factors grouped into five domains, namely Products and Technology, Natural Environment and Human made Changes to Environment, Support and Relationships, Attitudes and Services, Systems and Policies (WHO, 2007). In each domain, categories with titles and associated definitions are listed hierarchically with detailed categories on second, third and in some cases fourth level (Cieza & Stucki, 2008; Simeonsson, Sauer-Lee, Granlund, & Björck-Åkesson, 2010). This focus of this study was on the second-level categories in the said component of the ICF-CY, namely environmental factors. The 186 rights listed by the primary caregivers were grouped together, resulting in 28 different themes. These themes were then linked to ICF-CY Environmental codes.

4.6.1.1 Linkage procedure

In Section 4.6, the procedure that was followed to group similar items together and that resulted in 28 distinct themes, was discussed. Thereafter, the researcher awarded ICF-CY Environmental codes with titles and associated definitions to these themes. A second coder, a registered physiotherapist with long-

term experience of working with children and youth with disabilities and who holds a PhD in Disability Research, with a focus on the ICF-CY, independently linked the 28 different themes to ICF-CY Environmental codes. The researcher compared the two lists and accepted the changes based on recommendations made by the second rater. The second rater recommended that a more detailed description of the themes was needed to render it more concise and clear. Consistency with regard to ICF-CY code headings was also recommended to increase the reliability of the findings. Furthermore, it was suggested that the rules of Cieza et al., (2005) be followed, which stipulate that a lower level code should be used if a decision cannot be reached on a specific code. A third coder with experience in the ICF-CY and severe disability was requested to participate in a discussion related to the allocation of codes. Discussions continued until consensus was reached between the three coders, as a means of ensuring data triangulation (Thurmond, 2001). It was decided to link the rights both to codes (comprising the regulations) and to the persons or organizations covered by the regulations. The recommendations and suggestions were considered and the necessary adjustments were made.

In order to provide a deeper understanding of the data, all linkages to the different environmental domains were merged into frequencies, as displayed in Table 13.

Table 13

Rights with regard to the ICF-CY Environmental codes

Theme description	Freq.	%	Environmental codes
The right to school education	23	12.37	e583: General education and training services, systems and policies e585: Education and training services, systems and policies e586: Special education and training services, systems and policies
The right to safety <ul style="list-style-type: none"> • Public (social security) • Public environment • Home environment • Family members • Peers (bullying) • Teachers • Strangers • Community 	22	11.83	e150: Design, construction and building products and technology of buildings for public use, for example for physical safety of persons e155: Design, construction and building products and technology of buildings for private use e310/e410: Support and individual attitudes of immediate family e315/e415: Support and individual attitudes of extended family e320/e420: Support and individual attitudes of friends e325/425: Support and individual attitudes: acquaintances, peers, colleagues, neighbours and community members

Theme description	Freq.	%	Environmental codes
			e330/e430: Support and individual attitudes of people in positions of authority e345/e445: Support and individual attitudes of strangers e545: Civil protection, services, systems and policies e570: Social security, services, systems and policies
The right to be taken care of <ul style="list-style-type: none"> by primary caregivers 	12	6.45	e310/e410: Support and individual attitudes of immediate family e315/e415: Support and individual attitudes of extended family e575: General social support, services, systems and policies
The right to love and understanding	11	5.91	e310: Support of immediate family e410: Individual attitudes of immediate family members
The right of access to medical services	10	5.38	e110: For personal consumption e570: Social security, services, systems and policies e580: Health services, systems and policies
The right to freedom of speech	10	5.38	e410: Individual attitudes of immediate family members e430: Individual attitudes: people in positions of authority e595: Political services, systems and policies
The right to be respected <ul style="list-style-type: none"> by family by friends by strangers by teachers by the community 	10	5.38	e410: Individual attitudes of immediate family members e415: Individual attitudes of extended family e420: Individual attitudes of friends e425: Individual attitudes: acquaintances, peers, colleagues, neighbours and community members e430: Individual attitudes: people in positions of authority e440: Individual attitudes of personal care providers and personal assistants e445: Individual attitudes of strangers
The right as an individual	9	4.83	e595: Political services, systems and policies
The right to freedom	9	4.83	e595: Political services, systems and policies
The right to food	7	3.76	e110: For personal consumption e310: Support of immediate family e315: Support of extended family
The right against abuse <ul style="list-style-type: none"> physical abuse 	7	3.76	e310: Support of immediate family e315/e415: Support and individual attitudes of extended family e320/e420: Support and individual attitudes of friends e325/e425: Support and individual attitudes: acquaintances, peers, colleagues, neighbours and community members e330/e430: Support and individual attitudes: people in positions of authority e340/e440: Support and individual attitudes: personal care providers and personal assistants
The right to be accepted	7	3.76	e410: Individual attitudes of immediate family e415: Individual attitudes of extended family e420: Individual attitudes of friends

Theme description	Freq.	%	Environmental codes
			e425: Individual attitudes: acquaintances, peers, colleagues, neighbours and community members e430: Individual attitudes: People in positions of authority e440: Individual attitudes of personal care providers and personal assistants e450: Individual attitudes of health professionals
The right to a family life	6	3.23	e310: Support of immediate family e315: Support of extended family
The right to housing	5	2.69	e155: Design, construction, and building products and technology of buildings for private use e525: Housing services, systems and policies
The right to clothes	5	2.69	e115: For personal use in daily living
The right to be treated fairly	4	2.15	e410: Individual attitudes of immediate family members e415: Individual attitudes of extended family e420: Individual attitudes of friends e425: Individual attitudes: acquaintances, peers, colleagues, neighbours and community members e430: Individual attitudes: People in positions of authority e440: Individual attitudes of personal care providers and personal assistants e450: Individual attitudes of health professionals
The right to meet with groups/ friends	4	2.15	e320/e420: Support and individual attitudes of friends e325/e425: Support and individual attitudes: acquaintances, peers, colleagues, neighbours and community members
The right to play/toys	4	2.15	e115: For personal use in daily living
The right to clean/safe water	4	2.15	e110: For personal consumption e310: Support of immediate family e315: Support of extended family
The right to have rights	4	2.15	e595: Political services, systems and policies
The right to standard of living – own bed	3	1.61	e115: Products and technology for personal use in daily living
The right to special support and health care/therapeutic services	2	1.08	e580: Health services systems and policies
The right to be educated in home language	2	1.08	e585: Education and training services, systems and policies
The right to hygiene/best health care	2	1.08	e150: Design, construction and building products and technology for physical safety of persons in buildings for public use e155: Design, construction and building products and technology of buildings for private use e510: Services, systems and policies for the production of consumer goods
The right to religious freedom	1	0.54	e595: Political services, systems and policies
The right to information	1	0.54	e125: Products and technology for communication e130: Products and technology for education e535: Communication services, systems and policies

Theme description	Freq.	%	Environmental codes
			e560: Media services, systems and policies
The right to affordable transport to school/encouraged to go to school	1	0.54	e120: For personal indoor and outdoor mobility and transportation e310: Support of immediate family e315: Support of extended family e540: Transportation services, systems and policies e585: Education and training services, systems and policies
The right to electricity/safe home	1	0.54	e510: Services, systems and policies for the production of consumer goods e525: Housing services, systems and policies e530: Utilities services, systems and policies
TOTAL	186		

Note: Freq. = Frequency

4.6.1.2 Rights with regard to the ICF-CY Environmental codes

The results reflected in Table 13 show how the specific rights are grouped and linked to ICF-CY Environmental codes in order of descending frequency. Some rights, for example *the right to clothes* have only one code (e115). This is due to the specific nature of that construct, while some rights have up to 17 codes (for example *the right to safety*). This is because safety is a complex construct involving many different elements such as social security, home environment, strangers and the community. Most of the rights have two to three different codes exemplifying the compound nature of the construct.

The 28 different rights that were mentioned by the primary caregivers resulted in 915 linkages to 36 different second-level Environmental codes (see Table 13). No rights were linked to domain e2, i.e. Natural Environment and Human Made Changes to Environment. This can possibly be attributed to the fact that the children in this study had intellectual disabilities and hence did not have primary physical disabilities.

It is clear from Table 13 that the right to safety encompasses public and physical safety as well as home environment, family members, peers, teachers, strangers and the community. Eleven Environmental codes can be linked to the right against abuse. The right to be respected was linked to seven environmental codes. This right comprises family, friends, strangers, teachers and the community. Similarly, the right to be accepted and the right to be treated fairly are related to seven environmental codes as well. The right to food, the right to meet groups or friends and the right to information can only be linked to four environmental codes. It is evident from Table 13 that three environmental codes were provided for the right

to school education, the right to access to medical services, the right to freedom of speech, the right to clean and safe water, the right for hygiene care and the right to electricity. The right to be taken care of was linked to two environmental codes and encompasses primary caregivers. Table 13 shows that the right to love and understanding, the right to a family life, the right to housing and the right to affordable transport to school with the aim to encourage school visits were also linked to two environmental codes. In Table 13 it is clear that nine of the 28 rights, namely the right as an individual, the right to freedom, the right to clothes, the right to play, the right to have rights, the right to standard of living, the right to special support and health care, the right to be educated in the home language and the right to religious freedom were linked to one environmental code only.

Table 13 also shows that primary caregivers were mostly concerned about school education (12.37%), and safety rights (11.83%) since these occurred twice as much as the right mentioned in the third place. Furthermore, Table 13 indicates that primary caregivers considered other rights as important, with a frequency of 6.45% and 1.08% respectively. The rights least mentioned frequently by primary caregivers were the right to religious freedom, the right to information, the right to affordable transport to school and the right to electricity, with a frequency count of only 0.54% each.

A summary of the ICF-CY Environmental codes used for the rights is provided in Table 14.

Table 14

Environmental codes used for the rights of children

<u>e1</u>	<u>e3</u>	<u>e4</u>	<u>e5</u>
Products and technology (Seven e1 codes)	Support and relationships (Seven e3 codes)	Attitudes (Eight e4 codes)	Services, systems and policies (Fourteen e5 codes)
e110, e115, e120, e125, e130, e150, e155	e310, e315, e320, e325, e330, e340, e345	e410, e415, e420, e425, e430, e440, e445, e450	e510, e525, e530, e535, e540, e545, e560, e570, e575, e580, e583, e585, e586, e595
TOTAL = 89	TOTAL = 253	TOTAL = 377	TOTAL = 196
TOTAL = Nine-hundred-and-fifteen (915) linkages to 36 second-level Environmental codes			

These 915 linkages are presented graphically in Figure 3.

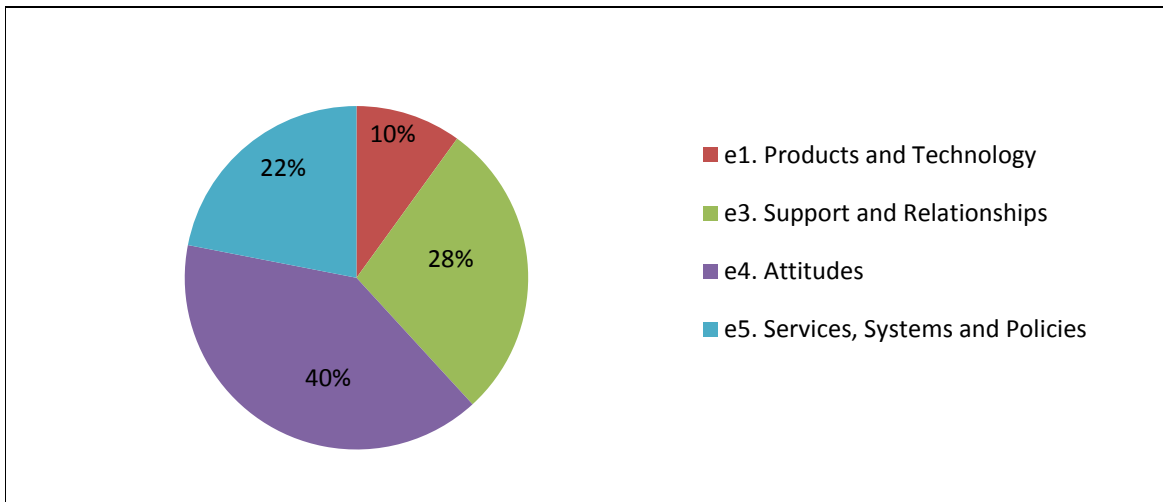


Figure 3. Rights with regard to ICY-CY Environmental domains

From Figure 3 it is clear that four environmental codes were represented, albeit with different frequencies. Attitudes (e4) was presented most frequently (40%), indicating its importance to primary caregivers. Products and Technology (e1) was presented with the lowest frequency (10%). Support and Relationships (e3) and Services, Systems and Policies (e5) frequencies of occurrence were 28% and 22% respectively.

It seems that primary caregivers want the immediate family, for example siblings and grandparents, to show not only encouragement, but also their love, respect and acceptance of the child with intellectual disability. Children with intellectual disabilities have the same human value as any other children and are entitled to basic human rights and fundamental freedoms, including the right to grow up in a family environment (WHO, 2010). The abilities of children with special needs to learn and develop are inextricably intertwined with the strengths and needs of their primary caregivers and other family members (WHO, 2010). It is evident from Figure 3 that primary caregivers also value support by and relationships with the immediate family, extended family, friends and other people as important (28%). In the case of children with intellectual disabilities who need a particular level of attention when caring for or looking after them, primary caregivers *Sometimes* find it hard to ask friends and family to assist (Redmond & Richardson, 2003). Therefore, primary caregivers and family seem to be important interaction partners of the child with special needs. As these children grow older, people in other settings (for example teachers) assume increasingly important roles as interaction partners (Granlund, Björck-Åkesson, Wilder, & Ylvén, 2008). It is also possible that primary caregivers considered the family and friends as an important natural context. The child's

functioning within the family is a strong predictor of both his/her current overall functioning and future development (Bronfenbrenner, 1999).

Figure 3 also indicates that primary caregivers considered services, systems and policies as important (22%). It seems that primary caregivers are of the opinion that their children with intellectual disabilities are entitled to rights and services in schools; also, that schools may not discriminate against children with disabilities. Furthermore, primary caregivers want their children to take part in school, to learn and to develop. Primary caregivers want to be proactive and take the necessary steps to ensure that their child receives appropriate services in school. When investigating the participation of children with disabilities in school activities, Almqvist and Granlund (2005) and Eriksson (2005) reported that the type and degree of disability and environmental factors had only low to moderate statistical relations to participation in school activities.

It is evident from Figure 3 that primary caregivers indicated products and technology with the lowest frequently (10%). It seems that primary caregivers considered products and technology not as important as other items to help their children participate in civic life and fulfil daily activities in and around the house and in the community. This is interesting, because research showed that growing up with a special need or disability made these challenges steeper, therefore interactive technologies can play a positive role in helping children with special needs manage these challenge by communicating with others, to better experience and enjoy the world (Alper, Hourcade & Gilutz, 2012). Children with disabilities have different needs regarding the structure of the house they live in and the school they attend. The wrong layout or structure of the house may cause problems and may even put the lives of children with disabilities at risk. It is also possible that primary caregivers with low income find it difficult to obtain appropriate funding and resources to build, buy or renovate homes for their child with special needs and this may be the reason why primary caregivers did not mention this as one of the needs for their children. For a developing child, a safe home environment is of utmost importance and providing such a home is, primarily, the responsibility of the parents (Kendrick, Barlow, Hampshire, Stewart-Brown, & Polnay, 2008). However, since most of the children in this study did not have motor impairments, physical accessibility might not have been such an important factor.

Table 15 shows that thirteen different rights mentioned by the primary caregivers were classified on the ICF-CY with a d-code (Activities and Participation).

These rights, which represent different articles in the UNCRC (see Table 16 for a list of the specific rights), all have the same d-code, namely d940 (Human rights). These 13 different rights could also be linked to e-codes, as shown in Table 14. It is interesting to note that no rights were linked to the ICF-CY categories *Body functions* and *Body structures*.

Table 15

Rights with regard to the ICF-CY Activities and Participation codes

Rights	Freq.	%	Participation Codes
The right to freedom of speech	10	5.38	d940: Human rights
The right as an individual	9	4.83	d940: Human rights
The right to freedom	9	4.83	d940: Human rights
The right against abuse (physical abuse)	7	3.76	d940: Human rights
The right to be accepted	7	3.76	d940: Human rights
The right to housing	5	2.69	d940: Human rights
The right to be treated fairly	4	2.15	d940: Human rights
The right to have rights	4	2.15	d940: Human rights
The right to be educated in home language	2	1.08	d940: Human rights
The right to religious freedom	1	0.54	d940: Human rights
The right to information	1	0.54	d940: Human rights
The right to electricity/safe home	1	0.54	d940: Human Rights
The right to play	4	2.15	d940: Human Rights
TOTAL	64	34.40	

It is noteworthy that the 13 needs listed in Table 15 account for 34.40% of the rights concerned. Amongst the rights that could be linked to the d-code, the right to freedom of speech was mentioned most frequently by caregivers (5.38%). The right as an individual and the right to freedom were both equally mentioned at 4.83%. Primary caregivers mentioned the right against abuse and the right to be accepted equally at 3.76%. The right to housing was mentioned at 2.69%, whilst the right to be treated fairly and the right to have rights were mentioned equally at 2.15%. Primary caregivers considered the right education at 1.08%. From Table 15 it appears that primary caregivers considered the right to religious freedom, the right to information and the right to electricity as less important and mentioned these at the lowest frequency of 0.54%.

4.6.2 CHILDREN'S HUMAN RIGHTS: A UNCRC PERSPECTIVE

The 28 different rights themes as indicated by the primary caregivers following an open-ended question, were linked with particular articles from the 3 P's, namely provision-, protection- and participation rights (Alderson, 2000) within the UNCRC, as described in Chapter 2. A second coder, with a postgraduate degree in pastoral

psychology and long-term experience of working with children and youth in the field of psychology, independently linked the 28 different themes to the articles of the UNCRC. In some cases, a particular theme was described with as many as five UNCRC articles (for example the right to safety), whilst in some cases 1 UNCRC article would suffice, (for example the right of access to medical services.) Each UNCRC article was subsequently coded as primarily referring to protection, participation or provision (Alderson 2000). Four articles (23, 24, 30 and 31) necessitate further discussion. The second coder recommended that article 23 and 24 should be grouped under provision rights, while the researcher had scored article 23 and 24 under participation rights. The researcher had scored article 30 and 31 under provision rights. In order to reach consensus, an expert panel with long-term experience in the field of disabilities were invited to assist with the grouping of all the articles according to the three different categories. The expert panel recommended that article 23, 30 and 31 should be grouped under participation rights, but that article 24 should be grouped under provision rights. Discussions continued until consensus was reached between the researcher, second coder and the expert panel. The recommendations were considered and the necessary adjustments were made. These results are presented in Table 16.

Table 16
Human rights according to the UNCRC

Rights	Freq.	%	UNCRC Articles	UNCRC articles according to three categories		
				Protection	Participation	Provision
The right to school education	23	12.37	23, 28, 29		23	28, 29
The right to safety	22	11.83	6, 9, 19, 24, 27	6, 9, 19		24, 27
The right to be taken care of	12	6.45	24, 27			2, 27
The right to love and understanding	11	5.91	9, 27	9		27
The right of access to medical services	10	5.38	24			24
The right to freedom of speech	10	5.38	12, 13		12, 13	
The right to be respected	10	5.38	12, 29		12	29
The right as an individual	9	4.83	8	8		
The right to freedom	9	4.83	12, 13, 14, 15		12, 13, 14, 15	
The right to food	7	3.76	6, 24, 27	6		24, 27
The right against abuse	7	3.76	19, 32, 34,	19, 32,		

UNCRC articles according to three categories						
			39	34, 39		
The right to be accepted	7	3.76	2, 30	2	30	
The right to a family life	6	3.23	9, 18	9		18
The right to housing	5	2.69	27			27
The right to clothes	5	2.69	27			27
The right to be treated fairly	4	2.15	2	2		
The right to meet groups/friends	4	2.15	15, 31		15, 31	
The right to play/toys	4	2.15	31		31	
The right to clean/safe water	4	2.15	6, 24, 27	6		24, 27
The right to have rights	4	2.15	5	5		
The right to standard of living – own bed	3	1.61	27			27
The right to special support and health care/therapeutic services	2	1.08	23, 24		23	24
The right to be educated in home language	2	1.08	28			28
The right for hygiene/best health care	2	1.08	24			24
The right to religious freedom	1	0.54	14		14	
The right to information	1	0.54	13, 17		13, 17	
The right to affordable transport to school/encouraged to go to school	1	0.54	28			28
The right to electricity/safe home	1	0.54	27			27
TOTAL	186					

From Table 16, it is clear that primary caregivers' were particularly concerned about school education, as 12.37% of the rights mentioned related to this aspect. In environments where little or no teaching occurs, the expectation for good education seems to be unlimited. To ensure that children with severe disabilities reach their full potential, highly qualified teachers are needed as well as external support that can lead to maximal achievement (for example the use of computer software programmes designed to enable children with ID to access electronic books) (Downing & MacFarland 2012). Safety rights (11.83%) were also frequently mentioned by primary caregivers as an important right. The right to be taken care of attained 6.45% and the right to love and understanding 5.91%. Primary caregivers mentioned the right to medical services, freedom of speech and respect with equal frequency (5.38%). The right as an individual and the right to freedom were mentioned the same number of times (4.83%). Table 16 shows that primary

caregivers mentioned the right to food, the right against abuse and the right to be accepted with a frequency of 3.76% each. Results show that primary caregivers indicated the right to a family life at 3.23% and the right to housing and clothes at 2.69%. Participants' responses clearly showed that primary caregivers felt that to be treated fairly, to have friends, to play, to have clean water and to have rights are equally important (2.15%). The right to a decent standard of living, especially to have a bed, is rated by primary caregivers at 1.61%. It is interesting to note that participants mentioned the right to therapeutic services, to be educated in the home language and the right to hygiene in only 1.08% of the times. The rights mentioned the least often by primary caregivers were the right to religious freedom, the right to information, the right to affordable transport to school and the right to electricity at 0.54%. However, bearing in mind that these responses were elicited through an open-ended question, the fact that they were mentioned at all should be seen as important in itself.

Table 16 shows that 22 different UNCRC articles were linked to the rights mentioned by primary caregivers. Furthermore, it is clear from Table 16 that primary caregivers mentioned article 27 (see Appendix B) most frequently, whilst article 17 was mentioned least of all. Other articles mentioned frequently by primary caregivers were article 24 (47 times) and article 9 (39 times). Article 6 and 29 were equally mentioned, i.e. 33 times. The results show that article 12 and 19 were also mentioned the same number of times (29) (see Appendix B).

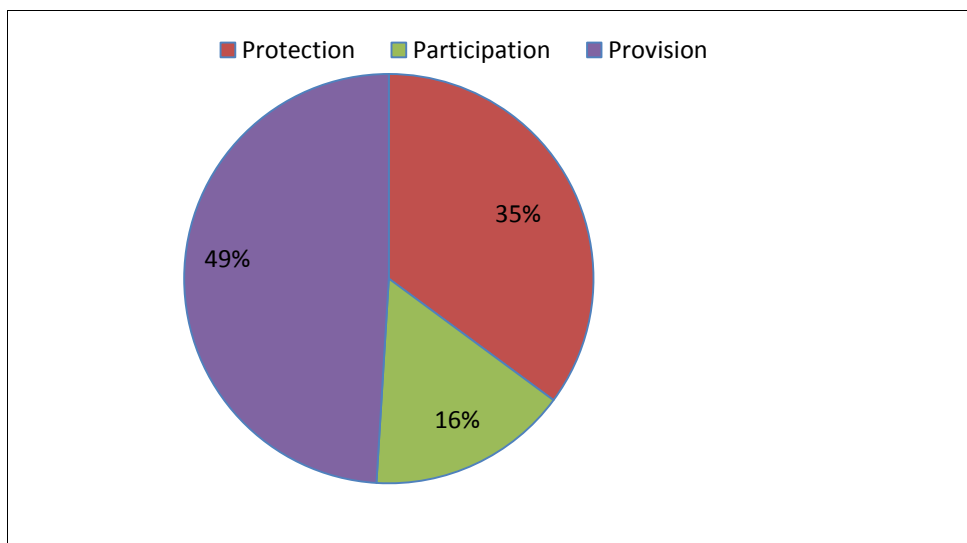


Figure 4. Provision, protection and participation rights

Figure 4.3 indicates how the different rights mentioned by participants were split according to provision, protection and participation rights, the so called the 3 P's (Anderson, 2000). Primary caregivers mentioned provision rights (49%) most frequently, followed by protection rights (35%), and finally participation rights (16%). It is interesting that all the rights mentioned by primary caregivers were from Part I of the UNCRC (Office of the United Nations High Commissioner for Human Rights, 2012).

A possible reason why caregivers mentioned provision rights as the most important (49%), might be the fact that primary caregivers saw good education and medical therapeutic care as important rights for their children. The provision of appropriate educational services for children with special needs has long been a common issue in education (Wang, 2009)

Protection rights, more specific safety rights were also mentioned frequently (11.83%) by primary caregivers. Primary caregivers want their children with intellectual disability to be protected from any kind of abuse, violence and mocking. Children with physical, sensory, intellectual or mental health impairments are at an increased risk of becoming victims of violence (UNICEF, 2005). In the present study, primary caregivers indicated that they must protect their children with special needs against any kind of stigma. These children are part of the wider community and as such are at risk for violence and bullying. Stigma and prejudice allow some members of the community to see children with disabilities as easy targets of abuse (West, Gandhi, & Palermo, 2007). The results depicted in Table 16 show that primary caregivers mentioned safety (11.83%) in and around the house as well as in the community as relatively important. They want their children with disabilities to be safe and secure. Children with disabilities are at an increased risk for home injuries including falls, burns, poisoning, and choking and may require additional safety precautions (UNICEF, 2005). Creating a safe environment for a child with special needs is an important step to ensuring the child's continued well-being and development. Children with intellectual disabilities are also at increased risk for sexual abuse. A study of approximately 55,000 children in Nebraska found that children with intellectual disabilities were 4.0 times more likely than children without disabilities to be sexually abused (Sullivan & Knutson, 2000).

It is evident from Figure 4 that primary caregivers mentioned participation rights the least (16%). A possible reason for this low percentage could be that primary caregivers felt that their children were already part of a family with either one

parent or both primary caregivers and were consequently involved in everyday life situations at home. There is no reason to assume that everyday life situations of children with disabilities should differ from those of other children, though the conditions for participation may differ (Adolfsson, 2011). Children with disabilities usually interact less with peers than typically developing children interact and they may need adult support to participate in activities outside the home and school settings (Coward, et al., 2004). Another possible reason for a frequency of 16%, could be that primary caregivers are of the opinion that their children with disabilities seem to participate during school hours in varied social activities.

Children with disabilities seem to participate in more varied social leisure activities, though less frequently, perhaps because adults introduce different activities creating opportunities for social involvement (Bedell, Cohn, & Dumas, 2005). Table 16 shows that primary caregivers indicated that rights such as freedom of speech (5.38%), respect (5.38%), and the right to freedom (4.83%), should be emphasised. Franklin and Sloper (2009) were of the opinion that children's participation was increasing, but that children with disabilities were still less likely to participate in decision making and that those with complex and multiple disabilities or those with little or no functional speech continued to be excluded. They also found that participation at any level was only happening for a small number of children with disabilities, namely those who were able to communicate, were most articulate and those who were confident.

4.6.3 CHILDREN'S HUMAN RIGHTS: A MASLOW'S HIERARCHY OF NEEDS PERSPECTIVE

Table 17 indicates how the 28 themes identified amongst the participants' answers were linked to Maslow's Hierarchy of needs. A second coder with a postgraduate degree in Augmentative and Alternative Communication (AAC) and long-term experience of working with children and youth with disabilities, independently looked at the 28 different themes. Differences were encountered. The second coder recommended grouping the right to be treated fairly under self-esteem needs, and the right to religious freedom under self-esteem as well as self-actualization needs. It was also recommended to group the right to freedom of speech under self-esteem and self-actualization needs. Discussions continued until consensus was reached between the second coder and the researcher. The recommendations were considered and the necessary adjustments were made.

Table 17

Rights with regard to Maslow's Hierarchy of Needs

Needs	Freq.	%	Maslow Hierarchy of Needs
The right to school education	23	12.37	Self-esteem & Self-actualization
The right to safety	22	11.83	Safety
The right to be taken care of	12	6.45	Biological and Physiological, Love and Belongingness
The right to love and understanding	11	5.91	Love and Belongingness
The right of access to medical services	10	5.38	Biological and Physiological
The right to freedom of speech	10	5.38	Self-esteem and Self-actualization
The right to be respected	10	5.38	Self-esteem
The right as an individual	9	4.83	Self-esteem and Self-actualization
The right to freedom	9	4.83	Self-esteem and Self-actualization
The right to food	7	3.76	Biological and Physiological
The right against abuse	7	3.76	Safety
The right to be accepted	7	3.76	Self-esteem and Love and Belongingness
The right to a family life	6	3.23	Love and Belongingness
The right to housing	5	2.69	Biological and Physiological
The right to clothes	5	2.69	Biological and Physiological
The right to be treated fairly	4	2.15	Self-esteem
The right to meet groups/friends	4	2.15	Love and Belongingness
The right to play/toys	4	2.15	Love and Belongingness
The right to clean/safe water	4	2.15	Biological and Physiological
The right to have rights	4	2.15	Biological and Physiological
The right to standard of living – own bed	3	1.61	Biological and Physiological
The right to special support and health care/therapeutic services	2	1.08	Biological and Physiological
The right to be educated in home language	2	1.08	Self-esteem and Self-actualization
The right for hygiene/best health care	2	1.08	Biological and Physiological and Safety
The right to religious freedom	1	0.54	Self-esteem and Self-actualization
The right to information	1	0.54	Safety and Self-esteem
The right to affordable transport to school/encouraged to go to school	1	0.54	Safety and Self-esteem
The right to electricity/safe home	1	0.54	Biological and Physiological

Figure 5 shows how the different rights were linked to Maslow's Hierarchy of Needs. Contrary to what was expected, needs were not necessarily mentioned according to Maslow's proposed hierarchy, because lower order needs were not mentioned more frequently than the higher order needs. In order to analyse this finding further, the different types of needs were grouped together as shown in Figure 5.

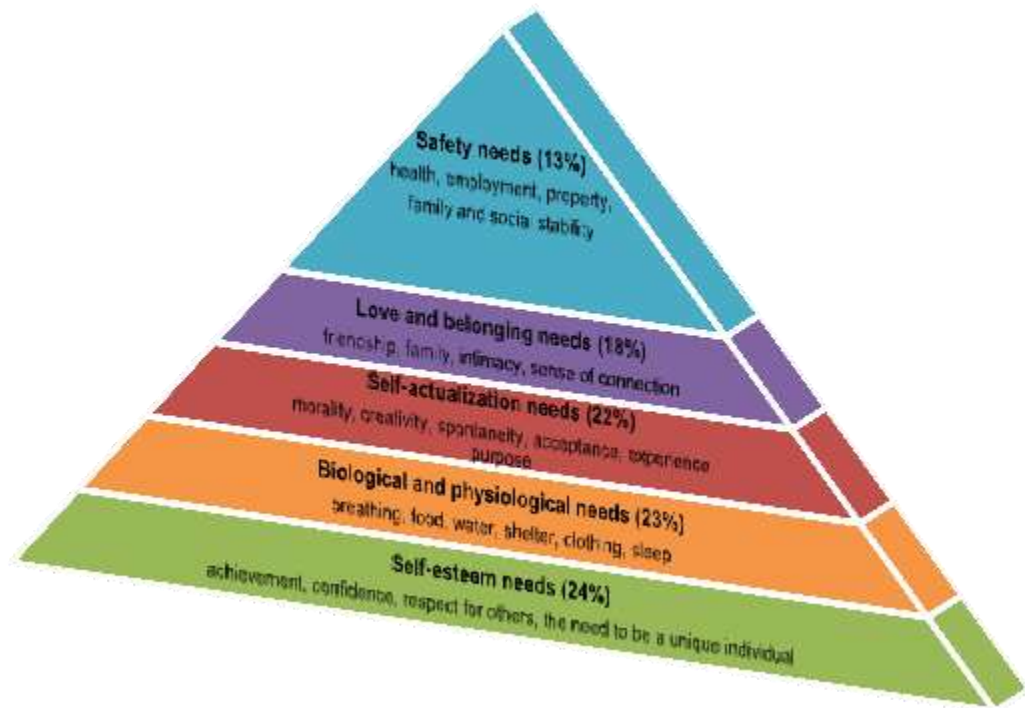


Figure 5. Rights linked to Maslow's Hierarchy of Needs (also see Figure 1.)

Figure 5 shows that rights were mentioned on all five levels of Maslow's Hierarchy, with frequencies ranging from 13%-24%. Primary caregivers mentioned self-esteem needs most frequently (24%). Self-esteem is a description of a person's overall sense of self-worth or personal value. A possible reason why participants considered self-esteem as a very important need is that the children involved all had intellectual disabilities, and therefore were in need of special care. The results also suggest that these children might be exposed to intolerant societal attitudes and at risk of being bullied at school and in society. The need for a tolerant environment is as important as the need for playing with friends (Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005).

Self-esteem is an important aspect of psychological functioning (Crocker & Major, 1989). Children who lack self-esteem may be more dependent on their primary caregivers and have lower academic and vocational goals. Hence, it was not surprising to find that the participants wanted to encourage self-esteem in their young children with intellectual disabilities. Primary caregivers want their children with disabilities to be competent and to develop as a person. The more competent a person perceives himself, the more likely he is to persevere in the presence of challenges (Prince & Howard, 2002). The fact that primary caregivers place such emphasis on self-esteem can possibly be attributed to the fact that they wanted their

children to rise to higher levels of development and independence. Primary caregivers want their children with ID to be treated with respect and decency. In this study, the results showed that primary caregivers stressed the importance of people in society who have knowledge about disability and that there should also be positive attitudes towards schooling for their children with ID in order to fulfil self-esteem needs. These needs have been described as a desire for self-respect based on accurate assessment by oneself and other trusted people. The development of a strong self-esteem and ego leads to feelings of self-confidence, worth, strength, and capability; these emotions propel behaviour toward the higher goals (Maslow, 1970). It is interesting to note that participants mentioned the lowest level of needs on Maslow's Hierarchy, namely, biological and physiological needs (23%), marginally less frequently than esteem needs (24%) as discussed above. Biological and physiological needs are the necessities for human survival. If these basic needs are not met, the human body simply cannot continue to function. According to Maslow (1970), basic needs are the most prominent ones and they completely dominate the person when they are not met. When the basic needs are not satisfied there cannot, according to Maslow's theory, be a possibility of moving to a next level. However, Maslow (1970) did concede that not everybody would proceed up the hierarchy in exactly the same way.

Results from the biographical data show that there is a definite tendency towards unemployment, a low income as well as a low level of education of primary caregivers who completed the questionnaire (Chapter 3, section 3.5.2.3). From the results obtained, it appears that these households belong to the middle- to low-income group. People living in families with incomes that exempt them from paying income tax (income of less than R60 000, 00 per annum) are considered to be living in poverty (South African Revenue-Service, 2012). They struggle to meet their basic needs, which could be the reason why these primary caregivers placed such a high premium on biological and physiological needs.

From Figure 5 it appears that, together with the previous two levels mentioned, primary caregivers mentioned self-actualization, the fifth level of need addressed by Maslow, also quite frequently (22%). Together, these three levels account for almost 75% of the answers. Maslow (1970) theorized that the ultimate goal of life is self-actualization, which is almost *Never* fully attained, but is rather something that all individuals try to strive to attain. It is interesting to note that Maslow (1970) recognized that a real sense of fulfilment does not come from

seeking simply your own welfare, but from living and doing things for a purpose beyond yourself. Each lower level need must be fulfilled to be able to move up the hierarchy to develop further as a person. Development cannot aim to fulfil these needs. In accordance with Maslow's Hierarchy of Needs, it appears that caregivers rather want to see that their children's lower needs be satisfied, before moving to the highest level, namely the level of self-actualization. For children to self-actualize, their primary caregivers need to help them to satisfy their more basic needs for health, safety, belonging, love and self-esteem. In this study, results show that primary caregivers mentioned self-actualization with a frequency of 22%; it seems, therefore, that they do assist to create life conditions that allow their children to actualize their own unique potential. Children with disabilities may be guided toward their goal of self-actualization by being encouraged to find their individual strengths and capacities (Croft, Boyer & Hett, 2009).

Interestingly, Figure 5 shows that eighteen percent of primary caregivers mentioned the need for love and belonging. One possible reason could be that most of the caregivers, whether it is a parent, foster parents, guardian or housemother of an orphanage, are of the opinion that children in their care receive lots of love, attention and care and that their children are part of a family. In children, the need for love and belonging are thus further met through the establishment of attachments to a stable group of carers, for example housemothers in orphanages. This suggests that, although primary caregivers may feel that the need for belonging and love is important, this need is being met; therefore, some of the other needs mentioned earlier may in fact play a bigger role in the development and rights of the child with ID. Goodenow (1993) found that when children felt they belonged, they were more motivated, had higher expectations of success, and believed in the value of their academic world.

Based on Maslow's Hierarchy of Needs, the need that was least often mentioned in this study, was the need for safety, with only at 13%. In South Africa with its high crime rate (SA Crime Report 2010/2011), it is surprising to note that primary caregivers did not mention the safety of their children with special needs more frequently. Caring for the safety of children may seem to be so obvious that it does not need mentioning. Security, stability, protection and freedom from fear, anxiety and chaos are seen as essential needs for these children. However, according to Prince and Howard (2002), safety needs also include personal security, financial security, health and well-being, a safety net against accidents/illness and

other adverse events. These needs for safety have not been met for some of the participants. The results in Table 16 show that caregivers are concerned about their children with disabilities being abused for example bullied by peers because of their disability.

As mentioned earlier, results showed that the participants are from middle to low income households. Studies showed that the quest for safety is a real issue for children growing up in poor neighbourhoods (Prince & Howard, 2002). Poor neighbourhoods are often overwhelmed by drugs, violence, and crime (Leventhal & Brooks-Gunn, 2000). Although primary caregivers did not single out safety as a predominant need, they still want their children with special needs to develop with a sense of safety, because 13% of the primary caregivers in this study indicated that safety was an important issue. Limited availability of safe, attractive areas within a neighbourhood may prevent neighbours from meeting and socialising and spending time with their peers (HM Treasury, 2008).

4.7 SUMMARY

This chapter presented the results and discussion of the study, which were organised, analysed and described according to the sub aims of the study. The reliability of the responses obtained was discussed. Next primary caregivers' responses to disability-specific questions were shown and analysed. This was followed by a discussion of the results obtained from Afrikaans-speaking primary caregivers of children with intellectual disabilities regarding their perceptions of whether their children's basic needs are met in terms of the UNCRC, with regards to assistive technology and also more general rights. Thereafter the rights mentioned in the open-ended question were allotted. Rights were then allotted the ICF-CY codes that measure environmental factors, selected articles from the UNCRC, as well as Maslow's five-stage Hierarchy of Needs.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter summarizes and integrates the findings of the study. A critical evaluation is provided and implications of the study are discussed. Recommendations for further research are presented.

5.2 CONCLUSIONS

The aim of the study was to describe to which extent Afrikaans-speaking primary caregivers perceive the basic needs of their young children (8;0 to 14;11) with intellectual disabilities to be met, in an attempt to describe children's rights as set out by the UNCRC. The survey instrument was the main instrument for data collection and was specifically developed for this purpose. To answer the research question, biographical information was obtained from the primary caregivers about their children with intellectual disabilities, as well as the TQQ and questions related to needs and rights. Fourteen Likert-scale questions were revised, refined and ranked by experts to correlate with the ICF-CY codes, Maslow's Hierarchy and selected articles from the UNCRC.

The results showed that 91.84% of primary caregivers believed that their children understood them when they told them to do something. This was confirmed by the fact that more than half of the primary caregivers (57.45%) indicated that their children learned to do things like other children their age. Furthermore, it was clear that 89.80% of primary caregivers believed that their children could speak and say recognizable words, although primary caregivers reported that 39.58% of the children's speech was different from what is considered normal.

Results also show that primary caregivers' responses to different assistive devices indicated that the basic needs of their children with ID were *Always* met in respect of glasses needed at home and somebody to help their children understand instructions. A low percentage (6.12%) of primary caregivers indicated that their children *Sometimes* had seizures, became rigid or lost consciousness, whilst studies reported a high occurrence of epilepsy in children between the ages of 5 and 16 years with mild, moderate or severe intellectual disability (Shephard & Hosking, 1989). This could be contributed to the fact that more than half of the primary

caregivers indicated that their children *Always* received medication at home when needed. The majority of participants felt that their children's needs were met in respect to different assistive devices.

Results show that primary caregivers' responses to different human rights indicated that they felt their children *Always* had clean water to drink (100%) and that there was *Always* someone to take care of their children at home. Primary caregivers indicated that the majority (93.88%) of the children had their own bed to sleep in and *Always* had food to eat (91.67%). Furthermore, results show that primary caregivers had varying opinions regarding suitable placement in school and the question regarding friends to play with at home. The question regarding friends yielded the smallest number of *Always* responses (53.06%). Regardless of that, 91.84% of the participants indicated that their children *Always* had toys to play with at home.

An open-ended question was also included to determine primary caregivers' perception of the rights of their children with intellectual disabilities. Participants were requested to list, in order of importance, the rights they might think of. A total of 186 rights were mentioned by primary caregivers. After a theme analysis, similar items were grouped together, resulting in 28 themes, which were subsequently linked to ICF-CY codes (Environmental Factors), selected articles of the UNCRC and Maslow's Hierarchy of needs.

The results showed that primary caregivers most frequently mentioned the right to school education and the right to safety. The rights least frequently mentioned by primary caregivers were the right to religious freedom, the right to information, the right to affordable transport to school and the right to electricity. However, given the fact that primary caregivers answered this question in an open-ended format, it means that they were concerned enough about these issues to mention them.

The four different environmental domains in the ICF-CY showed that *Attitudes* (e4) was mentioned most frequently (40%), followed by *Support and relationships* (e3) (28%) and *Services, systems and policies* (e5) (22%). *Products and technology* (e1) was mentioned least frequently (10%). This finding attests to the importance of addressing attitudes as part of human rights.

Subsequently, the different rights as indicated by the primary caregivers were grouped according to the UNCRC. Primary caregivers mentioned *provision rights* (50%) most often, followed by *protection rights* (35%), and finally *participation rights* (15%) (Table 16).

Finally, the rights mentioned by participants were linked to Maslow's Hierarchy of Needs. Results showed that responses from primary caregivers were linked to self-esteem needs most frequently, followed by biological and physiological needs, the need for self-actualization, the need for love and belonging and, lastly, the need for safety (Table 17). This is different from the original hierarchy, which follows the sequence of biological and physiological needs, the need for safety, the need for love and belonging, self-esteem needs and lastly, the need for self-actualization.

In conclusion, it appears that when primary caregivers were requested to list the rights they might think of, they most frequently mentioned intangible rights such as self-esteem rights. The level of self-esteem is affected by many factors and consequently it is difficult to measure the effects of self-esteem, because it is linked to an attitude.

5.3 CRITICAL EVALUATION OF THE STUDY

Certain factors may have influenced the results of this study in a positive or negative manner, thereby either strengthening or weakening it.

5.3.1 STRENGTHS OF THE STUDY

1. A pilot study was conducted prior to the main study and the necessary adaptations were made regarding the user friendliness of the questions, the instructions accompanying the questions and the method of data collection. The pilot study thus enhanced the quality of both the survey instrument and data collection procedures.
2. In terms of the survey instrument, face validity was strengthened with input from the panel of experts.
3. The blind-back translation (Durkin, 2001) process yielded a reliable translation, thereby strengthening the translation of the measuring instrument. This method of translation is regarded as highly effective for ensuring cultural and linguistic equivalence of the measure.

4. A response rate of 61.25% was achieved for completed and returned survey instruments, which can be regarded as a high response rate (Babbie, 2004).
5. In this study, the sample of 49 participants is seen as an adequate sample size—a minimum of 30 participants is acceptable for ensuring data that is statistically meaningful (Deal & Anderson, 1995; Cohen, 1995).

5.3.2 LIMITATIONS OF THE STUDY

The following limitations of the study were identified:

1. The study was restricted to a relatively homogeneous group of primary caregivers with Afrikaans as home-language, in a specific geographical area; for this reason, the results can only be generalized to this group.
2. The study was restricted to young children (8;0 to 14;11) with intellectual disabilities. The results can only be interpreted in a meaningful way for this group, because age and type of disability may have an effect on primary caregivers' perceptions of children's needs (Fournier, Davis, Ashweeta, Patnaik, Elliott, Dyer, Jasek & Phillips, 2010).

5.4 CLINICAL IMPLICATIONS

The most important finding of the study was that Afrikaans-speaking primary caregivers perceived that most of the human rights of their children with intellectual disabilities were met when basic needs were used as a proxy for human rights. The results from this study also provide additional evidence that primary caregivers considered school education and safety as the most important basic needs of their children. An important contribution is that the findings of this study with Afrikaans-speaking primary caregivers of children with intellectual disabilities are generally consistent with other studies worldwide, despite cultural and language differences (Bohrnstedt et al., 1981; Rogers & Wrightsman, 1978; General Mills, 1977). The results of the study also revealed evidence that the different rights which are grouped and linked with regard to the ICF-CY Environmental codes, the UNCRC and Maslow's Hierarchy of Needs, contributed to the fact that primary caregivers have specific perceptions of the needs and rights of their children with intellectual disabilities. Several factors added to the fact that primary caregivers considered certain needs more than they did others.

The results of this study may be useful to improve the understanding of primary caregivers' perception of their children's needs and to overcome social, legal, and practical barriers in claiming their human rights.

5.5 RECOMMENDATIONS FOR FURTHER RESEARCH

From the results of this study, some interesting tendencies were identified, which lead to the following recommendations for further research:

1. The questionnaire that was developed for the purpose of this study could be further refined in order to obtain a more comprehensive understanding of primary caregivers' perception of the basic needs of their children with intellectual disabilities (Shephard and Hosking, 1989). For example, the close link between basic needs and how they act as a proxy for human rights could be further explored.
2. Future research could be done on the African continent to investigate to which extent primary caregivers in other countries, perceive that basic needs of their children with intellectual disabilities' are met, as set out in the UNCRC. The African continent is home to a large number of persons with intellectual disabilities where more research, specifically with respect to their needs, is needed (Njenga, 2009).
3. This study used a homogeneous group of Afrikaans-speaking primary caregivers as participants, but it would be useful to follow up these findings by using participants from other language groups, because culture and language have an impact on perceptions (Cherney & Perry, 1996).
4. Further research could be done to compare parent's perceptions of rights to those of their children with ID, since limited studies have been done in which children's own voices are heard (Ruck et al., 1998).
5. It would be interesting to investigate primary caregivers' perception of their children's rights, by using participants whose children are younger than 8;0 or older than 14;11, since research has shown that age is an important variable in the perception of rights (Bohrstedt et al., 1981).

5.6 SUMMARY

This chapter concluded the research by summarizing the most important results with respect to the aim of the study. The study was critically evaluated in

terms of strengths and limitations, and clinical implications were discussed. Finally, suggestions for future research were made.

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Appendix A

Title registration

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Geagte mev Erasmus

TITELREGISTRASIE: STUDIERIGTING – MA AANVULLENDE EN ALTERNATIEWE KOMMUNIKASIE

Dit is vir my aangenaam om u mee te deel dat die volgende goedgekeur is:

ONDERWERP: An investigation into the realization of Children's Rights in South Africa: Perceptions of Afrikaans-speaking primary caregivers of children with intellectual disabilities

STUDIELEIER: Prof J Bornman

U aandag word in besonder op die volgende gevestig:

1. TERMYN VAN REGISTRASIE

- (a) U moet vir minstens een akademiese jaar as student vir die magistergraad geregistreer wees voordat die graad toegeken kan word.
- (b) U registrasie moet jaarliks voor April hernu word totdat u aan al die vereistes vir die magistergraad voldoen het. Geen herregistrasie sal na 31 Maart aanvaar word nie. U sal slegs geregtig wees op die leiding van u leier indien u jaarliks bewys van registrasie aan hom voorlê.

2. GOEDKEURING VIR INDIENING

Vir eksamendoeleindes moet u voldoende eksemplare vir elke eksaminator indien, tesame met 'n skriftelike verklaring van u leier dat hy/sy die indiening van die verhandeling goedkeur, sowel as 'n verklaring deur u, wat by Studenteadministrasie ingehandig word.

3. KENNISGEWING VOOR INDIENING

U moet my asseblief ten minste drie maande voordat u beplan om u verhandeling/skripsie in te dien van u voorneme in kennis stel.

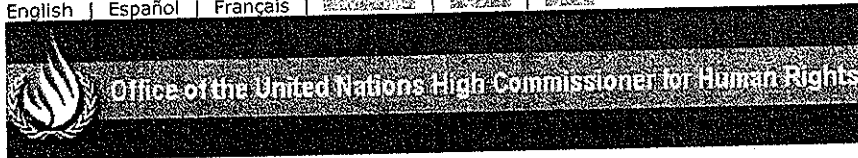
4. VOORSKRIFTE IN VERBAND MET DIE VOORBEREIDING VAN DIE VERHANDELING/SKRIPSIE ASOOK DIE SAMEVATTING IS OP DIE KEERSY VAN HIERDIE BRIEF UITEENGESIT.

Die uwe

nms DEKAAN: FAKULTEIT GEESTESWETENSKAPPE

Appendix B

Preamble: Convention on the Rights of the Child

[English](#) | [Español](#) | [Français](#) | [Arabic](#) | [Chinese](#) | [Russian](#)

[Countries](#) | [Issues](#) | [International Law](#) | [Human Rights Bodies](#) | [About OHCHR](#)

Related information:

Convention on the Rights of the Child

[Committee on the Rights of the Child \(CRC\)](#)

Text in PDF Format

[Status of ratification, Declarations and reservations](#)
Adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989
Entry into force 2 September 1990, in accordance with article 49

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[Preamble](#)
Preamble

The States Parties to the present Convention,

[Part I](#)
[Article 1](#)

Considering that, in accordance with the principles proclaimed in the Charter of the United Nations, recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

[Article 2](#)
[Article 3](#)

Bearing in mind that the peoples of the United Nations have, in the Charter, reaffirmed their faith in fundamental human rights and in the dignity and worth of the human person, and have determined to promote social progress and better standards of life in larger freedom,

[Article 4](#)
[Article 5](#)
[Article 6](#)

Recognizing that the United Nations has, in the Universal Declaration of Human Rights and in the International Covenants on Human Rights, proclaimed and agreed that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status,

[Article 7](#)
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Recalling that, in the Universal Declaration of Human Rights, the United Nations has proclaimed that childhood is entitled to special care and assistance,

[Article 11](#)
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Recognizing that the child, for the full and harmonious development of his or her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding,

[Article 18](#)
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Considering that the child should be fully prepared to live an individual life in society, and brought up in the spirit of the ideals proclaimed in the Charter of the United Nations, and in particular in the spirit of peace, dignity, tolerance, freedom, equality and solidarity,

[Article 23](#)
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Bearing in mind that the need to extend particular care to the child has been stated in the Geneva Declaration of the Rights of the Child of 1924 and in the Declaration of the Rights of the Child adopted by the General Assembly on 20 November 1959 and recognized in the Universal Declaration of Human Rights, in the International Covenant on Civil and Political Rights (in particular in articles 23 and 24), in the International Covenant on Economic, Social and Cultural Rights (in particular in article 10) and in the statutes and relevant instruments of specialized agencies and international organizations concerned with the welfare of children,

Bearing in mind that, as indicated in the Declaration of the Rights of the Child, "the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth",

Recalling the provisions of the Declaration on Social and Legal Principles relating to the Protection and Welfare of Children, with Special Reference to Foster Placement and Adoption Nationally and Internationally; the United Nations Standard Minimum Rules for the Administration of Juvenile Justice (The Beijing Rules); and the Declaration on the Protection of Women and Children in Emergency and Armed Conflict, Recognizing that, in all countries in the world, there are children living in exceptionally difficult conditions, and that such children need special consideration,

Taking due account of the importance of the traditions and cultural values of each people for the protection and harmonious development of the child, Recognizing the importance of international co-operation for improving the living conditions of children in every country, in particular in the developing countries,

Article 26

Have agreed as follows:

Article 27

PART I

Article 28

Article 1

Article 29

For the purposes of the present Convention, a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier.

Article 30

Article 2

Article 31

Article 32

1. States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.

Article 33

Article 34

2. States Parties shall take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members.

Article 35

Article 3

Article 36

Article 37

1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

Article 38

Article 39

2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.

Article 40

Article 41

3. States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.

Part II

Article 42

Article 4

Article 43

Article 44

States Parties shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention. With regard to economic, social and cultural rights, States Parties shall undertake such measures to the maximum extent of their available resources and, where needed, within the framework of international co-operation.

Article 45

Part III

Article 46

Article 5

Article 47

States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention.

Article 48

Article 49

Article 50

Article 6

Article 51

1. States Parties recognize that every child has the inherent right to life.

Article 52

2. States Parties shall ensure to the maximum extent possible the survival and development of the child.

Article 53

Article 54

Article 7

1. The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by his or her parents.

2. States Parties shall ensure the implementation of these rights in accordance with their national law and their obligations under the relevant international instruments in this field, in particular where the child would otherwise be stateless.

Article 8

1. States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference.

2. Where a child is illegally deprived of some or all of the elements of his or her identity, States Parties shall provide appropriate assistance and protection, with a view to re-establishing speedily his or her identity.

Article 9

1. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. Such determination may be necessary in a particular case such as one involving abuse or neglect of the child by the parents, or one where the parents are living separately and a decision must be made as to the child's place of residence.

2. In any proceedings pursuant to paragraph 1 of the present article, all interested parties shall be given an opportunity to participate in the proceedings and make their views known.

3. States Parties shall respect the right of the child who is separated from one or both parents to maintain personal relations and direct contact with both parents on a regular basis, except if it is contrary to the child's best interests.

4. Where such separation results from any action initiated by a State Party, such as the detention, imprisonment, exile, deportation or death (including death arising from any cause while the person is in the custody of the State) of one or both parents or of the child, that State Party shall, upon request, provide the parents, the child or, if appropriate, another member of the family with the essential information concerning the whereabouts of the absent member(s) of the family unless the provision of the information would be detrimental to the well-being of the child. States Parties shall further ensure that the submission of such a request shall of itself entail no adverse consequences for the person(s) concerned.

Article 10

1. In accordance with the obligation of States Parties under article 9, paragraph 1, applications by a child or his or her parents to enter or leave a State Party for the purpose of family reunification shall be dealt with by States Parties in a positive, humane and expeditious manner. States Parties shall further ensure that the submission of such a request shall entail no adverse consequences for the applicants and for the members of their family.

2. A child whose parents reside in different States shall have the right to maintain on a regular basis, save in exceptional circumstances personal relations and direct contacts with both parents. Towards that end and in accordance with the obligation of States Parties under article 9, paragraph 1, States Parties shall respect the right of the child and his or her parents to leave any country, including their own, and to enter their own country. The right to leave any country shall be subject only to such restrictions as are prescribed by law and which are necessary to protect the national security, public order (ordre public), public health or morals or the rights and freedoms of others and are consistent with the other rights recognized in the present Convention.

Article 11

1. States Parties shall take measures to combat the illicit transfer and non-return of children abroad.

2. To this end, States Parties shall promote the conclusion of bilateral or multilateral agreements or accession to existing agreements.

Article 12

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

Article 13

1. The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.

2. The exercise of this right may be subject to certain restrictions, but these shall only be such as are provided by law and are necessary:

(a) For respect of the rights or reputations of others; or

(b) For the protection of national security or of public order (ordre public), or of public health or morals.

Article 14

1. States Parties shall respect the right of the child to freedom of thought, conscience and religion.
2. States Parties shall respect the rights and duties of the parents and, when applicable, legal guardians, to provide direction to the child in the exercise of his or her right in a manner consistent with the evolving capacities of the child.
3. Freedom to manifest one's religion or beliefs may be subject only to such limitations as are prescribed by law and are necessary to protect public safety, order, health or morals, or the fundamental rights and freedoms of others.

Article 15

1. States Parties recognize the rights of the child to freedom of association and to freedom of peaceful assembly.
2. No restrictions may be placed on the exercise of these rights other than those imposed in conformity with the law and which are necessary in a democratic society in the interests of national security or public safety, public order (ordre public), the protection of public health or morals or the protection of the rights and freedoms of others.

Article 16

1. No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, or correspondence, nor to unlawful attacks on his or her honour and reputation.
2. The child has the right to the protection of the law against such interference or attacks.

Article 17

States Parties recognize the important function performed by the mass media and shall ensure that the child has access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health.

To this end, States Parties shall:

- (a) Encourage the mass media to disseminate information and material of social and cultural benefit to the child and in accordance with the spirit of article 29;
- (b) Encourage international co-operation in the production, exchange and dissemination of such information and material from a diversity of cultural, national and international sources;
- (c) Encourage the production and dissemination of children's books;
- (d) Encourage the mass media to have particular regard to the linguistic needs of the child who belongs to a minority group or who is indigenous;
- (e) Encourage the development of appropriate guidelines for the protection of the child from information and material injurious to his or her well-being, bearing in mind the provisions of articles 13 and 18.

Article 18

1. States Parties shall use their best efforts to ensure recognition of the principle that both parents have common responsibilities for the upbringing and development of the child. Parents or, as the case may be, legal guardians, have the primary responsibility for the upbringing and development of the child. The best interests of the child will be their basic concern.
2. For the purpose of guaranteeing and promoting the rights set forth in the present Convention, States Parties shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children.
3. States Parties shall take all appropriate measures to ensure that children of working parents have the right to benefit from child-care services and facilities for which they are eligible.

Article 19

1. States Parties shall take all appropriate legislative, administrative, social and educational

measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.

2. Such protective measures should, as appropriate, include effective procedures for the establishment of social programmes to provide necessary support for the child and for those who have the care of the child, as well as for other forms of prevention and for identification, reporting, referral, investigation, treatment and follow-up of instances of child maltreatment described heretofore, and, as appropriate, for judicial involvement.

Article 20

1. A child temporarily or permanently deprived of his or her family environment, or in whose own best interests cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the State.

2. States Parties shall in accordance with their national laws ensure alternative care for such a child.

3. Such care could include, inter alia, foster placement, kafalah of Islamic law, adoption or if necessary placement in suitable institutions for the care of children. When considering solutions, due regard shall be paid to the desirability of continuity in a child's upbringing and to the child's ethnic, religious, cultural and linguistic background.

Article 21

States Parties that recognize and/or permit the system of adoption shall ensure that the best interests of the child shall be the paramount consideration and they shall:

(a) Ensure that the adoption of a child is authorized only by competent authorities who determine, in accordance with applicable law and procedures and on the basis of all pertinent and reliable information, that the adoption is permissible in view of the child's status concerning parents, relatives and legal guardians and that, if required, the persons concerned have given their informed consent to the adoption on the basis of such counselling as may be necessary;

(b) Recognize that inter-country adoption may be considered as an alternative means of child's care, if the child cannot be placed in a foster or an adoptive family or cannot in any suitable manner be cared for in the child's country of origin;

(c) Ensure that the child concerned by inter-country adoption enjoys safeguards and standards equivalent to those existing in the case of national adoption;

(d) Take all appropriate measures to ensure that, in inter-country adoption, the placement does not result in improper financial gain for those involved in it;

(e) Promote, where appropriate, the objectives of the present article by concluding bilateral or multilateral arrangements or agreements, and endeavour, within this framework, to ensure that the placement of the child in another country is carried out by competent authorities or organs.

Article 22

1. States Parties shall take appropriate measures to ensure that a child who is seeking refugee status or who is considered a refugee in accordance with applicable international or domestic law and procedures shall, whether unaccompanied or accompanied by his or her parents or by any other person, receive appropriate protection and humanitarian assistance in the enjoyment of applicable rights set forth in the present Convention and in other international human rights or humanitarian instruments to which the said States are Parties.

2. For this purpose, States Parties shall provide, as they consider appropriate, co-operation in any efforts by the United Nations and other competent intergovernmental organizations or non-governmental organizations co-operating with the United Nations to protect and assist such a child and to trace the parents or other members of the family of any refugee child in order to obtain information necessary for reunification with his or her family. In cases where no parents or other members of the family can be found, the child shall be accorded the same protection as any other child permanently or temporarily deprived of his or her family environment for any reason, as set forth in the present Convention.

Article 23

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development

4. States Parties shall promote, in the spirit of International cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

Article 24

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:

(a) To diminish infant and child mortality;

(b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;

(c) To combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;

(d) To ensure appropriate pre-natal and post-natal health care for mothers;

(e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;

(f) To develop preventive health care, guidance for parents and family planning education and services.

3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.

4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.

Article 25

States Parties recognize the right of a child who has been placed by the competent authorities for the purposes of care, protection or treatment of his or her physical or mental health, to a periodic review of the treatment provided to the child and all other circumstances relevant to his or her placement.

Article 26

1. States Parties shall recognize for every child the right to benefit from social security, including social insurance, and shall take the necessary measures to achieve the full realization of this right in accordance with their national law.

2. The benefits should, where appropriate, be granted, taking into account the resources and the circumstances of the child and persons having responsibility for the maintenance of the child, as well as any other consideration relevant to an application for benefits made by or on behalf of the child.

Article 27

1. States Parties recognize the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development.

2. The parent(s) or others responsible for the child have the primary responsibility to secure,

within their abilities and financial capacities, the conditions of living necessary for the child's development.

3. States Parties, in accordance with national conditions and within their means, shall take appropriate measures to assist parents and others responsible for the child to implement this right and shall in case of need provide material assistance and support programmes, particularly with regard to nutrition, clothing and housing.

4. States Parties shall take all appropriate measures to secure the recovery of maintenance for the child from the parents or other persons having financial responsibility for the child, both within the State Party and from abroad. In particular, where the person having financial responsibility for the child lives in a State different from that of the child, States Parties shall promote the accession to international agreements or the conclusion of such agreements, as well as the making of other appropriate arrangements.

Article 28

1. States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular:

(a) Make primary education compulsory and available free to all;

(b) Encourage the development of different forms of secondary education, including general and vocational education, make them available and accessible to every child, and take appropriate measures such as the introduction of free education and offering financial assistance in case of need;

(c) Make higher education accessible to all on the basis of capacity by every appropriate means;

(d) Make educational and vocational information and guidance available and accessible to all children;

(e) Take measures to encourage regular attendance at schools and the reduction of drop-out rates.

2. States Parties shall take all appropriate measures to ensure that school discipline is administered in a manner consistent with the child's human dignity and in conformity with the present Convention.

3. States Parties shall promote and encourage international cooperation in matters relating to education, in particular with a view to contributing to the elimination of ignorance and illiteracy throughout the world and facilitating access to scientific and technical knowledge and modern teaching methods. In this regard, particular account shall be taken of the needs of developing countries.

Article 29

1. States Parties agree that the education of the child shall be directed to:

(a) The development of the child's personality, talents and mental and physical abilities to their fullest potential;

(b) The development of respect for human rights and fundamental freedoms, and for the principles enshrined in the Charter of the United Nations;

(c) The development of respect for the child's parents, his or her own cultural identity, language and values, for the national values of the country in which the child is living, the country from which he or she may originate, and for civilizations different from his or her own;

(d) The preparation of the child for responsible life in a free society, in the spirit of understanding, peace, tolerance, equality of sexes, and friendship among all peoples, ethnic, national and religious groups and persons of indigenous origin;

(e) The development of respect for the natural environment.

2. No part of the present article or article 28 shall be construed so as to interfere with the liberty of individuals and bodies to establish and direct educational institutions, subject always to the observance of the principle set forth in paragraph 1 of the present article and to the requirements that the education given in such institutions shall conform to such minimum standards as may be laid down by the State.

Article 30

In those States in which ethnic, religious or linguistic minorities or persons of indigenous origin exist, a child belonging to such a minority or who is indigenous shall not be denied the right, in community with other members of his or her group, to enjoy his or her own culture, to profess and practise his or her own religion, or to use his or her own language.

Article 31

1. States Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.
2. States Parties shall respect and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity.

Article 32

1. States Parties recognize the right of the child to be protected from economic exploitation and from performing any work that is likely to be hazardous or to interfere with the child's education, or to be harmful to the child's health or physical, mental, spiritual, moral or social development.
2. States Parties shall take legislative, administrative, social and educational measures to ensure the implementation of the present article. To this end, and having regard to the relevant provisions of other international instruments, States Parties shall in particular:
 - (a) Provide for a minimum age or minimum ages for admission to employment;
 - (b) Provide for appropriate regulation of the hours and conditions of employment;
 - (c) Provide for appropriate penalties or other sanctions to ensure the effective enforcement of the present article.

Article 33

States Parties shall take all appropriate measures, including legislative, administrative, social and educational measures, to protect children from the illicit use of narcotic drugs and psychotropic substances as defined in the relevant international treaties, and to prevent the use of children in the illicit production and trafficking of such substances.

Article 34

States Parties undertake to protect the child from all forms of sexual exploitation and sexual abuse. For these purposes, States Parties shall in particular take all appropriate national, bilateral and multilateral measures to prevent:

- (a) The inducement or coercion of a child to engage in any unlawful sexual activity;
- (b) The exploitative use of children in prostitution or other unlawful sexual practices;
- (c) The exploitative use of children in pornographic performances and materials.

Article 35

States Parties shall take all appropriate national, bilateral and multilateral measures to prevent the abduction of, the sale of or traffic in children for any purpose or in any form.

Article 36

States Parties shall protect the child against all other forms of exploitation prejudicial to any aspects of the child's welfare.

Article 37

States Parties shall ensure that:

- (a) No child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment. Neither capital punishment nor life imprisonment without possibility of release shall be imposed for offences committed by persons below eighteen years of age;
- (b) No child shall be deprived of his or her liberty unlawfully or arbitrarily. The arrest, detention or imprisonment of a child shall be in conformity with the law and shall be used only as a measure of last resort and for the shortest appropriate period of time;
- (c) Every child deprived of liberty shall be treated with humanity and respect for the inherent dignity of the human person, and in a manner which takes into account the needs of persons of his or her age. In particular, every child deprived of liberty shall be separated from adults unless it is considered in the child's best interest not to do so and shall have the right to maintain contact with his or her family through correspondence and visits, save in exceptional circumstances;

(d) Every child deprived of his or her liberty shall have the right to prompt access to legal and other appropriate assistance, as well as the right to challenge the legality of the deprivation of his or her liberty before a court or other competent, independent and impartial authority, and to a prompt decision on any such action.

Article 38

1. States Parties undertake to respect and to ensure respect for rules of international humanitarian law applicable to them in armed conflicts which are relevant to the child.
2. States Parties shall take all feasible measures to ensure that persons who have not attained the age of fifteen years do not take a direct part in hostilities.
3. States Parties shall refrain from recruiting any person who has not attained the age of fifteen years into their armed forces. In recruiting among those persons who have attained the age of fifteen years but who have not attained the age of eighteen years, States Parties shall endeavour to give priority to those who are oldest.
4. In accordance with their obligations under international humanitarian law to protect the civilian population in armed conflicts, States Parties shall take all feasible measures to ensure protection and care of children who are affected by an armed conflict.

Article 39

States Parties shall take all appropriate measures to promote physical and psychological recovery and social reintegration of a child victim of: any form of neglect, exploitation, or abuse; torture or any other form of cruel, inhuman or degrading treatment or punishment; or armed conflicts. Such recovery and reintegration shall take place in an environment which fosters the health, self-respect and dignity of the child.

Article 40

1. States Parties recognize the right of every child alleged as, accused of, or recognized as having infringed the penal law to be treated in a manner consistent with the promotion of the child's sense of dignity and worth, which reinforces the child's respect for the human rights and fundamental freedoms of others and which takes into account the child's age and the desirability of promoting the child's reintegration and the child's assuming a constructive role in society.
2. To this end, and having regard to the relevant provisions of international instruments, States Parties shall, in particular, ensure that:
 - (a) No child shall be alleged as, be accused of, or recognized as having infringed the penal law by reason of acts or omissions that were not prohibited by national or international law at the time they were committed;
 - (b) Every child alleged as or accused of having infringed the penal law has at least the following guarantees:
 - (i) To be presumed innocent until proven guilty according to law;
 - (ii) To be informed promptly and directly of the charges against him or her, and, if appropriate, through his or her parents or legal guardians, and to have legal or other appropriate assistance in the preparation and presentation of his or her defence;
 - (iii) To have the matter determined without delay by a competent, independent and impartial authority or judicial body in a fair hearing according to law, in the presence of legal or other appropriate assistance and, unless it is considered not to be in the best interest of the child, in particular, taking into account his or her age or situation, his or her parents or legal guardians;
 - (iv) Not to be compelled to give testimony or to confess guilt; to examine or have examined adverse witnesses and to obtain the participation and examination of witnesses on his or her behalf under conditions of equality;
 - (v) If considered to have infringed the penal law, to have this decision and any measures imposed in consequence thereof reviewed by a higher competent, independent and impartial authority or judicial body according to law;
 - (vi) To have the free assistance of an interpreter if the child cannot understand or speak the language used;
 - (vii) To have his or her privacy fully respected at all stages of the proceedings.
3. States Parties shall seek to promote the establishment of laws, procedures, authorities and institutions specifically applicable to children alleged as, accused of, or recognized as having infringed the penal law, and, in particular:

(a) The establishment of a minimum age below which children shall be presumed not to have the capacity to infringe the penal law;

(b) Whenever appropriate and desirable, measures for dealing with such children without resorting to judicial proceedings, providing that human rights and legal safeguards are fully respected. 4. A variety of dispositions, such as care, guidance and supervision orders; counselling; probation; foster care; education and vocational training programmes and other alternatives to institutional care shall be available to ensure that children are dealt with in a manner appropriate to their well-being and proportionate both to their circumstances and the offence.

Article 41

Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of the child and which may be contained in:

(a) The law of a State party; or

(b) International law in force for that State.

PART II

Article 42

States Parties undertake to make the principles and provisions of the Convention widely known, by appropriate and active means, to adults and children alike.

Article 43

1. For the purpose of examining the progress made by States Parties in achieving the realization of the obligations undertaken in the present Convention, there shall be established a Committee on the Rights of the Child, which shall carry out the functions hereinafter provided.

2. The Committee shall consist of eighteen experts of high moral standing and recognized competence in the field covered by this Convention. The members of the Committee shall be elected by States Parties from among their nationals and shall serve in their personal capacity, consideration being given to equitable geographical distribution, as well as to the principal legal systems.

3. The members of the Committee shall be elected by secret ballot from a list of persons nominated by States Parties. Each State Party may nominate one person from among its own nationals.

4. The initial election to the Committee shall be held no later than six months after the date of the entry into force of the present Convention and thereafter every second year. At least four months before the date of each election, the Secretary-General of the United Nations shall address a letter to States Parties inviting them to submit their nominations within two months. The Secretary-General shall subsequently prepare a list in alphabetical order of all persons thus nominated, indicating States Parties which have nominated them, and shall submit it to the States Parties to the present Convention.

5. The elections shall be held at meetings of States Parties convened by the Secretary-General at United Nations Headquarters. At those meetings, for which two thirds of States Parties shall constitute a quorum, the persons elected to the Committee shall be those who obtain the largest number of votes and an absolute majority of the votes of the representatives of States Parties present and voting.

6. The members of the Committee shall be elected for a term of four years. They shall be eligible for re-election if renominated. The term of five of the members elected at the first election shall expire at the end of two years; immediately after the first election, the names of these five members shall be chosen by lot by the Chairman of the meeting.

7. If a member of the Committee dies or resigns or declares that for any other cause he or she can no longer perform the duties of the Committee, the State Party which nominated the member shall appoint another expert from among its nationals to serve for the remainder of the term, subject to the approval of the Committee.

8. The Committee shall establish its own rules of procedure.

9. The Committee shall elect its officers for a period of two years.

10. The meetings of the Committee shall normally be held at United Nations Headquarters or at any other convenient place as determined by the Committee. The Committee shall normally meet annually. The duration of the meetings of the Committee shall be determined, and reviewed, if necessary, by a meeting of the States Parties to the present Convention, subject to the approval of the General Assembly.

11. The Secretary-General of the United Nations shall provide the necessary staff and facilities for the effective performance of the functions of the Committee under the present Convention.

12. With the approval of the General Assembly, the members of the Committee established under the present Convention shall receive emoluments from United Nations resources on such terms and conditions as the Assembly may decide.

Article 44

1. States Parties undertake to submit to the Committee, through the Secretary-General of the United Nations, reports on the measures they have adopted which give effect to the rights recognized herein and on the progress made on the enjoyment of those rights

(a) Within two years of the entry into force of the Convention for the State Party concerned;

(b) Thereafter every five years.

2. Reports made under the present article shall indicate factors and difficulties, if any, affecting the degree of fulfilment of the obligations under the present Convention. Reports shall also contain sufficient information to provide the Committee with a comprehensive understanding of the implementation of the Convention in the country concerned.

3. A State Party which has submitted a comprehensive initial report to the Committee need not, in its subsequent reports submitted in accordance with paragraph 1 (b) of the present article, repeat basic information previously provided.

4. The Committee may request from States Parties further information relevant to the implementation of the Convention.

5. The Committee shall submit to the General Assembly, through the Economic and Social Council, every two years, reports on its activities.

6. States Parties shall make their reports widely available to the public in their own countries.

Article 45

In order to foster the effective implementation of the Convention and to encourage international co-operation in the field covered by the Convention:

(a) The specialized agencies, the United Nations Children's Fund, and other United Nations organs shall be entitled to be represented at the consideration of the implementation of such provisions of the present Convention as fall within the scope of their mandate. The Committee may invite the specialized agencies, the United Nations Children's Fund and other competent bodies as it may consider appropriate to provide expert advice on the implementation of the Convention in areas falling within the scope of their respective mandates. The Committee may invite the specialized agencies, the United Nations Children's Fund, and other United Nations organs to submit reports on the implementation of the Convention in areas falling within the scope of their activities;

(b) The Committee shall transmit, as it may consider appropriate, to the specialized agencies, the United Nations Children's Fund and other competent bodies, any reports from States Parties that contain a request, or indicate a need, for technical advice or assistance, along with the Committee's observations and suggestions, if any, on these requests or indications;

(c) The Committee may recommend to the General Assembly to request the Secretary-General to undertake on its behalf studies on specific issues relating to the rights of the child;

(d) The Committee may make suggestions and general recommendations based on information received pursuant to articles 44 and 45 of the present Convention. Such suggestions and general recommendations shall be transmitted to any State Party concerned and reported to the General Assembly, together with comments, if any, from States Parties.

PART III

Article 46

The present Convention shall be open for signature by all States.

Article 47

The present Convention is subject to ratification. Instruments of ratification shall be deposited with the Secretary-General of the United Nations.

Article 48

The present Convention shall remain open for accession by any State. The instruments of accession shall be deposited with the Secretary-General of the United Nations.

Article 49

1. The present Convention shall enter into force on the thirtieth day following the date of deposit with the Secretary-General of the United Nations of the twentieth instrument of ratification or accession.
2. For each State ratifying or acceding to the Convention after the deposit of the twentieth instrument of ratification or accession, the Convention shall enter into force on the thirtieth day after the deposit by such State of its instrument of ratification or accession.

Article 50

1. Any State Party may propose an amendment and file it with the Secretary-General of the United Nations. The Secretary-General shall thereupon communicate the proposed amendment to States Parties, with a request that they indicate whether they favour a conference of States Parties for the purpose of considering and voting upon the proposals. In the event that, within four months from the date of such communication, at least one third of the States Parties favour such a conference, the Secretary-General shall convene the conference under the auspices of the United Nations. Any amendment adopted by a majority of States Parties present and voting at the conference shall be submitted to the General Assembly for approval.
2. An amendment adopted in accordance with paragraph 1 of the present article shall enter into force when it has been approved by the General Assembly of the United Nations and accepted by a two-thirds majority of States Parties.
3. When an amendment enters into force, it shall be binding on those States Parties which have accepted it, other States Parties still being bound by the provisions of the present Convention and any earlier amendments which they have accepted.

Article 51

1. The Secretary-General of the United Nations shall receive and circulate to all States the text of reservations made by States at the time of ratification or accession.
2. A reservation incompatible with the object and purpose of the present Convention shall not be permitted.
3. Reservations may be withdrawn at any time by notification to that effect addressed to the Secretary-General of the United Nations, who shall then inform all States. Such notification shall take effect on the date on which it is received by the Secretary-General.

Article 52

A State Party may denounce the present Convention by written notification to the Secretary-General of the United Nations. Denunciation becomes effective one year after the date of receipt of the notification by the Secretary-General.

Article 53

The Secretary-General of the United Nations is designated as the depositary of the present Convention.

Article 54

The original of the present Convention, of which the Arabic, Chinese, English, French, Russian and Spanish texts are equally authentic, shall be deposited with the Secretary-General of the United Nations. In witness thereof the undersigned plenipotentiaries, being duly authorized thereto by their respective Governments, have signed the present Convention.

^{1/} The General Assembly, in its resolution 50/155 of 21 December 1995, approved the amendment to article 43, paragraph 2, of the Convention on the Rights of the Child, replacing the word "ten" with the word "eighteen". The amendment entered into force on 18 November 2002 when it had been accepted by a two-thirds majority of the States parties (128 out of 191).

Appendix C

C1: Afrikaans survey instrument

C2: English survey instrument

C3: Original questionnaire developed by Simeonsson
and Granlund (2011)

OUER VRAELYS VIR PRIMÊRE VERSORGER

Dui aan in watter mate die volgende vrae van toepassing is op u kind. Plaas asseblief u kruisie (x) teenoor die mees relevante opsie. Daar is geen regte of verkeerde antwoorde nie. Voltooi asb ALLE vrae. Dankie vir u tyd en hulp.

		Kode van deelnemer: <input style="width: 20px; height: 15px;" type="text"/> <input style="width: 20px; height: 15px;" type="text"/>
		Kode van skool: <input style="width: 20px; height: 15px;" type="text"/>
1. Is u die gestremde kind se primêre versorger?	<input style="width: 40px; height: 15px;" type="text"/>	V1 <input style="width: 20px; height: 15px;" type="text"/>
2. Wat is u verwantskap met die gestremde kind?		V2 <input style="width: 20px; height: 15px;" type="text"/>
Vader	<input style="width: 40px; height: 15px;" type="text"/>	
Moeder	<input style="width: 40px; height: 15px;" type="text"/>	
Ander (spesifiseer asb) _____	<input style="width: 40px; height: 15px;" type="text"/>	
3. In watter taal maak u, u kinders groot?		V3 <input style="width: 20px; height: 15px;" type="text"/>
Afrikaans	<input style="width: 40px; height: 15px;" type="text"/>	
Engels	<input style="width: 40px; height: 15px;" type="text"/>	
Beide Afrikaans en Engels	<input style="width: 40px; height: 15px;" type="text"/>	
Ander (spesifiseer asb) _____	<input style="width: 40px; height: 15px;" type="text"/>	
4. Wat is u huidige verhoudingstatus?		V4 <input style="width: 20px; height: 15px;" type="text"/>
Getroud	<input style="width: 40px; height: 15px;" type="text"/>	
In 'n vaste verhouding	<input style="width: 40px; height: 15px;" type="text"/>	
Enkelouer	<input style="width: 40px; height: 15px;" type="text"/>	
Ander (spesifiseer asb) _____	<input style="width: 40px; height: 15px;" type="text"/>	
5. Wat is u huidige werkstatus?		V5 <input style="width: 20px; height: 15px;" type="text"/>
Werkloos	<input style="width: 40px; height: 15px;" type="text"/>	
Deeltydse werk	<input style="width: 40px; height: 15px;" type="text"/>	
Voltydse werk	<input style="width: 40px; height: 15px;" type="text"/>	
6. Wat is u ouderdom?		V6 <input style="width: 20px; height: 15px;" type="text"/>
21-30 jaar	<input style="width: 40px; height: 15px;" type="text"/>	
31-40 jaar	<input style="width: 40px; height: 15px;" type="text"/>	
41-50 jaar	<input style="width: 40px; height: 15px;" type="text"/>	
50+ jaar	<input style="width: 40px; height: 15px;" type="text"/>	

7. Wat is die hoogste opvoedkundige kwalifikasie wat u voltooi het?		V7	<input type="text"/>
Graad 10 of minder	<input type="text"/>		
Graad 12	<input type="text"/>		
1-4 jaar na skool	<input type="text"/>		
5-7 jaar na skool	<input type="text"/>		
8-10 jaar na skool	<input type="text"/>		
Ander (spesifiseer asb) _____	<input type="text"/>		
8. Wat is u totale huishoudelike inkomste per jaar?		V8	<input type="text"/>
Minder as R60 000 per jaar	<input type="text"/>		
Meer as R60 000 per jaar	<input type="text"/>		
9. Hoeveel persone woon in u huis?	<input type="text"/>	V9	<input type="text"/>
10. Dui asb. aan hoeveel ander kinders in u huis woon tussen die volgende ouderdomme.		V10	<input type="text"/>
1 jaar en 2 jaar	<input type="text"/>		
3 jaar en 4 jaar	<input type="text"/>		
Ouer as 5 jaar	<input type="text"/>		
11. Wat is die geslag van u gestremde kind?		V11	<input type="text"/>
Manlik	<input type="text"/>		
Vroulik	<input type="text"/>		
12. Hoe oud is u gestremde kind?		V12	<input type="text"/>
_____ Jaar _____ Maande	<input type="text"/>		
13. Het u gestremde kind 'n geboortesertifikaat?	<input type="text"/> Ja <input type="text"/> Nee	V13	<input type="text"/>
14. Was u kind reeds met geboorte gestremd?	<input type="text"/> Ja <input type="text"/> Nee	V14	<input type="text"/>
15. Het u gestremde kind toegang tot mediese dienste?	<input type="text"/> Ja <input type="text"/> Nee	V15	<input type="text"/>
16. Vergeleke met ander kinders, het u kind later begin sit, staan of loop?	<input type="text"/> Ja <input type="text"/> Nee	V16	<input type="text"/>
17. Vergeleke met ander kinders, het u kind probleme om te sien in die dag of in die nag?	<input type="text"/> Ja <input type="text"/> Nee	V17	<input type="text"/>
Indien nee, het u kind by die huis iets soos 'n bril om hom/haar te help sien?	<input type="text"/> Ja <input type="text"/> Nee	V18	<input type="text"/>

18. Ondervind u kind gehoorprobleme?	<input type="checkbox"/> Ja <input type="checkbox"/> Nee	V19 <input type="checkbox"/>
Indien ja, het u kind iets soos 'n gehoor-apparaat of kogleëre inplanting om hom/haar te help hoor?	<input type="checkbox"/> Ja <input type="checkbox"/> Nee	V20 <input type="checkbox"/>
19. Verstaan u kind wanneer opdragte aan hom/haar gegee word?	<input type="checkbox"/> Ja <input type="checkbox"/> Nee	V21 <input type="checkbox"/>
Indien nee, het u kind iemand by die huis wat hom/haar help om instruksies te verstaan?	<input type="checkbox"/> Ja <input type="checkbox"/> Nee	V22 <input type="checkbox"/>
20. Ondervind u kind probleme om te loop of om sy/haar arms te beweeg, of het hy/sy ander swakhede en/of stramheid in die arms en bene?	<input type="checkbox"/> Ja <input type="checkbox"/> Nee	V23 <input type="checkbox"/>
Indien ja, het u kind by die huis iets soos 'n rolstoel of loopraam wat hom/haar help om rond te beweeg?	<input type="checkbox"/> Ja <input type="checkbox"/> Nee	V24 <input type="checkbox"/>
21. Kry u kind soms epileptiese aanvalle, stuipe of verloor hy/sy, sy/haar bewussyn?	<input type="checkbox"/> Ja <input type="checkbox"/> Nee	V25 <input type="checkbox"/>
Indien ja, kry u kind by die huis die nodige medikasie?	<input type="checkbox"/> Ja <input type="checkbox"/> Nee	V26 <input type="checkbox"/>
22. Kan u kind praat, m.a.w. (hom/haarself verstaanbaar maak deur	<input type="checkbox"/> Ja <input type="checkbox"/> Nee	V27 <input type="checkbox"/>
Indien nee, het u kind by die huis iets soos 'n kommunikasiebord om hom/haar te help praat?	<input type="checkbox"/> Ja <input type="checkbox"/> Nee	V28 <input type="checkbox"/>
23. Leer u kind vaardighede aan op dieselfde manier as ander kinders van sy/haar ouderdom?	<input type="checkbox"/> Ja <input type="checkbox"/> Nee	V29 <input type="checkbox"/>
24. Verskil u kind se spraak op enige wyse van die normale (nie duidelik genoeg vir mense buite die huiskring nie?)	<input type="checkbox"/> Ja <input type="checkbox"/> Nee	V30 <input type="checkbox"/>
25. Vergeleke met ander kinders van sy/haar ouderdom, lyk u kind op enige wyse verstandelik agter, gestrem of stadig?	<input type="checkbox"/> Ja <input type="checkbox"/> Nee	V31 <input type="checkbox"/>

Dui aan in watter mate die volgende vrae van toepassing is op u kind. Merk u keuse met 'n kruisie (x) in die toepaslike blokkie.

26. Het u kind by die huis skoon water om te drink?	Altyd	Soms	Selde	Nooit	V32
27. Het u kind by die huis kos om te eet?	Altyd	Soms	Selde	Nooit	V33
28. Het u kind by die huis 'n plek om te slaap?	Altyd	Soms	Selde	Nooit	V34
29. Het u kind by die huis iets om mee te speel?	Altyd	Soms	Selde	Nooit	V35
30. Hou u kind by die huis daarvan as mense vir hom/haar kwaad word?	Altyd	Soms	Selde	Nooit	V36
32. Is daar iemand by die huis wat na u kind omsien?	Altyd	Soms	Selde	Nooit	V37
33. Het u kind by die huis vriende om mee te speel?	Altyd	Soms	Selde	Nooit	V38
34. Is u van mening dat u kind na sy/haar beste geplaas is in hierdie skool?	Altyd	Soms	Selde	Nooit	V39

35. Is u van mening dat u kind regte het?	Ja	Nee	V40
36. Indien u "ja" op vraag 35 geantwoord het, lys asseblief van die kinderregte waaraan u kan dink in die volgorde van belangrikheid.			
i.....			V41
ii.....			V42
iii.....			V43
vi.....			V44
v.....			V45
vi.....			V46

PRIMARY CAREGIVER QUESTIONNAIRE

Thank you for participating in our study. Please fill out all of the questions below.

1. Are you the primary caregiver of the child with a disability?	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; text-align: center;">yes</td> <td style="width: 50%; text-align: center;">no</td> </tr> </table>	yes	no	V1 <input style="width: 30px; height: 20px;" type="checkbox"/>
yes	no			
2. What is your relationship with the child with the disability?				
Father	<input style="width: 60px; height: 20px;" type="checkbox"/>	V2 <input style="width: 30px; height: 20px;" type="checkbox"/>		
Mother	<input style="width: 60px; height: 20px;" type="checkbox"/>			
other (please specify) _____	<input style="width: 60px; height: 20px;" type="checkbox"/>			
3. In what language do you raise your children?				
Afrikaans	<input style="width: 60px; height: 20px;" type="checkbox"/>	V3 <input style="width: 30px; height: 20px;" type="checkbox"/>		
English	<input style="width: 60px; height: 20px;" type="checkbox"/>			
Both Afrikaans and English	<input style="width: 60px; height: 20px;" type="checkbox"/>			
Other (Please specify) _____	<input style="width: 60px; height: 20px;" type="checkbox"/>			
4. What is your current relationship status?				
Married	<input style="width: 60px; height: 20px;" type="checkbox"/>	V4 <input style="width: 30px; height: 20px;" type="checkbox"/>		
In a constant relationship	<input style="width: 60px; height: 20px;" type="checkbox"/>			
Single parent	<input style="width: 60px; height: 20px;" type="checkbox"/>			
Other (Please specify) _____	<input style="width: 60px; height: 20px;" type="checkbox"/>			
5. What is your current work status?				
Unemployed	<input style="width: 60px; height: 20px;" type="checkbox"/>	V5 <input style="width: 30px; height: 20px;" type="checkbox"/>		
Part time employed	<input style="width: 60px; height: 20px;" type="checkbox"/>			
Full time employed	<input style="width: 60px; height: 20px;" type="checkbox"/>			
6. What is your age?	<input style="width: 60px; height: 20px;" type="checkbox"/>			
7. What is the highest educational qualification that you completed?				
Grade 10 or less	<input style="width: 60px; height: 20px;" type="checkbox"/>	V7 <input style="width: 30px; height: 20px;" type="checkbox"/>		
Grade 12	<input style="width: 60px; height: 20px;" type="checkbox"/>			
1-4 years after school	<input style="width: 60px; height: 20px;" type="checkbox"/>			
5-7 years after school	<input style="width: 60px; height: 20px;" type="checkbox"/>			
8-10 years after school	<input style="width: 60px; height: 20px;" type="checkbox"/>			
Other (please specify) _____	<input style="width: 60px; height: 20px;" type="checkbox"/>			
8. What is the total income of your household per annum?				
Less than R60 000 per annum	<input style="width: 60px; height: 20px;" type="checkbox"/>	V8 <input style="width: 30px; height: 20px;" type="checkbox"/>		
More than R60 000 per annum	<input style="width: 60px; height: 20px;" type="checkbox"/>			

9. How many people are living in your house?	<input style="width: 80px; height: 20px;" type="text"/>	V9 <input style="width: 40px; height: 20px;" type="text"/>				
10. Please indicate how many children, according to each age group, are living in your house?						
Children 1 to 2 years	<input style="width: 80px; height: 20px;" type="text"/>	V10 <input style="width: 40px; height: 20px;" type="text"/>				
Children 3 to 4 years	<input style="width: 80px; height: 20px;" type="text"/>					
Children older than 5 years	<input style="width: 80px; height: 20px;" type="text"/>					
11. What is the gender of your child with a disability?						
Male	<input style="width: 80px; height: 20px;" type="text"/>	V11 <input style="width: 40px; height: 20px;" type="text"/>				
Female	<input style="width: 80px; height: 20px;" type="text"/>					
12. How old is your child with a disability? _____ Years _____ Months						
	<input style="width: 80px; height: 20px;" type="text"/>	V12 <input style="width: 40px; height: 20px;" type="text"/>				
13. Does your child with the disability have a birth certificate?	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; text-align: center; padding: 2px;">yes</td> <td style="width: 50%; text-align: center; padding: 2px;">no</td> </tr> </table>	yes	no	V13 <input style="width: 40px; height: 20px;" type="text"/>		
yes	no					
14. Did your child at birth already have the disability?	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; text-align: center; padding: 2px;">yes</td> <td style="width: 50%; text-align: center; padding: 2px;">no</td> </tr> </table>	yes	no	V14 <input style="width: 40px; height: 20px;" type="text"/>		
yes	no					
15. Does your child with the disability have access to medical services?	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; text-align: center; padding: 2px;">yes</td> <td style="width: 50%; text-align: center; padding: 2px;">no</td> </tr> </table>	yes	no	V15 <input style="width: 40px; height: 20px;" type="text"/>		
yes	no					
16. When comparing your child with other children, did the child sit, stand and walk later than other children?	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; text-align: center; padding: 2px;">yes</td> <td style="width: 50%; text-align: center; padding: 2px;">no</td> </tr> </table>	yes	no	V16 <input style="width: 40px; height: 20px;" type="text"/>		
yes	no					
17. When comparing with other children, does your child have problems seeing during the day or at night?	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; text-align: center; padding: 2px;">yes</td> <td style="width: 50%; text-align: center; padding: 2px;">no</td> </tr> </table>	yes	no	V17 <input style="width: 40px; height: 20px;" type="text"/>		
yes	no					
If yes, does your child have something like glasses at home to help him/her to see?	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 25%; text-align: center; padding: 2px;">always</td> <td style="width: 25%; text-align: center; padding: 2px;">sometimes</td> <td style="width: 25%; text-align: center; padding: 2px;">seldom</td> <td style="width: 25%; text-align: center; padding: 2px;">never</td> </tr> </table>	always	sometimes	seldom	never	V18 <input style="width: 40px; height: 20px;" type="text"/>
always	sometimes	seldom	never			
18. Does your child experience hearing problems?	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; text-align: center; padding: 2px;">yes</td> <td style="width: 50%; text-align: center; padding: 2px;">no</td> </tr> </table>	yes	no	V19 <input style="width: 40px; height: 20px;" type="text"/>		
yes	no					
If yes, does your child have something like a hearing aid or cochlear implant to help him/her hear?	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 25%; text-align: center; padding: 2px;">always</td> <td style="width: 25%; text-align: center; padding: 2px;">sometimes</td> <td style="width: 25%; text-align: center; padding: 2px;">seldom</td> <td style="width: 25%; text-align: center; padding: 2px;">never</td> </tr> </table>	always	sometimes	seldom	never	V20 <input style="width: 40px; height: 20px;" type="text"/>
always	sometimes	seldom	never			

19. Does your child understand when instructions are given to him/her?

yes	no
-----	----

V21

If no, does your child have someone at home to help him/her to understand instructions?

always	sometimes	seldom	never
--------	-----------	--------	-------

V22

20. Does your child experience problems to walk or move his/her arms or have weakness and/or stiffness in his/her arms and legs?

yes	no
-----	----

V23

If yes, does your child have something like a wheelchair or walking frame at home to help him/her to move around?

always	sometimes	seldom	never
--------	-----------	--------	-------

V24

21. Does your child get epileptic fits, convulsions or does he/she lose consciousness?

yes	no
<input type="checkbox"/>	<input type="checkbox"/>

V25

If yes, does your child get the necessary medication at home?

always	sometimes	seldom	never
--------	-----------	--------	-------

V26

22. Can your child talk, or make him/herself understandable by using recognizable words?

yes	no
-----	----

V27

If no, does your child have something like a communication board at home to help him/her speak?

always	sometimes	seldom	never
--------	-----------	--------	-------

V28

23. Does your child learn skills in the same manner as other children his/her age?

yes	no
-----	----

V29

24. Does your child's speech differ at all from normal speech (not clear enough for people outside the household to understand)?

yes	no
-----	----

V30

25. In comparison to other children of his/her age, does your child appear to be mentally behind, disabled or slow?					
<table border="1" style="display: inline-table; margin: 0 10px;"> <tr> <td style="padding: 2px 10px;">yes</td> <td style="padding: 2px 10px;">no</td> </tr> </table>	yes	no	<table border="1" style="display: inline-table;"> <tr> <td style="padding: 2px 10px;">V31</td> <td style="width: 30px; height: 20px;"></td> </tr> </table>	V31	
yes	no				
V31					

Indicate to what extent the following questions are applicable to your child. Mark with a cross (x) in the appropriate block

26. Does your child have clean water to drink at home?	always	sometimes	seldom	never	V32
27. Does your child have food to eat at home?	always	sometimes	seldom	never	V33
28. Does your child have his or her own bed to sleep in at home?	always	sometimes	seldom	never	V34
29. Does your child have something to play with at home?	always	sometimes	seldom	never	V35
30. Does your child like it if someone becomes angry at him/her angry at home?	always	sometimes	seldom	never	V36
32. Is there someone who cares for and protects your child at home?	always	sometimes	seldom	never	V37
33. Does your child have friends to play with at home?	always	sometimes	seldom	never	V38
34. Are you of opinion that this school is the best placement for your child?	always	sometimes	seldom	never	V39
35. Are you of opinion that your child has rights?			yes	no	V40
36. If you answered "yes" to question 35, please list in order of importance the child's rights that you can think of.					
i.....					V41
ii.....					V42
iii.....					V43
vi.....					V44
v.....					V45
vi.....					V46

Original Questionnaire developed by Simeonsson and Granlund (2011)

1. Does (name) have access to enough drink or food?
2. Are medicines available for (name) if and when needed?
3. Does (name) have a safe place to rest or sleep?
4. Does (name) have a safe place to sleep?
5. Does (name) have a safe place to play outside?
6. Compared with children his/her age, does (name) have other children to play with.
7. Compared with children his/her age, does (name) have parents or caregivers who provides regular care for him/her.
8. Does (name) have a birth certificate and documentation of identity?
9. If (name) has difficulty getting around, are devices or equipment available to help him/her?
10. If (name) has difficulty using hands and fingers, are devices or equipment available to help him/her?
11. If (name) has difficulty watching or seeing things, are glasses or other equipment available to help him/her?
12. If (name) has difficulty listening or hearing, are devices or equipment available to help him/her?
13. Compared with children his/her age, does (name) have a school to attend?
14. If (name) has difficulty to understand what to do or to follow instruction, do other people adjust to that to help him understand?

Appendix D

Letter of approval: Gauteng Department of Education



**UMnyango WezeMfundo
Department of Education**

**Lefapha la Thuto
Departement van Onderwys**

Enquiries: Diane Buntting (011) 843 6503

Date:	16 MARCH 2011
Name of Researcher:	ERASMUS MA
Address of Researcher:	P.O. Box 935
	Newlands
	Pretoria
	0041
Telephone Number:	012 420 3062 / 072 591 3083
Fax Number:	012 420 3063
Email address:	<u>alta.erasmus@up.ac.za</u>
Research Topic:	An investigation into the realisation of Children's Rights in South Africa: Perceptions of Afrikaans speaking primary caregivers of children with disabilities
Number and type of schools:	ONE PRIMARY SCHOOL AND FOUR LSEN SCHOOLS
District/s/HO	GAUTENG EAST; TSHWANE SOUTH AND TSHWANE NORTH

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved to conduct the research. A separate copy of this letter must be presented to both the School (both Principal and SGB) and the District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted.

Permission has been granted to proceed with the above study subject to the conditions listed below being met, and may be withdrawn should any of these conditions be flouted:

1. *The District/Head Office Senior Manager/s concerned must be presented with a copy of this letter that would indicate that the said researcher/s has/have been granted permission from the Gauteng Department of Education to conduct the research study.*
2. *The District/Head Office Senior Manager/s must be approached separately, and in writing, for permission to involve District/Head Office Officials in the project.*
3. *A copy of this letter must be forwarded to the school principal and the chairperson of the School Governing Body (SGB) that would indicate that the researcher/s have been granted permission from the Gauteng Department of Education to conduct the research study.*

4. *A letter / document that outlines the purpose of the research and the anticipated outcomes of such research must be made available to the principals, SGBs and District/Head Office Senior Managers of the schools and districts/offices concerned, respectively.*
5. *The Researcher will make every effort obtain the goodwill and co-operation of all the GDE officials, principals, and chairpersons of the SGBs, teachers and learners involved. Persons who offer their co-operation will not receive additional remuneration from the Department while those that opt not to participate will not be penalised in any way.*
6. *Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal (if at a school) and/or Director (if at a district/head office) must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage.*
7. *Research may only commence from the second week of February and must be concluded before the beginning of the last quarter of the academic year.*
8. *Items 6 and 7 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education.*
9. *It is the researcher's responsibility to obtain written parental consent of all learners that are expected to participate in the study.*
10. *The researcher is responsible for supplying and utilising his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions and/or the offices visited for supplying such resources.*
11. *The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research report without the written consent of each of these individuals and/or organisations.*
12. *On completion of the study the researcher must supply the Director: Knowledge Management & Research with one Hard Cover bound and an electronic copy of the research.*
13. *The researcher may be expected to provide short presentations on the purpose, findings and recommendations of his/her research to both GDE officials and the schools concerned.*
14. *Should the researcher have been involved with research at a school and/or a district/head office level, the Director concerned must also be supplied with a brief summary of the purpose, findings and recommendations of the research study.*

The Gauteng Department of Education wishes you well in this important undertaking and looks forward to examining the findings of your research study.

Kind regards



Shadrack Phele MIRMSA
 [Member of the Institute of Risk Management South Africa]
 CHIEF EDUCATION SPECIALIST: RESEARCH COORDINATION

16 March 2011

The contents of this letter has been read and understood by the researcher.	
Signature of Researcher:	
Date:	

Appendix E

Letter of ethical approval



21 October 2011

Dear Prof Bornman,

Project: An investigation into the realisation of children's rights in South Africa: perceptions of Afrikaans-speaking primary caregivers of children with disabilities
Researcher: MA Erasmus
Supervisor: Prof J Bornman
Department: Centre for Augmentative and Alternative Communication
Reference number: 10569686

Thank you for your response to the Committee's letter of 12 May 2011.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 20 October 2011. Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof. John Sharp
Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: john.sharp@up.ac.za

Appendix F

Letter requesting consent from school principal



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

5 Maart 2012

Skoolnaam

.....
.....
.....
.....

INSAKE TOESTEMMING VIR DIE UITVOERING VAN NAVORSING BY U SKOOL

NAVORSINGSONDERWERP

An investigation into the realization of Children's Rights in South Africa: Perceptions of Afrikaans-speaking primary caregivers of children with intellectual disabilities.

RASIONAAL VAN DIE STUDIE

Regdeur die wêreld word individue met gestremdhede gekonfronteer met noemenswaardige struikelblokke ten opsigte van hulle menseregte. Menseregte word gesien as die basiese vereiste vir instandhouding van menswaardigheid en individuele vryheid. Die *United Nations Convention* bring onder ons aandag dat kinders met gestremdhede die reg het tot 'n mening wat gebaseer is op verworwe inligting en dat sodanige mening oorweeg moet word met inagneming van hulle ouderdom, vlak van volwassenheid en vermoëns.

Veral kinders met intellektuele gestremdhede is kwesbaar vir mishandeling en verwaarlosing, dus behoort ouers van hierdie kinders bewus te wees van hulle kinders se regte. Na aanleiding van navorsing is die duidelik dat families met intellektuele gestremde kinders beperkte hulpbronne beskikbaar het. Om hierdie rede is dit belangrik om dit wat beskikbaar is te oorweeg teenoor die regte van die gestremde kind.

Kinderregte word duidelik omskryf in die Grondwet en vorm die grondslag van Suid-Afrika se wetlike verantwoordelikheid teenoor kinders.

Centre for Augmentative and Alternative Communication (CAAC)
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)
Communication Pathology Building
University of Pretoria, Lynnwood Road
PRETORIA, 0002
Republic of South Africa

Fax/Faks: +27 86 510 0841
Tel: +27 12 420 2001

juan.bomman@up.ac.za
www.caac.up.ac.za

WAT IS DIE DOELWIT VAN DIE STUDIE?

Die primêre doelwit van hierdie studie is om die omvang te bepaal waartoe Afrikaanssprekende primêre versorgers ervaar, dat kinders met intellektuele gestremdhede in hulle sorg se regte beskerm word soos uiteengesit in die *United Nations Convention on the Rights of the Child (UNCRC)*.

Die sekondêre doelwitte soos hieronder gelys, omskryf die wyse waarop die primêre doel van die studie bereik sal word.

- Om 'n meetinstrument te ontwikkel en te vertaal wat persepies van primere versorgers met intellektuele gestremde kinders se basiese behoeftes sal bepaal soos uiteengesit deur die *UNCRC*.
- Om die omvang te beskryf waartoe primere versorgers hulle kinders met intellektuele gestremtheid se basiese behoeftes beskou, na aanleiding van Mashlow se Hierargie van Behoeftes.
- Om die omvang te beskryf waartoe primere versorgers hulle kinders met intellektuele gestremtheid se basiese behoeftes beskou, na aanleiding van geselekteerde artikels van die *UNCRC*.
- Om die omvang te beskryf waartoe primere versorgers hulle kinders met intellektuele gestremtheid se basiese behoeftes beskou, na aanleiding van die *International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)* se kodes wat omgewingsfaktore meet.

WAT SAL VAN ONS AS SKOOL VERWAG WORD?

Met goedkeuring van hierdie versoek sal die navorser toestemming ontvang om die voorgestelde navorsingsstudie by u skool te doen. Dit behels die verskaffing van toepaslike inligting van leerders soos benodig. Dit sal die navorser in staat stel om leerders se primêre versorger as 'n moontlike deelnemer aan die studie te identifiseer. Alle inligting sal streng vertroulik hanteer word.

Verder sal u ook toestemming verleen aan die navorser om die skoolterrein vir die uitvoering van die navorsing te gebruik.

SAL ONS TOEGANG TOT DIE NAVORSINGSRESULTATE HÊ?

Die navorsingsresultate sal na voltooiing van die projek versoek beskikbaar gestel word. Die resultate sal as harde kopie, sowel as in elektroniese format by die Universiteit van Pretoria vir 15 jaar gestoor word, as deel van die etiese vereistes van die universiteit. Navorsingsresultate mag ook in artikel format aan professionele persone verskaf word.

Centre for Augmentative and Alternative Communication (CAAC)
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)
Communication Pathology Building
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juan.bomman@up.ac.za
www.caac.up.ac.za

SAL ONS TOEGANG TOT DIE NAVORSINGSRESULTATE HÊ?

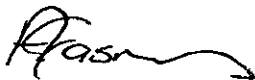
Die navorsingsresultate sal na voltooiing van die projek versoek beskikbaar gestel word. Die resultate sal as harde kopie, sowel as in elektroniese format by die Universiteit van Pretoria vir 15 jaar gestoor word, as deel van die etiese vereistes van die universiteit. Navorsingsresultate mag ook in artikel format aan professionele persone verskaf word.

WIE KAN GENADER WORD INDIEN EK ENIGE VERDERE NAVRAE HET?

Indien u meer inligting benodig, is u welkom om my te kontak by 0725913083 of alta.erasmus@up.ac.za

Ek vertrou dat hierdie brief u met genoegsame inligting voorsien om die navorser die toestemming te gee om die navorsingsstudie by u skool uit te voer.

Die uwe



Naam: Alta Erasmus
Navorser



Juan Bornman
Studieleier

Appendix G

Letter of approval from school principal

Vir amptelike gebruik

Ek _____ (Skoolhoof se naam)

(merk in die toepaslike blokkie)

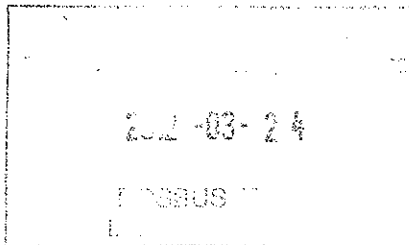
Gee toestemming

Gee nie toestemming nie

dat Mev Erasmus haar studie by _____ (naam van skool)
kan uitvoer.

.....
Handtekening

Geteken te PRETORIA op 24 MAAKT (dag) 2012 (jaar)



Centre for Augmentative and Alternative Communication (CAAC)
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)
Communication Pathology Building
University of Pretoria, Lynnwood Road
PRETORIA, 0002
Republic of South Africa

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juan.bornman@up.ac.za
www.caac.up.ac.za

Appendix H

Letter requesting primary caregivers' consent



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

5 Maart 2012

Geagte Ouer

INSAKE OUERINLIGTING- EN TOESTEMMINGS BRIEF

NAVORSINGSVOORSTEL

An investigation into the realization of Children's Rights in South Africa: Perceptions of Afrikaans-speaking primary caregivers of children with intellectual disabilities.

RASIONAAL VAN DIE STUDIE

Regdeur die wêreld word individue met gestremdhede gekonfronteer met noemenswaardige struikelblokke ten opsigte van hulle menseregte. Menseregte word gesien as die basiese vereiste vir instandhouding van menswaardigheid en individuele vryheid. Die *United Nations Convention* bring onder ons aandag die feit dat kinders met gestremdhede die reg het tot 'n mening wat gebaseer is op verworwe inligting en dat sodanige mening oorweeg moet word met inagneming van hulle ouderdom, vlak van volwassenheid en vermoëns.

Veral kinders met intellektuele gestremdhede is kwesbaar vir mishandeling en verwaarlosing, dus behoort ouers van hierdie kinders bewus te wees van hulle kinders se regte. Na aanleiding van navorsing is dit duidelik dat families met intellektuele gestremde kinders beperkte hulpbronne tot hulle beskikking het. Om hierdie rede is dit belangrik om dit wat beskikbaar is te oorweeg teenoor die regte van die gestremde kind.

Kinderrregte word duidelik omskryf in die Grondwet en vorm die grondslag van Suid-Afrika se wetlike verantwoordelikheid teenoor kinders.

WAT IS DIE DOELWIT VAN DIE STUDIE?

Die primêre doelwit van hierdie studie is om die omvang te bepaal waartoe Afrikaanssprekende primêre versorgers ervaar, dat kinders met gestremdhede in hulle sorg se regte beskerm word soos uiteengesit in die *United Nations Convention on the Rights of the Child (UNCRC)*.

Die sekondêre doelwitte soos hieronder gelys, omskryf die wyse waarop die primêre doel van die studie bereik sal word:

- Om 'n meetinstrument te ontwikkel en te vertaal wat persepies van primere versorgers met intellektuele gestremde kinders se basiese behoeftes sal bepaal soos uiteengesit deur die *UNCRC*.
- Om die omvang te beskryf waartoe primere versorgers hulle kinders met intellektuele gestremheid se basiese behoeftes beskou, na aanleiding van Mashlow se Hierargie van Behoeftes.
- Om die omvang te beskryf waartoe primere versorgers hulle kinders met intellektuele gestremheid se basiese behoeftes beskou, na aanleiding van geselekteerde artikels van die *UNCRC*.
- Om die omvang te beskryf waartoe primere versorgers hulle kinders met intellektuele gestremheid se basiese behoeftes beskou, na aanleiding van die *International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)* se kodes wat omgewingsfaktore meet.

HOEKOM IS MY DEELNAME BELANGRIK?

U deelname in hierdie navorsingsprojek hou geen direkte voordeel vir u in nie.

U insette sal wel 'n bydrae lewer om te bepaal wat die grootte van die omvang is tot watter mate Afrikaanssprekende primêre versorgers besef, dat kinders met intellektuele gestremdheid in hulle sorg se regte uitvoer word soos uiteengesit is in die *UNCRC*. U deelname sal waardeur word.

WAT SAL VAN MY AS DEELNEMER VERWAG WORD?

Om u deelname aan die studie moontlik te maak, word u versoek om die aangehegte toestemmingsbrief te voltooi en aan die skool terug te stuur. U word ook versoek om die nodige vraelyste te voltooi wat op 'n voorafbepaalde tyd, datum en plek aan u uitgedeel sal word. Die nodige reëlings in die verband sal vroegtydig aan u gekommunikeer word.

Alle inligting wat deur u verskaf word, sal as vertroulik hanteer word. U sal slegs 'n respondente nommer ontvang vir statistiese doeleindes. U sal nie onderwerp word aan enige risiko's nie.

WAT IS MY REGTE AS 'n DEELNEMER IN DIE STUDIE?

U deelname in hierdie navorsingsprojek is vrywillig. U mag op enige tydstip u onttrek van die studie sonder enige nagevolge.

SAL EK TOEGANG HÊ TOT DIE NAVORSINGSRESULTATE?

Die navorsingsresultate sal na voltooiing van die projek op versoek, beskikbaar gestel word.

Die navorsingsresultate sal as harde kopie sowel as in elektronieseformaat by die Departement Biblioteekdienste van die Universiteit van Pretoria vir 15 jaar gestoor word.

WIE KAN GENADER WORD INDIEN EK ENIGE VERDERE NAVRAE HET?

Indien u meer inligting verlang, is u welkom om my te kontak by 0725913083 of alta.erasmus@up.ac.za

Dankie byvoorbaat vir u tyd en samewerking.

Die uwe



Alta Erasmus
Navorsers



Juan Bornman
Studieleier

Ek _____ verleen hiermee geskrewe en ingeligte toestemming om te kan deelneem aan bogenoemde studie wat ten doel stel om 'n bydrae te lewer om te bepaal wat die grootte van die omvang is tot watter mate Afrikaans sprekende primêre versorgers besef, dat kinders met gestremdheid in hulle sorg se regte uitgevoer word soos uiteengesit is in die *Verenigde Konvensie van Nasies*.

Ek is ten volle bewus wat van my verwag gaan word. Ek is ook bewus dat deelname aan die studie vrywillig is en dat ek die reg het om ten enige tyd te onttrek.

.....
Hantekening

Geteken teop.....datum

Appendix I

Raw data: Responses of primary caregivers

Vraag 35

01

- Reg op geleerdheid (skool) ¹ Art 28 ✓
- Vryheid van spraak ³ Art 12, 13 ✓
- Reg tot sekuriteit ² Art 19

02

- Reg op goeie skoolopvoeding ¹ Art 28,
- Reg op gemaklike & liefdevolle huishouding ⁴ Art 31, 9.
- Reg op uitspraak oor dinge wat pla ³ Art 12, 13
- Reg om as normale mens behandel te word ²³ Art 6,
- Reg op ontspanning & beskerming ¹⁰ Art 31, 11, 38, 19,
- Reg om keuses uit te oefen ² Art 12.

04

- Veilige omgewing ² Art 19
- Veilige blyplek ² Art 27
- Liefde te kan he van almal ⁴ Art 21, 27, 31
- Mediese toegang ⁵ Art 24
- Voedsel, klere, bed, konomie ⁶ Art 27.
- Om vriende te kan he en te kan speel ⁹ Art 15

07

- Veilige tuiste ² Art 19,
- Medies ⁵ Art 24
- Kos en klere ⁶ Art 27
- Toegang na 'n goeie skool ¹ Art 28,
- Reg om altyd veilig te voel ² (19)
- Reg om te praat ³ Art 12, 13.

09

- Reg op vryheid ¹⁷ Art 19
- Reg op spraak ³ Art 12, 13
- Reg op menswaardigheid ¹⁵ Art 27
- Reg op gelykheid ²⁰ Art 27

Vraag 35

01

- Reg op geleerdheid (skool) ¹ Art 28 ✓
- Vryheid van spraak ³ Art 12, 13 ✓
- Reg tot sekuriteit ² Art 19

02

- Reg op goeie skoolopvoeding ¹ Art 28,
- Reg op gemaklike & liefdevolle huishouding ⁴ Art 31, 9.
- Reg op uitspraak oor dinge wat pla ³ Art 12, 13
- Reg om as normale mens behandel te word ^{2,3} Art 6,
- Reg op ontspanning & beskerming ¹⁰ Art 31, 11, 38, 19,
- Reg om keuses uit te oefen ¹⁷ Art 12.

04

- Veilige omgewing ² Art 19
- Veilige blyplek ² Art 27
- Liefde te kan he van almal ⁴ Art 21, 27, 31
- Mediese toegang ⁵ Art 24
- Voedsel, kler, bed, komberse ⁷ Art 27.
- Om vriende te kan he en te kan speel ⁹ Art 15

07

- Veilige tuiste ² Art 19,
- Medies ⁵ Art 24
- Kos en kler ⁶ Art 27
- Toegang na 'n goeie skool ¹ Art 28,
- Reg om altyd veilig te voel ² (A)
- Reg om te praat ³ Art 12, 13.

09

- Reg op vryheid ¹⁷ Art 19
- Reg op spraak ³ Art 12, 13
- Reg op menswaardigheid ¹⁵ Art 27
- Reg op gelykheid ²⁰ Art 27

10

- Ek wil graag net sien dat my twee kinders se stemme ook gehoor word en nie stil gemaak word nie, want hulle het ook die reg as iets hulle pla om te praat ³ Art 12, 13

11

- Mag 'n kind nie sielkundig afkraak nie ¹⁵ Art 19
- Mag 'n kind nie met voorwerpe slaan nie ¹¹ Art 37, Art 19

13

- Albei ouers van die kind is oorlede —
- Geen ander klein kinders in die huis —
- Kry aandag en hulp met skoolwerk ³ Art 12 ?
- Eie kamer ³ Art 16
- Word soos 'n eie kind behandel ¹²
- Hou saam vakansie, eet uit ens. ²⁴ } Art 21

14

- My seun moet ook regte he ²⁸ Art 12, 4

15

- Reg van spraak ³ Art 10, 13
- Reg van veiligheid ² Art 27
- Niemand mag hom seer maak nie bv. Fisiek mishandeling, seksuele mishandeling, bly veilig ¹¹ Art 19, 36 Art 19, 36, 34, 35, 32

16

- Reg op onderwys ¹ Art 28
- Reg op veilige huisvesting ¹⁸ Art 27
- Reg op mediese ⁵ sorg ¹³ Art 24
- Reg op vryheid tot godsdiens ⁷ Art 14
- Reg op voedsel ⁶ Art 27
- Reg tot toegang tot inligting ¹⁴ Art 13, 17

17

- Sy weet dat sy nie na enige mense moet gaan wat haar roep nie ² Art 42
- Reg op leerling ² Art 28
- Reg op beskerming ¹⁷ Art 19, 36, 34, 35, 32,
- Reg tot vryheid ⁴
- Reg tot liefdadigheid ¹⁵
- Reg om gerespekteer te word

10

- Ek wil graag net sien dat my twee kinders se stemme ook gehoor word en nie stil gemaak word nie, want hulle het ook die reg as iets hulle pla om te praat ³ Art 12, 13

11

- Mag 'n kind nie sielkundig afkraak nie ¹⁵ Art 19
- Mag 'n kind nie met voorwerpe slaan nie ¹¹ Art 37, Art 19

13

- Albei ouers van die kind is oorlede —
- Geen ander klein kinders in die huis —
- Kry aandag en hulp met skoolwerk ⁸ Art 12 ?
- Eie kamer ³ Art 16
- Word soos 'n eie kind behandel ¹² }
- Hou saam vakansie, eet uit ens. ²⁴ } Art 21

14

- My seun moet ook regte he ²⁸ Art 12, 4

15

- Reg van spraak ³ Art 10, 13
- Reg van veiligheid ² Art 27
- Niemand mag hom seer maak nie bv. Fisiek mishandeling, seksuele mishandeling, bly veilig ¹¹ Art 19, 36 Art 19, 36, 34, 35, 32

16

- Reg op onderwys ¹ Art 28
- Reg op veilige huisvesting ¹⁸ Art 27
- Reg op mediese ⁵ sorg Art 24
- Reg op vryheid tot godsdiens ¹³ Art 14
- Reg op voedsel ⁶ Art 27
- Reg tot toegang tot inligting ¹⁴ Art 13, 17

17

- Sy weet dat sy nie na enige mense moet gaan wat haar roep nie ² Art 42
- Reg op leerling ¹ Art 28
- Reg op beskerming ² Art 19, 36, 34, 35, 32,
- Reg tot vryheid ¹⁷
- Reg tot liefdadigheid ⁴
- Reg om gerespekteer te word ¹⁵

18

- Reg om in sy moedertaal onderrig te word ¹⁶ Art 30
- Onderrig te ontvang volgens se vermoë ¹⁶ Art 28, 29
- Dat die "boelies" in die skool vasgevat sal word ² Art 15

21

- Reg op enige iets wat sy ³ sê ? Art 12, 13
- Reg op enige iets wat sy ¹⁷ doen —
- Reg op enige ding wat sy ¹⁷ doen —

22

- Reg om met maats te ⁹ speel., maar hulle knou om vreeslik af en spot hom Art 15

24

- Reg op geleerdheid ¹ Art 28
- Reg op veiligheid ² Art 35, 36, 37, 11, 19
- Reg op behuising ¹⁸ Art 27
- Reg op versorging ¹² Art 27
- Reg op liefde en waardering ⁴ Art 15

26

- Kind is vanuit 'n onstabiele omgewing beveilig ² —
- Toegang tot basiese ¹² versorging Art 27
- Toegang tot mediese ⁵ dienste Art 24
- Toegang tot skolastiese opleiding Art 28, 29
- Word behandel volgens ²⁸ voorskrifte van kindernet Art 2
- Toegang tot terapeutiese ¹⁹ dienste Art 24

28

- Sy kan vrylik ³ praat Art 12, 13
- Regte soos 'n ²⁸ normale person Art 27
- Geen mishandeling ¹¹ Art 19, 37
- Sy net soos ²⁸ ander wat regte het (Art 27)
- Niemand is beter ²⁰ as ander nie Art 30
- Werk, speel, maak ²² nie saak gestremd is nie-dis nie siekte nie Art 23

32

- Op 13 self ¹⁷ besluite kan neem Art 42
- Besluit of die skool die regte besluit is vir himself/of hy gelukkig is Art 3

17

18

- Reg om in sy moedertaal onderrig te word ¹⁶ Art 20
- Onderrig te ontvang volgens se vermoë ¹ Art 28, 29
- Dat die "boelies" in die skool vasgevat sal word ² Art 15

21

- Reg op enige iets wat sy sê ³ ? Art 12, 13
- Reg op enige iets wat sy doen ¹⁷ —
- Reg op enige ding wat sy doen ¹⁷ —

22

- Reg om met maats te speel, maar hulle knou om vreeslik af en spot hom ⁹ Art 15

24

- Reg op geleerdheid ¹ Art 28
- Reg op veiligheid ² Art 35, 36, 37, 11, 19
- Reg op behuising ¹⁸ Art 27
- Reg op versorging ¹² Art 27
- Reg op liefde en waardering ⁴ Art 15

26

- Kind is vanuit 'n onstabiele omgewing beveilig ² —
- Toegang tot basiese versorging ¹² Art 27
- Toegang tot mediese dienste ⁵ Art 24
- Toegang tot skolastiese opleiding ¹ Art 28, 29
- Word behandel volgens voorskrifte van kinderwet ¹⁸ Art 2
- Toegang tot terapeutiese dienste ¹⁹ Art 24

28

- Sy kan vrylik praat ³ Art 12, 13
- Regte soos 'n normale persoon ²⁸ Art 27
- Geen mishandeling ¹¹ Art 19, 37
- Sy net soos ander wat regte het ²⁸ (Art 27)
- Niemand is beter as ²⁰ ander nie Art 30
- Werk, speel, maak nie saak gestremd is nie-dis nie siekte nie ²² Art 23

32

- Op 13 self besluite kan neem ¹⁷ Art 42
- Besluit of die skool die regte besluit is vir himself/of hy gelukkig is Art 3

17

16

- Sy huis taal te kan kommunikeer en by die skool met hom te kommunikeer in Afrikaans Art 30
- Spesiale onderrig mot regtig die beste uitgevoer word Art 28
- Spesiale toerusting vir gestremdheid moet makliker gekombaar wees vir die kind bekostigbaar wees Art 24, Art 23.
- Die skool mot voorsiening maak vir die kinder swat spesiale onderrig kry dat dit daar is soos toelaes, bekostigbare en betroubare vervoer, want as die land staak ly die kinders daar onder Art 28, 23

35

- Reg om die regte skool te kan bywoon Art 28
- Reg om aanvaarding Art 30
- Reg om erken te word om wie hy is Art 30
- Reg om sy mening te lig Art 12, 13
- Reg om net hy te wees Art 20
- Reg om regverdig behandel te word en so normaal as moontlik groot te word. Art 2

36

- Reg tot liefde en respek Art 19, 21 (seen art wat "liefde" - net "care")
- Reg tot hulpbronne (kós, wáter ens) Art 27
- Reg op identiteit as individu Art 7, 8,
- Reg as person Art 7, 8
- Reg tot veiligheid Art 19

38

- Versorg te word Art 27.
- Verhouding met familie goed Art 18, Art 9.
- Gesels en kommunikeer goed Art 15
- Help waar kan
- Luister as praat Art 12
- Geniet maatjies Art 15

39

- Versorging Art 27.
- Voeding Art 27
- Opvoeding Art 28, 29
- Hygiene Art 27
- Behuising Art 27
- Beskerming Art 19

16

- Sy huis taal te kan kommunikeer en by die skool met hom te kommunikeer in Afrikaans Art 30
- Spesiale onderrig mot regtig die beste uitgevoer word Art 28
- Spesiale toerusting vir gestremdheid moet makliker gekombaar wees vir die kind bekostigbaar wees Art 24, Art 23.
- Die skool mot voorsiening maak vir die kinder swat spesiale onderrig kry dat dit daar is soos toelaes, bekostigbare en betroubare vervoer, want as die land staak ly die kinders daar onder Art 28, 23

35

- Reg om die regte skool te kan bywoon Art 28
- Reg om aanvaarding Art 30
- Reg om erken te word om wie hy is Art 30
- Reg om sy mening te lig Art 12, 13
- Reg om net hy te wees Art 2, 20
- Reg om regverdig behandel te word en so normaal as moontlik groot te word. Art 2

36

- Reg tot liefde en respek Art 19, 21 (seen art wat "liefde" - net "care")
- Reg tot hulpbronne (kós, water ens) Art 27
- Reg op identiteit as individu Art 7, 8,
- Reg as person Art 7, 8
- Reg tot veiligheid Art 19

38

- Versorg te word Art 27.
- Verhouding met familie goed Art 18, Art 9.
- Gesels en kommunikeer goed Art 15
- Help waar kan
- Luister as praat Art 12
- Geniet maatjies Art 15

39

- Versorging Art 27.
- Voeding Art 27
- Opvoeding Art 28, 29
- Hygiene Art 27
- Behuising Art 27
- Beskerming Art 19

43

- Reg op gelykheid ²⁰ Art 30
- Reg tot huislike dinge ²⁴ Art 27
- Reg om skool te gaan Art 28
- Reg to vryheid 17

44

- Reg op beskerming ² Art 19
- Reg op liefde en versorging ⁴ Art 27
- Reg op toegang to opleiding Art 28
- Reg op toegang tot mediese behandeling ⁵ Art 24

46

- Reg om lief te he ⁴ 2
- Reg om beskerm te word Art 19
- Reg om skool toe te gaan Art 28
- Reg om gesondheids dienste ⁵ Art 24
- Reg om verstaan te word ²²
- Reg om 'n huis te he ¹⁸ Art 27

48

- Die reg tot onderwys ¹ Art 28
- Reg tot veiligheid ² Art 19
- Die reg tot liefde en aandag ⁴ (ouers)
- Mag nie mishandel word nie Art 19
- Die reg om op sy regte ²³ te staan Art 12, 13
- Die reg om gerespekteer te word ¹⁵ Art 30

49

- Die reg om skool te gaan ¹ Art 28
- Die reg om te leer ¹ Art 28
- Die reg om te speel ¹⁰
- Die reg om gehelp te word deur opgeleide mense ¹⁹
- Die reg om 'n huis te he ¹⁸ Art 27
- Die reg om ongeskikheidspensioen te kry 12

47

- Respekteer te word ¹⁵
- Sosiaal met ander te verkeer ⁹ Art 15
- Dieselfde skole en vaardighede ¹ Art 28

43

- Reg op gelykheid ²⁰ Art 30
- Reg tot huislike dinge ²⁴ Art 27
- Reg om skool te gaan ¹ Art 28
- Reg to vryheid 17

44

- Reg op beskerming ² Art 19
- Reg op liefde en versorging ⁴ Art 27
- Reg op toegang to opleiding ¹ Art 28
- Reg op toegang tot mediese behandeling ⁵ Art 24

46

- Reg om lief te he ⁴ 2
- Reg om beskerm te word ² Art 19
- Reg om skool toe te gaan ¹ Art 28
- Reg om gesondheids dienste ⁵ Art 24
- Reg om verstaan te word ²²
- Reg om 'n huis te he ¹⁸ Art 27

48

- Die reg tot onderwys ¹ Art 28
- Reg tot veiligheid ² Art 19
- Die reg tot liefde en aandag ⁴ (ouers)
- Mag nie mishandel word nie ¹ Art 19
- Die reg om op sy regte ²³ te staan Art 12, 13
- Die reg om gerespekteer te word ¹⁵ Art 30

49

- Die reg om skool te gaan ¹ Art 28
- Die reg om te leer ¹ Art 28
- Die reg om te speel ¹⁰
- Die reg om gehelp te word deur opgeleide mense ¹⁹
- Die reg om 'n huis te he ¹⁸ Art 27
- Die reg om ongeskikheidspensioen te kry 12

47

- Respekteer te word ¹⁵
- Sosiaal met ander te verkeer ⁹ Art 15
- Dieselfde skole en vaardighede ¹ Art 28

51

- ² Sekuriteit, Art 19
- Kwaliteit opvoeding Art 28, 29
- ²² Aanvaarding Art 30
- Die reg tot gevorderde onderwys Art 28, 29
- Die reg om te kan kies ¹⁷ Art 12

52

- Reg op gesondheid ⁵ Art 24
- Reg op opvoeding/skool Art 28
- Reg op veiligheid Art 19
- Reg op versorging ¹² Art 27
- Reg op gesonde ²⁴ huishouding Art 27
- Reg om besluite ¹⁷ te neem Art 12, 13

58

- Sy basiese behoeftes ¹² moet bevredig word Art 27
- Moet ordentlike skoolonderrig kry Art 12, 13
- Moet soos 'n normale mens ²³ behandel word Art 15
- Moet ordentlike mediese versorging kry as ouers nie mediese fonds het nie Art 24

71

- Veiligheid en liefde ² en ⁴ Art 19
- Kos en water ²⁷ Art 27
- Kleres en bed ⁷ Art 27
- Speelgoed ¹⁰ Art 27

72

- Om beskerm te word te word ¹⁵ veral teen mense wat hulle spot Art 19
- Kos ⁶ Art 27
- Kleres ⁷ Art 27
- Behuising ¹⁸ Art 27
- Toegang tot gesondheidsdienste ⁵ Art 24
- Elektriesiteit en lopende water ²⁶ en ²⁷ Art 27

73

- Kind is vanuit 'n onstabiele omgewing beveilig ² Art 19
- Toegang tot basiese versorging ¹² Art 27
- Toegang tot mediese dienste ⁵ Art 24
- Toegang tot skolastiese ¹ opleiding Art 12, 13

51

- Sekuriteit, ² Art 19
- Kwaliteit opvoeding ²² Art 28, 29
- Aanvaarding ²² Art 30
- Die reg tot gevorderde onderwys Art 28, 29
- Die reg om te kan kies ¹⁷ Art 12

52

- Reg op gesondheid ⁵ Art 24
- Reg op opvoeding/skool ² Art 28
- Reg op veiligheid ² Art 19
- Reg op versorging ¹² Art 27
- Reg op gesonde huishouding ²⁴ Art 27
- Reg om besluite ¹⁷ te neem Art 12, 13

58

- Sy basiese behoeftes ¹² moet bevredig word Art 27
- Moet ordentlike skoolonderrig kry ¹ Art 12, 13
- Moet soos 'n normale mens ²³ behandel word Art 15
- Moet ordentlike mediese versorging kry as ouers nie mediese fonds het nie ⁵ Art 24

71

- Veiligheid en liefde ² ⁴ Art 19
- Kos en water ⁶ ²⁷ Art 27
- Kleres en bed ⁷ ⁸ Art 27
- Speelgoed ¹⁰ Art 27

72

- Om beskerm te word ¹⁵ te word veral teen mense wat hulle spot Art 19
- Kos ⁶ Art 27
- Kleres ⁷ Art 27
- Behuising ¹⁸ Art 27
- Toegang tot gesondheidsdienste ⁵ Art 24
- Elektriesiteit en lopende water ²⁶ ²⁷ Art 27

73

- Kind is vanuit 'n onstabiele omgewing beveilig ² Art 19
- Toegang tot basiese versorging ¹² Art 27
- Toegang tot mediese dienste ⁵ Art 24
- Toegang tot skolastiese ¹ opleiding Art 12, 13

- Word behandel volgens voorskrifte van kinderwet ²⁸ Art 42.
- Toegang tot terapeutiese dienste ¹⁹ Art 24

76

- Die reg tot spraak ³ Art 12, 13
- Die reg tot onderwys op skool ¹ Art 28
- Die reg tot beter opvoeding ¹ Art 29
- Die reg tot volle beskerming ² Art 19
- Die reg tot 'n gesonde lewe ² Art 27
- Die reg tot liefde ⁴

79

- Moet op haar regte staan ²³ Art 12, 13
- Moet nee kan sê as sy mishandel word ¹ Art 19?

- Word behandel volgens voorskrifte van kinderwet ²⁸ Art 42.
- Toegang tot terapeutiese dienste ¹⁹ Art 24

76

- Die reg tot spraak ³ Art 12, 13
- Die reg tot onderwys op skool ¹ Art 28
- Die reg tot beter opvoeding ¹ Art 29
- Die reg tot volle beskerming ² Art 19
- Die reg tot 'n gesonde lewe ¹² Art 27
- Die reg tot liefde ⁴

79

- Moet op haar regte staan ²³ Art 12, 13.
- Moet nie kan sê as sy mishandel word ¹ Art 19?