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Disability in South Africa: Collective Recourse for Family Members as right bearers

Mini-Dissertation in the fulfilment of the requirements for the Master's degree programme MPhil in Multidisciplinary Human Rights in the Faculty of Law, Centre for Human Rights, University of Pretoria

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I, **Ruth Marie Stubbs**, Student number, **21260258**, declare that I am the author of this mini dissertation in MHR801, code 04251024.

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DEDICATION

This mini dissertation is dedicated to the children and to each and every one of their family members who wake up every morning and face a day filled with unnecessary challenges. Challenges unrelated to the child's disability, challenges imposed by society which bring about attitudinal and environmental barriers which could be avoided. This mini dissertation is dedicated to their courage and strength to do what needs to be done every day. May this in some way assist them in finding a voice, a voice which can be used as a collective in the spirit of Ubuntu empowering them within their rights as right bearers, highlighting the fact that disability not only affects an individual but affects an entire family unit and is therefore a collective not an individual disability.

ACKNOWLEDGEMENTS

KEYWORDS

Human Rights   Individual   Myths   Right bearers   Siblings   Society   Superstitions   Transport   Ubuntu

ABSTRACT

The purpose of the study is to highlight the very real fact that disability does not only affect the life of the individual with the disability but it also affects each and every member of an affected family. This will include extended family members. Every person is entitled to rights and freedoms as stipulated in the South African Constitution and these extend to family members within an affected family. The main contribution of this study is to put forward an argument for the collective recourse for family members as right bearers with a particular focus on housing, transport, education, health care, grants and general accessibility within communities. The study also highlights the effects perceptions of disability have within societies. The study demonstrates that stigma, myths and superstitions surrounding disability shun and isolate not only the individual but all associated with the individual. These attitudinal and environmental barriers infringe upon the living philosophy of Ubuntu. This philosophy emphasises and continually reinforces the concept of "I am, because you are". In other words, a person is a person through other people, each sharing a common humanity and oneness. Bringing the principle of Ubuntu to bear on the regime of disability rights would therefore highlight disability as a collective issue, thus bringing affected families and their rights into the realm of disability rights.

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Disability in South Africa: Collective Recourse for Family Members as right bearers

Chapter 1
Overview of the study

1.1 Motivation

Working within the field of disability in South Africa I have been struck by the family dynamics within a family that has a child living with a disability. Dealing with families on a daily basis and observing first-hand how husbands and wives, brothers and sisters, grandmothers and grandfathers and aunts and uncles not only interact with the child with the disability, but with each other and the impacts these interactions have on the family as a collective unit has drawn me to the topic for my research. The emphasis of this study will be on the impact on the family of having a family member living with a disability and the rights recourse such a family can have as a collective.

Divorce, isolation, family conflict, sibling rivalry, financial strain, 'traditional' beliefs, stigma, housing, transportation, health system are but a few observations made. Disempowerment is embodied within this dynamic on numerous levels. Having no choice but to stay at home to attend to the child with a disability brings about diminished employment and social opportunities. Based on this severe isolation and lack of support is experienced. Through being isolated lack of knowledge regarding legislation and policy and lack of knowledge regarding basic rights is personified. All the above therefore amalgamate and serve to disempower family members and perpetuate the issues and challenges. Knowing that there

is very little support for families in South Africa and seeing how this lack of support directly affects a family as a unit has further motivated my research and begs the question of the collective recourse of family members and their position and status as right bearers within this family dynamic. Within the traditional Western ideological view of rights discourse only individuals are seen as right bearers which, contrasts with the African perspective which is based upon and grounded in a holistic and communal orientation.

1.2 Research Problem

The World Health Organisation describes disability as an umbrella term which covers various impairments, activity limitations and restrictions to participation.[1] Disability affects physical, cognitive and sensory functioning and due to this it limits and restricts participation in everyday functioning and life which directly affects all involved in the life of the individual. Therefore, disability cannot just be seen as only a health issue, but rather, as described by the WHO, a complex phenomenon which reflects the interactions of an individual's body and the society in which the individual lives. There are not only physical bodily barriers, but environmental and social barriers too which need to be addressed.[2]

According to the WHO World Report on Disability approximately 15% of the world's population lives with a disability of sorts. Between 2% to 4 % of those people experience significant difficulty in functioning.[3] Statistics South Africa rate the national disability prevalence at 7,5% of the population. Females at 8,3%, males at 6,5%. The prevalence of specific disabilities shows 11% visual difficulties, 4,2% cognitive difficulties, 3,6% hearing difficulties, 2% communication, and walking and self-care difficulties.[4] SA Stats also showed that access to education and employment opportunities was difficult for persons with more severe disabilities.[5]

The purpose of this study is to explore the effect disability has on the family as a unit and to understand the far reaching short and long-term effects it has on the entire family taking the impact on the parents as individuals, the marriage of the parents, the financial status of the family, the interpersonal and the social lives of the siblings and taking the effect on the

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[1] World Health Organisation (WHO) *World report on disability* (2011)

[2] WHO (n2)

[3] WHO (n3)

[4] Statistics South Africa (STATSSA) Census 2011 Report 03-01-59: *Profile of persons with disabilities in South Africa* (2011)

[5] STATSSA (n2)

extended family relationships and the dynamics into consideration. In her article titled "Family Relationships" ,which is based on her research and personal interactions with families, freelance writer Jen Thorpe, a previous teacher and day care worker, states that 50% of all marriages end in divorce. This percentage is between 80% and 90% for couples who have a child with a disability.[6] This percentage is higher within families with one or more children with disabilities. Families with a child on the autistic spectrum research report divorce rates at 85%.[7]

Siblings of children with disabilities experience an array of stress factors which if went unchecked and unaddressed can lead to significant emotional, behavioural and functional problems. The feelings of jealousy and resentment are a reality as the sibling with the disability receives, what is perceived as, preferential treatment. Siblings are often expected to assist with the care of the sibling with the disability and often take on extra household chores.[8] Milevsky confirms that, 'siblings may feel neglected because much of the parents' emotional energy is directed toward the child with the disability, leaving little emotional energy for the other children in the family'.[9] According to Milevsky, 'siblings of children with disabilities are at a greater risk than average of developing emotional issues, anxiety, and stress. These problems are known as internalizing issues, not obviously visible, and may be an attempt by these siblings to hide their problems; they may want to be well-behaved or protect their already overburdened parents. Other issues that these siblings may face are peer problems, as well as a lack of engagement in extracurricular activities and academic issues as a result of limited time and money'[10] which further highlights the very real risk, often undetected siblings are at.

Based on the above statistics the aim of this research is to determine the effect collective rights would have on South African families who have a child with a disability. By collective rights I mean the rights of the entire group, in this instance the family as a unit, and not just the rights of the individual who has the disability. This study explores what those effects are

[6]'Divorce Rate Higher Among Couples With Special Needs Children'.https://www.families.com/divorce-rate-higher-among-couples-with-special-needs-children (accessed 22nd September 2018)
[7]'Divorce and Children with Disabilities' https://www.children-and-divorce.com/divorce-and-children-with-disabilities.html (accessed 22nd September 2018)
[8]'Emotional Problems Facing Siblings of Children With Disabilities'https://www.psychiatryadvisor.com/childadolescent…siblings… (accessed 22nd September 2018)
[9]Emotional Problems Facing Siblings of Children with Disabilities'https://www.psychiatryadvisor.com/childadolescent…siblings… (accessed 22nd September 2018)
[10]'Siblings of Children with Disabilities' https://www.psychologytoday.com/us/...brothers...sisters/.../siblings-children-disabilitie... (accessed 22nd September 2018)

on emotional, psychological, social, financial levels of the family as a unit. An analysis of legal rights will also be included to highlight the understanding and level of empowerment families feel they have, regarding the right they have to housing, work, family, healthy environment, health services, social services. The impact on the family and the rights recourse of a family within this context, as a collective, needs to be unpacked highlighting which of those effects have short term impact, and which have long-term impact. Further discussion emphasising how these effects impact the family as well as the extended family and if these are short or long-term effects for different members of the Family unit. All of these questions are to be explored against a South African background. The South African Constitution and the Convention on the Rights of People with Disabilities (CRPD) and the Optional Protocol to the CRPD speak to the promotion and protection of the rights of people with disabilities. However, as I will show the implementation thereof is sadly lacking and families are left unsupported and without the backing they are desperately in need of.

The African Committee of Experts on the Rights and Welfare of the Child (ACERWC) considered South Africa's initial report, which was submitted in accordance with State Parties obligation under aticle 43, of the African Charter on the Rights and Welfare of the Child. The concern raised was that due to the prevalence of violence, corruption, poverty and inequality, compounded by the lack of adequate training for persons who work for and with children, the full realisation is not being met even though laws and policies are in place.[11] The Committee urged, that all legislative administrative and other necessary measures be used to expedite awareness raising and capacity building of those who work in child related matters. They further recommended the effective and efficient use of budget to promote and protect the rights of children and to bring in accountability by which to bind officials that are involved in corruption.[12] The Committee continues to advise the South African State Party, to secure access to medical care to all children without any discrimination.[13] An important point to be highlighted due to the fact that disability is severely marginalised and to further discriminate intensifies this marginalisation compounding an already contentious issue.

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[11]Concluding Recommendations by the African Committee of Experts on the Rights and Welfare of the Child (ACERWC) On the Republic of South Africa initial report on the status of implementation of the African Charter on the Rights and Welfare of the Child
[12]Concluding Recommendations ACERWC (n2)
[13]Concluding Recommendations ACERWC (n3)

The effects of disability are far reaching and do not end at the rights of the child with the disability. The entire family is affected and is fundamentally altered with life changing effects which directly affect the rights of each individual family member. This research therefore intends to unpack the effects on the human rights of each family member and through doing so offer recommendations in order to ensure that families are better supported and that disability is seen and understood in the context of an entire family unit and not just the person living with disability.This research argues for each family member to be seen, acknowledged and viewed as the bearer of rights for the individual and in so doing be empowered to action a call for the implementation of these rights. Numerous, reported and unreported, cases further motivate the topic I have chosen. Within each of these cases it is evident that the stigma around disability not only isolates but disempowers families. .

The CRPD and its Optional Protocol was adopted, on 13 December 2006, at the United Nations Headquarters in New York. It was opened for signature on 30 March 2007 and entered into force on 3 May 2008. The promotion and protection to ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity[14] is the purpose of the convention as a human rights instrument with an explicit social development dimension. A broad categorization of persons with disabilities has been adopted which reaffirms that all human rights and fundamental freedoms must be enjoyed by all persons with all types of disabilities.[15] In the preamble (a) it recalls the principles proclaimed in the Charter of the United Nations which recognizes the inherent dignity and worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world.[16] Preamble (c) continues by reaffirming the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination.[17] However, preamble (k) expresses concern that, despite these various instruments and undertakings, persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world.[18] This is where the basis of my research topic begins and is further supported by the CRPD preamble (e) which recognizes that disability is an evolving concept

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[14]The Convention on the Rights of Persons with Disabilities and its Optional Protocol (CRPD)
[15]CRPD (n2)
[16]The Convention on the Rights of Persons with Disabilities and its Optional Protocol preamble (a)
[17]The Convention on the Rights of Persons with Disabilities and its Optional Protocol preamble (c)
[18]The Convention on the Rights of Persons with Disabilities and its Optional Protocol preamble (k)

and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.[19] In 2016, in terms of the applicable policy framework, the White Paper on the Rights of Persons with Disabilities was launched by the Department of Social Development. It provides clarity on various issues such as the development of standard operating procedures for mainstreaming disability and at the same time sets out norms and standards regarding which discriminatory barriers should be removed and continues to broadly outline stakeholder responsibilities.

The African Charter on Human and Peoples' Rights does not exclusively deal with disability. In article 18(4) the rights of persons with disabilities are made mention of by stating that in keeping with their physical and moral needs the aged and the disabled have the right to 'special measures of protection'.[20] African Charter on the Rights and Welfare of the Child article 13 provides for the 'handicapped child'.[21] In February 2016, the African Commission on Human and Peoples' Rights adopted the Draft African Protocol on the Rights of Persons with Disability. This aims to address continued exclusion, harmful practices, and discrimination affecting those with disabilities, especially women, children, and the elderly. In a state report submission, the South African Human Rights Commission acknowledges the strides made by the South African government in domesticating the CRPD through the development of national disability policy, the White Paper on the Rights of Persons with Disabilities in 2016.

To sum up within a South African context people with disabilities face insurmountable forms of discrimination across numerous spheres which directly impacts their access to health services, education, transport, employment to name just a few. These barriers faced, however, do not only impact their lives on a daily basis but impact on the lives of those associated with them within their family context. It is due to this that the argument for collective recourse for family members as right bearers is presented.

1.3 Significance of the study

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[19] The Convention on the Rights of Persons with Disabilities and its Optional Protocol preamble (e)
[20] The African Charter on Human and Peoples' Rights article 18(4)
[21] African Charter on the Rights and Welfare of the Child article 13

Discrimination against people with disabilities is present and persists in various social and economic spheres within South Africa and these directly influence the effect disability has on South African families. Seen through the lens of a human rights perspective the platform upon which barriers are built and the core reason for these barriers is discrimination. Barriers such as transportation, extreme poverty, lack of access to disability grants, neglect, stigma, poor hospital governance, budgeting issues, and corruption all have a negative and far reaching impact on the health of people with disabilities. Apathy and the lack of value placed on the life of a person with disability further compounds the situation. It is within the context of this South African background that my research will explore and investigate the impact and extent to which disability affects a family as a collective and to what degree this affects their understanding of their role as right bearers. The research intends to explore this aspect and in so doing formulate a right-regime that family members can have recourse to.

1.4 Research question

The main research question asks what legal recourse do families in South Africa have as collective right bearers? Are there far reaching short and long-term effects, across the wide spectrum of human rights, which impact on each individual within the family unit?

1.5 Literature review

There are various reading materials and resources available written at various levels and covering various elements from different perspectives on the topic of disability. These include legislation and various international and national state reports as well as international conventions and instruments. Available books to be read enhance and supplement the research which is available and speak to the same vein. Seligman and Benjamin discuss family and social systems and delve into the fundamentals of becoming a parent to a child with a disability as well as the effect on the entire family unit.[22] McHugh addresses the very real and complex emotional dynamic between a child growing up with a sibling with a disability as well as the fine balance parents walk attending equally to the

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[22]M Seligman & R Benjamin *Ordinary families, special children: a systems approach to childhood disability* (1989)

needs of both.[23] Read addresses the impact disability has on mothers, a neglected minority, and the overall perception of motherhood and how it differs when diversity such as disability enters the equation.[24] Malhotra and Rowe discusses various narratives surrounding barriers to education, to employment, to transport and how these directly effective inclusion into society.[25]

Giallo and Gavidia-Payne focus on family health and adaptations within the family unit including social adjustments within the family's extended social sphere. Socio economic factors are also brought into the discussion as relevant and of importance. Risk and resilience factors and the impact thereof are also discussed in light of parental contributions to the sibling adjustment process.[26] Mandleco et al acknowledge that considerable research has been done on the raising of children with disabilities but very little on the link between parent and sibling functioning. Their study therefore concentrates on the relationship between parental perceptions of family functioning and the social skills and behavioural problems of siblings of school going age.[27] Naylor and Prescott discuss the fact that previous research does suggest that a child with a disability does have an effect on family life, and that although the need for sibling support is acknowledged the implications are unclear.[28]

Superstition and myths surrounding disability and the prevailing stigma associated with disability in Africa cannot be excluded from the literature review as they play a critical role in the critique and analysis of the impact disability has within a South African context. Epic's interactive blog, Disability in Africa: Superstition and Tradition, will be included in the literature review as part of the analysis of the family's right to collective recourse and in so doing unpack the impact the role that superstition and tradition play within this specific family context. An online article published in The African Journal of Disability titled, " Religion, culture and discrimination againsts persons with disabilities in Nigeria", highlights the fact that 'many of these practices are exclusionary in nature and unfair. They are either

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[23]M McHugh *Special Siblings: growing up with someone with a disability* (1999)
[24]J Read *Disability, the family and society: listening to mothers* (2000)
[25]R Malhotra & M Rowe *Exploring disability identity and disability rights through narratives: finding a voice of their own* (2014)
[26]R Giallo & S Gavidia-Payne 'Child, parent and family factors as predictors of adjustment for siblings of children with disability' (2006) *Peer-reviewed Source: Journal of intellectual disability research:2006*
[27]B Mandleco et al 'The Relationship between family and sibling functioning in families raising a child with a disability'(2003) *Peer-reviewed Source: Journal of Family Nursing 9, no4 (2003): 365-396*
[28]A Naylor & P Prescott 'Invisible children? The need for support groups for siblings of disabled children' (2004) *Peer-reviewed Source: British Journal of Special Education v31 n4*

embedded in or sustained by religion, culture and beliefs about disability and persons with disabilities."[29]

As does Bjorn's observations in some communities in Kenya and Zimbabwe, 'a child with a disability is a symbol of a curse befalling the whole family. Such a child is a "shame" to the whole family, hence their rejection by the family or the community. Children who are met by those beliefs and attitudes can hardly develop to their full potential: "They get less attention, less stimulation, less education, less medical care, less upbringing and sometimes less nourishment than other children'.[30]

The above literature review shows that much research has been done on the topic, but sadly lacks a South African context and perspective. The reason being that people tend to rely on international literature and use this as a basis upon which to guide South African implementation. The issue however, is that factors such as poverty, stigma, traditional beliefs, lack of social services, poor access to transportation, failing health system, faltering education system are realistic issues faced by South African families on a daily basis and these are not taken into account and not considered within the literature reviewed. International literature therefore reflects the ideals based on what is available within well resourced Western countries which do not experience the lack of support and poor infrastructure which South African families face. It is here, within this gap of a lack of South African context, that my topic will be explored and researched and in so doing contribute towards the debate of the impact disability has on an entire family unit living in South Africa within South African communities.

1.6 Research methodology

The research methodology to be used will be a desktop review and content analysis of documents applicable to disability related matters, published government reports, relevant published reports, statistical publications as well as other sources and findings. Through a qualitative analysis approach, part determined by personal work experienced within the

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[29]The African Journal of Disability online article 'Religion, culture, and discrimination against persons with disabilities in Nigeria' https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5433448/
[30]Disability Studies Quarterly, Vol 32, No 2 (2012) Past and Present Perceptions Towards Disability: A Historical Perspective http://dsq-sds.org/article/view/3197/3068

disability sector, an understanding of underlying reasonings, opinions and perspectives will be gained and used to unpack the effect disability has on an entire family unit and the rights of parents, siblings, extended family members as collective right bearers. Matters pertaining the effects and the impacts the child with the disability has had on the individual on a personal level will be included taking all family members rights into consideration. The effects and impacts these have long term will be unpacked in view of far reaching effects with implications which influence present and future collective rights.

1.7 Chapter outline

In an attempt to answer the research question the mini dissertation will present with five chapters. Chapter two will be an introductory chapter outlying the definition of disability and statistics of disability from a global perspective as well as a South African perspective. It will include a philosophical approach of an African perspective of disability bringing African community stigma surrounding disability into the realm of the discussion.

Chapter three will discuss the impact disability has on a family as a unit in a South African context. It will explain and give examples as to how individual family members are affected and the manner in which their rights as individuals are ignored and left unsupported. Chapter four will concentrate on what the law offers a family as a collective of rights bearers and will offer a critique of the implementation of the existing South African legislation, policy and Disability Framework. Chapter five, the concluding chapter, will consolidate all preceding chapters and will offer concluding comments and recommendations

Chapter 2

An African perspective on disability

2.1 Introduction

This chapter serves to introduce and discuss various aspects of disability. The first section of which will seek to canvass the various definitions of disability. The next section of the chapter will chart out prevalence of disability through highlighting various statistics relating to disability from an international perspective as well as a South African perspective. This will be followed by a section dedicated to a philosophical approach based on an African perspective of disability including various myths, stigmas and superstitions and how these relate and impact on family units. The chapter will conclude by bringing the above into perspective through highlighting the consequences attitudinal and environmental barriers towards disabilities have on individuals and their families within South African communities. It is of utmost importance to highlight and emphasise this specific African perspective in order to shed light on the dilemmas faced within the context of a family living with a child

with a disability in South Africa and thereby addressing the issue of family members as right bearers through the living philosophy of Ubuntu.

2.2 Defining disability

There are numerous definitions of disability and each speaks to different and varied aspects of disability. A common and recurring theme within these definitions is that of a person having a physical or mental impairment which directly and substantially affects ability to participate in day to day activities over a prolonged period of time. Mobility, dexterity, coordination, continence, speech, hearing, sight, memory, concentration, behaviour are affected on various levels and in varied degrees.[31] The World Health Organisation uses an umbrella term when defining disability which covers various impairments, activity limitations and restrictions to participation.[32] It recognises the important fact that due to physical, environmental, attitudinal and social barriers disability affects all involved in the life of the individual thus reflecting and questioning the role society plays in interactions with a person with a disability and their family.

The preamble to the United Nations Convention on the Rights of Persons with Disabilities and Optional Protocol recognises that disability is an evolving concept which results from interactions with attitudinal and environmental barriers.[33] Throughout the centuries there have been numerous evolvements of definitions and classifications of people with disabilities. The biomedical definition describes disability as an illness or impairment which needs to be cured. If the person cannot be cured they are removed from society. The philanthropic definition regards disability as a tragedy with the person seen as an object of sympathy in need of charity and pity who needs to be cared for in separate institutions and given handouts. The sociological definition defines disability as a form of human difference, a deviation from social norms and acceptable levels of activity performance. The economic definition defines disability as a social cost due to the extra resources people with disabilities require and their limited productivity within the work force. The socio-political definition defines disability within the context of a social environment rather than on the

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[31]https://www.disabled-world.com/definitions/disability-definitions.php (accessed 12th January 2019)
[32]WHO (n4)
[33]UN convention on the rights of persons with disabilities and optional protocol preamble (e)

perceived inability of the person. The social environment and the barriers and challenges faced within this context are therefore the focus.[34]

Regardless of which definition is used the point of the matter is that all definitions agree on the essential fact that disability has a pronounced and prolonged effect on individuals with disabilities as well as their families. This point therefore emphasises one of the questions posed and dealt with in this study which questions the individual 'I' versus the collective 'we', querying if it is just the individual with the disability that is affected by the disability or if the effect of the disability spills over and morphs into the lives of family members.

2.3 Charting out Prevalence of Disability in the world and in South Africa

Based on the above questions and various research done it can be said that disability does indeed affect all within the family unit and it is therefore essential to consider statistics in order to reflect on the impact disability has on the individual as well as each family member. According to the WHO World Report on Disability approximately 15% of the world's population lives with a disability and between 2% to 4 % of those people experience significant difficulty in functioning.[35] Census 2011 was conducted in all provinces of South Africa from 9th to 31st October 2011 and from this census statistics South Africa rate the national disability prevalence at 7,5% of the population which translates to 2,870,130 people with females at 8,3% and males at 6,5%. The prevalence of specific disabilities shows 11% visual difficulties, 4,2% cognitive difficulties, 3,6% hearing difficulties, 2% communication, and walking and self-care difficulties.[36] SA Stats also showed that access to education and employment opportunities was difficult for persons with more severe disabilities.[37] However, eNCA reported in an article dated 9th September 2014 that the civil society organisation Disabled People of South Africa (DPSA) are disputing the figures released by Stats SA. According to DPSA, the prevalence of disability is almost double the amount (14%) compared to the Stats SA figure of 7.5%.[38] As DPSA are a recognised, reputable and well respected civil society organisation within South Africa their input with regard to stats is of utmost importance and raises some serious

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[34]Disabled People South Africa (DPSA) 'A Pocket Guide on Disability Equity' https://www.westerncape.gov.za/general-publication/disability-definitions-models-and-terminology (accessed 12th January 2019)
[35]WHO (n5)
[36]STATSSA (n3)
[37]STATSSA (n4)
[38]https://www.enca.com/self-declaration-key-accurate-disability-figures (accessed 16th January 2019)

concerns, as it is only through exact information gained that assitance can be given to families.

The difficulty in obtaining accurate statistics is that self-declaration is relied upon. Self-declaration refers to family members openly disclosing who lives within the walls of their home. Openly declaring if they have a person with a disability within the household. People gathering the information simply knock on doors, ask questions and tick boxes. They do not look within the rooms of the houses nor do they run tests on individuals they simply ask a series of questions and are therefore reliant on honest and transparent answers. Due to stigma and negative connotations surrounding disability more often than not people do not disclose a disability within a household for fear of discrimination and repercussions. This failure to disclose distorts the facts and warps the actual numbers and percentages leaving the statistics reflected inaccurate and lacking in substantial evidence. Present statistics therefore need to be viewed in this light and seen as estimation at the very least. Discussions with and reports from various organisations and civil society entities involved within the disability sector should be brought to the table and these along with statistics collected should be reflected upon and comparisons should be made. Then from there a more accurate statistic agreed upon and given to be published. The importance of doing this cannot be underestimated as from statistics gathered state budgets are set and if statistics only reflect half of the reality of disability at grass roots level then only half of the need for service provision is budgeted for. This therefore leaves a deficit in the budget for the actual need within communities and once again feeds into the lack of support for individuals and their families within communities leaving them vulnerable and at risk to the devastating effects of lack of health care and social grants which perpetuate an already dire situation.

2.4 Worldwide perspective on Disability

With over 1 billion people of the world's population living with a disability it is widely acknowledged on a global platform that people with disabilities face numerous physical, social, economic and attitudinal barriers that prevent them from participating as equal members of society and often keep them from accessing education, employment, social

and legal support systems[39] and although the disability movement has advanced considerably since the international community's adoption of the United Nations Convention on the Rights of Persons with Disabilities ignorance and major legal and policy challenges remain which stand as barriers to advancing full equality and the fundamental human rights of people with disabilities around the world.[40] Limitations and stigmas placed upon people with disabilities by others within communities and society worldwide escalates the marginalisation, prejudice and social isolation and exclusion which infringes upon their equal and inalienable rights. Combined efforts however of world organisation bodies, non-government organisations and organisations of persons with disabilities are showing developments in global interventions striving towards the restoration of the human rights of people with disabilities.

2.5 Superstitions, myths and associated stigma from an African perspective

What is African? The best way to answer this question is to reflect on the speech "I am an African" made by Thabo Mbeki the then vice president of South Africa under the presidency of Nelson Mandela on the occasion of the passing of the new Constitution of South Africa in May 1996.[41] Within the stanzas of this speech vivid images are conjured which express deep and powerful emotion surrounding the concept of African and encompasses the concept that all born on the African continent are African. I, therefore, write from an African perspective gained from being born in Africa as well as working within communities which are home to others born in Africa. However, I do declare my position as a South African from a different cultural group and ethnicity and so share my observations gained from work done within South African communities which reflect a different culture and ethnicity. Stigma surrounding disability is therefore discussed from an African perspective taking into consideration that each culture has a different set of values and beliefs, traits and characters which set them apart from other cultures. Stigma comes from the Greek word of the same spelling and it means mark or puncture burned into the skin to signify disgrace. Figuratively it is commonly used for the negative stereotype or reputation attached to something.[42] Stigma is described as a 'strong lack of respect for a person or a group of

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[39]Global perspectives on disability, human rights and accessing justice 2013-2014 McGill Centre for Human Rights and Legal Pluralism
[40]Global perspectives on disability, human rights and accessing justice 2013-2014 McGill Centre for Human Rights and Legal Pluralism
[41]https://thisisafrica.me/i-am-an-african-by-sa-former-president-thabo-mbeki/ (viewed 28thMay 2019)
[42]https://www.vocabulary.com/dictionary/stigma (accessed 19th January 2019)

people or a bad opinion of them because they have done something society does not approve of'.[43] Stigma towards people with disabilities limits access to education, health care, housing and employment, damages social relationships and social participation which reduces self-esteem and dignity and leads to violation and abuse of human rights.[44] The culture of a people is what sets them apart from other human societies within the bigger family of humanity[45] and embodies a set of social, moral, religious, political, aesthetic and economic values which are upheld by each particular culture and which differ from culture to culture. The discussion of stigma associated with disability is therefore specifically discussed from an African perspective and the attitudinal barriers experienced due to this associated stigma which more often than not results in severe discrimination with devastating and at times fatal results. These attitudinal barriers are deeply rooted in superstitions and myths which are rife and have very real consequences not only for the individual with the disability but for each of their family members too. Respect, integrity and dignity are what families are stripped of within communities which view the sheer existence of the person with a disability as taboo. The Constitution of the republic of South Africa 1996, Bill of Rights upholds these very values which are more often than not ignored and violated by myths and superstitions.

Superstition and myths surrounding disability and the prevailing stigma associated with disability in Africa is a very complex and controversial matter which in depth research shows stems from the belief that disability is caused by supernatural forces, extra marital affairs, demons, ghosts and curses as punishment for perceived wrongdoings by the family. For instance, Nigerian communities believe that disability is a curse from God for perceived gross disobedience of God's commandments. It is also perceived that the cause is due to ancestral violations of social norms such as stealing, fighting, breaking of laws. Family sins such as incest, adultery, illegal or unapproved marriage by the societal elders and arguing or fighting with the elders.[46]

It is said that amongst the Ashanti people of Ghana children with disabilities were categorised as 'animal-like' and abandoned on the banks of rivers or near to the sea in order for them to return to their own kind.[47] In communities in Zimbabwe and Kenya a child with a disability is a symbol of a curse which has befallen the family and is therefore

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[43]https://dictionary.cambridge.org/dictionary/english/stigma (accessed 19th January 2019)
[44]https://seechange.ie/2013/07/29/the-effect-of-stigma/ (accessed 19th January 2019)
[45] GE Idang, 'African culture and values' (2015) Phronimon vol 16 n 2
[46]M Nyangweso 'Disability in Africa: A Cultural/Religious Perspective' East Carolina University, June 2018 (unpublished)
[47]Nyangweso (n2)

considered a 'shame' to the entire family.[48] In Namibia it is believed that Albinism is a direct consequence of the mother having sex with a ghost or a white man. It is common belief in Tanzania that people with Albinism are ghosts who are cursed and that their body parts ward off bad luck and bring wealth and success. This belief has fatal consequences for people with Albinism as they are captured and forced to endure the horrific amputation of their limbs whilst they are alive. They consequently succumb to these horrendous injuries and die. It is also believed that HIV/AIDS can be cured by having sex with girls with Albinism leaving young girls at serious risk of abduction and rape.[49] In Guinea-Bissau epilepsy is widely thought of as being caused by evil spirits, or as a punishment for perceived wrongdoing. Scoliosis, curvature of the spine and various deformities caused by contractures of the limbs are explained as the consequences of a curse and drooling due to excessive saliva production is explained as the possession by demons and ill-gotten financial gain.[50]

These myths and superstitions feed into associated stigma which leave individuals and their families vulnerable to abuse and gross violations of their human rights. Bunning states that, 'the burden of caring for family members with disabilities also leads to discrimination by association and the stigma associated with people with disabilities is so great that it also extends to anyone trying to help. The implication being that anyone offering help would also give birth to a disabled child'.[51] Bunning further elaborates and states that, 'what tends to happen is that these types of cultural beliefs affect how individuals with disabilities view themselves and how other people see them. Attributing the child's condition to some form of malevolent preternatural force by reference to demons, evil spirits and witchcraft contributes to the view of disability as both undesirable and unacceptable'.[52]

The matter of M*abogoana and the Limpopo Provincial Department of Social Development*[53] brought before the SAHRC highlights the challenges of stigma and abuse that people with disabilities continue to face in South Africa. In this particular case, a man with a disability had been kept in isolation and locked up by his mother for 19 years. This level of gross

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[48]Nyangweso (n3)
[49]Nyangweso (n4)
[50]K Bunning 'Dispelling myths about disability in South Africa' (2017) Press Release East Anglia University
[51]Bunning (n2)
[52]Bunning (n3)
[53]Findings of an own accord investigation by the South African Human Rights Commission in the matter of Mabogoana and the Limpopo Provincial Department of Social Development, LP/1314/102

human rights violation brought on through stigma is of great concern and further highlights the need for research on the effect disability has on the entire family. In this case one needs to take a step back and acknowledge the fact that it is not only the man with the disability that has suffered. The case also needs to be viewed from the perspective of the mother who through being left unsupported and ostracised had no choice but to isolate her son and in so doing protect them both from the discrimination faced.

The main point here is that these views have a knock-on effect for the entire family unit, the consequences of which leave basic human rights severely affected. Take for example the right of a mother to go to work, Article 6 of the Committee of Economic, Social and Cultural Rights recognises the right to work, which includes the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts and calls upon states to take steps to ensure the full realisation of this right.[54] Article 15 of the African Charter on Human and Peoples' Rights provides for every individual's right to work under equitable and satisfactory conditions and for equal pay for equal work.[55] Protocol to the African Charter on Human and Peoples rights on the Rights of Women in Africa Article 3(1) reaffirms women's right to dignity inherent in all human beings.[56] Article 13(a) obliges states to adopt and enforce legislative and other measures to guarantee women equal opportunities in work and career by amongst others, promoting equality of access to employment.[57] This right is more often than not severely affected as the mother is unable to find employment due to the fact that she is forced to stay at home and take care of her child as there is no one who is prepared to take care of the child whilst she goes to a place of employment. This therefore also leaves her without an income and without the financial means to support her child which then leads to a very dire situation and perpetuates the cycle of poverty so many families find themselves in. This is a sad reality and there are countless mothers in similar situations and each scenario is directly linked to the superstitions and myths which are the cause of stigmas placed on mothers which leave them isolated, alone and unsupported.

In order for changes in perceptions to occur and in order for these changes to be effective commitment by state parties to proactively support and implement legislation, policy laws and policy needs to occur. Through being seen to actively be involved in awareness raising

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[54]Committee of Economic, Social and Cultural Rights Article 6
[55]African Charter on Human and People's Rights Article 15
[56]Protocol to the African Charter on Human and People's rights on the Rights of Women in Africa Article 3(1)
[57]Protocol to the African Charter on Human and People's rights on the Rights of Women in Africa Article 13(a)

campaigns which specifically address stereotypes, prejudice, discrimination and harmful practices relating to persons with disabilities as stated in article 8 of the UN Convention of the Rights of Persons with Disabilities, governments would show their influence in this important role in helping to avoid, prevent and remedy harmful cultural beliefs or practices. The government of Tanzania has shown their commitment through the launch of special task forces mandated to investigate the killings of people with Albinism. The Tanzanian state party has further shown their commitment through implementing education campaigns, appointing people with Albinism to parliament. They have also banned all traditional healers, people using ethnomedicine, long-established methods passed down from healer to healer instead of contemporary medicine, to treat various illness and witchdoctors, types of healers who treats ailments believed to be caused by witchcraft, from practising their trade which negatively effects people with Albinism. Through doing so making the killing of persons with Albinism a capital crime and working with police and communities to end the abuse of people with Albinism.[58] The governments of Kenya and Uganda have reported that it has been noted that progressive government policy had helped to gradually change attitudes towards disability. Through these examples, the importance of the integration of disability awareness, education and services in all public institutions can be seen. Furthermore the collaboration between governments and national and regional disability organisations, NGOs and international organisations can be seen as an effective means of intervention in the legal and policy arenas which further implement the reduction and prevention of discrimination and harmful practise against those with disabilities supporting and reinforcing the rights of people with disabilities.

2.6 Conclusion

The sad reality is that myths and superstitions more often than not justified by culture and religion create and reinforce very cruel stigmas resulting in severe societal, environmental and attitudinal consequences for individuals and their families. At times some of these consequences are fatal. This persistent violation and abuse and mistreatment of persons with disability requires cultural and religious redress through debunking misconceptions and in so doing affirm the core values of cultural traditions and religions. One such core value being family and the importance thereof and another the living concept of Ubuntu. The

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[58]Action on Albinism in Africa Consultative Forum 17-19 June 2016 Dar es Salam (United Republic of Tanzania)

significance and the magnitude of Ubuntu cannot be underestimated as it emphasises and continually reinforces the concept of 'I am, because you are'. In other words a person is a person through other people each sharing a common humanity and an oneness which encompasses 'you and me both'. The concept of only becoming a person once you have assisted and aided another heightens your profile and status within the community through good deeds and community acknowledgement. However, superstitions, myths and stigma passed down from generation to generation skews this valuable concept and mars the importance of Ubuntu.

These societal, environmental and attitudinal barriers therefore need to be unpacked in light of stigmas as well as Ubuntu and it needs to be discussed within an African context. From this point of departure a perspective needs to be gained as to how the two can be bridged within communities in order to ensure that families with family members living with a disability are better supported and embraced within the spirit of Ubuntu and not left rejected, abandoned and isolated.

Chapter 3
Collective impact of disability on affected family members

3.1 Introduction

The previous chapter dealt with the various definitions of disability incorporated in disability dialogues throughout the world. Disability related statistics from an international and South African perspective were included which led to an analysis of the various African specific stigmas and myths surrounding disabilities and the consequences thereof within African communities. Chapter three serves to link the two chapters through discussing the impact

disability has on a family as a unit living in South Africa. It will give examples of how individual family members are affected on a daily basis and the manner in which their rights as individuals are ignored and left unsupported. The first section will discuss the family dynamics in affected families. Section two will highlight the rights framework for affected families which will be proceeded by a section discussing the disability specific South African infrastructure in relation to grants, housing, health services, education and transport. The impact barriers to disability have on the collective rights of family members within the scope of these basic fundamental daily activities will be further unpacked and discussed.

3.2 Family Dynamics in Affected Families

The impact of disability is profound, complex and multi-layered. Each layer has a definitive impact not only on the individual with the disability but the family as a unit and each individual within that family unit. It would be unfair and a gross misinterpretation to presume that this multi-layered impact is isolated and only affects the individual. Seligman and Benjamin discuss the link between family and social systems defining family systems as, 'the family operating as an interactive unit, in which what affects one member affects all members'.[59] This they then link to social systems and the expectations society has and places on people in various roles within society thereby influencing the manner in which parents relate to and respond to their child. These societal expectations in turn vary from society to society across the world and influencing factors of these expectations depend on the perception and associated connotations of disability within each society.

Family dynamics are in general a juggling act for most and there is an overall fine balance to be reached in maintaining a healthy positive status quo in an average family. Within a family that has a child with a disability the status quo is subjected to constant, on-going turbulence and counterforces. Family health is challenged through adaptations within the family unit, social adjustments within the family's extended family as well as an interconnected social sphere. Socio economic factors are experienced on an exaggerated negative scale escalating risk and seriously challenging the resilience of families. Parent and sibling functioning is challenged as the stark difference between parental perceptions and sibling social and behavioural manifestations emphasise break downs which have far

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[59] Seligman et al (n2)

reaching effects. The high divorce rate in families with children with disabilities further confirms the impact disability has within a family unit. The emphasis therefore should be on supporting families and assisting with the implementation of healthy family strategies which reinforce the family structure and builds on the strength and value of a family unit foundation which is resilient to challenges and societal, attitudinal and environmental discriminatory barriers. Reinforcing the rights of each individual within the family unit and each individual's role as a right bearer within the family unit would further strengthen the resolve and influence of each individual family member. Every family has various members. These members differ with regard to biological relationship, gender, age and position within the family. Some families have both biological parents present with male and/or female siblings, maternal and/or paternal grandmothers, grandfathers or both grandparents present. Male and/or female cousins are at times present and so an extended view of a family unit is to be taken into account within the context of the meaning of family members within this chapter.

McConkey et al have examined the role of family members in tackling stigma in developing countries and have established four main strategies. The first being the nurturing of development which entails actively nurturing their child's development through taking their child outside the home and participating in family and community events despite criticism from others. African mothers have a deep faith in God and they draw on this faith to provide them with resolve and resilience. It is the commonality which draws mothers together and in so doing provides each with much needed emotional support as well as with informational and practical support based on each mother's personal experience. It is these parental interactions which play a crucial role in making families proactive change agents for their children.[60] This first strategy feeds directly into the second which speaks to inclusion of the child into the community and society in which they live. The benefits of the child interacting with others and others interacting with the child goes a far way in dispelling the myths and superstitions. Through this inclusion relationships are formed and the fear dissipated as tolerance and acceptance of perceived differences replace discrimination and rejection. The third strategy is information sharing in order to demystify disability. According to McConkey 'myths and superstitions persist because they go unchallenged which is why many parents associations place such an emphasis on giving parents information about

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[60]Bunning (n4)

disabilities so that they in turn can pass this information onto others'.[61] Advocacy is the fourth strategy as evidence shows that parental advocacy plays a vital role in lobbying politicians and governments with regard policy and legislation change and implementation and the provision of essential support services. However, McConkey warns that sustaining the above-mentioned strategies 'in the face of rejection and intransigence requires a vast amount of physical and emotional energy from parents and they need allies to maintain their resilience'.[62]

3.3 Disability Rights Framework: Effectiveness of the Framework for Affected Families

UNICEF is in agreement with the World Report on Disability by the World Health Organisation which estimates that there are around 93 million children under the age of 14 living with some type of disability in the world.[63] This figure is a rough estimation and it is suspected that the figure could be much higher. Each of these children face discrimination on every level not because of the intrinsic nature of their disability but rather due to prejudice based on ignorance which leads to social exclusion and isolation which is exasperated by the severe and unforgiving effects of poverty which is entrenched in lack of service provision and support. Approximately 426 million people with disabilities in developing countries live below the poverty line and are often among the 15 to 20% most vulnerable and marginalized poor in such countries.[64] The cumulative impact therefore is on the human rights of each individual, rights which are universal, indivisible and interdependent, rights which should be applied without discrimination to every human being as their inherent right for being human which in turn also apply to each family member. It is therefore not just the individual with the disability whose right to respect, dignity, and life is denied but each family member too.

The 54 articles representing the Convention on the Rights of the Child (CRC) were adopted by the UN General Assembly in 1989 and came into force in 1990. This holistic treaty embodies social, economic, cultural, civil and political rights and serves to confirm that children are entitled to rights, like adults, but in light of their vulnerability they are also

[61]Bunning (n5)
[62]Bunning (n6)
[63]https://www.unicef.org/disabilities/ (viewed 28th May 2019)
[64]Using the human rights framework to promote the rights of children with disabilities: Discussion Paper An analysis of the synergies between CRC, CRPD and CEDAW

entitled to additional levels of protection. In 2006 the UN adopted the Convention on the Rights of Persons with Disabilities and in so doing secured the objective of the promotion of the rights of people with disabilities which is clearly outlined in Article 1 which states, 'the purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'.[65] It clearly supports inclusion, equality and non-discrimination and emphasises that persons with disabilities are entitled to live within their communities, to make their own choices and to play an active role in society and enjoy the freedoms experienced by others within society which further highlights a real commitment to a truly inclusive and universal human rights framework.

A group of 18 independent experts make up the Committee on the Rights of Persons with Disabilities who are tasked to oversee the promotion and implementation of the Convention. All States are obliged to report regularly on the implementation of the embodied rights in each of their countries. Based on each report suggestions and comments are made to ensure and promote further progress. Civil society organizations and national human rights institutions also contribute to the reviews. The Special Rapporteur on the Rights of Persons with Disabilities was created by the Human Rights Council and has the mandate to research and gather information on violations of the rights of persons with disabilities and to provide technical assistance to that purpose.

The Promotion of Equality and Prevention of Unfair Discrimination Act aims to prevent unfair discrimination through the promotion of equality and a culture of democracy, the protection of human dignity and the prevention of unfair discrimination based on one or more grounds, including disability.[66] In order to give effect to the obligations in terms of the South African Constitution and international human rights instruments concerning amongst others, the offence of hate crimes and hate speech the Prevention and Combating of hate Crimes and Hate Speech Bill has been established. The reporting on the implementation, application and administration of this Act is mindful of section 9(3) and (4) of the Constitution which provides that neither the State nor any person may, directly or indirectly, discriminate unfairly against anyone on one or more grounds, including disability.[67] Section 10 of the Constitution provides that everyone has inherent dignity and the right to have their

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[65]The Convention on the Rights of Persons with Disabilities Article(1)
[66]The Promotion of Equality and Prevention of Unfair Discrimination Act
[67]The South African Constitution

dignity respected and protected.[68] Section 7(2) of the Constitution provides that the State must respect, protect, promote and fulfil all the rights enshrined in the Bill of Rights, which is the cornerstone of democracy in South Africa.[69] According to the Act the severity of the emotional and psychological impact of hate crimes and hate speech extends beyond the victim, to the group to which the victim belongs or is perceived to belong and 3(1) of the Act states that a hate crime is an offence recognised under any law, the commission of which by a person is motivated by that person's prejudice or intolerance towards the victim of the crime in question because of one or more of the following characteristics or perceived characteristics of the victim or his or her family member or the victim's association with, or support for, a group of persons who share the said characteristics (b) Albinism, (f) Disability.[70]

In view of the above it is important to reflect upon whether or not this is enough to ensure that significant change is being seen through the Disability Rights Framework which is specifically tasked with the implementation thereof. In addition to this one of the questions in this research is raised which emphasises the awareness of individual family members of these policies and legislation and their ability and conviction to enforce enough influence to implement and action these essential aspects.

3.4 South African support infrastructure in relation to disability

Within a South African framework how does the above-mentioned legislation within the disability framework assist and aid families with regard to housing, transport, service provision, medical assistance, education. Does the framework offer a guarantee that the basic rights of the individual and their family are catered for or is it merely talk without action? At what degree of risk does the non-implementation thereof have on families? If a family do not have access to health care how does this affect the financial status of the family? Do families have to make decisions between bread to eat and medication for their child? Are grants received enough money to assist families with their financial needs? Do families receive the necessary support and information with regard to accessing basic

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[68]The South African Constitution
[69]The South African Constitution
[70]The Prevention and Combating of hate Crimes and Hate Speech Bill

services? These are the questions which working in the field I too often encounter and sadly too often the response is in the negative.

3.4.1 Grants for people with disabilities in South Africa

In order to qualify for a disability grant the South Africa Social Security Agency stipulate that a person must have a physical or mental disability which renders the person unable to work for a period longer than 6 months. A permanent disability grant is awarded if the disability continues for more than a year however this does not mean the person will receive the grant for life just that it will continue for longer than a 12-month period. A temporary disability grant is awarded if the disability lasts for a continuous period of not less than six months and not more than 12 months. To qualify the person must be a South African citizen or permanent resident or have refugee status, be between 18 and 59 years of age, not be cared for in a state institution, have a 13 digit bar-coded ID, not earn more than R 78 120 as a single person with assets worth more than R 1 115 400 and R 156 240 as a married person with assets more than R 2 230 800.[71]

In order to qualify for a care dependency grant the applicant and child must be a South African citizen, permanent resident or refugee and must be a resident in South Africa. The child must be under the age of 18 years and not cared for in a state institution. The applicant and spouse must meet the requirements of the means test; foster parents are excluded from these criteria. A medical report and assessment confirming permanent/ severe disability must be submitted.

Grants are apparently difficult to apply for and consequently the process involved very time consuming and confusing. Family members applying for and obtaining grants on behalf of family members living with varying disabilities have a story to tell, one which highlights the difficulties and challenges of applying for a disability grant. Many families do not have the correct information with regard to the application process and often feel frustrated at the lack of support and guidance which leaves them despondent and isolated. When grants are accessed these are often the sole means of income for the family and so people with

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[71]http://www.sassa.gov.za/index.php/social-grants/disability-grant (accessed 9th February 2019)

disabilities effectively become the bread winners for their families. This amount therefore does not get used for the purpose it is intended i.e. support for the person with the disability but instead gets used for the needs of the entire family. Within more rural communities a child with a disability more often than not lives with the grandparents. The household in many instances supports other younger able-bodied grandchildren and relatives who are unemployed. The grant along with the pension received therefore supports the extended household.

3.4.2 Housing for people with disabilities in South Africa

The Reconstruction and Development Programme Policy was brought about in 1994 with the aim of implementing a South African socio-economic policy framework. It is estimated, from data available from the department of human settlements, that 2,930,485 RDP houses were built and issued between 1994 and 2015. One of the objectives being poverty alleviation which incorporated a housing delivery policy. This housing delivery policy prioritised the delivery of houses first and foremost to the elderly and those with disabilities which were mandated to be suitable and specific to their needs, accessible and close to essential amenities. The Housing Code therefore was given provision for variation of the subsidy to allow for the enhancement of houses in order to accommodate specific disabilities and applicants therefore specify their personal needs on application forms and include a doctor's report and full medical records to verify their specific needs within a living environment. However, many report that they do not get a house that meets their needs and that they themselves pay for the installation of ramps and rails and any other special adaptations required which come at quite an expense. Mbovane reports that standard houses are built and issued to people with disabilities and are only modified and adapted when pressure is applied. He argues the point through quoting a wheelchair user who states that, 'I can't enter my own RDP without being lifted off the wheelchair first … Every door inside the house I must access by being lifted first'.[72]

In June 2015, after in-depth consultations with various civil society organisations the department of human settlements developed the draft Special Housing Needs Policy and Programme the aim of which was to provide housing opportunities for persons unable to live independently in standard-type housing or require assistance in terms of a safe,

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[72]'RDP houses unfit for people with disabilities' eNCA 19 July 2018 Thamsanqa Mbovane

supportive and protected living environment.[73] In addition the main objective was to provide capital grants to approved and registered NGOs "for the acquisition or development of new and/or the extension of and/or upgrading or refurbishment of existing special-housing needs facilities for persons or households with special-housing needs".[74]

The Department of Human Settlement, in response to a study by the SA Human Rights Commission (SAHRC) which found that due to a lack of consensus as to which government department mandate should cover the provision of the policy it had not been finalised, expressed that whilst prepared to bear primary responsibility of implementation it was concerned as to who would be responsible for oversight and funding operational management post construction.[75]

As a result of this an argument arises challenging the fact that effective intergovernmental cooperation is essential for the execution of the special-needs housing policy in addition it highlights the heavy burden placed on non-profit organisations (NPOs) to assist government in its provision of special-needs housing.[76]

The argument therefore stands that housing remains a bone of contention which places affected families at risk of inadequate and substandard housing which does not accommodate for the specific needs of their family member living with a disability. This in turn directly affects their living conditions as they attempt to cater for the needs of their entire family unit.

3.4.3 Health services for people with disabilities in South Africa

A variety of wheelchairs ranging in size from adult to paediatric are available on national tender. This means that a person in need of a wheelchair is entitled to obtain a wheelchair suited to their specific needs from the local government hospital or clinic to which they are registered. However, more often than not the procurement of these from specific service providers are subject to government budget constraints. Consequently, this results in people being placed onto long wait lists at these facilities. As a result of these long wait lists

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[73]Special-needs housing still a dream' City Press 25 June 2017 Sinethemba Memela, Tatenda Muranda and Querida Saal researchers with the SAHRC
[74]'Special-needs housing still a dream' City Press 25 June 2017 Sinethemba Memela, Tatenda Muranda and Querida Saal researchers with the SAHRC
[75]'Special-needs housing still a dream' City Press 25 June 2017 Sinethemba Memela, Tatenda Muranda and Querida Saal researchers with the SAHRC
[76]Special-needs housing still a dream' City Press 25 June 2017 Sinethemba Memela, Tatenda Muranda and Querida Saal researchers with the SAHRC

and under resourced facilities access to assistive devices is delayed leaving people with disabilities at high risk of developing unnecessary secondary complications.

These complications have a direct effect on the family members taking care of the individuals. No wheelchair means that the mother, grandmother, sister needs to carry the child on their back. This therefore leads to serious back injuries which have a knock-on effect for these women. Necessary medications are often not available and parents are then forced to buy the medication from a pharmacy, an expense they can ill afford. Sunscreen for individuals with Albinism should be issued at hospitals and clinics as without it they are at risk of developing various forms of skin cancer, as this does not occur families need to buy this essential commodity. Diapers for those with incontinence issues are meant to be readily available and without cost at local hospitals and clinics. When on occasion they are issued the amount received is minimal and lasts 3 to 4 days at the most. This then leaves families with the added expense of diapers or the use of towelling nappies or simply no nappies at all which have a negative impact on personal hygiene. Inadequate health services have serious consequences for families and impacts not only their financial status but puts family members themselves at risk of serious health issues both physically and emotionally as they make various attempts to rectify the matter.

3.4.4 Education for children with disabilities in South Africa

According to Donohue et al UNESCO estimates that only 10% of children with disabilities attend school in Africa.[77] In South Africa the Department of Education estimates that up to 70% of children with disabilities do not attend school. Cultural attitudes dictate whether or not a child with a disability receives an education and it is found that many children do not attend school as the perception is that they cannot learn.[78] According to Donahue and Bornman as schools charge tuition fees it has financial implications which are therefore also a deciding factor for many families. It may not been seen as economically feasible to send a

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[77]D Donohue & J Bornman 'The challenges of realising inclusive education in South Africa' (2014) S. Afr. j. educ. vol.34 n.2
[78]Donohue et al (n2)

child with a disability to school especially if there are other children of school-going age to consider, bearing in mind that these children have the prospect of bringing an income into the family a prospect the child with a disability is perceived not to have.[79] At times siblings are restricted from attending school as they are required to assist their parents with the care of the sibling with a disability. School activities and extramural activities are also affected as the sibling takes on what is considered their share of the responsibility of the care of their sibling. Affected siblings therefore experience a direct effect which impacts on their individual right to education.

3.4.5 Transport for people with disabilities in South Africa

In South Africa buses and minibus taxis are a common means of transport. These are used throughout the country by daily commuters who rely on this mode of transport as their sole means of transport. The fee structure per person per trip is calculated accordingly. These fees are paid upon commencement of the journey. Taxi drivers charge a mother, boarding a taxi with her child in a wheelchair, full adult fare for the mother and full adult fare for the wheelchair and full price for the child, if that is, that they actually stop for the mother which, more than often they do not. Due to this, mothers often do not take their children to school or to hospitals and clinics for necessary check-ups and essential medical interventions leaving the children susceptible to serious health implications. Out of necessity the therapists at hospitals and clinics offer to give the mothers transport money, often out of their own purses, in order to ensure that they can continue with the essential therapy programmes the children are so desperately in need of. Lack of transport leaves mother's vulnerable and once again at risk of developing severe back injuries as they are once again forced to carry their children on their backs. Lack of transport again puts the individuals with disabilities at risk as they are denied their right to access not only health care facilities but shops, churches, community functions, schools. Mothers and siblings too are denied these basic rights of socialisation as due to these unfair discriminatory transport costs they are forced to stay at home with their child or sibling.

In September 2007 the South African Rail Commuter Corporation (SARCC), the SA National Taxi Association Council (SANTACO) and the Department of Transport briefed the

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[79]Donohue et al (n3)

Committee on transportation for people with disabilities, a parliamentary monitoring group. [80] Even though current policies, design guidelines and implementation plans were discussed for users with special transportation needs the Committee raised concerns about the challenges and lack of accessible transportation in South Africa. SA National Taxi Council Secretary General, Mr. Philip Taaibosch, SANTACO Secretary General, outlined three key issues of cost, problems and challenges of actual transportation of wheelchairs and availability of resources in the provision of services for people with disabilities. One of the problems mentioned was that wheelchairs occupied a paying seat on vehicles; hence some drivers would charge additional costs. The insensitivity of taxi drivers towards the plight of people with disabilities was acknowledged by SANTACO and as a part of the transformation and repositioning of the taxi industry; a Disability Transport Desk would be established to be headed by the Secretary General of SANTACO.

3.5 Conclusion

As it can be seen from the above that the impact of disability is experienced throughout the entire family and the rights of all members are affected by disability. Disability therefore can be seen as having a collective impact on the rights of each family member and it is these rights which need to be highlighted and then catered for to ensure that as a family unit each member has a clear and definitive understanding of their recourse to these rights.

The role of families is emphasised by Rohwerder who states that families are central in improving perceptions of persons with disabilities and that each family member is a lead advocate in the fight against negative attitudes and discrimination.[81] It starts with the experiences children have within their families and the manner in which the child is encouraged and supported in bolstering and preserving their individual identities in the face of this stigma. If the family as a unit show a collective acceptance, belief in and love for the child it reinforces the child's love for self and augments self-awareness and acceptance of self. This then can positively influence the communities in which they live.

Families need to be aware of, have knowledge of and be cognisant of national as well as global legislation and policies. Through empowering themselves family members can not

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[80] Meeting report: 'Joint monitoring committee on the improvement of quality of life and status of children, youth and disabled persons – Transport for People with Disabilities' 7 September 2007
[81] B Rohwerder ' Disability stigma in developing countries' Institute of Development Studies

only change perceptions within their own families and other families and communities but in so doing counter ignorance and misrepresentation and consequently bring about a change of perception that disability only effects the individual who has the disability and not a collective family unit and in so doing highlight the importance of Ubuntu and reaffirm the ever important 'I am because you are'.

Chapter 4

A Discussion on the implementation of the South African disability rights framework

4.1. Introduction

In chapters two and three relevant information pertaining disability was analysed, discussed and highlighted within the realm of affected families. These included the various definitions of disability, disability related statistics from an international and South African perspective, the various African specific stigmas and myths surrounding disabilities and the consequences thereof. The impact disability has on a family as a unit living in South

Africa was discussed in light of family dynamics with specific focus on the rights framework for within a disability specific South African infrastructure related to grants, housing, health services, education and transport. The impact barriers to disability have on the collective rights of family members was further unpacked. This chapter aims to consolidate information presented in preceding chapters through a discussion of the disability rights framework and the questionable implementation thereof thus highlighting the plight of family members within the reality of their daily lives and the perspective of their roles within the sphere of their collective recourse as right bearers. Section one will focus on the redefinition of disability. Section two will highlight legislation which will be followed by a section which will offer a discussion of the disability framework. The final section will consolidate information presented. Throughout the meaning of disability rights will be emphasised as equal and inalienable just like the rights of all other citizens living within communities across South Africa and the world in general.

4.2. Redefining disability

The definition of disability has long been debated and disputed with various organisations calling for a redefinition within the context of the fact that through focusing on the perceived inability of people the definition is inadvertently bringing about stigmatisation and categorisation.[82] This results in isolation and discrimination. Due to this consideration, the Integrated National Disability Framework propose a socio-political approach to disability, whereby disability is located within a social environment in place of a medical one. This redefinition takes cognisance of the viewpoint that disability is a social construct and most of its effects are inflicted by social environments.[83] The British Council of Organisations of Disabled People take the same viewpoint and emphasise that, "disability is the disadvantage or restriction of activity caused by a society that takes little or no account of people who have impairments and thus excludes them from mainstream activity."[84]

In other words, it is not "the disability" nor is it the wheelchair that disables a person but it is the stairs, for example, leading to a building that do. Similarly, it is not the disability but the lack of appropriate support within everyday activities and lack of access to everyday

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[82]https://www.westerncape.gov.za/general-publication/disability-definitions-models-and-terminology These guidelines on disability terminology and definitions are taken from "A Pocket Guide on Disability Equity" prepared by Disabled People South Africa (DPSA).
[83]https://www.westerncape.gov.za/general-publication/disability-definitions-models-and-terminology These guidelines on disability terminology and definitions are taken from "A Pocket Guide on Disability Equity" prepared by Disabled People South Africa (DPSA
[84]Different approaches to defining disability, British Council of Organisations of Disabled People

amenities such as transportation, adequate health care and education that disables a person and consequently places unnecessary burdens and challenges onto the family as collective right bearers.

4.3. South African legislation

In order to guide, promote and encourage successful inclusion of persons with varying disabilities into mainstream society South Africa has adopted a number of policies.[85] It has been acknowledged that the conceptualisation of the issue of disability as a human right and a development issue needs to occur in order to correct past discriminatory practices against persons with disabilities and in so doing bring about a new approach and way of thinking which will usher in a legal framework to protect the human rights of persons with disabilities in all spheres of governance.[86] The realignment of a number of national policies has therefore occurred in order to redress inequalities and in so doing empower persons with disabilities. The adopted legislative framework and guidelines include:

- Ratified CRPD
- Ratified CRPD Optional Protocol
- The Constitution of the republic of South Africa 1996
- Employment Equity Act,1998
- Blind Persons Act, 1968
- Disability Grants Act, 1968
- Second Pension Laws Amendment Act, 1970
- Special Pensions Act, 1996
- Special Pensions Amendment Act, 1998
- Welfare Laws Amendment Act, 1997
- Workmen's Compensation Act, 1941
- White paper on the transformation of the Public Service 1995
- White Paper on Affirmative Action in the Public Service, 1997
- White Paper on Integrated National Disability Strategy, 1997
- White Paper 6 on Special Needs Education, 2001

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[85]Census 2011: Profile of persons with disabilities in South Africa Pali Lehohla Report No. 03-01-59 Statistician-General
[86]Census 2011: Profile of persons with disabilities in South Africa Pali Lehohla Report No. 03-01-59 Statistician-General

- South African International Relations and Cooperation Framework; The Presidency, RSA 1997

- White Paper on Integrated National Disability Strategy

- White Paper on Special Needs Education

- Promotion of Equality and Prevention of Unfair Discrimination Act, 1996

- Basic Conditions of Employment Act,1997

- Skills Development Act,1998

- Broad Based Black Economic Empowerment Act, 2003

- UN Convention on the Rights of Persons with Disabilities (CRPD)

The South African Constitution is very clear with regard to the principles of non-discrimination based on disability and displays an unambiguous stance with regard to equal opportunity, accessibility, respect for and support of diversity and the promotion of full inclusion into society.[87] The National Development Plan boldly outlines South Africa's development agenda for the period of time from the year 2010 to the year 2030 and within this agenda stipulates the need to create an inclusive social protection system that addresses vulnerability and responds to the needs of those at risk which includes persons with disabilities.[88] Through moving from a medical model to a social model, disability is viewed in a different light. Within this new perspective disability is viewed through a human rights lens within a developmental arena and in so doing changes the perception that persons with disabilities are unproductive and therefore in need of care. This change in perception is evidence that a paradigm shift with regard to the conceptualisation of disability has occurred and is further emphasised in the White Paper on Integrated National Disability Strategy (INDS) of 1997. The existence of these structures should therefore encourage review and align and include national priorities such as poverty reduction, education, employment, health, safety and security as well as equal access to opportunities and services which if effectively implemented will ensure that the rights of persons with disabilities and their best interests are promoted, implemented and achieved on an equal basis.[89]

4.4. The implementation of the disability framework

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[87]Census 2011: Profile of persons with disabilities in South Africa Pali Lehohla Report No. 03-01-59 Statistician-General
[88]Census 2011: Profile of persons with disabilities in South Africa Pali Lehohla Report No. 03-01-59 Statistician-General
[89]Census 2011: Profile of persons with disabilities in South Africa Pali Lehohla Report No. 03-01-59 Statistician-General

The stark disjuncture between what is written within State policy and within a legislative framework and what is being experienced on a daily basis by affected families is blinding and one cannot help but question the validity thereof, the lack of which casts serious doubt on the sincerity thereof. An example of this would be access to a disability grant which should in all intents and purposes be an easy smooth flowing process which family are well supported in. It is however, plagued by challenges which Tesemma attributes to the "determination of eligibility, bureaucratic hurdles, and the high opportunity cost of accessing these benefits."[90] The positive benefits for successful candidates is the reduction of deprivation, boosted household health, improved economic status and financial bearing as well as the positive impact contributing to the household budget has on the self-esteem of the person with the disability.[91]

As noted in chapter 3, however, dire poverty and high unemployment rates result in a person with a disability lacking control over how the grant is spent and is often left without a cent as the monies are distributed across a wide spectrum of household needs which often include obligations to extended family members. This very real fact is not accounted for and should be addressed within the disability framework in order to ensure that family members are suitably supported within their role as financial managers and custodians of the grant received and are duly informed and decidedly aware of other subsidies available to them such as SARS rebates which allow a family who pay tax to claim 33, 3% of the qualifying out of pocket medical expenses which includes disability related expenses.[92] Family members should also be informed and well versed with regard to the State's obligations towards health care with regard to distribution of appropriate wheelchairs, various forms of therapy, essential medications, a supply of nappies as well as food supplements prescribed by a dietician to boost nutritional intake. Knowing what prerogatives are available will reduce the cost to families and lessen the negative financial burdens experienced.

The consequence of high disability related costs rendering services and associated necessities unaffordable in many cases result in a perpetual downward spiral into poverty from which many families cannot escape. Empowering family members with a voice is key to empowering them as right bearers within the context of their family circumstance and plays an essential part in ensuring that the concern echoed by some that grants create a

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[90]ST Tesemma 'Economic discourses of disability in Africa: An overview of lay and legislation narratives' (2014) ADRY6
[91]Tesemma (n2 above)
[92]Tax and Disability – SARSwww.sars.gov.za/ClientSegments/Individuals/Tax-Stages/Pages/Tax-and -Disability.aspx

degree of dependency and thereby encourage a lack of motivation to seek employment by family members is dispelled.

Ironically the only manner in which grants can be conferred is on proof of a family member's perceived "abnormality". This undermines not only the dignity of the person with the disability but each family member as they too are labelled as cursed and therefore isolated within communities further perpetuating the lack of support for family members.

Turning to transportation, education, health care seen as fundamentals which suffer a similar fate severely impacting mothers, fathers, grandparents and siblings. Ubuntu is questioned as families stand alone and unsupported leaving them vulnerable to discrimination which at times leads to abuse.

Consequently Nyangweso argues that "there is a need for aggressive criminalization of behaviour that undermine the welfare of people with disabilities"[93] and through some form of punishment enforcement for behaviour that endangers the rights of persons with disabilities transformation of attitude and mind-set towards persons with disability would occur and that all countries have a responsibility towards this in order to adequately promote the rights of persons with disability.[94] As various African countries have ratified the United Nations Convention on the Rights of Persons with Disabilities they are expected to act towards protecting the rights of people with disabilities and therefore States need to take cognisance of the fact that religious values and cultural beliefs are often used to sanction the deplorable treatment of people with disabilities and with this in mind States need to embrace the role of religion and culture and incorporate the affirming values from these influencing factors in order to reinforce Ubuntu and fortify support of family members. As Archbishop Desmond Tutu is very fond of saying, "I am a person through other people. My humanity is tied to yours. "Ngwena proposes a refocus of the frame of reference of disability which moves from society's preoccupation with individual impairment to one of collective societal failure to accommodate and include people with disabilities and their families on an equal basis into society[95] and in so doing placing the focus of disability squarely in the center of a platform which insists on accommodating persons with disabilities. This refocus would abolish the legacy of systematic inequality and discrimination and prevent society from simply standing by and watching persons with

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[93]Unpublished: M Nyangweso 'Disability in Africa: A Cultural/Religious Perspective' unpublished, East Carolina University, June 2018
[94]Unpublished: M Nyangweso 'Disability in Africa: A Cultural/Religious Perspective' unpublished, East Carolina University, June 2018
[95]C Ngwena 'The rights of persons with disabilities: call to action!' (2016) The University of Pretoria Op-Ed

disability making attempts to assimilate into an ableist society intended for persons without disabilities and would instead mobilise society in dismantling disabling barriers and in so doing create an inclusive society[96] for all by all.

Ngwena poses a pertinent question regarding the meaning of disability rights within a South African context and argues that the language of human rights can only take the disability agenda so far. He further argues that it should seek to overcome mere words in order to be translated into something much more concrete and unless this happens these empty words make no difference in the lives of right bearers at grass roots level.[97]

4.5. Conclusion

The Constitution rejects any behaviours or actions which diminish equality and dignity and in so doing instigate and promote marginalisation. The equality clause signifies substantive equality, which emphasises societal obligation to remove barriers which prevent others, including persons with disabilities, from participating on an equal basis with others.[98] However, as discussed in preceding chapters experiences of persons with disabilities and their affected family members attest to the fact that this constitutional promise is undermined, unfulfilled and lacking in allegiance to those it made the promise. This leaves families burdened and impoverished with inadequate access to socio-economic sectors such as housing, education, transport, employment, vocational training, health care, sport and social amenities, the exclusion of which does not only affect the person with the disability but each and every family member.

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[96]Ngwena(n2 above)
[97]Ngwena(n3 above)
[98]Ngwena(n4 above)

Chapter 5

Conclusion and recommendations

Conclusion

At some stage or another we all face hardships and difficulties and challenges on various levels within our lives. People with disabilities however experience these much more frequently and with greater impact and ferocity. Their families experience these too as they grapple with not only trying to assist the affected family member but with balancing their own needs and inalienable rights within this complex scenario which leaves the entire family disenfranchised. Having conducted an in-depth study on the above-mentioned topic I can conclude that people with varying disabilities face a myriad of challenges and associated

barriers which not only effect their lives but the lives of their family members and has far reaching effects across the entire family unit.

It is safe to say that there are many challenges and that these should be seen from a socio-economic perspective and that the issues of lack of resources and serious governance issues compound the challenges which have a deep rooted foundation in discrimination fuelled in part by stigmas, myths and superstitions and in part by the perception that disability affects only the individual. Through educating the general populace on matters pertaining disability the challenges and barriers could be mitigated. By acknowledging that policy barriers play an instrumental part in supressing family members in their roles as right bearers and mobilising families to take a stance would be a good start in implementing a collective recourse. Through empowering family members to address the programmatic barriers limiting the effective provision of basic rights to healthcare delivery, grants, transport, housing, voices will be heard and changes made.

This dissertation posed two main research questions. Firstly, asking what legal recourse families had as collective right bearers in South Africa? Secondly if there were far reaching short and long-term effects, across the wide spectrum of human rights, which impact on each individual within the family unit? These were posed within a South African context in order to highlight the dynamic experienced within South African communities which are the homes of many children with disabilities and their affected families. Consequently, chapter one laid the foundation and gave the background and an introduction to the topic. Chapter two focused on definitions and statistics and incorporated important global and essential South African perspectives highlighting the various African specific stigmas and myths and the negative impact these have on individuals as well as family members. Chapter three linked with chapter two through further highlighting the stark reality of direct consequences to daily life activities and the lack of fundamental service provision and the negative effect these had on affected family members further highlighting the collective effect disability has on their individual rights. Chapter four served to consolidate information presented in preceding chapters through a discussion of the disability rights framework and the questionable implementation thereof thus highlighting the plight of family members within the reality of their daily lives and the perspective of their roles within the sphere of their collective recourse as right bearers.

Throughout each chapter it became increasingly evident that it is essential to affirm family members as right bearers in order to empower them into holding the state accountable for its unfulfilled promises. The disability rights framework should be explained to family members, they should be made aware of its existence and should be guided and supported in using it to their advantage. By not knowing about it and not knowing how to implement they are left none the wiser. Family members need to know that they can raise their voices, that they can challenge the system, that they do not have to passively accept an up to five year waiting list to obtain a wheelchair for their family member in dire need nor accept disprin when their child needs epilium to control seizures. They need to know that through raising their voices and making it publicly known that they receive very little support, that the service provision they are entitled to is severely lacking on all levels and in all aspects affected families will be sending a loud and clear message that boldly states that what is offered is an afterthought and is simply not enough nor good enough to assist them in their prominent role as right bearers for their family member. They need to know that they do have the right to speak up which is clearly stated as freedom of expression in the Bill of Rights, Chapter 2 of the the Constitution of the Republic of South Africa 1996 and do therefore have the right to demand what ableist society simply gets. Siblings need to be able to attend school and not take on the responsibility of a caregiver role, State should supply community assistance. "Gogos" should not have to carry teenagers on their backs; the State should supply wheelchairs on request and not simply place people on extensive waitlists spiraling out of control. Mothers should not have to face rejection and humiliation when trying to place their child in a school, they should be informed enough to know that they have legal rights to insist on education for their child. Being told that their child is "uneducable" is not acceptable and goes against their right to education and diminishes their dignity.

Recommendations

I firmly believe that the only effective way of asserting the rights of people living with varying disabilities is by acknowledging and honoring the rights of the people who live with them. In other words concrete steps need to be taken to empower family members as collective right bearers to raise disability-consciousness through including their rights and accentuating the fact that disability is not an individual condition but a collective quandary which needs societal embodiment reflecting the concept of "I am because you are" espousing the values of Ubuntu in recognition that for human beings to develop, grow and flourish each and

every relationship they encounter needs to be conducted in such a manner as to promote and uphold the well-being of others. Through upholding each and every family member affected by disability I do believe that they will be able to stand as collective right bearers and in so doing bring about effective change.

This can be achieved through:-

- Addressing the gap in scholarly discussions about disability rights to expand it to a collective view of disability.

- Reformulating the debate around disability rights to include the collective affected family unit .

- Addressing the gap in the debate between individual rights and collective rights highlighting the point that in the instance of disability impact depends upon the recognition of collective rights.

- Initiating dialogue around disability through cultural and religious redress in order to debunk misconceptions and affirm the core values of cultural traditions and religions. One such core value being family and the importance thereof and another the living philosophy of Ubuntu.

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