



**THE HUMAN RIGHTS PROTECTION MECHANISMS IN PLACE FOR
CHILDREN WITH INTELLECTUAL DISABILITIES: A
COMPARATIVE ANALYSIS OF ZAMBIA, KENYA, AND SOUTH
AFRICA.**

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Dedication

This year, 2017, marks 9 years since the day I lost my mother, Enes Chalwe. I dedicate this work-of-my-hands to her. She will always be my biggest inspiration. Continue resting in peace my queen.

Abstract

Children with intellectual disabilities are one of the most marginalized groups in society. One of the reasons for this is that people lack the understanding of intellectual disability. Marginalization results into isolation, as a result, this leads to the denial of the enjoyment of human rights which other non-disabled persons get to enjoy. International human rights law recognizes that children with intellectual disabilities are human rights holders. The CRC was the first international human rights treaty to prohibit discrimination because of disability and it recognized the rights of children with disabilities. The CRPD is entirely dedicated to upholding the rights of persons with disabilities. Both conventions give children with intellectual disabilities the rights to education and health. Countries which have rectified these conventions give their consent to be bound by the provisions in both conventions. The right to education and health are important rights in the inclusion of children with disabilities into society. Education is vital as it helps to unlock other fundamental rights. It helps children with disabilities to climb the academic ladder and to contribute to the economy of a country. Inclusive education is an important element that each country should aspire to achieve because it helps to eliminate discrimination, and learners get to appreciate diversity. An adequate health system helps to prevent further disabilities, and it helps to ensure that children with disabilities grow to their fullest potential. Therefore, this study aims at exploring the protection mechanisms which are in place in Zambia, Kenya, and South Africa regarding the rights to education and health for children with intellectual disabilities. Protection mechanisms in this context implies the legislation in place in these countries, such as, the Constitution and other laws which specifically touch on education and health of children with disabilities. These laws will be analysed if at all they meet the international human rights standards stipulated in the CRC and CRPD. Best practices will be explored, and recommendations will be given to Zambia.

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List of Acronyms

CRC	Convention on the Rights of the Child
CSO	Civil Society Organization
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled Persons Organization
FPE	Free Primary Education
PEPUDA	Promotion of Equality and Prevention of Unfair Discrimination
PWD	Persons with Disabilities
NGO	Non-Governmental Organization
OHCHR	Office of the United Nations High Commissioner for Human Rights
SEN	Special Education Needs
UN	United Nations
UNICEF	United Nations International Children's Emergency Fund
USD	United States Dollars
WHO	World Health Organization

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INTRODUCTION

Disabilities in children can happen due to many reasons. This may be because of being born with a disabling health condition or impairment, disability because of an illness, injury, or poor nutrition.¹ Across African countries, most children with intellectual disabilities are not enjoying the same benefits stemming from the human rights protection mechanisms which are in place as compared to able-bodied children. Children with intellectual disabilities are often denied the enjoyment of their rights to education and health. In the context of this thesis, protection mechanisms include legislation in a country such as the constitution, and other laws. This thesis focuses on these human rights protection mechanisms and analyzing them if at all they meet international human rights standards.

Children with intellectual disabilities possess developmental deficiencies, and as such they usually find it difficult to “cope independently”.² The World Health Organization (WHO) has defined intellectual disability as “a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence)”.³ This disability occurs before adulthood, and it also leads to social impaired social functioning.⁴ This means that children with intellectual disabilities will often find it difficult to engage into social interactions with other able-bodied children. Most importantly, it is known that this type of disability transpires at congenital or at prenatal stage, and from poor nutrition.⁵” Within the United Nations (UN) the term “disability” is defined as “any restriction or lack (resulting from an

¹ World Health Organisation (WHO) and United Nations International Children’s Emergency Fund (UNICEF), ‘Early Childhood Development and Disability: A discussion paper’, 2012, Available from http://apps.who.int/iris/bitstream/10665/75355/1/9789241504065_eng.pdf Accessed on 29 January 2017, p. 7.

² WHO, ‘Definition: Intellectual Disability,’ 2017, Available from <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability> (Accessed on 4/02/2017)

³ Ibid; Other terms that have been used to refer to intellectual disability include, developmental disability, developmental delay, mental handicap, or people with learning impairments or difficulties.

⁴ Ibid.

⁵ See UNICEF, ‘Children and Young People with Disabilities. Fact Sheet,’ United Nations (U.N), 2013, p. 27.

impairment) of ability to perform an activity in the manner or within the range considered normal for a human being”.⁶

This thesis focuses on the Convention on the Rights of the Child (CRC), and the Convention on the Rights of Persons with Disabilities (CRPD). The CRC is dedicated to the protection of the rights of the child, and the CRPD is entirely dedicated to the rights of persons with disabilities. Since this thesis will be dealing with children who are intellectually disabled, these two Conventions are adequate parameters in determining if at all the legal frameworks in the countries to be discussed meet the international human rights standards (that is, the CRC and CRPD standards) in protecting the rights of these children.

The CRC “was the first human rights treaty that contained a specific reference to disability (article 2 on non-discrimination) and a separate article 23 exclusively dedicated to the rights and needs of children with disabilities”.⁷ Article 2 of the CRC places a duty on State parties not to discriminate against a child with a disability because of his or her disability. Article 4 of the CRC places an obligation on State parties to ensure that the administrative and legislative measures they undertake are for the benefit of upholding the rights and freedoms of the child.⁸ Article 23 helps to ensure that State parties “(...) recognize the right of the disabled child to special care (...)” in the provision of health care services -taking in account the prevailing social conditions that the child’s guardians or parents may be facing at the time.⁹

Article 24 of the CRC stipulates that State parties have an obligation to ensure that no child is deprived of their right to access health care facilities.¹⁰ Apart from this, the CRC protects the

⁶ Arvind Sharma, Perspectives on Inclusive Education with Reference to the United Nations, p. 317, *Universal Journal of Educational Research* 3(5): 317 – 321, 2015

⁷ Committee on the Rights of the Child, General Comment No.9 (2006) The rights of children with disabilities, 27 February 2007, par. 2.

⁸ CRC, Article 4, p. 2;

⁹ Ibid, Article 23 (2), p. 7.

¹⁰ Ibid, Article 24 (1), p. 7.

right to education for children with intellectual disabilities. Under Articles 28 and 29, State parties must ensure that the school curriculum takes into consideration each child's talent; the curriculum must be administered with due respect to human dignity; and the aim of education should be for the full development of the child's mental and physical capacity.¹¹

Children with intellectual disabilities fall under the realm of persons with disabilities in the CRPD. The CRPD defines persons with disabilities as “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”¹² The CRPD recognizes the need for children with disabilities to “(...) have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children (...)”.¹³ To repeat, Article 7 of the CRPD, which is entirely dedicated to the rights of children with disabilities places an obligation on State parties to the CRPD to put in place measures which ensure that children with disabilities are full beneficiaries of the enjoyment of the human rights and freedoms on an equal basis with other able-bodied children. In all these efforts of ensuring that the disabled child enjoys human rights on an equal basis with non-disabled children, the child's best interests should be of prime consideration.¹⁴

Holding awareness raising campaigns is one of the ways to promote and protect the rights of children with intellectual disabilities. Article 8 of the CRPD has specified that this can be done by “[f]ostering at all levels of the education system, including in all children from early age, an attitude of respect for the rights of [children with intellectual disabilities]”.¹⁵

¹¹ Ibid, Article 28 (2) and Article 29 (1) (a), p. 8-9.

¹² CRPD, Article 1, p. 4.

¹³ Ibid, Preamble (r), p. 2.

¹⁴ Ibid, Article 7 (2), p. 8.

¹⁵ Ibid, Article 8 (2) (b), p. 8.

The CRPD is the first legally binding instrument to include a reference to the concept of inclusive education in its provisions.¹⁶ Article 24 of the CRPD requires that State parties must ensure “an inclusive education system at all levels and lifelong learning”.¹⁷ “The [CRPD] thus makes inclusive education the principle and special education the exception”.¹⁸ Additionally, State parties have a duty to put in place “[e]ffective individualized support measures (...) provided in environments that maximize academic and social development, consistent with the goal of full inclusion”.¹⁹

Article 25 of the CRPD stipulates that State parties must not provide health care services in a discriminatory manner.²⁰ Furthermore, State parties should “[p]rovide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children (...)”.²¹

This thesis focuses on children with intellectual disabilities because they present a different challenge when it comes to ensuring that their rights to education and health are realized. Whilst other disability groups, such as the physically disabled, can be accommodated in society through the provision of ramps, and through the establishment of wide doors for easier access of wheelchairs. This is not the case for children with intellectual disabilities. For them to be fully included into society, there is need to look at both their impairment and the organization

¹⁶ Committee on the Rights of Persons with Disabilities, General Comment No. 4 (2016) on the right to inclusive education, 25 November 2016, par. 2.

¹⁷ CRPD, supra note 12, Article 24 (1), p. 16.

¹⁸ Gauthier De Beco, The Right to Inclusive Education according to Article 24 of the UN Convention on the Rights of Persons with Disabilities: Background Requirements and (Remaining) questions, p. 274, *Netherlands Quarterly of Human Rights*, vol. 32/3, 263 -287, 2014.

¹⁹ CRPD, Article 24 (2) (e), p. 17.

²⁰ Ibid, Article 25, p. 18.

²¹ Ibid, Article 25 (b), p. 18.

of society, to understand their difference, and coming up with better initiatives to realize their human rights.

The rights to education, and health will be the prime focus of this thesis. These rights are vital to the inclusion of children with intellectual disabilities into society. Unfortunately, in Zambia and in many other African countries these rights are still far from being realized for children with intellectual disabilities. The 2010 census in Zambia reviewed that children with intellectual disabilities account for the lowest group of persons with disabilities to have completed primary education.²² This statistic gives a snapshot of how far back children with intellectual disabilities are when it comes to the enjoyment of their right to education. With regards to health, the 2010 Census reviewed that disease is the highest cause of disability amongst the disabled population in Zambia, and it accounts for 35.2 per cent.²³ The exact figure is not known in relation to the number of children that had fallen sick, as a result, it led to the upshot of the intellectual disability.

People with intellectual disability account for 1.1 per cent of the total population of persons with disabilities, which is about 2 million out of around 13 million of the total country population as of 2010.²⁴ The CRC committee in its concluding observation on the second to fourth reports on Zambia noted that “[t]here is a lack of comprehensive data on children with disabilities” and thus, advised the government to “[c]ollect and analyze data on the situation of all children with disabilities (...) among other things (...) type of disability (...)”.²⁵

²² Central Statistics Office (CSO), ‘2010 Census of Population and Housing: National Analytical Report,’ p. 73., 2012. Lusaka, Zambia.

²³ Ibid., p. 73.

²⁴ Ibid, p. 73; The World Bank puts the Zambian population as of 2016 at 16.59 million. A Census of the entire population is carried every after 10 years in Zambia.

²⁵ Committee on the Rights of the Child, concluding observations on the combined second to fourth periodic reports of Zambia, 14 March 2016, par. 45-46.

Therefore, the purpose of this thesis is to analyze the protection mechanisms in Zambia, Kenya, and South regarding the protection of the rights to education and health for children with intellectual disabilities. The following section will offer an explanation on why the two rights have been chosen and why these jurisdictions (countries) have been selected. Additionally, there will be an explanation on how the Civil Society Organizations (CSOs) help to fill in the gaps left by the government, and help children with intellectual disabilities.

Scope and Justification for this study

This thesis contributes to the discussion on the need to protect the rights of children with intellectual disabilities regarding their rights to education and health. As the Committee on the Rights of Persons with Disabilities noted in its General Comment 4 on the right to inclusive education, it identified children with intellectual disabilities as being one of the groups amongst persons with disabilities at risk of exclusion from education.²⁶ As such, this thesis will help to highlight if the legislation in Zambia, Kenya, and South Africa – specifically those laws which should help protect children with intellectual disabilities in realizing their right to education and health – if they are adequate and are meeting the international standards as set out in the CRC and CRPD. Additionally, this research will reveal some of the best practices that are being carried out in any of the three countries which help to ensure that the rights to education and health are realized for children with intellectual disabilities.

Education is a “fundamental human right because it unlocks the exercise and enjoyment of other fundamental rights”.²⁷ The right to education impacts on individual liberty, freedom, and human dignity. For children with intellectual disabilities, inclusive and early childhood

²⁶ Committee on the Rights of Persons with Disabilities, *supra* note 16, par. 6.

²⁷ Bekker as quoted by Trynie Boezaart, ‘A constitutional perspective on the rights of children with disabilities in an education context,’ p. 456., 2012, *South African Public Law*, vol. 27, Issue 2. Available from [http://www.repository.up.ac.za/bitstream/handle/2263/20908/Boezaart_Constitutional\(2012\).pdf?sequence=1](http://www.repository.up.ac.za/bitstream/handle/2263/20908/Boezaart_Constitutional(2012).pdf?sequence=1) (Accessed 4/02/2017)

education “provides a window of opportunity to prepare for life-long learning and participation, while preventing potential delays in development and disability”.²⁸ In fact, it is a vital period that helps to ensure that their full potential is realized, and as such it exposes them to “greater opportunities (...) to climb the academic ladder, and eventually contribute to national development”.²⁹

However, the problems that perpetuate intellectual disability arise from the fact that most children in Africa start school late which results in the late identification of the disability.³⁰ Additionally, “[b]y implication, intervention strategies come later when these children have outgrown the recommended school starting age”.³¹ This delayed intervention has a negative effect on the child as it furthers the disability.

The right to health has been described by the Committee on the Rights of the Child in its General Comment 15, on the right of the child to the enjoyment of the highest attainable standard of health;

as an inclusive right, extending not only to timely and appropriate prevention, health promotion, curative, rehabilitative and palliative services, but also a right to grow and develop to their full potential and live in conditions that enable [children] to attain the highest standard of health through the implementation of programmes that address the underlying determinants of health.³²

Disease and disability are considered as one of the many factors which hinder the development of the child in their “(...) state of complete physical, mental and social well-being (...)”.³³ In fact, the right to health “is a matter of social justice and of respecting the inherent dignity of all

²⁸ WHO and UNICEF, *supra* note 1, p. 5.

²⁹ Tsitsi Chataika, Judith Anne Mckenzie, Estelle Swart, Marcia Lyner-Cleophas, ‘Access to education in Africa: responding to the United Nations Convention on the Rights of Persons with Disabilities,’ p. 392., 2012, *Disability & Society vol. 27 (3)*

³⁰ *Ibid*, p. 393.

³¹ *Ibid*, p. 393.

³² Committee on the Rights of the Child, General Comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable health (art. 24), p. 2.

³³ *Ibid*, p. 2.

human beings, as well as, an investment in the future – as healthy children grow into more effective producers and parents”.³⁴ An adequate health care system helps to ensure that identification and early intervention strategies are put in place for the benefit of children with intellectual disabilities. Through regular visits and surveillance at health care centers, hospitals, or clinics, it becomes possible to identify the disability because critical information relating to a child such as cognitive, social-emotional, and sensory-motor skills are assessed.³⁵

As it has already been established this thesis will focus on three countries namely Zambia, Kenya, and South Africa for the following reasoning:

Zambia is a party to both the CRC and the CRPD, it rectified them in 1991 and 2010 respectively. Article 23 of the Constitution of Zambia stipulates the grounds on which discrimination is prohibited. Unfortunately, it does not expressly provide disability as a ground on which discrimination is prohibited.³⁶ The Constitution of Zambia does not sufficiently give “express provisions as to the promotion and protection of disability rights”.³⁷ It does not provide for the protection of the rights of children under the Bill of Rights.³⁸

In addition, the Bill of Rights does not include provisions of economic, social, and cultural rights. This becomes problematic for the courts in Zambia to consider the justifiability of the rights of children with intellectual disabilities, such as, education and health when they are violated.³⁹ To meet its obligations under the CRC, the State party enacted the Education Act in

³⁴ UNICEF, ‘Children with Disabilities,’ 2013 *The State of the World’s Children 2013 Executive Summary*, p. 3., Available from <http://www.unicef.org/pacificislands/UNII38269.pdf> (Accessed 29/01/2017)

³⁵ WHO and UNICEF, *supra* note 1, p. 22.

³⁶ See the Constitution of Zambia, Article 23 (3)

³⁷ Likando Kalaluka, ‘Towards an Effective Litigation Strategy of Disability Rights: The Zambian Experience,’ p. 175., 2013, *African Disability Rights Yearbook*, vol. 1.

³⁸ *Ibid*, p. 175; See also Constitution of Zambia, Part III.

³⁹ *Ibid*, p. 177

2011. It also repealed and replaced the Persons with Disabilities Act (PWD) in 2012 to meet its obligations under the CRPD.

The Zambian government has made some significant progress with regards to the promotion and protection of the rights of children with intellectual disabilities. Some positive key measures include: the enactment of the PWD Act in 2012; the development of the National Disability Policy in 2013; the government provides bursaries for children with disabilities; it has set up social welfare schemes such as the Social Cash Transfers to meet the needs of disadvantaged households especially those with persons with severe disabilities; and it enacted the Education Act in 2011 which prohibits discrimination based on disability (it also makes education compulsory and imposes criminal sanctions for non-compliance).⁴⁰ However, to date only 3, 366 persons with disabilities are registered across the country making it impossible to find out how many children with intellectual disabilities are currently in either regular or special schools.⁴¹

Kenya is a party to both the CRC and CRPD. It ratified them in 1990 and 2008 respectively. The Kenyan Constitution came into force in 2010. “The protection of human rights and fundamental freedoms, including economic and social rights, is safeguarded under Chapter Four of the Constitution of Kenya (...) which sets out a progressive Bill of Rights enjoyable by all individuals in Kenya”.⁴²

⁴⁰ See Responses by the Government of Zambia to the List of Issues in Relation to the Combined Second to Fourth Periodic Reports Submitted at the 71st Session of the Convention on the Rights of the Child (CRC) – 22nd January 2016 In Geneva, Switzerland, p. 7. Available from http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Countries.aspx?CountryCode=ZMB&Lang=EN (Accessed 16/03/2017)

⁴¹ Ibid, p. 13.

⁴² Committee on the Rights of Persons with Disabilities, initial reports of State parties due in 2010 – Kenya, par. 27, Available from http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Countries.aspx?CountryCode=KEN&Lang=EN (Accessed 16/03/2017)

Section 27 of the Kenyan Constitution is the equality and discrimination clause. Under this section, disability and age have been listed as grounds on which direct or indirect discrimination is prohibited by the State party.⁴³ Section 27 (6) of the Constitution demands that affirmative action programmes should be put in place to put wrongs to right of any past suffering by disadvantaged groups.⁴⁴ Section 43 (economic and social rights) gives every person the right to education, the highest standard of health care and health services.⁴⁵

Section 53 (children rights) gives every child the right to “free and compulsory basic education” and the right “to basic nutrition (...) and health care”.⁴⁶ Section 54 (disability rights) gives children with intellectual disabilities the right “to access educational institutions and facilities (...) which are integrated into society to the extent compatible with the interests of the person” and “to access materials and devices to overcome constraints arising from a person’s disability”.⁴⁷

The Kenyan government enacted the Children’s Act in 2002. This Act domesticates provisions of the CRC, and the African Charter on the Rights and Welfare of the Child. This Act is undergoing some amendments to ensure that it meets the standards set-out in Section 53 (Children rights) of the Kenyan Constitution.⁴⁸

The PWD Act was enacted in 2003 and it precedes the ratification of the CRPD in 2008. It is currently under review to meet the obligations set out in the CRPD. The Committee on the Rights of Persons with Disabilities in its concluding observation, 2015, on the initial report

⁴³ The Constitution of Kenya (2010), Section 27 (4), p. 24.

⁴⁴ Ibid, Section 27 (6), p. 24.

⁴⁵ Ibid, Section 43 (a) (f), p. 31.

⁴⁶ Ibid, Section 53 (1), p. 35-36

⁴⁷ Ibid, Section 54 (1) (b) (e), p. 37.

⁴⁸ Committee on the Rights of the Child, Combined third, fourth, and fifth periodic reports of State parties due in 2012 – Kenya, par. 3., Available from http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Countries.aspx?CountryCode=KEN&Lang=EN (Accessed 6/03/2017)

from Kenya has stipulated that the government needs to complete the review process of the Act within a specific time frame, and to “(...) bring it into line with the provisions of the Convention and the human rights-based approach to disability”.⁴⁹

Good progress has been made by the Kenyan government in the promotion and protection of the rights of children with intellectual disabilities such as: the “[p]rovision of pre-service and in-service training to teachers so that they can respond to diversity in the classroom”; constantly engaging with teachers through the Kenya Institute of Curriculum Development in “(...) formulating and adapting curriculum and learning materials to suit learners with special needs and disabilities”; and “[t]raining of healthcare professionals at all levels to ensure the informed and respectful treatment of persons with disabilities seeking medical care (...)”.⁵⁰ The State party has shown serious commitment in championing the rights of persons with disabilities by successfully completing its initial phase of the reporting cycle on the status of the rights of persons with disabilities in the country as per Article 35 of the CRPD.⁵¹ The next country report is due in 2022.

South Africa is a party both the CRC and CRPD, which it ratified in 1995 and 2007, respectively. The South Africa Constitution (1996) prohibits discrimination based on disability in section 9.⁵² The Constitution has provisions on economic, social, and cultural rights. Section 27 of the Constitution stipulates that everyone has the right to health care services.⁵³ Section

⁴⁹ Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Kenya, par. 6., Available from http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Countries.aspx?CountryCode=KEN&Lang=EN (Accessed 16/03/2017)

⁵⁰ Committee on the Rights of Persons with Disabilities, List of Issues in Relation to the initial report of Kenya. Replies of Kenya to the list of issues, 2015, par. 62., Available from http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Countries.aspx?CountryCode=KEN&Lang=EN (Accessed 16/03/2017)

⁵¹ The Government of Kenya submitted its first report to the CRPD committee in 2012, a report which it was initially supposed to submit 2 years after the ratification of the Convention in 2010.

⁵² The Constitution of the Republic of South Africa (1996), Section 9 (3), p. 6.

⁵³ Ibid, Section 27 (a).

28 provides an array of rights targeting specifically children such as the right to “basic health care services and social services”, education, and in all these efforts “[a] child’s best interests are of paramount importance (...)”.⁵⁴ Section 29 of the Constitution guarantees everyone the right to education.⁵⁵

The South African Schools Act (1996) regulates education for all children aged between 7 to 18 years of age, including children with disabilities.⁵⁶ In 2000, the Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA or “Equality Act”) was enacted. This law precedes the ratification of the CRPD by the State. Lawmakers passed this law to ensure that rights of disadvantaged groups such as those of children with intellectual disabilities are protected from vices such discrimination. The Equality Act helped to establish Equality Courts where cases because of discrimination can be litigated.⁵⁷ The Children’s Act was enacted by the South African government in 2005 to meet its obligations under the CRC.

Important progress has been made by the South African government through the fulfillment of its obligations under the CRPD with the completion of its initial reporting cycle.⁵⁸ This highlights the country’s commitment towards the fulfilment of the rights of persons with disabilities.

In addition, good practice is also evident in governmental initiatives such as the implementation of the National Plan of Action for children which is guided by the provisions set out in the

⁵⁴ Ibid, Section 28 (c) (f) (ii) (2).

⁵⁵ Ibid, Section 29 (1) (a).

⁵⁶ Committee on the Rights of Persons with Disabilities, Initial reports of State parties due in 2009. South Africa. p. 39, Available from http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Countries.aspx?CountryCode=ZAF&Lang=EN (Accessed 16/03/2017)

⁵⁷ Joseph J. Hahn, ‘Your Guide to the South African Equality Courts. A Step by Step Process to Empower Paralegals, Community Leaders and Human Rights Educators,’ p. 2., 2015, *International Senior Lawyers Project*, Available from <http://www.probono.org.za/wp-content/uploads/2015/11/Equality-Court-Handbook-2015.pdf> (Accessed 4/02/2017)

⁵⁸ The South African government submitted its initial report to the CRPD in 2014.

CRC, and the consideration of the child's best interest is paramount in this program.⁵⁹ Another commendable feature is that the South African government has made significant efforts in terms of data collection. As of 2016, 118, 645 children with disabilities were attending special schools on the national level.⁶⁰ Intellectual disability is the fifth most common type of disability consisting of about 206,000 people out of "(...) an impairment prevalence rate of 10.3 % (5,334,905) for South Africa".⁶¹ Another feature worthy of mention is that the country has introduced full service/inclusive schools in all its 9 provinces for persons with disabilities and those people from disadvantaged backgrounds.⁶² Some special schools are now being turned into resource centres for the full service/inclusive schools.

Most importantly, there is case law which supports the view that children with intellectual disabilities must enjoy the right to education (or health) on an equal basis with non-disabled children. In the *Western Cape Forum for Intellectual Disability v. Government of the Republic of South Africa*, the Western Cape High Court ruled in favor of the applicant in that the government had failed to provide "reasonable measures to make provision for the educational needs of severely and profoundly intellectually disabled children in the Western Cape".⁶³ Such a decision by the High Court is important because it helps to start a process of holding the State accountable for non-fulfillment of Constitutional rights for children with intellectual disabilities.

⁵⁹ Department of Women, Children and People with Disabilities, 'National Plan of Action for Children in South Africa 2012-2017, p. 15 Available from https://www.unicef.org/southafrica/SAF_resources_npac.pdf (Accessed 16/03/2017); This program has been running from 2012 and it will finish in 2017.

⁶⁰ See Committee on the Rights of Persons with Disabilities, *supra* note 56, pp. 7- 10; See also Committee on the Rights of the Child, Replies of South Africa to the list of Issues, p. 36.

⁶¹ *Ibid*, pp. 7- 10; See also Committee on the Rights of the Child, Replies of South Africa to the list of Issues, p. 36.

⁶² Department of Basic Education, Guidelines for Full-service/Inclusive Schools, 2010, Education White Paper 6, Special Needs Education-Building an Inclusive Education and Training System Available from <http://www.ibe.unesco.org/curricula/southafrica/> (Accessed on 18/09/2017)

⁶³ *Western Cape Forum for Intellectual Disability v. Government of the Republic of South Africa and Government of the Province of the Western Cape*, Case No. 18678/2007, 11 November 2010, par. 52 (1), p. 31.

Another aspect that this thesis will focus on relates to the role that the Civil Society Organizations (CSOs) play in ensuring that the rights of children with intellectual disabilities are promoted and protected in society. A CSO can be defined as “a sphere of social life that is public but excludes government activities”.⁶⁴ These organizations often help to meet the needs of disadvantaged groups of people, such as children with intellectual disabilities, in cases where there is a lack of governmental will or effort. Tasks carried out by CSOs include holding awareness raising campaigns, advocacy work, offering counselling services, and conducting medical assessments. On the other hand, it is important to understand that both the CRC and the CRPD do not place any obligation on CSOs to provide these services in the same way they do on State parties. Thus, services provided by CSOs are given on a “voluntary [basis] and [through] individual commitment”.⁶⁵

Methodology

This thesis is based on a comparative country analysis of the existing legal frameworks in Zambia, Kenya, and South Africa, in relation to children with intellectual disabilities’ right to education and health. Legislation in the three countries will be analysed in terms of its adequacy in meeting international human rights standards (that is, the CRC and CRPD) particularly those which touch on education and health. All the three countries have rectified the CRC and CRPD, as such, they are bound by their provisions. This thesis will rely on an analysis of Non-Governmental Organization (NGO) Reports and Government Reports, UN body reports, case law, CRC and CRPD reports and documentation, journals, scholarly articles and reliable internet sources. Other materials that will also be analyzed include books, papers, and

⁶⁴ Magdolna BIRTHA, ‘NOTHING ABOUT CRPD MONITORING WITHOUT US’: A CASE STUDY ON THE INVOLVEMENT OF THE DISABILITY MOVEMENT IN POLICY-MAKING IN ZAMBIA,” 2013, *African Disability Rights Yearbook*, vol. 1. p. 121.

⁶⁵Ibid, p. 121.

dissertations that have touched on this topic or are related to it so that they can help to add some clarity to this discourse.

Limitation of the Study

This thesis is not based on primary sources of information such as structured interviews and questionnaires.

Outline of Chapters

This thesis is divided into 4 chapters. Chapter One entitled human rights and children with intellectual disabilities will start with an elaboration on how children with intellectual disabilities have legal rights, human rights. Thereafter, the rights that they have under international human rights law will be explained. This will be followed by outlining the positive obligations which State parties have under international human rights law. Apart from this, the role played by the CSOs in helping children with intellectual disabilities to realize their rights will be elaborated. Lastly, a conclusion will follow.

Chapter two entitled comparative country analysis - the right to inclusive education, firstly will begin with an overview of the CRC and CRPD standards regarding the right to inclusive education. Secondly, an analysis of the legal framework in Zambia and the role that the CSOs play in advancing the right to inclusive education for children with intellectual disabilities will follow. Thirdly, an analysis of the legislation in Zambia vis-a-vis CRC and CRPD standards will follow. The same format of analysis of the legal framework and the role the CSOs play, then following it up with an analysis of the legislation vis-a-vis CRC and CRPD standards will be used for both Kenya and South Africa. Fourthly, a section highlighting some of the best practices which comply to the CRC and CRPD standards regarding the right to inclusive education will be elaborated. This will be followed by a section elaborating on the hinderances or draw backs in realizing this right. Lastly, a chapter conclusion will be drawn.

Chapter three which is entitled comparative country analysis – the right to health, begins by giving an outline of the CRC and CRPD standards regarding the right to health. This chapter follows the same format as the one outlined for chapter two, the only difference being that chapter 3 looks at the right to health.

Chapter four will highlight the findings and it will offer recommendations to Zambia. The findings will include a focus on the best practices which are currently being employed by the government in any of the three countries which help children with intellectual disabilities to realize their rights to education and health. Finally, a conclusion of the entire thesis will be drawn from everything that will be explained.

Conclusion

This introduction has offered an insight into what will be involved with regards to this thesis. The plight of children with intellectual disabilities has only recently begun to be documented and this thesis aims at adding more understanding to a topic that is very important in society. Coming from an African context, children with intellectual disabilities are often sidelined and excluded in their societies which culminates into the denial of their human rights to education and health. These two rights are important rights in ensuring that children with intellectual disabilities become active members of the African society. Education helps to unlock the exercise and enjoyment of other fundamental human rights, and adequate health care helps to ensure that early identification and prevention of disability in children. These two rights help children with intellectual disabilities to reach their full potential in society, thus, their importance.

Chapter 1 – Human Rights and Children with Intellectual Disabilities

1.0. Introduction

The conceptualization of the rights of children with intellectual disabilities has been gradually shifting for the last two decades. This shift has resulted in viewing children with intellectual disabilities as subjects of legal rights, and not mere objects to which charity and welfare provisions should only be directed towards. Charitable efforts and welfare provisions have helped children with intellectual disabilities, however, with the coming of the CRC into force in 1990, and most importantly the coming into force of the CRPD in 2007 it has resulted into viewing them as human rights holders.⁶⁶ Moreover, there is a need to move away from “notions of ‘rescuing’ the child, but on investment in removing (...) cultural, economic, communication, mobility and attitudinal barriers that impede the realization of the child’s rights (...)”.⁶⁷ To repeat, the CRC and CRPD primarily place obligations on State parties who have rectified either one or both of the Conventions to champion the rights of disabled children. CSOs such as NGOs or Disabled Persons Organizations (DPOs) are not in any way bound by these obligations, but may offer their help on a charitable basis or based on organization strategy.

There is a difference between an NGO and a DPO especially in terms of their composition. DPOs are a type of NGO “that is particular in terms of its composition and leadership (...) both the membership and leaders are persons with disabilities themselves”.⁶⁸ On the other hand, NGOs may represent a specific group of persons with disabilities or represent persons with disabilities generally, and membership to such an organization is not based on a person’s disability.⁶⁹

⁶⁶ CRPD, Article 4 (3), p. 6.

⁶⁷ UNICEF, *supra* note 34, p. 3.

⁶⁸ Magdolna BIRTHA, *supra* note 64, p. 121.

⁶⁹ *Ibid*, p. 122-123.

Therefore, this chapter will focus on the rights of children with intellectual disabilities under international human rights law. A special attention to, but not restricted to the CRC and CPRD will be elaborated. In other words, the focus of that section will be primarily based on the two Conventions, but this is not to disregard other Conventions. Additionally, the positive obligations that State parties have under the two Conventions under international human rights law will also be explained. This will be followed by the role that CSOs play in ensuring that the rights of children with intellectual disabilities are protected.

1.1. The Rights of Children with intellectual Disabilities in International Human Rights Law

The United Nations Universal Declaration of Human Rights (UDHR) in 1948 envisioned societies across the world where “all human beings are born free and equal in dignity and rights”.⁷⁰ This document contains principles to which States should ascribe to based on equal human rights amongst all people, children included. Before the coming into force of the CRPD in 2007, the rights of children - including those with intellectual disabilities - were protected under the CRC which has been in force since 1990. It is worth mentioning that although the CRC protects the rights concerning children, the practicality of these provisions is difficult because children are mainly reached through their parents or guardians – as such they do not directly represent themselves on matters which concern them.

It should be noted that, Article 3 of the CRC maintains that ““(…) the best interests of the child shall be a primary consideration” in all matters which concern them.⁷¹ In fact, the Committee

⁷⁰ According to United Nations Universal Declaration of Human Rights under Article 1. This was adopted in 1948 by an overall vote of 48 to 0, those in favour and disfavour, respectively. Unfortunately, this document is not legally binding. These are values that countries should seek to uphold. It is also important to understand that the word disability was only used once in the entire document and this is in relation to Article 25 which relates to the adequate health and well-being of people. The article gives people the right to social security based on disability, unemployment, old age, illness, and women who lose their partners.

⁷¹ CRC, Article 3 (1), p. 2.

on the Rights of Children has stipulated that “(...) an adult’s judgment of a child’s best interests cannot override the obligation to respect all the child’s rights under the Convention”.⁷²

The CRC was the “only core international treaty to contain an explicit recognition of disability as a ground for discrimination and was the first such treaty to incorporate a specific provision on the rights of the disabled children”.⁷³ Indeed, Article 2 places disability as one of the grounds on which discrimination is prohibited.⁷⁴ Article 23 of the CRC focuses on an array of aspects for children with disabilities.⁷⁵ Most importantly, subparagraphs (1) (2) and (3) of Article 23 of the CRC contains provisions which to a large extent targets children with disabilities.

Under subgraph (1) of Article 23 of the CRC, State parties have a duty to “(...) facilitate the child’s active participation in the community”.⁷⁶ In this regard, active participation entails that children with intellectual disabilities should be included in activities which take place in society such as participating in recreational activities “(...) as a means of achieving optimum development (...)”.⁷⁷ For example, an inclusive approach to education will require that children with intellectual disabilities are participating in recreational activities in the school setting, such as sports, on an equal basis with other able-bodied children in society.⁷⁸

Subparagraph (2) of Article 23 of the CRC conceptualizes “the right of the disabled child to special care”.⁷⁹ Special care and assistance has also been referred to in the preamble of the

⁷² Committee on the Rights of the Children, General Comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration (art. 3, para. 1), p. 2.

⁷³ Andrea Broderick, ‘The Right to Education for Persons with Disabilities,’ p. 56, in *The Long and Winding Road to Equality and Inclusion for Persons with Disabilities*, 2015

⁷⁴ CRC, Article 2 (1), p. 2.

⁷⁵ Ibid, Article 23, p. 7.

⁷⁶ Ibid, Article 23 (1), p. 7.

⁷⁷ Committee on the Rights of the Child, General Comment No. 17 (2013) on the right of the child to rest, leisure, play, recreational activities, cultural life and the arts (art. 31), p. 5. Available from http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=5&DocTypeID=11 (Accessed 17/03/2017)

⁷⁸ UNICEF, supra 34, p. 4.

⁷⁹ CRC, Article 23 (2), p. 7.

CRC. According to the Committee on the Rights of the Child in its General Comment 9 on the rights of children with disabilities, this refers to investing in mechanisms which will help eliminate discrimination against children with disabilities – paragraph 3 of Article 23 of the CRC further elaborates on these provisions which include access to health care services and education, and offering assistance free of charge to the parents or other care givers – after an assessment of their financial situation.⁸⁰

Subparagraph (3) of Article 23 of the CRC is a build-up from subparagraph (2), and it continues on the same note of ensuring that children with disabilities have an adequate development through effective access to education and health care services.

Unquestionably, there was a need to build upon the provisions of the CRC especially in relation to the rights of children with disabilities because most of the provisions of Article 23 touched on many aspects which address their needs. Hence, with the coming of the CRPD into force in 2007 it “represents the first binding normative framework that seeks to ensure the promotion and protection of the human rights of persons with disabilities on an equal basis with others”.⁸¹ Article 7 of the CRPD is entirely devoted to children with disabilities and requires that State parties are taking all the appropriate steps of ensuring that “all human rights and fundamental freedoms” are enjoyed on an equal basis amongst children, disabled or able-bodied.⁸²

1.1.1. A special focus on, but not restricted, to the CRC and the CRPD

The CRC is the first internationally binding and extensive Convention specifically adopted to consider the needs of children. “It’s wide spread ratification – by all UN members except the United States and Somalia – suggests its consistency with a strong level of international consensus on the way children should be treated in a wide variety of areas and

⁸⁰ Ibid, Article 23 (3), p. 7.

⁸¹ Andrea Broderick, *supra* note 73, p. 67.

⁸² CRPD, Article 7, p. 7.

circumstances”.⁸³ Its merits include the breadth in which it tackles issues relating to children in all circumstances, and its detailed inclusion of autonomous rights for them.⁸⁴ For example, Article 12 of the CRC gives children the right to express themselves freely, especially for those who can do so. The CRC also contains provisions under the realm of first and second-generation rights, as well as those related to humanitarian efforts.

The CRC provisions can be grouped into four key provisions which include participation, protection, provision, and prevention.⁸⁵ These key thematic areas are inter-linked and may overlap in many aspects showing just how each aspect is indivisible, and dependent on the fulfillment of the others. Furthermore, the Committee on the Rights of the Child has stated that the Convention is based on four guiding principles. These include:

(under) Article 2, which provides for the right of every child to enjoy his/her Convention rights without discrimination of any kind; Article 3 which requires that the best interests of the child are a primary consideration in all action taken concerning children; Article 6 which recognizes the right of the child to life, survival and development; and Article 12 which provides (...) to every child capable of forming a view the right to express that view freely in all matters concerning him/her (...).⁸⁶

Apart from this, it also includes different provisions aimed at promoting the well-being of children in different settings such as health and education. Under Article 24 of the CRC, children have the right to access effective health care services.⁸⁷ Articles 28 and 29 of the CRC tackle issues which concern the right to education based on “equal opportunity”.⁸⁸ Education must be accessible or available to every child for them to achieve their fullest potential.⁸⁹

⁸³ Ursula Kilkelly, ‘Using the Convention on the Rights of the Child in Law and Policy: Two Ways to Improve Compliance,’ p. 180., in Antonella Invernizzi and Jane Williams (eds.) *The Human Rights of Children from Visions to Implementation*. 2011.

⁸⁴ Ibid, p. 180.

⁸⁵ Ibid, p. 180.

⁸⁶ Ibid, p. 180.

⁸⁷ CRC, Article 24 (1), p. 7.

⁸⁸ Articles 28 and 29 of the CRC provide an illustration on the right to education for children. Article 28 elaborates on the State obligations, such as, the need to ensure that children have access to education as they progress to adulthood. Article 29, which explains the aims of education, stipulates that education should aim at helping the child’s development in terms of his or her personality, and talents to achieve their full potential.

⁸⁹ Ibid, p. 8-9.

Apart from this, the CRPD also has rights and duties which help to respect, promote, and protect the rights of children with intellectual disabilities. Article 3 of the CRPD is entirely based on the general principles that should guide State parties in the implementation of the CRPD. Some of these principles include; “non-discrimination”; “the full and effective participation and inclusion in society”; “equality of opportunity”; and “respecting the evolving capacities of children” are key for children with intellectual disabilities.⁹⁰ To repeat, Article 7 of the CRPD is entirely devoted to the rights of children with disabilities. This article champions for the need to ensure that the human rights and fundamental freedoms are enjoyed equally between all children, able-bodied or disabled.⁹¹

In addition, Article 24 of the CRPD stipulates that children with intellectual disabilities should have access to an education environment which is inclusive, and not discriminatory.⁹² Most importantly, inclusion and the principle of participation as indicated under Article 3 (c) of the CRPD work together. To attain one, there is need to make sure that the other has been effectively achieved. Inclusion is the principle which requires that “whatever benefits accrue to members of society are a heritage of all people, not just those that are able-bodied”.⁹³ In fact, in the school set-up this entails that appropriate measures must be put in place for children with intellectual disabilities so that they are able to participate in this school environment, as such, this will lead to a positive impact on effective participation. Special schools do not foster the principle of inclusion, and as such does not lead to effective participation. Segregated schools for children with intellectual disabilities furthers discrimination.⁹⁴

⁹⁰ CRPD, Article 3, p. 5.

⁹¹ Ibid, Article 7, p.7.

⁹² Ibid, Article 24 (1), p. 16.

⁹³ Jones as quoted by Andrea Broderick, *supra* note 73., p. 70.

⁹⁴ Bronagh Byrne, ‘Hidden contradictions and conditionality: Conceptualizations of inclusive education in international human rights law,’ 2013, *Disability & Society*, vol. 28, Issue 3, p. 234.

Article 25 of the CRPD gives persons with disabilities the right to education. Health services must meet the individual needs of the disabled person “including early identification and intervention” (...) “services [must be] designed to minimize and prevent further disabilities (...) among children” (...).⁹⁵ Early identification is paramount because it helps in “development of policies, strategic planning and service provision,” and most importantly, can help to provide for “holistic responses and link school-based learning with home and community interventions”.⁹⁶ Indeed, this interplay of the rights in the CRPD helps to accentuate the indivisibility and inter-connectedness of the rights.

1.2. Positive obligations of State parties under International Human Rights Law

When States ratify Conventions, they give their consent to be bound by all the provisions thereof. Implementation of the provisions in CRC and the CRPD calls for action from the State party to ensure that the rights enshrined in the conventions are implemented in that country. Henry Shue suggests that “for every basic right – and many other rights as well – there are three types of duties, all of which must be performed if the basic right is to be fully honored (...)”.⁹⁷ He proposed three sets of duties which include the need: “to avoid depriving”; “to protect from deprivation”; and “to aid the deprived”.⁹⁸

Article 2 of the CRC places a duty on State parties to ensure that all the rights thereof are implemented “(...) without discrimination of any kind (...)”.⁹⁹ The State party must also ensure that “(...) all appropriate measures (...)” are undertaken with the view of protecting the child.¹⁰⁰

⁹⁵ CRPD, Article 25 (b), p. 18.

⁹⁶ WHO and UNICEF, *supra* note 1, p. 7-25.

⁹⁷ Henry Shue as quoted by Oliver De Schutter, ‘The Typology of State’s Obligations,’ p. 1., 2012, Available from <https://www.wcl.american.edu/hracademy/Class2-Reading1-DocumentationFile.pdf> Accessed on 13 February 2017,

⁹⁸ *Ibid*, p. 1.

⁹⁹ CRC, Article 2 (1), p. 2.

¹⁰⁰ *Ibid*, Article 2 (2), p. 2.

The principle of non-discrimination requires that groups who are at the margin of society are identified, such as children with intellectual disabilities, and special measures such as legislation and policies which look into their well-being – are enacted to ensure that their rights are protected against discrimination.

The CRPD was essentially adopted to look into the issues which affect persons with disabilities. Provisions in the preamble and Article 1 prohibit discrimination because of disability.¹⁰¹ Article 4 of the CRPD places a strong obligation on State parties “[t]o take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination (...)” against children with disabilities.¹⁰² One of the measures to be undertaken as championed by CRPD includes awareness-raising. Article 8 of the CRPD places a duty on State parties to “(...) raise awareness throughout society, including at the family level (...)” regarding children with disabilities.¹⁰³ “Awareness-raising, information and education play an essential role in eliciting the transformation in society which the Convention pursues”.¹⁰⁴ The purpose of awareness-raising is that it helps to:

recognize that practical implementation is not solely about the adoption of a legal or policy framework, and that steps need to be taken to dismantle the entrenched attitudes, cultures and environments which infuse the value systems of (...) societies and cultures (...) which continue to obstruct the inclusion and participation of persons with disabilities on an equal basis with others.¹⁰⁵

Article 4 (1) (a) (b) (c) and (e) of the CRPD requires that State parties should promote and protect the rights of children with intellectual disabilities through government policies and

¹⁰¹ CRPD, Preamble (h) (j) and Article 1, p. 4.

¹⁰² Ibid, Article 4 (1) (b), p. 5.

¹⁰³ Ibid, Article 8, p. 8.

¹⁰⁴ Blog by Victoria Lee, Program Manager within the Human Rights, and Disability Unit of the UN Office of the High Commissioner for Human Rights. It was written on the 10th anniversary of the CRPD. Awareness-raising, access to information and freedom of expression were some of the key themes she tackled. 2016, Available from <https://www.article19.org/resources.php/resource/38592/en/10-years-on-from-the-crpd:-raising-voices-to-raise-awareness> (Accessed 15/03/2017)

¹⁰⁵ Ibid.

programmes that are carried out.¹⁰⁶ Most importantly, provisions in the CRPD extend the protection of the rights of children with intellectual disabilities even to non-state agents. Article 4 (1) (e) of the CRPD requires that State parties should “(...) take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise”.¹⁰⁷ This is significant in that “(...) a considerable degree of discrimination against disabled people stems from the private sphere of society”.¹⁰⁸ In other words, State parties need to ensure that it protects children with intellectual disabilities from discriminatory practices from State agents, other organizations, or any other person for that matter.

An important aspect about both the CRC and CRPD is that there should be involvement of the child in the implementation process of the provisions thereof. Article 12 of the CRC requires that State parties must “(...) assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child (...)”.¹⁰⁹

Similarly, Article 7 of the CRPD further advances that State parties should ensure that views of children with disabilities are taken into consideration when implementing its provisions, and that they are “(...) provided with disability and age-appropriate assistance to realize” their rights.¹¹⁰

The individual needs of persons with disabilities are different. It is fallacious to conclude otherwise. Thus, this provision requires that “(...) all actions concerning children with disabilities (...)” will primarily be based on their “(...) best interests (...)”.¹¹¹ To put it

¹⁰⁶ CRPD, Article 4 (1) (c), p. 5.

¹⁰⁷ Ibid, Article 4 (1) (e), p. 6.

¹⁰⁸ Andrea Broderick, *supra* note 73, p. 81.

¹⁰⁹ CRC, Article 12 (1), p. 4.

¹¹⁰ CRPD, Article 7 (3), p. 8.

¹¹¹ Ibid, Article 7 (2), p. 8.

differently, activities involving budgetary-allocation, policy formulation, social and economic planning should ensure that the views of the children with disabilities are taken in account.¹¹²

The development of the child is the key mandate under the CRC. Under Article 6 (2) of the CRC, the term ‘development’ has been described to include a variety of dimensions. The Committee on the Rights of the Child in its General Comment No. 5, on general measures of implementation of the CRC, indicated that this term encompasses the “physical, mental, spiritual, moral, psychological, and social” aspects of a child.¹¹³

Prior to the CRPD coming into force, Article 23 of the CRC was the only provision which placed positive obligations on State parties to implement the rights of children with disabilities. This article gives State parties the duty to ensure that “special care” is provided for children with disabilities.¹¹⁴ The term ‘special care’ resonates with the term ‘development’ as stipulated under Article 6 (2) of the CRC. Other measures that can help to foster special care have been elaborated under Article 23 (3) of the CRC.¹¹⁵ For children with intellectual disabilities to develop, there is need for “(...) early intervention actions as part of the regular delivery system as opposed to structuring separate or parallel services (...)”.¹¹⁶ Helping families with children with intellectual disabilities is another aspect which can foster special care through “social protection initiatives such as social cash transfers, which have been shown to benefit children”.¹¹⁷

¹¹² Committee on the Rights of the Child, General Comment No. 20 (2016) on the implementation of the rights of the child during adolescence, p. 7; The Committee on the Rights of the Child in its General Comment No. 5 emphasized on this aspect by stipulating that “[l]istening to children should not be seen as an end in itself, but rather as a means by which States make their interactions with children and their actions on behalf of children ever more sensitive to the implementation of children’s rights”. See Committee on the Rights of the Child, General Comment 5 (2003), on the General measures of implementation of the CRC, p. 4.

¹¹³ Committee on the Rights of the Child, General Comment No. 5 (2003), on the general measures of implementation of the CRC. p. 4.

¹¹⁴ CRC, Article 23 (2), p. 7.

¹¹⁵ Ibid, Article 23 (3), p. 7.

¹¹⁶ WHO and UNICEF, *supra* note 1, p. 26.

¹¹⁷ UNICEF), *supra* note 34, p. 3.

Article 24 (1) of the CRC requires that State parties must ensure that children in their country are enjoying the “(...) highest attainable standard of health (...)”.¹¹⁸ The Committee on the Rights of the Child in its General Comment No. 15, on the right of the child to the enjoyment of the highest attainable standard of health, has interpreted this provision as having to take into consideration the “child’s biological, social, cultural and economic preconditions (...)”.¹¹⁹

Since children with intellectual disabilities are mostly under the care of their families, this assessment of the preconditions helps to highlight the prevailing conditions that a child is facing vis-a-vis the impact on the disability. Poor people are “less educated”, “lack access to information, influence and resources, which may cause them to live in poor living conditions and without proper medical care” which has an adverse effect on the disabled child.¹²⁰ Thus, the State parties needs to make resources available so that they provide the necessary “range of facilities, goods, services, and conditions that provide equality of opportunity for every child (...)”.¹²¹

Additionally, State parties must “(...) strive to ensure that no child is deprived of his or her right of access to (...) health care services”.¹²² This “(...) imposes a strong duty of action for State parties to ensure that health and other relevant services are available and accessible to all children, with special attention to under-served areas and populations”.¹²³ Article 24 (2) of the CRC has a cluster of positive obligations that States must undertake in pursuant of adequate health such as: “provision of necessary medical assistance and health care to all children”; “[t]o combat diseases and malnutrition (...) within the framework of primary health care”; and “[t]o ensure that all segments of society, particular parents and children, are informed, have access

¹¹⁸ CRC, Article 24 (1), p. 7.

¹¹⁹ Committee on the Rights of the Child, *supra* note 15, p. 4.

¹²⁰ UN, ‘Persons with Disabilities and Multiple Discrimination – Rights of Special Groups,’ Available from <http://www.un.org/esa/socdev/enable/comp508.htm#8.1> Accessed on 13 February 2017.

¹²¹ Committee on the Rights of the Child, *supra* note 112, p. 4.

¹²² CRC, Article 24 (1), p. 7.

¹²³ Committee on the Rights of the Child, *supra* note 112, p. 4.

to education and are supported in the use of basic knowledge of child health and nutrition (...).¹²⁴

Similarly, Article 25 of the CRPD advances further that the “(...) the right to the enjoyment of the highest attainable standard of health (...)” for children with intellectual disabilities should be “(...) without discrimination on the basis of disability”.¹²⁵ A State party has the responsibility of ensuring that it puts in place an “(...) early identification and intervention (...)” mechanism for children with disabilities.¹²⁶ This aspect of the health system has a key significance especially to the health of children with intellectual disabilities. “Systems for early identification are required in order to facilitate timely access to services to support the development of children at significant risk for developmental delays, and to prevent potential issues, such as a loss of confidence in parenting skills”.¹²⁷ These systems for early identification include examination services for children at health facilities, immunization campaigns, and general child-health care services.¹²⁸

This article further stipulates that health care professionals should provide health care services on an equal basis to both disabled and non-disabled children “(...) including on the basis of free and informed consent by, inter alia raising awareness of the human rights, dignity (...) through training and the promulgation of ethical standards for public and private health care”.¹²⁹

The CRC committee in General Comment No. 20, stipulated that State parties should sought for “(...) an enabling environment to encourage appropriate health seeking behavior by parents

¹²⁴ CRC, Article 24 (2), p. 7.

¹²⁵ CRPD, Article 25, p. 18.

¹²⁶ Ibid, Article 25 (b), p. 18.

¹²⁷ WHO and UNICEF, supra note 1, p. 22.

¹²⁸ Ibid, p. 22.

¹²⁹ CRPD, Article 25 (d), p. 18.

and children”.¹³⁰ Health seeking behaviors are created in an environment when people are educated about health practices, dangers of discriminatory practices, and when services are made available.¹³¹

Articles 28 and 29 of the CRC place obligations on State parties to ensure that education is achieved “progressively” based on the principle of equal opportunity.¹³² Just like the other provisions under the CRC, the child here should be at the core of the implementation process. State parties should aim at developing “the child’s personality, talents and mental and physical abilities” through education provision.¹³³

On the other hand, the CRPD is the first international legally binding treaty to refer to the concept of inclusive education.¹³⁴ The Human Rights Council has advanced that “[o]nly inclusive education systems can provide both quality of education and social development for persons with disabilities”.¹³⁵ It is incorrect to assume that by just placing children with intellectual disabilities into mainstream schools, this will fulfill this aspect of inclusive education. “Inclusive education implies more than placing students with disabilities in mainstream schools; it means making them feel welcome, respected and valued”.¹³⁶

Inclusive education is a fundamental concept in helping to ensure that diversity is understood and appreciated in society. The Committee on the Rights of Persons with Disabilities has further stipulated that:

(...) the right to inclusive education entails a transformation in culture, policy, and practice in all formal and informal education environments to accommodate the differing requirements and identities of

¹³⁰ Committee on the Rights of the Child, *supra* note 112, p. 4-5.

¹³¹ *Ibid*, p. 4-5.

¹³² CRC, Article 28 (1), p. 8.

¹³³ *Ibid*, Article 29 (1) (a), p. 9.

¹³⁴ Committee on the Rights of Persons with Disabilities, *supra* note 16, par.2.

¹³⁵ Human Rights Council, Thematic Study on the right of persons with disabilities to education (A-HRC-25-29) (2013), par. 68.

¹³⁶ *Ibid*, par. 68.

individual students, together with a commitment to removing the barriers that impede that possibility. It involves strengthening the capacity of the education system to reach out to all learners.¹³⁷

Moreover, Article 24 of the CRPD requires State parties to put in place measures such as training the teachers different educational techniques so that they can meet the needs of children with disabilities in the classroom.¹³⁸

Catelina Devadas, the U.N. Special Rapporteur on the Rights of Persons with Disabilities, notes that: “[e]ducation systems must move away from an approach requiring children with disabilities to adapt to the needs of mainstream schools to one in which the education system adjusted and responded to the needs of all children”.¹³⁹ Since the State parties have the primary duty to provide education to its citizenry, it should ensure that the principle of inclusion is used as its guiding tool as “(...) inclusive education (is) best for all students because learning together (teaches) students to value diversity, build social capital and lay the foundation for inclusive communities”.¹⁴⁰

1.3. The role played by CSOs in Protecting the Rights of Children with Intellectual Disabilities

CSOs play a vital role in the protection of the rights of children with intellectual disabilities. It is important to understand that the CRC and the CRPD does not place obligations on CSOs the same way they do on State parties. The CRPD calls for active consultation and involvement of DPOs in the decision-making process on issues that deal with the provisions of the

¹³⁷ Committee on the Rights of Persons with Disabilities, *supra* 16, par.9.

¹³⁸ CRPD, Article 24 (4), p. 17.

¹³⁹ Statement by Catelina Devadas, the U.N. Special Rapporteur on the Rights of Persons with Disabilities, at the Committee on the Rights of Persons of Persons with Disabilities’ on the right to education of persons with disabilities. This was during a meeting held by the committee on the general discussion of article 24 of the CRPD. This was published on 15 April 2015. Available from <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15847&LangID=E> (Accessed 15/02/2017)

¹⁴⁰ *Ibid*

Convention.¹⁴¹ Article 33 (3) of the CRPD refers to the need for DPOs to be “closely” consulted and “actively” be involved in the “decision-making processes”, and monitoring process of the implementation of the provisions of the CRPD by the State parties.¹⁴² Like “[t]he well-known mantra ‘[n]othing about us without us,’ (...) the involvement of persons with disabilities should be considered as one of the key elements in the successful implementation of the CRPD”.¹⁴³ The collaboration between State parties and CSOs helps in “resource mobilization efforts, (to) amplify the impact of equity-focused advocacy, strengthen the reach and impact of services and programmes for the worst deprived children and communities, and ensure that results are sustainable”.¹⁴⁴

Article 33 of the CRPD introduces a triangulation concept in terms of how the “balance of power and functions between the government, the national human rights institution and civil society” should work.¹⁴⁵ In other words, a national framework must be established to coordinate activities between the government, national institution, and the CSOs for the implementation of the CRPD.¹⁴⁶ This concept is primarily based on the role the government plays in ensuring that it protects and promotes the fundamental freedoms and rights of children with disabilities.¹⁴⁷ The National Human Rights Institution (NHRI) must be an independent body to the government which must help foster accountability, and ensure that the government follows its obligations under international human rights law.¹⁴⁸ The NHRI is set up by the government, but as an independent body.¹⁴⁹ Additionally, it has the mandate to “receive and

¹⁴¹ CRPD, Article 4 (3), p. 6.

¹⁴² Ibid, Article 33 (3), p. 25 and Article 4 (3), p. 6.

¹⁴³ Magdolna Birtha, supra note 64, p. 120.

¹⁴⁴ UNICEF, ‘Civil Society Partnerships,’ 2010, Available from https://www.unicef.org/disabilities/index_65711.html (Accessed 16/02/2017).

¹⁴⁵ Magdolna Birtha, supra note 64, p. 120.

¹⁴⁶ CRPD, Article 33 (2), p. 25.

¹⁴⁷ Magdolna Birtha, supra 64, p. 120.

¹⁴⁸ Ibid, 120.

¹⁴⁹ Office of the High Commissioner on Human Rights, ‘Paris Principles: 20 years guiding the work of National Human Rights Institutions,’ 2013, Available from <http://www.ohchr.org/EN/NewsEvents/Pages/ParisPrinciples20yearsguidingtheworkofNHRI.aspx>. (Accessed 16/02/2017).

consider complaints of human rights violations (...) assist in the development of democratic institutions and organize capacity building especially in areas of accountability, the rule of law and democracy”.¹⁵⁰ This concept brings in the “the voice of civil society and in particular persons with disabilities”.¹⁵¹ A key principle guiding this concept of triangulation is coordination.

Ways in which CSOs help children with intellectual disabilities include: through advocacy work relating to their legal rights to education; by helping to fund empirical research to find out underlying causes to barriers in social services such as health; and by helping to support the government with pilot projects that should be set-up, with the view of scaling up the successful ones.¹⁵² Moreover, “[w]ith their knowledge of the national political context, numerous social networks, and direct access to communities, civil society organizations have the potential to dramatically strengthen the reach and impact of interventions in child protection, education, health (...)”.¹⁵³

Conclusion

This chapter has helped to show that children with intellectual disabilities have human rights and this has been well documented in the CRC and CRPD. These two conventions helped to provide a shift from viewing children with intellectual disabilities as objects of charity provisions to being viewed as human rights holders. As recognized in the CRC and CRPD, children with intellectual disabilities have the right to education and health, and countries that have rectified these two conventions are required to implement these rights, and the many others. State parties are not the only entity which help children with intellectual disabilities.

¹⁵⁰ Ibid

¹⁵¹ Magdolna Birtha, *supra* note 64, p. 120.

¹⁵² Open Society Foundations, ‘The Value of Inclusive Education,’ 2015, Available from <https://www.opensocietyfoundations.org/explainers/value-inclusive-education> Accessed on 16 February 2017.

¹⁵³ UNICEF, *supra* 144.

CSOs and DPOs play a vital role in this process. It is important to note that the provisions of these conventions do not impose the same duties on CSOs and DPOs as they do on State parties. CSOs and DPOs help children with intellectual disabilities on a voluntary and charitable basis. They have a key role to play as they advocate for equal enjoyment of human rights between children with disabilities and non-disabled children. They help to shed light on vices such as discrimination in society. Lastly, they provide important checks and balances on government activities, a feat which should be recognized.

Chapter Two – Comparative Country Analysis: The Right to Inclusive Education.

2.0. CRC and CRPD Standards Regarding the Right to Inclusive Education.

As Broderick points out, “[u]ntil the adoption of the CRPD, international human rights law did not recognize a right to inclusive education within the mainstream school system”.¹⁵⁴ “To maximalise the chances of children with disabilities to enjoy equal treatment, Article 24 of the CRPD proclaims the right to inclusive education”.¹⁵⁵ “From a legal point of view, there is no consensus on the definition of the concept of ‘inclusive education’”.¹⁵⁶

The Committee on the Rights of Persons with Disabilities in its General Comment No. 4, on the right to inclusive education, has stated that it “entails a transformation in culture, policy and practice in all formal and informal educational environments to accommodate the differing requirements and identities of individual students, together with a commitment to removing the barriers that impede that possibility”.¹⁵⁷ In other words, inclusive education does not call for the placing of children with intellectual disabilities into special schools because this would

¹⁵⁴ Andrea Broderick, *supra* 73, p. 274; The CRPD is the first international convention to include the principle or idea of the right to inclusive education. See Committee on the Rights of Persons with Disabilities, *supra* 16, par. 2.

¹⁵⁵ Gauthier De Beco, *supra* 18, p. 272.

¹⁵⁶ *Ibid*, p. 275

¹⁵⁷ See Committee on the Rights of Persons with Disabilities, *supra* 16, par. 9.

mean that a segregated school system would be created outside the mainstream education system. “Inclusive education recognizes that all children are different and acknowledges that children with [intellectual] disabilities should be able to participate in the general education system”.¹⁵⁸

Inclusive education goes beyond integration of learners with disabilities in the classroom. Integration “seeks merely to ensure that the disabled learner fits in with the ‘norm’”.¹⁵⁹ An inclusive education system “is designed to ensure that persons with disabilities can participate fully and access the right to education on an equal basis with others, entailing the elimination of barriers restricting participation and the provision of material support where necessary”.¹⁶⁰

It should be noted that the right to education has been in existence since the UDHR which declared that everyone has the right to education.¹⁶¹ Discussions on establishing an inclusive learning environment have been in existence before the coming into force of the CRPD in 2007. The Salamanca Statement and Framework for Action on Special Needs Education “was the first major international human rights document to recognize the diversity of learners and the need for accommodations”.¹⁶² “It marked the beginning of the acknowledgement at the international level of the importance of educating children in inclusive learning environments”.¹⁶³

Unlike the CRPD which advocates for the right to inclusive education, the CRC is silent on that matter. Article 28 of the CRC explains the State obligations which must be implemented “in the establishment of educational systems and in ensuring access thereto”.¹⁶⁴ According to

¹⁵⁸ United Nations High Commissioner for Human Rights as quoted by Gauthier De Beco, *supra* 18, p. 275.

¹⁵⁹ Andrea Broderick, *supra* 73, p. 283.

¹⁶⁰ *Ibid*, p. 283.

¹⁶¹ Universal Declaration of Human Rights (UDHR), Article 26

¹⁶² Andrea Broderick, *supra* 73, p. 277.

¹⁶³ *Ibid*, p. 277.

¹⁶⁴ Committee on the Rights of the Child, General Comment No. 1 (2001) Article 29 (1) Aims of Education, 17 April 2001, par. 9.

Verhellen, Covell and Howe they “identify articles 28 and 23 [of the CRC] as providing rights to education”.¹⁶⁵ They state that article 28 gives children the right to free primary education, in the same way, “[a]rticle 23 (2) provides for the right of the child with disabilities to have accessible education”.¹⁶⁶

Disabled children have the right to “special care” meaning that State parties must place care and assistance as a high priority for disabled children by ensuring that they “have effective access to and benefit from education (...)”.¹⁶⁷ Article 23 (3) of the CRC “gives further rules regarding the costs of specific measures and precisions as to what assistance [State parties] should try to achieve”.¹⁶⁸ This includes providing education “(...) free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child (...)”.¹⁶⁹

In other words, by considering the financial situation of the parents or guardians of the child, State parties have an obligation of providing education free of charge. State parties must make the provision of education compulsory for every child, and they should provide financial assistance to those children in need to help them get an education.¹⁷⁰

State parties must “[m]ake educational (...) information and guidance available and accessible to all children”.¹⁷¹ Article 28 of the CRC places an obligation on State parties to ensure that

¹⁶⁵ Verhellen, Covell and Howe as quoted by Dawn Zinga and Sherri Young, ‘Children’s Rights to Education: Contextualizing Its Expression in Developed and Developing Countries’, in *Children’s Rights: Multidisciplinary Approaches to Participation and Protection* (2008) Tom O’Neill and Dawn Zinga (ed.), p. 86-87.

¹⁶⁶ Ibid, p. 86.

¹⁶⁷ See CRC, Article 23 (2); Committee on the Rights of the Child, supra 7, par. 14 (b)

¹⁶⁸ Ibid, par. 12.

¹⁶⁹ See CRC, Article 23 (3)

¹⁷⁰ Ibid, Article 28 (1) (b)

¹⁷¹ Ibid, Article 28 (d)

children attend school regularly, they should reduce the drop-out rates and ensure that the tenets set out in the CRC are upheld when implementing children's right to education.¹⁷²

Article 29, paragraph 1, of the CRC sets out the aims which should govern the provision of education in each State party. These aims include; "the holistic development of the full potential of the child (29 (1) (a)), including development of respect for human rights (29 (1) (b)), an enhanced sense of identity and affiliation (29 (1) (c)), and his or her socialization and interaction with others (29 (1) (d)) and with the environment (29 (1) (e))".¹⁷³ In this regard, the right to education for all children should not only be a matter of access, as advocated by Article 28 of the CRC, but also of the content being provided.¹⁷⁴ Thus, State parties must ensure that the school curriculum is directed towards what is relevant for the:

child's social, cultural, environmental, and economic context and to his or her present and future needs and take full account of the child's evolving capacities; teaching methods should be tailored to the different needs of different children.¹⁷⁵

Article 24 of the CRPD places an obligation on States to ensure that they provide an inclusive education for children with intellectual disabilities without discrimination and based on equal opportunity.¹⁷⁶ It is the duty of States to prohibit all discrimination in the school environment and to offer protection to persons with disabilities against such discrimination.¹⁷⁷

Goals or core principles of inclusive education demanded by Article 24 (1) include: non-discrimination; equality of opportunities; development of human potential; human dignity; self-worth; individualized learning methods; accessibility of structures and facilities;

¹⁷² Dawn Zinga and Sherri Young, *supra* note 165, p. 87; See CRC, Article 28 (e)

¹⁷³ Committee on the Rights of the Child, *supra* note 164, par. 1.

¹⁷⁴ *Ibid*, par. 3.

¹⁷⁵ *Ibid*, par. 9.

¹⁷⁶ See CRPD, Article 24 (1)

¹⁷⁷ See Committee on the Rights of Persons with Disabilities, *supra* note 16, par. 13.

strengthening of human rights and freedoms; and appreciating the diversity of learners with disabilities.¹⁷⁸

State parties must ensure “that children with disabilities are not excluded from free and compulsory primary education (...) on the basis of disability”.¹⁷⁹ It is a State obligation to ensure that “[p]ersons with disabilities can access an inclusive, quality and free primary education (...) on an equal basis with others in the community in which they live”.¹⁸⁰

To help children with intellectual disabilities benefit from the provisions of education, States have the duty of providing reasonable accommodation according to the needs of each child.¹⁸¹ Failure to provide reasonable accommodation constitutes disability discrimination.¹⁸²

Reasonable accommodation “means necessary and appropriate modification and adjustment not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others all human rights and fundamental freedoms”.¹⁸³ According to the Committee on the Rights of Persons with Disabilities, it is a State’s duty to provide reasonable accommodation and it is “(...) enforceable from the moment an individual with an impairment needs it in a given situation (...) in order to enjoy her or his rights on an equal basis in a particular context”.¹⁸⁴ In fact, “the provision of reasonable accommodation is [a State] obligation which has to be fulfilled immediately”.¹⁸⁵

¹⁷⁸ Andrea Broderick, *supra* note 73, p. 281; See CRPD Article 24 (1)

¹⁷⁹ See CRPD, Article 24 (2) (a)

¹⁸⁰ *Ibid*, Article 24 (2) (b)

¹⁸¹ *Ibid*, Article 24 (2) (c)

¹⁸² William Aseka and Arlene S. Kanter, ‘The Basic Education Act of 2013: Why is it one step forward and two steps back for children with disabilities in Kenya’, p. 43 - 45, *African Disability Rights Yearbook*, vol. 2. 2014, Pretoria University Law Press.

¹⁸³ See CRPD, Article 2.

¹⁸⁴ Committee on the Rights of Persons with Disabilities, General Comment No. 2. Article 9; Accessibility 22 May 2014, par. 26.

¹⁸⁵ Gauthier De Beco, *supra* 18, p. 278.

Andrea Broderick has stated that “[a]rticle 24 of the CRPD does not prohibit segregated education explicitly”.¹⁸⁶ Special education is permitted in some situations to help meet the educational needs of blind, deaf-blind or deaf persons.¹⁸⁷ Gauthier de Beco has further argued that the blind, deaf-blind or deaf persons “should be allowed to be educated in special schools, although this option should not prevent them from asking to be able to participate in the general education system”.¹⁸⁸

According to Gauthier de Beco, he has stated that there “is still ambiguity as to whether Article 24 (2) (e) of the CRPD makes room for special education”.¹⁸⁹ He has argued that for those States which still have special schools in place, these cannot be suddenly closed because this will result into discrimination of children with disabilities.¹⁹⁰ Therefore;

There should be a gradual move from segregated to inclusive education systems. Such a transition can be achieved by establishing a mixed form of education. One of the solutions is to bring the two systems to the same campus so that the knowledge and materials from special schools can be used in regular schools. Special schools will then be transformed as learning resource centres.¹⁹¹

Special schools “cannot be ruled out [because] for a limited number of children reasonable accommodations are not possible or support measures not desired”.¹⁹² This is true for children with multiple and serious impairments.¹⁹³ Most importantly, it is always important to bear in mind that Article 24 of the CRPD does not prevent States from establishing special schools nor does it compel them to do so. “Providing special education to [children with intellectual disabilities] is (...) permissible as long as this is not done [because of] their impairments but on the basis of the barriers to their participation in society”.¹⁹⁴ It should be noted that, “inclusive

¹⁸⁶ Andrea Broderick, *supra* 73, p. 286.

¹⁸⁷ See CRPD Article 24 (3)

¹⁸⁸ Gauthier de Beco as quoted by Andrea Broderick, *supra* 73, p. 286

¹⁸⁹ Gauthier De Beco, *supra* 18, p. 284.

¹⁹⁰ *Ibid*, p. 285.

¹⁹¹ *Ibid*, p. 285.

¹⁹² *Ibid*, p. 285.

¹⁹³ *Ibid*, p. 285.

¹⁹⁴ *Ibid*, p. 285

education recognizes that all children are different and acknowledges that children with disabilities should be able to participate in the general education system”.¹⁹⁵

The right to inclusive education falls under the realm of economic, social, and cultural rights, and as such, each State party must progressively realize this right within the maximum available resources.¹⁹⁶ “State parties have (...) to put in place their resources with a view to fully realizing the right to inclusive education and immediately take steps to this end, even though the objective does not have to be reached right away”.¹⁹⁷ This does not mean that the right to inclusive education can simply be postponed, but rather State parties must have a timeframe, show a strategy and monitor results for the purpose of realizing the right to inclusive education.¹⁹⁸

Article 24 (4) demands that State parties to the CRPD must train, and employ the appropriate teachers and staff who can meet the needs of children with intellectual disabilities.¹⁹⁹

It should be noted that, inclusive education is in accordance with the tenets of the social model of disability advocated for in the entire CRPD. This model “defines disability as the interaction between the impairments of persons with disabilities and the physical and social barriers to their participation in society”.²⁰⁰ “The social model considers persons with disabilities no longer as objects of charity but as subjects of rights”.²⁰¹ A child’s intellectual disability “is considered as a social construct and society should be capable of correcting its own failure to be more inclusive”.²⁰² In this regard, State parties have a duty of ensuring that they eliminate

¹⁹⁵ Ibid, p. 275.

¹⁹⁶ See CRPD, Article 4 (2)

¹⁹⁷ Gauthier De Beco, supra 18, p. 275.

¹⁹⁸ Ibid, p. 275-6.

¹⁹⁹ See CRPD, Article 24 (4).

²⁰⁰ Gauthier De Beco, supra note 18, p. 269.

²⁰¹ Ibid, p. 269.

²⁰² Ibid, p. 269.

discrimination and harmful stereotypes, promote participation, recognize diversity and eliminate barriers to learning.²⁰³

The Committee on the Rights of Persons with Disabilities in its General Comment No. 4, on the right to inclusive education, has warned that persons with intellectual disabilities are at more risk to exclusion from education than other groups of disabled persons.²⁰⁴ This is because “[p]eople with intellectual disabilities are frequently a low priority in government planning and policy development”.²⁰⁵ There is a lack of understanding about the abilities possessed by persons with intellectual disabilities which has led to negative imagery and language, discrimination, stigma, and stereotypes.²⁰⁶ As such, realizing the right to inclusive education should be a matter prioritized by each State party to the CRPD.

2.1. Zambia

2.1.1. Analysis of the Legal Framework in Zambia and the role the CSOs play in advancing the right to inclusive education for children with intellectual disabilities.

The Constitution of Zambia has undergone some amendments since coming into force in 1996 with the most recent of them happening in 2016. Despite all these amendments taking place one area that has remained unchanged is the Bill of Rights contained under Part III of the 1996 Constitution.²⁰⁷ The current Zambian Constitution does not provide for the protection of economic, social, and cultural rights. The 2016 referendum failed to meet the required

²⁰³ See Committee on the Rights of Persons with Disabilities, *supra* note 16, par. 9

²⁰⁴ *Ibid*, par. 6.

²⁰⁵ Families Special Interest Research Group of IASSIDD, Families supporting a child with intellectual or developmental disabilities: the current state of knowledge, p. 7, *Journal of Applied Research in Intellectual Disabilities*, Sept; 27 (5): 420-30, 2014

²⁰⁶ See WHO and World Bank, World Report on Disability, p. 6, WHO 2011.

²⁰⁷ See the Constitution of Zambia (1996), Part III on the Protection of Fundamental Rights and Freedoms.

threshold to amend the Bill of Rights which is still being used up to today.²⁰⁸ In this regard, the Right to Education (as an economic right) is not protected under the current Bill of Rights in the Constitution.²⁰⁹ Article 23 of the Zambian Constitution provides protection against discrimination.²¹⁰ According to Article 23 (2) it states that “(...) no person shall be treated in a discriminatory manner by any person acting by virtue of any written law or in performance of the functions of any public office or any public authority”.²¹¹

The Education Act was enacted in 2011 to reinforce “early childhood care, development and education” in the country.²¹² There are two Ministries in Zambia responsible for implementation of the Education Act, these are the Ministry of Higher Education and the Ministry of General Education. The focus of this thesis will be based on the work carried out by the Ministry of General Education.

The Education Act demands for the compulsory school attendance and stipulates that a parent must “enroll a child who has attained the school going age at an education institution and [must] ensure the child’s attendance at the educational institutional”.²¹³ The Act places obligations on the Minister of General Education to ensure that there is equal access to learning institutions, especially for the poor and vulnerable children such as those with intellectual disabilities.²¹⁴ Section 19 of the Education Act prohibits discrimination of a learner by a learning institution in any manner.

²⁰⁸ See Emelda Musonda’s column on the failed 2016 Zambian referendum entitled ‘Lessons from the failed referendum’ Available from <https://www.daily-mail.co.zm/lessons-from-the-failed-referendum/> (Accessed 16/05/2017); It is still unknown when a new referendum will take place to vote for a new Bill of Rights.

²⁰⁹ See the Constitution of Zambia 1996, Part III on the Protection of Fundamental Rights and Freedoms.

²¹⁰ Ibid, Article 23 (3); Discrimination is prohibited based on race, tribe, sex, place of origin, marital status, political opinions, color, or creed. Disability and age have not been explicitly listed as grounds on which discrimination is prohibited.

²¹¹ Ibid, Article 23 (2).

²¹² See the Education Act, Part IV, Section 14, 2011, Republic of Zambia

²¹³ Ibid, Section 17 (1).

²¹⁴ Ibid, Section 22.

The Education Act places an obligation on the Minister of General Education to “ensure equal access to quality education to all learners including poor and vulnerable children”.²¹⁵ Section 22 (3) (a) and (b) of the Education Act prohibits denial of admission of an applicant into an education institution because they are unable to pay or have not paid school fee, and are unable to provide school clothing or other important items in the school set up.

Section 23 of the Education Act targets learners with special needs such as children with intellectual disabilities – it demands that the Minister of General Education must ensure “equality of access to, participation and the benefit of educational institutions for learners with special educational needs, promote interventions at all levels of the educational institutions.”²¹⁶

The Act also demands that “[a] learner with special education needs shall, to the greatest extent possible, be integrated into mainstream educational institutions”.²¹⁷

The PWD Act was enacted in 2012, and it has domesticated the provisions of the CRPD in Zambia.²¹⁸ Section 4 (b) (k) requires that children with disabilities are protected from discrimination, and that respect should be paid to a child’s developing capacity.²¹⁹ The Minister of Community Development, Mother, and Child Health must work together with the Minister of General education to “(...) ensure that the education system is inclusive at all levels and early life-long learning (...)”.²²⁰ The two Ministers have to ensure that children with intellectual disabilities are not excluded from the compulsory and free primary education;

²¹⁵ Ibid, Section 22 (1).

²¹⁶ Ibid, Section 23 (1).

²¹⁷ Ibid, Section 23 (5); Section 23 (6) stipulates that “[a] learner with an exceptional degree of special education needs may, where need is established, be transferred from an inclusive education institution to a special education institution or from a special education institution to an inclusive education institution”.

²¹⁸ As much as Zambia has legislation which has domesticated the provisions of the CRPD, the country does not have a National Policy on Disability. The PWD Act gives children with intellectual disabilities rights which they can claim in case of non-fulfillment against the State. A policy on disability helps to provide a roadmap on which government and other non-state actors can coordinate their efforts in uplifting the rights of children with intellectual disabilities. “Without a policy framework, the roles of Government and other stakeholders in issues of disability and development lacks direction, legitimacy, and proper coordination”. See Committee on the Rights of the Child, *supra* 25, par. 103, p. 28.

²¹⁹ See PWD Act 2012, Section 4 (b) (k), Republic of Zambia.

²²⁰ Ibid, Section 22.

reasonable accommodation is provided in the learning institutions; individualized support systems are provided in the education system to help in the advancement of the educational and social aspects of children; and they must ensure that the education of children “(...) with intellectual disabilities, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development”.²²¹

Additionally, Section 21 (2) (g) of the PWD Act emphasizes the need to provide information to parents, guardians, and children with intellectual disabilities on the available services which are in place for early stimulation and education to help prevent the development of disabilities in children.²²² Section 21 (2) (h) stipulates “that children with disabilities [should] enjoy all human rights on an equal basis with other children and [they should] have equal opportunities and equal access to education (...)”.²²³

2.1.2. A focus on work by CSOs

Unlike State parties who have the obligation of ensuring that they implement the provisions of the CRC and CRPD upon ratification, CSOs are not required to do so. They help children with intellectual disabilities based on the organizational strategy, free will and on charity basis. CSOs have an important role to play in helping children with intellectual disabilities because they help to fill in the gaps wherever government provisions are missing.

²²¹ Ibid, Section 22 (2) (a) (b) (c) (d) (e) and (h)

²²² Ibid, Section 21 (2) (g)

²²³ Ibid, Section 23 (2) (h)

Special Hope Network (SHN) is a faith-based NGO located in Lusaka, Zambia and has been in operation since May 2010.²²⁴ The organization works specifically with children who have intellectual disabilities. Through its Community Care Centers, the organization helps to provide children with intellectual disabilities educational support, among others. “The [Community Care] Centers are *Multi-modal, multi-disciplinary*-using various therapeutic and educational models so that the Centre becomes a “one-stop-shop” for care”.²²⁵ The organization has also set-up a classroom for children with intellectual disabilities at Kasisi Orphanage (the oldest orphanage in Zambia).

Cheshire Homes Society of Zambia is another organization helping children with intellectual disabilities. It has been in existence as a non-profit organization since 1973.²²⁶ Some of the core objectives of the organization include the promotion of inclusive education and increasing the number of children with intellectual disabilities who attend primary education.²²⁷ The Organization has five core functional areas which are in education, health, inclusion, work and income, and child protection. The organization works with various catholic congregations in Zambia. These churches help in the running of some of the homes which house children with disabilities. Unfortunately, challenging the government to change discriminatory laws is not part of its listed objectives.

²²⁴ SHN offers educational and health support to children with intellectual disabilities through its Community Resource Centers. Through its resource center the organization helps to generate some funding for its operations to help provide for additional programs for those who cannot pay. SHN works with various partners such as Kasisi Orphanage (the oldest orphanage in Zambia); See also, ‘U.VA. Student project to aid Zambian Disabled Children Earns Davis Prize’, Available from <https://news.virginia.edu/content/uva-student-project-aid-zambian-disabled-children-earns-davis-prize> (Accessed 30/09/2017).

²²⁵ See Special Hope Network, Community Care Centres, Available from <https://specialhopenetwork.org/community-care-centers/> (Accessed on 18/09/2017)

²²⁶ Some of the organization’s partners as well as funders include the European Union, The German Embassy, Churches Health Association of Zambia (CHAZ), and Lililane Fonds. The organization runs three inclusive education projects in Zambian. Comic Relief and the European Union are funding inclusive education projects in Zambian towns namely Choma, Kafue, Kalomo, Livingstone, Mazabuka, Monze and Pemba.

²²⁷ See Cheshire Homes Society of Zambia, Available from <http://www.cheshirehomessocietyzambia.org/index.php/education/> (Accessed on 18/09/2017)

2.1.3. An analysis of the Legislation vis-à-vis CRC and CRPD Standards.

The current Bill of Rights in the Zambian Constitution does not provide for the right to education, and Article 23 which protects against discrimination has not placed disability as a ground on which discrimination is prohibited.²²⁸ As such the right to education is not enforceable in Zambian courts making it difficult for children with intellectual disabilities to sue the State in cases of non-implementation of this right.²²⁹ It should be noted that despite the Zambian government ratifying the CRC in 1991, its provisions have not yet been domesticated.²³⁰

In most rural areas in Zambia, “[m]ost parents with [children] with disabilities – especially those with intellectual disabilities find it difficult to take their children to school especially when schools are very far away from their homes (...)”.²³¹ As a result, this has led to inaccessibility of schools because of long distances, and these children do not get to benefit from education as required by Article 28 of the CRC. The long distances to schools tend to compromise the implementation of the some of the provisions in the Education Act in Zambia such as compulsory and free universal education for all children. This goes against the provisions of Article 28 of the CRC.²³²

Zambia introduced Free Basic Education (FBE) in 2002 to increase access to primary education for all children in the Country. This in practice, however, has proved to be very difficult to implement. Children in rural areas, where poverty levels are high, are failing to

²²⁸ See Constitution of Zambia, Article 23 (3); Likando Kalaluka, *supra* note 37, p. 175-177.

²²⁹ Likando Kalaluka, *supra* note 37, p. 175-177.

²³⁰ See Julia Sloth -Nielsen, “A Developing Dialogue – Children’s Rights, Children’s Law, and Economics: Surveying Experiences from Southern and Eastern African Law Reform Processes, p.3., *Electronic Journal of Comparative Law*, Vol. 12.3 (December 2008)

²³¹ Masauso Chirwa, ‘Inclusive Education: A Study of Opportunities and Challenges for Children with Disabilities. A Case of Zambia. p, 39. Masters Thesis, Linnaeus University, Sweden. Available from <http://Inu.diva-portal.org/smash/record.jsf?pid=diva2%3A421429&dswid=9067> (Accessed on 11/09/2017)

²³² See Article 28 of the CRC; The Education Act 2011 Zambia, Section 17 (1).

progress academically because their parents cannot afford to purchase school related items such as uniforms and shoes.²³³

A research carried out by Masauso Chirwa reviewed that “(...) most parents opt sending children without disabilities to school – especially when resources were inadequate for all children to go to school”.²³⁴ “The [r]ationale behind it is that the able-bodied can look after their siblings with [intellectual] disabilities in future”.²³⁵

Indeed, this is disappointing because Article 28 of the CRC demands for equal access to quality education for all learners, and Article 24 of the CRPD demands that inclusive education should be provided without discrimination and based on equal opportunity. As such, the country is failing to meet its international obligations stipulated by the two articles in the two conventions.

It should be note that, although the words integration and inclusion in the Education Act are used synonymously when it comes to the placement of children with intellectual disabilities into the mainstream school set-up, the two terms are different, and must not be confused.²³⁶

In terms of Special Education Needs (SEN) the Education Act stipulates that “[a] learner with special educational needs shall, to the greatest extent possible, be integrated into mainstream educational institutions”.²³⁷ However, in practice this is not taking place in Zambia. Children with disabilities continue to face discrimination in their communities, and this is perpetuated by the lack of inclusive schools for children with disabilities; special schools remain the only option available to children with disabilities to get an education.²³⁸

²³³ Masauso Chirwa, supra note 231. p, 35.

²³⁴ Ibid, p, 35.

²³⁵ Ibid, p, 35.

²³⁶ See the Education Act 2011 Zambia, Section 5 and 6; See Andrea Broderick, supra 73, p. 283; See Committee on the Rights of Persons with Disabilities, supra note 16, par. 11.

²³⁷ Committee on the Rights of the Child, supra note 7, par. 67.

²³⁸ Committee on the Rights of the Child, supra note 48, par. 144.

2.2. Kenya

2.2.1. Analysis of the Legal Framework in Kenya and the role the CSOs play in advancing the right to inclusive education for children with intellectual disabilities.

The right to education is protected in the Bill of Rights contained under chapter four of the Kenyan Constitution. Article 27 is a non-discrimination clause and it prohibits discrimination by the State based on a person's disability or age.²³⁹ Article 27 (6) calls for affirmative action programs and the need to formulate legislation to provide redress measures to help persons who are disadvantaged. The right to education, being an economic and social right, is protected under Article 43 (1) (f).²⁴⁰ Article 53 (1) (b) guarantees every child in Kenya the right to “free and compulsory basic education”.²⁴¹ Article 54 of the Kenyan Constitution is a stand-alone Article for persons with disabilities. This provision entitles children with disabilities to have “(...) access to educational institutions (...) that are integrated into society to the extent compatible with the interests of that [child]”.²⁴²

In the *Kenya Society for the Mentally Handicapped (KSMH) v. The Attorney General and others*, the petitioner sued the State for violating the rights of persons with intellectual disabilities, one of the reasons being that the State was “discriminating against them in the provision of support and services”.²⁴³ The petitioner stipulated that the State had violated the

²³⁹ See Constitution of Kenya 2010, Article 27 (4)

²⁴⁰ Ibid, Article 43 (1) (f)

²⁴¹ Ibid, Article 53 (1) (b); Article 53 (2) requires that the best interests of the child will be of “paramount importance in every matter concerning the child”.

²⁴² Ibid, Article 54 (1) (b); Article 56 further calls for the State to undertake affirmative programs for marginalized groups such as children with intellectual disabilities in the education setting

²⁴³ See *Kenya Society for the Mentally Handicapped (KSMH) v. The Attorney General, National Council for Persons with Disabilities, The Minister of Education, The Minister for Health, The Minister for Medical Services, The Minister of Gender, Children and Social Development, The United Disabled Persons for Kenya (as an interested Party) and the Kenya Paraplegic Organization (as an interested Party)*. Petition No. 155A of 2011, par. 5.

rights of persons with intellectual disabilities, and one of the grounds of violation was that the National Council for Persons with Disabilities, a state agency;

had been slow to formulate and develop measures and implementing policies designed to achieve equal opportunities for persons with (...) intellectual disabilities to obtain an education (...) to recommend measures to prevent discrimination against persons with disabilities contrary to Articles 21 (3), 28 and 27 (1).²⁴⁴

Despite the court dismissing this petition because the petitioners did not present facts and evidence supporting their legal arguments, the case helps to test some of these legal provisions stipulated in the Constitution.²⁴⁵

The Kenyan government enacted the Education Act in 2013 with the purpose of implementing Article 53 (b) of the Kenyan Constitution which guarantees free and compulsory education for all children.²⁴⁶ Section 4 of the Education Act contains the values and guiding principles which the Ministry of Education, Science and Technology (MOEST) is mandated to uphold when providing education in Kenya. Specific to children with disabilities include the right of every child to free and compulsory education; protection of every child from discrimination; protection of every child in a public school to equal standards of education; respecting the views of the child in matters which affect the child; and most importantly “nondiscrimination, encouragement and protection of the marginalized, [children] with disabilities and those with special needs”.²⁴⁷ Perhaps the most progressive provision of the Education Act has been stipulated in Section 28 which states that every child has the right to free and compulsory education.²⁴⁸

According to Section 34 (2) of the Education Act, one of the areas on which discrimination is prohibited because of disability is in the admission process of school places in Kenyan

²⁴⁴ Ibid, par. 5.

²⁴⁵ Ibid.

²⁴⁶ William Aseka and Arlene S. Kanter, *supra* note 182, p. 34.

²⁴⁷ See Basic Education Act 2013 Kenya, Section 4 (s)

²⁴⁸ Ibid, Guiding Principles under Section 28 (1)

schools.²⁴⁹ Section 39 recognizes the government's responsibility in fostering the right to education - the Cabinet Secretary has the duty to "ensure that the children belonging to marginalized, vulnerable or disadvantaged groups are not discriminated against and prevented from pursuing and completing basic education".²⁵⁰ The Cabinet Secretary must also "provide special education and training facilities for talented and gifted (...) pupils with disabilities".²⁵¹ Sections 44 and 45 give the mandate to the Cabinet Secretary to establish and maintain special schools for children with disabilities.²⁵² It should be noted that, the Education Act is currently undergoing some changes to meet the special needs of children with disabilities.²⁵³

The PWD of Kenya came into force in 2004, this was way before the country ratified the CRPD in 2008. As such, most of its provisions are yet to be harmonized in line with the CRPD.²⁵⁴ The PWD Act of Kenya is silent on some key definitions in relation to who a child is, a person with a disability and what are assistive devices and tools.²⁵⁵ This creates a lot of vagueness when it comes to understanding the provisions which follow in the PWD Act. The right to education is protected under section 18. This Article demands that special attention is to be given to persons with special needs such as those with disabilities in terms of school enrolment, as well as, in curriculum, examinations, auxiliary service, and physical education requirements.²⁵⁶ Section 19 creates an obligation for the government institutions to create an integrated system of special and non-formal education for persons with disabilities.²⁵⁷

²⁴⁹ Ibid, Section 34 (2)

²⁵⁰ Ibid, Section 39 (c)

²⁵¹ Ibid, Section 39 (g)

²⁵² Sections 44 and 45 of the Basic education entitled Establishment and management of special institutions and regulations in special needs educations respectively relate to the establishment and management of special schools by the government of Kenya through the work of the Cabinet Secretary.

²⁵³ Committee on the Rights of Persons with Disabilities, *supra* note 42, par. 188.

²⁵⁴ Ibid, par. 84; The PWD Act is currently being amended and it is before parliament for enactment.

²⁵⁵ See Persons with Disabilities Act 2003 Kenya, Part 1 - Preliminary

²⁵⁶ Ibid, Section 18 (2)

²⁵⁷ Ibid, Section 19

The Children's Act was enacted in 2001, and it domesticates provisions of the CRC.²⁵⁸ It should be noted that this Act came into force prior to the PWD Act of Kenya in 2003 and the CRPD in 2006. Through the Kenya Law Reform Commission, the Kenyan government has begun amending some of the Act's provisions to offer more protection to children with disabilities.²⁵⁹

Section 5 of the Children's Act prohibits discrimination based on disability. Section 7 (2) asserts that every child has the right to free basic and compulsory education in "accordance to Article 28 of the CRC".²⁶⁰ Section 12 which deals specifically with children with disabilities stipulates that children with intellectual disabilities have the "(...) right to be treated with dignity, and to be accorded appropriate (...) education and training free of charge or at a reduced cost whenever possible".²⁶¹

2.2.2. A focus on work by CSOs

The Kenya Association for Intellectually Handicapped (KAIH) is a support group of parents established in 1971 which helps both adults and children with intellectual disabilities.²⁶² The association is one of the leading organizations in Kenya which helps champion the right to education for children with intellectual disabilities. The association has advocated for the establishment of inclusive schools in Kenya for persons with intellectual disabilities. Some of the challenges the association faces include; a lack of early identification and assessment services for children with intellectual disabilities; insensitive and discriminatory legal and policy provisions in Kenya; and a high prevalence of poverty in the country which has resulted into an increase in cases of intellectual disabilities, thus, hampering some of the measures in place which aim at reducing the prevalence of this type of disability.

²⁵⁸ This law precedes the Ratification of the CRPD in 2008 and the enactment of the Kenyan Constitution in 2010.

²⁵⁹ Committee on the Rights of Persons with Disabilities, *supra* note 42, par. 260.

²⁶⁰ See Children's Act 2001 Kenya, Section 7 (2)

²⁶¹ *Ibid*, Section 12.

²⁶² Kenya Association for Intellectually Handicapped (KAIH). Available from <https://www.Kaihid.org> (Accessed 30/09/2017)

In 2012, a petition was brought before the Kenyan High Court by the KSMH and KAIH - and one of the grounds of this petition was that the Ministry of Education had “(...) ignored, neglected or declined to establish a sound legal policy framework governing education (...) of (...) intellectually disabled children contrary to Articles 21 (3), 27 and 28” of the Kenyan Constitution.²⁶³ However, the High Court ruled against the petitioners because they did not “(...) set out specific policies for [the court] to examine and make an appropriate assessment for itself”.²⁶⁴ The High Court also stated that there were other alternatives to consider when it comes to addressing grievances dealing with laws and policies concerning persons with disabilities especially since addressing such grievances requires a wide consultation amongst various stakeholders.²⁶⁵

2.2.3. An analysis of the Legislation vis-à-vis CRC and CRPD Standards.

The Children’s Act (2001) domesticates provisions of the CRC. The Act gives every child in Kenya the right to free basic education. To achieve this, in 2003 the Kenyan government re-introduced the Free Primary Education Program (FPE). Free primary learning was initially started in 1963 after Kenya gained its independence. It was part of an initiative to fulfil the Kenya African National Union (KANU) manifesto.²⁶⁶ However, in practice Basic Education is not entirely free in Kenyan government schools. In most of these schools, pupils pay non-tuition payments to buy desks, for examinations, development, and electricity.²⁶⁷ It questions

²⁶³ See Kenya Society for the Mentally Handicapped (KSMH) v. The Attorney General, National Council for Persons with Disabilities, *supra* note 243, par. 5 (d).

²⁶⁴ *Ibid*, par. 13.

²⁶⁵ *Ibid*, par. 20.

²⁶⁶ Bhoke Chacha and Agnes P. Zani (Dr), The Impact of Free Primary Education on Pupil-Teacher Ratio in Kuria East Constituency, Kenya, p. 1, Available from <https://www.scribd.com/mobile/document/266208572/The-Impact-of-Free-Primary-Education-on-Pupil-Teacher-Ratio-in-Kuria-East-Constituency-Kenya> (Accessed 23/11/2017)

²⁶⁷ Committee on the Rights of the Child, *supra* note 48, par. 217.

the whole notion of education being free in government schools, and it undermines the State's obligation to fulfill Article 28 (1) (a) of the CRC.²⁶⁸

The Education Act falls short of meeting some of the international human rights law standards as enunciated in the CRPD in the following ways;

The Education Act adopts a medical model of disability, and not a social model of disability as advocated for in the entire CRPD.²⁶⁹ The Kenyan government has defined special schools as those whose "purpose is to help a particular class of children not only to attain education but some form of treatment or care".²⁷⁰ It should be noted that, it is the negative imagery and attitudes towards persons with impairments which brings about disability. It is the society which needs changing, and not the treatment of persons with impairments.

The Education Act does not mention what should encompass an inclusive education system.²⁷¹ There is no mention of the right to inclusive education in the Act, as such, it becomes difficult to justify why an inclusive education system is needed for children with intellectual disabilities. "Article 24 of the CRPD specifically guarantees the right to education for all children (...) as an obligation on state parties to provide an 'inclusive education system'".²⁷² The Education Act is silent on this matter.

The Education Act fails to provide reasonable accommodation to children with intellectual disabilities.²⁷³ Disability discrimination is commonplace in most Kenyan schools because of

²⁶⁸ See Committee on the Rights of Persons with Disabilities, supra note 42, par. 185; United Disabled Persons of Kenya, "A Shadow Report to the initial Report on the Rights of Persons with Disabilities (CRPD) to the UN Committee on the Rights of Persons with Disabilities", p.40, Available from http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Countries.aspx?CountryCode=KEN&Lang=EN (Accessed 31/08/2017)

²⁶⁹ William Aseka and Arlene S. Kanter, supra note 182, p. 37.

²⁷⁰ See the Basic Education Act Part 1-Preliminary, 2013, p. 10.

²⁷¹ William Aseka and Arlene S. Kanter, supra note 182, p. 35; As much as Article 24 of the CRPD does not prohibit the establishment of special schools in some instances, the Education Act ignores entirely the right to inclusive education.

²⁷² Ibid, p. 35.

²⁷³ Ibid, p. 46

the government's failure to provide reasonable accommodation in the school environment for children with disabilities.²⁷⁴

Edmund Rice International has noted that "(...) some schools continue to discriminate against children with [intellectual disabilities] by refusing them admission".²⁷⁵ There is also a shortage of teachers who are trained to meet the needs of children with intellectual disabilities.²⁷⁶ The State is failing in its duties to train enough teachers in disability related issues, and to protect persons with disabilities in the school environment from discrimination.

The Education Act "(...) does not declare that all children have a right to education on an equal basis with other non-disabled children; nor does it require the removal of barriers for their full inclusion".²⁷⁷ "The Act legislates the status quo in education by segregating children with disabilities in so-called 'special schools'".²⁷⁸ The Act makes no mention of the right to inclusive education as the best form of education stipulated in Article 24 of the CRPD.²⁷⁹

The PWD Act, which came into force before the ratification of the CRPD, falls short of meeting the CRPD standards in the following ways; Disability in the Act has been defined as an impairment which "(...) impacts adversely on social, economic or environmental participation".²⁸⁰ This definition is discriminatory as it fails to highlight that it is the social

²⁷⁴ William Aseka and Arlene S. Kanter have defined disability discrimination as the failure to provide reasonable accommodation. Reasonable accommodation may involve changing admission rules that may exclude children with intellectual disabilities from the school system and provision of tutoring services to those children with intellectual disabilities so that they are not lagging behind their counterparts in the school environment.

²⁷⁵ Edmund Rice International, "Children Rights in Kenya", p.3, Available from http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Countries.aspx?CountryCode=KEN&Lang=EN

²⁷⁶ Ibid, p.2.

²⁷⁷ William Aseka and Arlene S. Kanter, supra note 182, p. 37.

²⁷⁸ See Section 44 of the Basic Education Act 2013, Kenya. Also, as explained by William Aseka and Arlene S. Kanter, supra note 182, p. 35.

²⁷⁹ William Aseka and Arlene S. Kanter, supra note 182, p. 35.

²⁸⁰ See PWD Act 2003, Part 1 (2).

barriers in society which adversely affects the participation of persons with disabilities, and not the impairment that the child may have.²⁸¹

There is also a need to have an ““open definition”, where the long-term element is not a compulsory requirement” for disability.²⁸² The definition of discrimination leaves out some crucial elements such as the provision of reasonable accommodation because failure to provide this amounts to disability discrimination.²⁸³ Gilbert Oduor Onyango has further argued that by defining disability and not what causes disability the law risks excluding some groups of people in that definition, and as such brings about the impossibility of introducing ““on an equal basis with others” standard which would easily apply if legislation defined the person rather than the state of being”.²⁸⁴

The PWD Act gives the authority for the establishment of special schools for children with intellectual disabilities.²⁸⁵ Again, this is against the spirit of inclusion in Article 24 of the CRPD. The Act adopts a medical model of disability as a basis for intervention in the provision of education to children with intellectual disabilities.²⁸⁶ There is nowhere in the PWD Act which recognizes the right to inclusive education for persons with disabilities on an equal basis with their non-disabled counterparts.²⁸⁷

In Kenya’s initial report to the Office of the United Nations High Commissioner for Human Rights (OHCHR), it was reported that “39 percent of children with disabilities attended

²⁸¹ Gilbert Oduor Onyango, ‘A social-legal critique of the legal framework for the Promotion of Rights of Persons with Disabilities in Kenya’, p. 20, Available from <https://thesis.eur.nl/pud13191/Gilbert%2520Oduor> (Accessed 31/08/2017) (Also as explained by the CRPD Preamble (e))

²⁸² United Disabled Persons of Kenya, supra note 268, p.14 (Also as explained by the CRPD Committee in *S.C v. Brazil*, par. 6.3.)

²⁸³ See the Persons with Disabilities Act 2003 Part 1-Preliminary, p. 5.

²⁸⁴ Gilbert Oduor Onyango, supra note 281, p. 21.

²⁸⁵ See Section 18 (3) and 19 of the Persons with Disabilities Act 2003, Kenya.

²⁸⁶ Gilbert Oduor Onyango, supra note 281, p. 21.

²⁸⁷ The right to inclusive education was only firmly enshrined under Article 24 of the CRPD when it came into force in 2007 – as such one may argue that it is the reason the PWD Act of Kenya (2003) is silent on an inclusive learning environment approach for persons with disabilities – since it predates the coming into force of the CRPD.

mainstream preschool, with 37 percent of students with disabilities having received a primary education (...).²⁸⁸ “These numbers, though challenging to confirm, contribute to the estimated 140 million school-aged children who are out of school”.²⁸⁹ There is still a lot of work to be done by the Kenyan government to ensure that more children get to realize their right to quality and inclusive education.

2.3. South Africa

2.3.1. Analysis of the Legal Framework in South Africa and the role the CSOs play in advancing the right to inclusive education for children with intellectual disabilities.

The South African Constitution which came into force in 1996, contains a progressive Bill of Rights (Chapter 2), which is also guided by International Law. Section 9 of the Constitution is the equality clause, it places disability as one of the grounds on which discrimination is prohibited either directly or indirectly by the State.²⁹⁰ Section 29 of the Constitution stipulates that everyone has the right to a basic education.²⁹¹

The South African Schools Act, 1996 regulates the education for all children between the age of 7 to 18. According to Section 3 (2) of the Act, the Minister of Education must “determine the ages of compulsory attendance at school for learners with special education needs”.²⁹² Section 5 (1) stipulates that public schools must admit all learners without unfairly discriminating them in any way possible. Section 5 (3) demands that no learner should be denied admission into a public school on grounds that they are unable to pay school fees.

²⁸⁸ Brent C. Elder, Right to Inclusive Education for Students with Disabilities in Kenya, p. 22., *Journal of International Special Needs Education Vol. 18, No. 1. Pp. 18 – 28*; Committee on the Rights of Persons with Disabilities, supra note 49, par. 176, p. 34.

²⁸⁹ United Nations Educational, Scientific, and Cultural Organization (UNESCO) as quoted by Brent C. Elder, supra note 288, p. 22.

²⁹⁰ See the Constitution of the Republic of South Africa, Section 9 (3).

²⁹¹ Ibid, Section 29 (1) (a).

²⁹² See the South African Schools Act 1996, Section 3 (2).

“Section 12 of the South African Schools Act obliges members of the executive councils responsible for education at provincial level, to ensure that education [for children with intellectual disabilities], where reasonably practicable, at ordinary public schools”.²⁹³

PEPUDA came into force in 2003. This is the Country’s anti-discriminatory law, and it precedes the ratification of the CRPD by the government of South Africa in 2007.²⁹⁴ Section 2 of the PEPUDA sets out the objects of the Act which includes, amongst others; promotion of equality; eradication of unfair discrimination; and the provision of remedies for victims of unfair discrimination.²⁹⁵ Section 4 of the Act contains the guiding principles, which should be recognized and considered when applying the Act. This includes, among others, “[t]he existence of systematic discrimination and inequalities, particularly in respect of (...) disability in all spheres of life as a result of past and present unfair discrimination (...)”.²⁹⁶

Section 6 stipulates that “[n]either the State nor any person may unfairly discriminate against any person”.²⁹⁷ Section 9 specifically targets persons with disabilities such as children with intellectual disabilities. It stipulates that no person should unfairly discriminate against any other person because of disability, this includes through “failing to eliminate obstacles that unfairly limit or restrict persons with disabilities from enjoying equal opportunities or failing to take steps to reasonably accommodate the needs of such persons”.²⁹⁸

The Children’s Act, 2005 domesticates provisions of the CRC. Section 2 outlines the objects of the Act which includes, among others; “to provide care and protection to children who [need] care and protection”; “to recognize the special needs that children with disabilities may have”; “and generally, to promote the protection, development and well-being of children”.²⁹⁹ Section

²⁹³ Committee on the Rights of Persons with Disabilities, *supra* note 56, par. 200.

²⁹⁴ The Act has undergone some amendments, the most recent one coming in 2008.

²⁹⁵ PEPUDA (2003), Section 2. Republic of South Africa

²⁹⁶ *Ibid*, Section 4 (2) (a)

²⁹⁷ *Ibid*, Section 6.

²⁹⁸ *Ibid* Section 9 (c).

²⁹⁹ See the Children’s Act 2005 South Africa, Section 2 (g) (h) (i)

6 contains the general principles set to guide the implementation of the Children's Act. Section 6 (2)(d) helps to ensure that a child is protected from unfair discrimination on any ground including disability. Section 6 (2) (f) demands that all actions and decisions concerning a child must "recognize a child's disability and create an enabling environment to respond to the special needs that the child has".³⁰⁰ Section 11 is dedicated to children with disabilities, and here consideration must be given to "making it possible for the child to participate in (...) educational activities, recognizing the special needs that the child may have".³⁰¹

2.3.2. A focus on the work by CSOs

The Western Cape Association for Persons with Disabilities is one of the nine (9) provincial Associations located in South Africa. One of the areas of service provision includes helping children with intellectual disabilities realize their right to inclusive education. To achieve this the association helps parents by "empowering them with knowledge of their children's right to education whilst supporting them in their efforts to access this right", and "collaborating with key stakeholders to make [the right to inclusive education] a reality for as many children with disabilities as possible".³⁰²

Another organization which has taken the mandate to help children with intellectual disabilities is the Western Cape Forum for Intellectual Disability (WCFID). It has been in existence for over 45 years in South Africa. The organization is comprised of parents with children with intellectual disabilities, and other professionals. One of the areas of work by the organization involves carrying out advocacy work to help children with intellectual disabilities realize their right to inclusive education.

³⁰⁰ Ibid, Section 6 (2) (f)

³⁰¹ Ibid, Section 11 (1) (b)

³⁰² The association provides education opportunities for children with intellectual disabilities living in rural areas through its nine (9) rural Special Day Care Centres. These centres are essential for children who may be living far away from mainstream schools or special schools. See more at <http://www.wcapd.org.za/services/children/education/> (Accessed 19/09/2017)

In a judgement delivered in 2010, WCFID had sued the South African government for its failure to provide education to children with profound or severe intellectual disabilities in the Western Cape Province. Apart from this, the State was sued for the unfair distribution of financial resources between children with intellectual or profound disabilities and those without disabilities.³⁰³ The financial support the State gave in the Western Cape Province was less for the disabled children when compared to what it provided for non-disabled children.³⁰⁴

The State argued that “no amount of education [would] be beneficial [to children with severe or profound intellectual disabilities] and they will be dependent on the imparting of life skills to them by their parents”.³⁰⁵ In its decision, the Western Cape High Court stipulated that in as much as organizations such as WCFID come in to provide educational support to disabled children, this “does not relieve the state from its constitutional obligation”.³⁰⁶ The High Court found a violation of the right to basic education, equality, human dignity and protection from neglect or degradation for children with profound and intellectual disabilities.³⁰⁷

Some progress has been made to date in relation to this case and the realization of the right to inclusive education for children with profound and severe intellectual disabilities in South Africa. In December 2016, WCFID made a submission to the draft policy on the Provision of Quality Education and Support for Children with Severe to Profound Intellectual Disability and Draft Learning Programme.³⁰⁸ A Grant Framework for the implementation of the policy and programme was submitted to the National Treasury on 2 December 2016 – relating to how Provincial Education Departments will spend 477 million rands (about 35 million United States Dollars (USD)) over the coming three years in the 2017 Medium Term Expenditure

³⁰³ See *Western Cape Forum for Intellectual Disability v. Government of the Republic of South Africa and Government of the Western Cape*, supra note 63.

³⁰⁴ *Ibid.*, par. 3.8.

³⁰⁵ *Ibid.*, par. 17.

³⁰⁶ *Ibid.*, par. 24.

³⁰⁷ *Ibid.*, par. 52.

³⁰⁸ See more at www.wcfid.co.za/page26.html (Accessed on 19/09/2017)

Framework. The Western Cape Government also made some improvements in terms of their government expenditure on education from 34 million rands (about USD 2.5 million) in 2011 to 60 million rands (about USD 4.4 million) in 2014.³⁰⁹

2.3.3. An analysis of the Legislation vis-à-vis CRC and CRPD Standards.

Section 29 (1) (a) guarantees the right to a basic education for every South Africa citizen. This is a unqualified right “(...) not subject to the availability of resources and therefore must be directly and immediately implemented”.³¹⁰ About 500,000 children with disabilities are out of school in South Africa, indicating that the State still has a long way to go in fulfilling its national and international obligation on implementing the right to education for every child with a disability in the country.³¹¹ Thus, this statistic should makes it urgent for the State to implement the right to education.

Discriminatory practices are still prevalent in many of the South African schools today which continue to undermine legislation in place which must help children with intellectual disabilities to realize their right to education, and the State meeting its international obligations.

“In many cases, children with intellectual disabilities (...) are particularly disadvantaged”.³¹²

³⁰⁹ Ibid.

³¹⁰ The Right to Education for Children with Disabilities Alliance, “Alternative Report to the UN Committee on the Rights of Persons with Disabilities in response to South Africa’s Baseline Country Report of March 2013 on the UN Convention on the Rights of Persons with Disabilities, with particular reference to the provisions of Article 24”, January, 2017, par. 1. Available from <http://www.google.co.zm/url?sa=t&source=web&rct=j&url=https://pmg.org.za/files/> (Accessed 12/09/2017); See Section 27, “Submission on the Right to Education for Persons with Disabilities in South Africa to the Committee on the Rights of Persons with Disabilities” March 2015, p. 3. Available from www.right-to-education.org/blog/right-education-children-disabilities-south-africa-section27-s-action-national-research-and (Accessed 11/09/2017); See Department of Basic Education, “Report on the implementation of Education White Paper 6: An Overview for the Period 2013 - 2015” p. 7; Figures may differ and the accuracy of such figures may be questionable but there is an overall agreement that there is a high number of children with disabilities who are eligible for primary education who are out of school in South Africa.

³¹¹ Ibid, par. 1.

³¹² Human Rights Watch, “Complicit in Exclusion” South Africa’s Failure to Guarantee an Inclusive Education for Children with Disabilities” p. 2, Available from <http://www.hrw.org/report/2015/08/18/complicit-exclusion/south-africas-failure-guarantee-inclusive-education-children> (Accessed on 12/09/2017)

Compulsory basic education for children with intellectual disabilities is impeded by school fees in many of the South African schools. Primary education is not free which is a breach of the government's international obligation as stipulated in Article 28 of the CRC and Article 24 of the CRPD.³¹³ These costs have an adverse impact on children with intellectual disabilities because they must pay such costs in special schools, in addition to other expenses on uniforms and food, which their counterparts the non-disabled children do not get pay.³¹⁴ Such fees are an obstacle for children with intellectual disabilities in accessing education in the country.

Furthermore, Human Rights Watch found that parents of children with disabilities “are asked to hire and pay for private special care assistants as a pre-condition to enroll in a mainstream classroom”.³¹⁵ Such admission practices in schools discriminate against children with intellectual disabilities - and in situations where a parent does not hire a special care assistant this limits the participation of children with disabilities in the school environment– this results to an unequal learning environment between disabled children and other abled-bodied children in the mainstream school environment.³¹⁶ This is a breach of the country's international obligation to provide special assistants, and to ensure that children with disabilities get an education on an equal basis with other non-disabled children.

Disability discrimination is prevalent in many schools in the country. “Since ratifying the CRPD in 2007, South Africa has not adopted a clear binding definition of “reasonable

³¹³ Ibid, p. 26.

³¹⁴ Ibid, p. 27; Children with intellectual disabilities may have to pay school fees because no special school has been listed as a “no fee school” in South Africa. About 80 per cent of the mainstream schools in South Africa are listed as “no fee schools”, with about 60 percent of the school population benefiting from this (See Nontobeko Mtshali, “A little more money for no-fee schools”, *IOL News*, 20th January 2015. Available from <http://www.iol.co.za/news/south-africa/gauteng/a-little-more-money-for-no-fee-schools-1806803> (Accessed 19/08/2017)

³¹⁵ Ibid, p. 35; See also Committee on the Rights of the Child, *supra* note 7, par.65, p. 18.

³¹⁶ Ibid, p. 35.

accommodation” in its education guidelines”.³¹⁷ A definition in law and policy is key in helping officials at national, provincial and district levels to understand what the term should encompass to ensure that an inclusive education system is achieved for children with intellectual disabilities and it creates an enforceable provision especially when incorporated into law.³¹⁸ There is a lack of support services and learning materials in most schools, materials which are essential to help children with disabilities in the learning environment to realize their right to inclusive education on an equal basis with other non-disabled children.³¹⁹

Special Schools are still being created in South Africa where children with intellectual disabilities are segregated in their communities when it comes to attaining an education. This has exacerbated discrimination against children with intellectual disabilities. The creation of special schools goes against the spirit being championed by Article 24 of the CRPD on inclusive education. In this aspect, the country is failing in its international obligation to ensure that “inclusion” which is advocated by Article 24 of the CRPD is achieved in South African education system.³²⁰

It should be noted that, “[d]espite section 12 of the Schools Act, provincial officials and school principals have not made sufficient provision for the placement and support of learners with disabilities”.³²¹ Most of the parents with children with intellectual disabilities carry the burden of providing reasonable accommodation despite it being a governmental obligation as per Article 24 of the CRPD.³²² This becomes expensive for most of the parents, as a result, it leads to the exclusion of children with intellectual disabilities from attaining an education.

³¹⁷ Ibid, p. 25; Human Rights Watch interview with Lindiwe Mokate, basic education and children’s rights commissioner, and Advocate Bokankatla Joseph Malatji, disability rights commissioner, South African Human Rights Commission, Johannesburg, January 2015; Human Rights Watch Interview with Legal and Policy team, Section 27, Johannesburg, October 2014.

³¹⁸ Ibid, p. 25.

³¹⁹ Ibid, p. 48,

³²⁰ CRPD, Article 24 (2) (e), p. 17

³²¹ The Right to Education for Children with Disabilities Alliance, supra note 310, par. 5. p. 5.

³²² Ibid, par. 4. p. 4-5.

Apart from this, there is no legislation in South Africa that has been enacted “(...) which gives full effect to the right to education within an inclusive education system for children with [intellectual] disabilities.³²³ As such, “(...) the domestication of Article 24 of the UN CRPD is fragmented and piecemeal”.³²⁴

The right to inclusive education for children with intellectual disabilities is dependent on the implementation of the Education White Paper 6, which has proved to be wholly insufficient.³²⁵

The insufficiency of the Education White Paper 6 was highlighted in *Western Cape Forum for Intellectual Disability v. Government of the Republic of South Africa*, a case which dealt with some misconceptions about children with profound and severe intellectual disabilities and their ineducability.³²⁶ The South African High Court ruled that “[Education] White Paper 6 (...) makes no provision for [children with severe and profound intellectual disabilities] to be catered for by special schools at present”.³²⁷

The implementation plan as set out in the Education White Paper 6 spans over a period of 20 years, that is from 2001 to 2021, making it only possible for the school system to accommodate children with severe and profound intellectual disabilities in 2021.³²⁸ This 20-year

³²³ Ibid, par. 16. p. 6; There is no piece of legislation on disabilities, as such provisions which protect children with intellectual disabilities are found scattered across various policies under the guidance of Integrated National Disability Strategy.

³²⁴ Ibid, par. 16. p. 6.

³²⁵ Ibid, par. 17., p 6 – 7; “The Education White Paper 6 on Special Needs Education: Building an Inclusive Education and Training System (“White Paper 6”)” is a government policy run by the Department of Basic Education in South Africa. It was enacted in 2001 as a way in which government plans to implement education for persons with disabilities. This policy embodies the principles of inclusive education as stipulated under Article 24 of the CRPD. The strategy employed by this policy is that it aims at providing education for persons with disabilities depending on the level of need/support that the person may need to overcome the learning barriers that they are experiencing. As such, learners with high level support needs are required to attend special schools; those with moderate needs are required to attend full-service schools where tools that could help them attain an education are available, which are not available at ordinary schools; and those with low level support needs may attend ordinary schools.

³²⁶ *Western Cape Forum for Intellectual Disability v. Government of the Republic of South Africa and Government of the Western Cape*, supra note 63.

³²⁷ Ibid, par. 18. p. 11.

³²⁸ *Western Cape Forum for Intellectual Disability v. Government of the Republic of South Africa and Government of the Western Cape*, (2011) SA 87(WCC) [2010] ZAWCHC 544; 18678/2007 (11 November 2010), par. 28. p. 19.

implementation plan is against the immediate realization of the right to basic education for children with intellectual disabilities as stipulated by South Africa's Constitutional Court.³²⁹ "Moreover, the judge declared that the Western Cape's Department of Basic Education had failed to "take reasonable measures to make provision for the educational needs of severely and profoundly intellectually disabled children in the Western Cape", thus breaching their constitutional rights to a basic education, protection from neglect or degradation, equality and human dignity".³³⁰

Article 24 (4) of the CRPD places an obligation to State parties "(...) to employ teachers, including teachers with disabilities (...) and to train professionals and staff who work at all levels of education".³³¹ However, some teachers in South African schools are not specifically trained to help teach children with intellectual disabilities.³³² The few that may have such training do not have support staff who may help provide education services, such as, social workers and occupational therapists.

2.4. CRC and CRPD Standards Regarding the Right to Inclusive Education

2.4.1. Positive steps by States in achieving the right to inclusive education for children with intellectual disabilities as per CRC and CRPD standards.

When State parties ratify the CRC and CRPD they give their consent to be bound by the provisions thereof. Article 28 of the CRC gives children with intellectual disabilities the right

³²⁹ *Governing Body of the Juma Masjid Primary School and Another v. Ahmed Asruff Essay N.O. and Others* 2011 (8) BCLR 761 (CC) par. 37.

³³⁰ Human Rights Watch, *supra* note 312, p. 17; See also, *Western Cape Forum for Intellectual Disability v. Government of the Republic of South Africa and Government of the Western Cape*, (2011) SA 87(WCC) [2010] ZAWCHC 544; 18678/2007 (11 November 2010), par. 52 (1)

³³¹ See CRPD Article 24 (4).

³³² Human Rights Watch, *supra* note 312, p. 59.

to education. To fulfill this mandate, the Zambian government introduced the FPE Policy in 2002 to increase literacy levels and the enrollment of learners into public schools.³³³

It should be noted that, the Education sector in Zambia “receives the largest budgetary allocation at approximately 20 per cent of the total national budget”.³³⁴ The FPE Policy has had some positive outcomes which has seen an increase in the “net enrolment from 71 percent in 1999 to over 97 per cent in 2013”.³³⁵ However, figures are not present to show just how much this percentage increment represents the enrolment of children with intellectual disabilities. The 2010 census in Zambia reviewed that children with intellectual disabilities occupy lowest category of persons with disabilities attending primary education.³³⁶ Long distances, unfavorable traditional practices, and financial constraints continue to hamper the implementation of the FPE Policy in Zambia.³³⁷

In 2003, the Kenyan government re-introduced FPE in all government run schools. This policy “gave more pupils from poor backgrounds an opportunity to access primary education which had eluded them for several decades (...)”.³³⁸ “An assessment of the achievements of the FPE in the Kenya Economic Survey of 2010 noted that the program had increased primary school enrolment by almost 50% from 5.9 million to 8.8 million in a period of 7 years”.³³⁹ Information is not available to indicate the figures which represent children with disabilities.

In the 2010/2011 financial year, the Kenyan government allocated 2,000 Kenyan Shillings (about USD 20) per child with a disability/s to ensure that they have all the necessary materials

³³³ See “Education for All 2015 National Review Report: Zambia”, p. 5.

³³⁴ Ibid, p. 1.

³³⁵ Ibid, p. 5.

³³⁶ Central Statistical Office, *supra* note 22, p.73.

³³⁷ Committee on the Rights of the Child, *supra* note 25, par. 124, p. 34; See Masauso Chirwa, *supra* note 231, p. 39.

³³⁸ Bhoke Chacha and Agnes P. Zani (Dr), *supra* note 266, p. 1

³³⁹ Ibid, p. 3.

to attain an education.³⁴⁰ Only 1,020 Kenyan shillings (about USD 10) was allocated to children without disabilities for the same purpose.³⁴¹ However, 2000 Kenyan shillings for educational purposes for children with disabilities falls short to what has been recommended to the Kenyan government by various stakeholders. A minimum of 17,000 Kenyan Shillings (about USD 165) is what has been recommended to the government to help meet the educational needs for children with disabilities.³⁴² Other challenges facing FPE in Kenya include overcrowding, high pupil-teacher ratio, and scarcity of learning materials.³⁴³

In 2015, the Kenyan government through the MOEST (together with the United States Agency for International Development (USAID) launched a USD 53.8 million-dollar project called Tusome (“*Let’s Read*” in Kiswahili) aimed at improving teacher capacity, and reading skills of about 5.4 million pupils country wide.³⁴⁴ “Nearly 60,000 teachers will be benefiting from additional training and will participate in a new teacher appraisal system to improve performance in between 2015 – 2019”.³⁴⁵

United Kingdom’s Department for International Development (DFID) and USAID are funding this project, whilst MOEST oversees the implementation process. It should be noted that, USAID and DFID are under no obligation to implement this project and they are doing so based on free will and organizational strategy. The Kenyan government has an obligation of

³⁴⁰ See Committee on the Rights of Persons with Disabilities, *supra* note 42, par. 185; United Disabled Persons of Kenya, *supra* note 268, p. 40,

³⁴¹ *Ibid*, par. 185; *Ibid*, p.40.

³⁴² *Ibid*, par. 185; *Ibid*, p.40.

³⁴³ Bhoke Chacha and Agnes P. Zani (Dr), *supra* note 266, p. 3.

³⁴⁴ Tusome Early Grade Reading Activity. Available from <https://www.usaid.gov/sites/default/files/documents/1860/Tusome%20%20Factsheet%202016.pdf> (Accessed on 24/11/2017)

³⁴⁵ All-Party Parliamentary Group (APPG) on Global Education for All and Global Campaign for Education, Accessing Inclusive Education for Children with Disabilities in Kenya, p. 8, APPG on Global Education for All, Global Campaign for Education. Available from <https://www.leonardcheshire.org/sites/default/files/Accessing-inclusive-education-children-disabilities-kenya-gce-appg-report-february-2016.pdf> (Accessed 24/11/2017)

ensuring that international cooperation is established and maintained with partners for the betterment of the children with disabilities.³⁴⁶

The right to inclusive education can be achieved over a period. Positive steps in achieving inclusive education are being undertaken in South Africa with the introduction of full-service/inclusive schools. With financial support from the European Union (EU) the number of full-service/inclusive schools has increased over the years from having only 30 in 2002 to 715 in 2015.³⁴⁷ This help from the EU to the Department of Education in South Africa has been taking place since 2004 to help learners from disadvantaged backgrounds and those with disabilities to attain an education in an inclusive classroom environment.³⁴⁸ It should be noted that funding from the EU is done at free will and it has no obligation under international law to do so.

Full-service/inclusive schools have been defined as “schools (...) that will be equipped and supported to provide for the full range of learning needs among all [the] learners”.³⁴⁹ The South African Schools Act is the guiding the development of such schools. Some special schools are being used as resource centres to the full-service/inclusive schools. The impetus for the creation of full-service/inclusive schools is a landmark achievement of the post-apartheid era which aims at cutting “ties with the past and recognizing the vital contribution that [persons] with disabilities are making and must continue to make, but as part of and not isolated from the flowering of our nation”.³⁵⁰

³⁴⁶ See CRPD, Article 32

³⁴⁷ Presentation by Mathanzima Hubert Mveli Acting Deputy Director General at the Department of Basic Education, Progress Report on Inclusive Education and Special Needs Education, Portfolio on Basic Education Meeting, 30th May 2017. Slide No. 9, Available at <http://pmg-assets.s3-website-eu-> (Accessed 18/09/2017).

³⁴⁸ See Capacity4dev.eu, Working Towards Inclusive Education in South Africa, Available from <https://europa.eu/capacity4dev/articles/working-towards-inclusive-educatio-south-africa> (Accessed 24/09/2017)

³⁴⁹ Department of Education, Education White Paper 6. Building an Inclusive Education and Training System, July 2001, p. 22, South Africa.

³⁵⁰ Introduction by Professor Kadel Asmal, Minister of Education, *supra* note 350, p. 4.,

Full service/inclusive schools are part of the large-scale policy reforms of the 1990s and early 2000s in South Africa by the African National Congress (ANC) government which championed principles of equality, equity, and access to services to populations that had been disadvantaged during the apartheid era, such as persons with disabilities. Inclusive provision of services such as education were non-existent during the apartheid regime, especially for persons with disabilities.

Some challenges facing these schools include; some teachers in ordinary schools have little experience working with children with intellectual disabilities, most of them are worried if at all they will be able to teach them, and feel that special schools are better suited to cater for their needs.³⁵¹ “Special schools have a fixed idea of the type of child they are serving and at times hold onto children who could manage with support or accommodations in a mainstream school”.³⁵² These schools are being viewed as a different form of special school, and funding priorities has continued to favor special schools.³⁵³

2.4.2. Drawbacks in achieving the right to inclusive education in State Parties as Per CRC and CRPD standards.

The Bill of Rights in Zambia does not protect economic, social, and cultural rights such as the right to education.³⁵⁴ There are a few other measures in place which can offer remedy in cases of violation of this right such as Education Act. This Act gives “[a] child (...) the right to free basic education” and this aspect complies with the country’s international obligation as set out in Article 28 (1) (a) of the CRC and Article 24 (2) (a) of the CRPD.³⁵⁵ The education sector

³⁵¹ Promoting the Right to Education for Children with Disabilities, “What is Inclusive Education?” Fact Sheet 2, p. 2., Available from <http://www.included.org.za/R2ecwdsite/docs/> (Accessed on 18/09/2017)

³⁵² Ibid

³⁵³ See Presentation by Mathanzima Hubert Mveli, supra note 347, Slide No. 100; See B Qwelane, Director: Inclusive Education, Free State Province, Implementation of Inclusive Education in South Africa, The Road to full Service Schools, p. 8., Basic Education Department, Republic of South Africa.

³⁵⁴ See the Constitution of Zambia (1996)

³⁵⁵ See Education Act, Section 15

has experienced an improvement in the public education expenditure rate which has seen a gradual increase from 15.3 per cent in 2006 to around 20 per cent of the entire government expenditure in 2014/2015.³⁵⁶

Despite these improvements, the education sector is still facing a lot of challenges which has negatively affected the realization of the right to education for children with intellectual disabilities. “Fifty percent of primary schools (government and grant-aided community schools) still charge school fees [despite] the government’s free primary education policy, and 27 percent of students in government and grant-aided primary schools actually pay the school fees”.³⁵⁷ According to the World Bank (2015), on average annually students pay about Zambian Kwacha (ZMW) 31 (about 3 USD).³⁵⁸ Most families especially in rural areas cannot afford to pay such fees. Masauso Chirwa observed that in such situations parents will send children without disabilities to school in times when resources are low based on a rationale that these able-bodied children will take care of their disabled siblings in future.³⁵⁹

Another drawback is that primary schools in Zambia “continue to partially rely on private sources of funding (students’ out of pocket money)”.³⁶⁰ According to the World Bank Staff Analysis, “[c]ombining public and private sources, primary (...) schools receive ZMW 35 (USD 3) (...) annual revenue per student (...)”.³⁶¹ School “grants cover only 64 percent” of the revenue in primary schools.³⁶² The remaining 36 percent will need to be covered using revenues from other sources, such as, through the Parent-Teacher Association (PTA) fee.³⁶³ This

³⁵⁶ The World Bank, Education Public Expenditure Review in Zambia, p. 52, 2015, Available from www.worldbank.org (Accessed 24/09/2017)

³⁵⁷ Ibid, p. 52.

³⁵⁸ Ibid, p. 52.

³⁵⁹ Masauso Chirwa, supra note 231, p. 35.

³⁶⁰ The World Bank, supra note 256, p. 52

³⁶¹ Ibid, p. 52.

³⁶² Ibid, p. 52.

³⁶³ Ibid, p. 52.

questions the whole notion of primary education being free in Zambia because in practice it is not.

The Kenyan government re-introduced the FPE in 2003. Unlike the Zambian constitution which does not have provisions for economic and social rights, the Kenyan constitution does protect the right to education for every citizen. The country enacted the Basic Education Act in 2013 and “[t]he Government is currently revising [it] to address the special needs of children with disabilities”.³⁶⁴ Despite recording significant improvements in terms of net enrolment rates since the re-introduction of the FPE, the country faces some challenges when it comes to the implementation of the right to education.

Some children with intellectual disabilities are not getting an education because of standard costs which apply to every school going child in terms of books, uniforms and other disability related costs on assessments and transport.³⁶⁵ “Special Educational Needs schools are predominantly low-fee paying schools and whilst there is a pupil stipend for children with disabilities, children are only able to access these after being assessed in an ‘Educational Assessment Resource Centre’ (EARC)”.³⁶⁶ These centres have serious “shortages of resources” as such “leading to gaps in meeting EARC’s role to identify, assess and refer children with disabilities, moreover the additional stipend given does little to cover the cost of fees and additional support required”.³⁶⁷

To repeat, UNESCO has stated that barriers to inclusive education in Kenya are due to “poor teacher recruitment and training programs, especially in rural areas, monolingual curriculum,

³⁶⁴ Committee on the Rights of Persons with Disabilities, *supra* note 42, par. 188.

³⁶⁵ All-Party Parliamentary Group (APPG) on Global Education for All and Global Campaign for Education, *Accessing Inclusive Education for Children with Disabilities in Kenya*, *supra* note 345, p. 8.

³⁶⁶ *Ibid.*, p. 8.

³⁶⁷ *Ibid.*, p. 8.

access to basic learning materials” such as books, lunch and drinking water “and the government’s ability to provide for these financial responsibilities”.³⁶⁸

To achieve inclusive education, it is pivotal to have qualified and well trained personnel, such as teachers and social workers, to handle the SEN for disabled children. A research carried out APPG in Kenya, reviewed that “the majority of children with disabilities in Kenya have multiple disabilities, however only 1 % of teachers trained in special needs education have received specific training on how to include and work with children with multiple disabilities”.³⁶⁹In 2005, the Kenyan government had set a target of having one SEN teacher attached to each government school in the country, however, the successful implementation of the FPE has led to rapid increase in the number of pupils enrolled at these schools surpassing the number of SEN teachers available.³⁷⁰

As of 2015, the government in Kenya introduced a stipend to encourage teachers to work in SEN schools.³⁷¹ However, “[t]his financial incentive is only for teachers who practice in special schools rather than [all] trained SEN teachers working with children with disabilities - which has inadvertently created a situation where teachers who are trained and teaching children with disabilities in mainstream schools to lose out”.³⁷² This has created a situation whereby teachers who are trained to cater for the SEN for children with disabilities opting to work in segregated schools or special schools and not in mainstream schools “which does not help towards the goal of achieving inclusion in mainstream education”.³⁷³

³⁶⁸ UNESCO as quoted by Brent C. Elder, *supra* note 288, p. 20.

³⁶⁹ All-Party Parliamentary Group (APPG) on Global Education for All and Global Campaign for Education, *supra* note 345, p. 8.

³⁷⁰ *Ibid*, p. 8.

³⁷¹ *Ibid*, p. 8.

³⁷² *Ibid*, p. 8.

³⁷³ *Ibid*, p. 8.

Plaudits should be given to the South African government for undertaking the initiative of introducing an inclusive education system very early on in the Education White Paper 6 in 2001. However, achieving inclusive education for children with intellectual disabilities is still a challenge. Special schools are still present in South Africa “despite the push for the educational inclusion of learners with disabilities more than a decade ago” in the Educational White Paper 6.³⁷⁴ As of 2010, 104, 633 learners with disabilities were enrolled into public special schools in the country.³⁷⁵ “Research has found that although teachers often report that they agree with the idea of inclusion, they actually believe that the needs of learners with disabilities are best met in separate classrooms, particularly those learners with greater special needs and more severe disabilities”.³⁷⁶ There is a prevalence of a lack of support and resources coupled with negative attitudes which have compromised inclusion in South African schools.³⁷⁷

This lack of support has resulted into the South African government being sued by a CSO which provides educational support to children with severe and profound intellectual disabilities. In the *Western Cape Forum for Intellectual Disability v. Government of the Republic of South Africa*, the applicant sued the State for its lack of educational support measures for children with severe and profound intellectual disabilities in the Western Cape Province.³⁷⁸

In addition, the State was sued for its unfair distribution of financial resources because it provided less for children with disabilities when compared to their counterparts the non-

³⁷⁴ Dana Donohue and Juan Bornman, The Challenges of Realizing inclusive education in South Africa, p. 4 – 5, *South African Journal of Education*; 2014; 34 (2), University of Pretoria.

³⁷⁵ Committee on the Rights of Persons with Disabilities, supra note 56, par. 206, p. 40.

³⁷⁶ Dana Donohue and Juan Bornman, supra note 374, p. 4 – 5.

³⁷⁷ Ibid, p. 4 – 5.

³⁷⁸ *Western Cape Forum for Intellectual Disability v. Government of the Republic of South Africa and Government of the Western Cape*, supra note 63.

disabled children.³⁷⁹ The High Court of South Africa ruled against the State and it stated that the Education White Paper 6 is inadequate because it “makes no provision for [learners with severe and profound intellectual disabilities] to be catered for by special schools”.³⁸⁰ In fact, “[t]he [high] court did not entertain the provision of services by non-governmental organizations as the proper fulfilment of the right to education”.³⁸¹

The State is the duty-bearer in fulfilling the rights of children with intellectual disabilities, as such, it has the responsibility of ensuring that education is made available and accessible for this group of persons.³⁸² More importantly, the High Court found a violation of the basic right to education, equality, human dignity and protection from neglect or degradation.³⁸³

A significant number of children with disabilities are still out of school in South Africa, “[t]he Department of Basic Education estimates that the number of children with disabilities of school-going age who are not at school, could be as high as 480, 036, based on their own calculations [Statistics South Africa’s] 2010 General Household Survey Data”.³⁸⁴ As stipulated by the South African High Court in the *Western Cape Forum for Intellectual Disability v. Government of the Republic of South Africa*, the Education White Paper 6 is inadequate. “The incremental implementation of White Paper 6 over 20 years is inconsistent with section 29 of the Constitution of the Republic of South Africa, which requires the State to implement

³⁷⁹ *Western Cape Forum for Intellectual Disability v. Government of the Republic of South Africa and Government of the Western Cape*, supra note 63, par. 3.8.

³⁸⁰ *Ibid*, par. 18.

³⁸¹ Petronell Kruger, A critical Appraisal of *Western Cape Forum for Intellectual Disability v. Government of the Republic of South Africa* 2011 5 SA 87 (WCC), p. 762, *PER: 2015vol. 18:3*; *Western Cape Forum for Intellectual Disability v. Government of the Republic of South Africa and Government of the Western Cape*, supra note 63, par. 24.

³⁸² *Ibid* (Petronell Kruger) p. 762.

³⁸³ *Western Cape Forum for Intellectual Disability v. Government of the Republic of South Africa and Government of the Western Cape*, supra note 63, par. 52.

³⁸⁴ Committee on the Rights of Persons with Disabilities, supra note 56, p. 40.

measures and make budgetary allocations so that the right to education is a matter of priority and, as such, requires urgent revision”.³⁸⁵

Conclusion

This chapter has explored the CRC and CRPD standards regarding the right to ‘inclusive’ education for children with intellectual disabilities. State parties to both the CRC and CRPD are duty bearers and as such they have an important responsibility of ensuring that they implement provisions as stipulated in Article 28 and 29 of the CRC, and Article 24 of the CRPD. Inclusive education entails changing the entire education system to accommodate children with intellectual disabilities. It is the society, the school environment, which needs to be changed to ensure that an enabling environment is created for children with intellectual disabilities. Article 24 of the CRPD does not prohibit special schools entirely because such schools are essential in helping with educational needs for children with severe and multiple disabilities. However, the creation of special schools should be based on the severity of a child’s disability and not solely because of the disability or impairment which the child possesses. To achieve inclusive education, State parties must ensure that they have well qualified and trained personnel in school environments to help children with intellectual disabilities. Important assistive devices which will help them in classroom and outside participation should be put in place. Putting children with disabilities and non-disabled children in the same learning environment will help eliminate discrimination and it will result to the appreciation of diversity amongst the learners.

³⁸⁵ Ibid, par. 219, p. 42.

Chapter Three – Comparative Country Analysis: The Right to Health

3.0. CRC and CRPD Standards Regarding the Right to Health

The right to health for children is recognized under Article 24 of the CRC. WHO defines health as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”.³⁸⁶ According to the Committee on the Rights of the Child in its General Comment 15 on the right of the child to the enjoyment of the highest attainable standard of health, “[t]he notion of “the highest standard of health” takes into account both the child’s biological, social, cultural and economic preconditions and the State’s available resources (...)”.³⁸⁷ This notion of health by the Committee on the Rights of the Child goes in hand with the definition by WHO because it takes into account other factors, such as social factors, as contributing aspects to the health of the child.

The normative content of Article 24 of the CRC as stipulated in General comment 15 is that “[c]hildren’s right to health contains a set of freedoms and entitlements”.³⁸⁸ “The freedoms, which are of increasing importance in accordance to the growing capacity and maturity, include the right to control one’s health and body (...) freedom to make responsible choices”.³⁸⁹ Entitlements to the right to health include “access to a range of facilities, goods, services and conditions that provide equality of opportunity for every child to enjoy the highest attainable standard of health”.³⁹⁰

State parties have an obligation of ensuring that they provide quality health services, and this includes “prevention, promotion, treatment (...) and palliative care services”.³⁹¹ To ensure that

³⁸⁶ WHO, “What is the WHO definition of Health?”, Available from <http://www.who.int/suggestions/faq/en/> (Accessed 24/11/2017)

³⁸⁷ See CRC, Article 24 (1) of the; Also, see the Committee on the Rights of the Child, *supra* 32, p. 4.

³⁸⁸ See the Committee on the Rights of the Child, *supra* 32, p. 4.

³⁸⁹ *Ibid*, p. 4.

³⁹⁰ *Ibid*, p. 4.

³⁹¹ To ensure that the right to health for children with intellectual disabilities is realized, quality health services should be provided. These can be provided on two levels, namely, the primary level and secondary level. The primary level services should be of adequate quality and of the right quantity. These services should be available

children with intellectual disabilities realize their right to health, States have an obligation of ensuring that they have well trained personnel in place to deliver quality services.³⁹²

Additionally, “Article 24, paragraph 1, imposes a strong duty of action by State Parties to ensure that health and other relevant services are available and accessible to all children, with special attention to under-served areas and populations”.³⁹³ Reducing infant and child mortality is an obligation placed on State parties to the CRC in realizing the right to health for children with intellectual disabilities.³⁹⁴ Some of the ways to accomplish this includes screening children for any birth defects and providing care for newborn babies.

States have an obligation of ensuring that they provide all the required medical assistance and health care to all children including children with intellectual disabilities with an “emphasis on the development of primary health care”.³⁹⁵ States should identify and eliminate financial, cultural, and institutional barriers to ensure that the right to health is achieved.³⁹⁶ Health services should be provided as close as possible to where the child’s family lives to achieve universal access for all children, including children with intellectual disabilities, to primary health services, especially in community set-ups.³⁹⁷

Article 24 (2) (c) of the CRC places an obligation on State parties to apply the “(...) readily available technology” in providing primary health care.³⁹⁸ This can be done through the provision of “[m]obile arrangements and community-based efforts [which] can substantially

to all children, both in the rural and urban set-ups, and must be within the reach of all children not just in the physical aspect but manageable in terms of the financial aspect too. Secondary and tertiary level care “should also be made available, to the extent possible, with functional referral systems linking communities and families at all levels of the health care system”.

³⁹² See the Committee on the Rights of the Child, *supra* 32, p. 4.

³⁹³ *Ibid*, p. 4.

³⁹⁴ See CRC Article 24 (2) (a).

³⁹⁵ *Ibid*, Article 24 (2) (b).

³⁹⁶ See the Committee on the Rights of the Child, *supra* 32, p. 4.

³⁹⁷ *Ibid*, p. 5.

³⁹⁸ See CRC Article 24 (2) (c).

reduce some [health] risks and [they] should be made universally available”.³⁹⁹ Measures such as growth and development monitoring in early childhood, and immunization against the most prevalent childhood diseases can help prevent further disabilities in children with intellectual disabilities.⁴⁰⁰

States parties are required “[t]o ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health (...)”.⁴⁰¹ Providing information on child health includes; health behavior information such as substance use, smoking and alcohol drinking; and early detection and management of a child’s complication. Regarding early detection, the Committee on the Rights of the Child has recommended that “[s]tate parties establish systems of early detection and early intervention as part of their health services (...) services should be both community- and home-based, and easy to access.”⁴⁰² “Information should be physically accessible, understandable and appropriate to children’s age and educational level”.⁴⁰³

Dissemination of this information in all areas within the country especially in rural areas is a State duty. Realizing the right to health is interlinked to realizing the right to education for children with intellectual disabilities. That is, if one’s health is poor this will have a negative impact on their ability to attain an education. Similarly, a lack of education will have a negative effect on a person’s ability to access health care because through education people get a better understanding of health care benefits, for example, through reading. States should ensure that

³⁹⁹ See the Committee on the Rights of the Child, *supra* 32, p. 6.

⁴⁰⁰ *Ibid*, p. 7.

⁴⁰¹ See CRC Article 24 (2) (e)

⁴⁰² See Committee on the Rights of the Child, *supra* 7, p. 16; Developmental screening as a form of early detection is an essential component in identifying disability in children. This process occurs during immunization visits at medical centres/clinics. Here progress in terms of the child’s development is measured against significant development milestones such as walking, talking, standing, crawling, sitting, and handling items. Children that fall short in meeting these intended targets should be identified and sent for further assessments, if necessary. This will enable health professional to put in place measures that can halt the development of further disability.

⁴⁰³ See the Committee on the Rights of the Child, *supra* 32, p. 7.

to realize the right to health for children with intellectual disabilities, they will have to meet the parameters of availability, accessibility, acceptability, and quality.⁴⁰⁴

Article 25 of the CRPD recognizes “the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”.⁴⁰⁵ State parties to the CRPD have the obligation to provide the same quality, affordable or free health care services to children with intellectual disabilities as they provide to non-disabled children.⁴⁰⁶ It should be noted that, it is vital to read Article 25 and Article 4 (2) both of the CRPD in the same light. This is because the right to health falls under economic and social rights, thus, states have the duty to progressively realize it. “It thus imposes an obligation to move as expeditiously and effectively as possible towards [the] goal” of realizing the right to health for children with intellectual disabilities.⁴⁰⁷ This entails that the State has the duty of ensuring that it builds health infrastructures, train health care professionals, and implement health care legal and policy reforms which should help in the realization of the right to health. These duties cannot all be done immediately, as such, the State has the duty to put in place a strategy and a timeframe of achieving them overtime.

Article 25 (b) of the CRPD demands that State parties must provide those services needed by persons with disabilities because of their disabilities, “including early identification and intervention (...) designed to minimize and prevent further disabilities, including among children [with intellectual disabilities]”.⁴⁰⁸ State parties have the obligation of ensuring that to realize the right to health for children with intellectual disabilities they will need to provide

⁴⁰⁴ Ibid, p. 12.

⁴⁰⁵ See CRPD Article 25.

⁴⁰⁶ Ibid, Article 25 (a)

⁴⁰⁷ OHCHR, CESCR General Comment No.3: The Nature of State Parties’ Obligations (Art.2, Para. 1, of the Covenant) E/1991/23, par. 9, 14 December 1990.

⁴⁰⁸ See CRPD Article 25 (b)

health services as close to the child's community, especially in rural settings where health centers may not be available.⁴⁰⁹

Article 25 (d) of the CRPD demands that State parties must provide the same quality of health services to both disabled children and non-disabled children in their respective countries including on a free basis.⁴¹⁰ State parties must ensure that they “[p]revent discriminatory denial of health care or health services (...)” because of disability.⁴¹¹

3.1. Zambia

3.1.1. Analysis of the Legal Framework in Zambia and the role the CSOs play in advancing the right to health for children with intellectual disabilities.

It has been already established that the Zambian Constitution does not protect social and economic rights, and as such the right to health for children with intellectual disabilities is not protected under the current Bill of Rights. The Persons with Disabilities (PWD) Act, 2012, protects the right to health for children with intellectual disabilities. Section 27 of the Persons with Disabilities Act gives the Minister of Community Development, Mother, and Child Health the responsibility to work with Minister of Health to ensure that children with intellectual disabilities have access to health services.⁴¹² The two Ministers must ensure that they give orders relating measures which “provide [children with intellectual disabilities] with the same range, quality and standard of free or affordable health care and programmes as provided to other persons (...)”.⁴¹³ Section 27 (b) of the PWD Act stipulates that the two Ministers should direct health services to children with intellectual disabilities which are specific to their

⁴⁰⁹ Ibid, Article 25 (c)

⁴¹⁰ Ibid, Article 25 (d)

⁴¹¹ Ibid, Article 25 (f)

⁴¹² See Persons with Disabilities Act, 2012, Zambia, Section 27.

⁴¹³ Ibid, Section 27 (a).

disability. Some of the measures may include early identification and intervention measures, and services which aim at stopping further disabilities in children with intellectual disabilities.

To achieve the right to health for children with intellectual disabilities, health services should be provided as “close as possible to people’s own communities, including rural areas”.⁴¹⁴ The two Ministers have the responsibility of prescribing measures which “require health professionals to provide care of the same quality to [children with intellectual disabilities] as to others, including on the basis of free and informed consent (...)”.⁴¹⁵ Section 27 (f) gives the responsibility to the Minister of Community Development, Mother and Child Health and the Minister of Health to put in place measures which forbid discriminatory denial of health care services against children with intellectual disabilities.

According to Section 28 (1) (a) of the PWD Act the Minister of health has the responsibility of developing health policies and measures which should provide for “free general and specialist medical care (...) and appropriate assistive devices for [children with intellectual disabilities]”.⁴¹⁶ The Minister of Health has the responsibility of formulating health policies and programmes which should help in the prevention of disability.⁴¹⁷ The Minister of Health must provide for “systems to avail appropriate facilities and personnel to local health institutions for the benefit of [children with intellectual disabilities]”.⁴¹⁸ Section 28 (2) of the Persons with Disabilities Act requires that education on disability and disability related matters must be part of the health care programmes. Section 30 of the PWD Act requires the Minister of Health and the Minister of Community Development, Mother and Child Health to “provide for periodic screening of children [with intellectual disabilities] in order to detect, prevent and

⁴¹⁴ Ibid, Section 27 (c)

⁴¹⁵ Ibid, Section 27 (d)

⁴¹⁶ Ibid, Section 28 (1) (a)

⁴¹⁷ Ibid, Section 28 (1) (b)

⁴¹⁸ Ibid, Section 28 (1) (d).

manage disability”.⁴¹⁹ The Minister of Health must create and run working health assessment and resource centers at health facilities which aim at early diagnosis to mothers and children – this is for the purpose of establishing the early onset of disability in children.⁴²⁰

3.1.2. A focus on work by CSOs

Special Hope Network in Zambia helps children with intellectual disabilities to realize their right to health. This is organization was selected because it is one of the most progressive organizations in the country. In July 2017, the organization was “one of the winners of the Disability and Inclusion Challenge for Organizations doing unique work with children around the world who have disabilities”.⁴²¹ The Organization through the United Kingdom (UK) Department for International Development will receive seed funding, and design support from IDEO.org for the coming eighteen months.⁴²² To help the children with intellectual disabilities to realize the right to health in Zambia, parents should take their children to clinics on regular intervals and for check -ups – in doing so parents should be able to identify the children who are failing to meet the required developmental milestones.⁴²³ “Through this project [the organization] will be finding a simple, free way for clinical officers to notify [the organization] when they have a child they have concerns about”.⁴²⁴

⁴¹⁹ Ibid, Section 30

⁴²⁰ Ibid, Section 31

⁴²¹ New Grant from Open: IDEO! Available from <https://specialhopenetwork.org/2017/07/13/new-grant-from-openideo/> (Accessed on 30/09/2017)

⁴²² IDEO.org is a non-profit organization which implements human centred designs by imagining and carrying out products, services, and experiences through helping disadvantaged people in communities globally. A “Human-centred design” is an approach which aims at establishing contacts with users in their homes and or work places to establish relationships and get a better understanding of their needs. It involves a “process of ideation – coming up with lots of new solutions, prototyping these solutions, and ultimately working with partners to bring these solutions to market”. Available from https://www.philanthropy.com/resources/audio/podcast-putting-human-center/6172/?cid=cdfd_home (Accessed on 30/09/2017).

⁴²³ New Grant from Open: IDEO! supra 421.

⁴²⁴ Ibid; The project adopts a “human-centered design” which aims at putting the users and their needs at the forefront of the project.

3.1.3. An analysis of the Legislation vis-à-vis CRC and CRPD Standards.

Realizing the right to health for children with intellectual disabilities in Zambia, and meeting its international obligations as set out in the CRC and CRPD faces some significant challenges. Accessing Rural Health Centers (RHC) is problematic for children with intellectual disabilities, as they often are left behind at home due to the long distances that are between some communities and RHC.⁴²⁵ A research carried out by Hege Johanne Magnussen found that “the sick child was not brought to the clinic in person, but the parents or other family members were sent to collect drugs after explaining the signs and symptoms to the health worker at the rural health center”.⁴²⁶ This was mainly because of the challenge which some parents with children with intellectual disabilities are faced with of carrying their disabled child for long distances.⁴²⁷ RHC are inadequate in providing health care to children with intellectual disabilities. Hege Johanne Magnussen further reported that there is “a lack of strategies to identify, administer, and follow-up with children with [intellectual] disabilities, and the provision from RHC was often only through the management of common conditions”.⁴²⁸ In other words, poor identification of disability is prevalent in most of the RHC, and health workers are usually more concerned about other conditions that the child may be showing – paying little attention to the

⁴²⁵ According to the Ministry of Health (MOH), within 29 kilometres (Km) Rural Health Centres (RHC) are required to help a population of about 10,000 people. A RHC must provide help to about 500 households within a 5 Km distance. In 2006 user fees in public hospitals were abolished to increase access to primary health care especially for the persons in disadvantaged positions. See Hege Johanne Asting Magnussen, *Childhood Disability in Rural Zambia: A Qualitative Study on the Use of Health Care Services*, Masters Thesis, University of Oslo, May 2011, p. 17, Available from <https://www.duo.uio.no/handle/10852/30039> (Accessed on 30/09/2017)

⁴²⁶ Ibid p. 49; This creates a situation whereby health officials only get to give medication based on the understanding of parents or guardians, which is often limited. The child is denied the assessment of disability in such a situation, and overtime may lead to the development of other disabilities.

⁴²⁷ Ibid, p. 49.

⁴²⁸ Ibid, p. 55.

potential disability the child may have.⁴²⁹ Some of the reasons for this is that there is a lack of right technical, human, and financial resources allocated to child health care, and some health workers lack adequate training in identifying disability in children.⁴³⁰

Lack of information on disability in RHC has further hampered the realization of the right to health for children with intellectual disabilities.⁴³¹ As such, most of the parents stop bringing their children to RHC because they do not find them to be helpful.⁴³² To repeat, this lack of information on disability has resulted in situations whereby some health workers will be treating children with intellectual disabilities for common conditions without knowing that the child has a disability.

3.2. Kenya

3.2.1. Analysis of the Legal Framework in Kenya and the role the CSOs play in advancing the right to health for children with intellectual disabilities.

Section 43 of the Kenyan Constitution gives every person in Kenya the right “to the highest attainable standard of health [including] the right to health care services (...)”.⁴³³ Section 53 of the Constitution, which is entirely dedicated to children’s rights, gives every child the right to

⁴²⁹ Ibid, p 56 - Due to the heavy workloads which most of the medical personnel have and the lack of proper training in disability identification, there is a growing tendency to prescribe and give medication to only common conditions such as fever, diarrhoea, headache whilst paying little or no attention to the assessment of the disability. Some parents do not actively seek answers to understand the condition which their child may have and in times when information is provided, some parents do not get to understand its meaning.

⁴³⁰ See Convention on the Rights of the Child, supra note 25, p.12, par. 48.

⁴³¹ See Hege Johanne Asting Magnussen, supra note 425, p. 50.

⁴³² Ibid p. 49 - Since RHC lack the expertise to help children with intellectual disabilities, this has acted as a barrier to bringing the disabled child to the health facilities. RHC only offer limited services to children with intellectual disabilities, as such the only option they provide is referral letters to higher hospitals, and leaving it up to the parents to either take up this option or not. This option is often not taken up by most parents because of the “long distances to these higher (referral) hospitals, lack of transport money, bad reputation of the higher health facilities, lack of resources to cater for upkeep in towns/cities, and the general unwillingness to leave behind their sources of generation of income in their communities to travel to towns/cities”.

⁴³³ See Section 43 (1) (a) of the Constitution of Kenya; “Accessibility to health facilities in Kenya is estimated at 52 per cent based on a 5 Km radius norm although there are variations across the country especially in the Northern part of Kenya”. See Republic of Kenya, Combined 8th – 11th Periodic Report on the African Charter of Human and Peoples Rights, November 2014, p. 36.

health care.⁴³⁴ Just like all other rights in the Constitution, the right to health should be enjoyed without discrimination of any kind as set out in Article 27.

The PWD Act, 2004, of Kenya requires that the National Council for Persons with Disabilities to be represented in the implementation of health care programmes by the Ministry of Health which target persons with disabilities. In this regard, the Ministry of Health (in collaboration with the National Council for Persons with Disabilities (NCPWD)) has the purpose of preventing disability; ensuring that early identification mechanism are in place; ensuring that health care services, at an affordable price, are availed to children with intellectual disabilities; “availing field medical personnel to local health institutions for the benefit of [children with intellectual disabilities]”; and to ensure that medical assistance is available to children with intellectual disabilities.⁴³⁵

Section 9 of the Children’s Act, 2001, of Kenya gives the “right to health and medical care provision” to every child in Kenya, including children with intellectual disabilities.⁴³⁶ This is the responsibility of both the parents and the Kenyan Government. Section 12 gives children with intellectual disabilities the right to medical treatment.

3.2.2. A focus on work by CSOs

The Autism Support Centre (Kenya) is a non-profit organization which was formed in 2003, and it helps over 100 children with autism in Nairobi.⁴³⁷ “Only recently has Autism Spectrum

⁴³⁴ Ibid, Section 53 (1) (c); Article 56 of the Kenyan Constitution places an obligation on the State to ensure that the right to health care services is realized for children with intellectual disabilities by putting in place “affirmative action programmes”; In Kenya, medical services for all children below the age of 5 years is free upon the recommendation of a social worker.

⁴³⁵ See PWD Act, Section 20; The National Council for Persons with Disabilities (NCPWD) helps to oversee the implementation of the Children’s Act in Kenya.

⁴³⁶ See the Children’s Act, 2001, Kenya, Section 9.

⁴³⁷ Autism is an early developmental disorder which impacts on the central nervous system and occurs at a very early age in children. This disability can be associated with intellectual disability as well as physical disability. Early detection, education therapies involving both the family and child can help reduce symptoms and increase development and learning abilities. Some of the symptoms may include poor eye contact, poor speech development, and repetitive behavior.

Disorder become recognized in Kenya” and “[b]efore this, children on the spectrum were beaten, hidden away, or killed because it was believed that were possessed by demons”.⁴³⁸ As such, this organization is vital to helping children with disabilities to access health care facilities, and to raise awareness about Autism in the country. The organization operates “Kenya’s first autism mobile clinic” to “reach out to children with autism who may not have transport to the existing therapy clinics in the country”.⁴³⁹

3.2.3. An analysis of the Legislation vis-à-vis CRC and CRPD Standards.

Despite having the legal provisions in place to help children with intellectual disabilities realize their right to health, Kenya is still far from meeting its international obligations as set out in the CRC and CRPD. Staff in some health institutions in Kenya still lack the means to detect intellectual disability early.⁴⁴⁰

Despite the Constitution of Kenya facilitating the devolution of health care services at the County level making them more accessible for children with intellectual disabilities, accessing health care services is still a problem at district level hospitals.⁴⁴¹ These hospitals are mostly “under staffed, under budgeted and do not stock the medicine needed by [children with intellectual disabilities] (...)”.⁴⁴² “Inefficiency in health systems is a major cause of inaccessibility of health care services for the majority of Kenyans”.⁴⁴³

Some of these problems are because of “managerial, financial, and organizational problems such as imbalances in staffing, limited input in hours by staff, transport facility shortage, a lack

⁴³⁸ See Autism Support Centre, Autism in Kenya, available from <http://www.autismcenterkenya.org> (Accessed 27/11/2017)

⁴³⁹ Ibid

⁴⁴⁰ Committee on the Rights of the Child, supra 48, p. 29.

⁴⁴¹ United Disabled Persons of Kenya, supra 268, p. 40.

⁴⁴² Ibid, p. 40.

⁴⁴³ Office of the High Commissioner for Human Rights, p. 2. Available from http://www.ohchr.org/Documents/Issues/Children/Study/RightHealth/KenyaNationalCommissionHR_2.pdf&ved=0ahUKEwi19vODydrWAhVoCsAKHcSXA_0QFggmMAA&usq=AOvVaw04XEmmuykzwPORVniMI7tt (Accessed on 30/09/2017)

of maintenance of equipment leading to delays in referrals and high mortality rate, lack of drugs due to corruption in procurement process.”⁴⁴⁴

Research conducted by the Kenya National Commission on Human Rights (KNCHR) in 2014 discovered that information is in formats which is inaccessible.⁴⁴⁵ As such, “most persons with disabilities shunned away from seeking services (...)”.⁴⁴⁶ High hospitals fees were also another stabling block for children with intellectual disabilities which hinders accessibility to medical services.⁴⁴⁷ The Commission further reported that information availability was problematic in most health centers as such “most [children with intellectual disabilities] have to rely on their care givers for information and have to communicate to institutions through intermediaries”.⁴⁴⁸

3.3. South Africa

3.3.1. Analysis of the Legal Framework in South Africa and the role the CSOs play in advancing the right to health for children with intellectual disabilities.

Section 27 (1) of the South African Constitution entitles everyone, including children with intellectual disabilities, to have access to medical health care services.⁴⁴⁹ Section 28 (1) (c) of the Constitution is entirely dedicated to children’s rights, and here every child has the right to health care services.

⁴⁴⁴ Ibid, p. 2; Kenya National Commission on Human Rights (KNCHR), From Norm to Practice. A Status Report on the implementation of the Rights of Persons with Disabilities in Kenya, July 2014, p. 28.

⁴⁴⁵ KNCHR, Ibid, p. 24

⁴⁴⁶ Ibid, p. 24.

⁴⁴⁷ In Kenya, children with intellectual disabilities need to be assessed in public hospitals to be registered by the National Council for Persons with Disabilities (NCPWD), and these charges ranges from 1500 Khs (about 15 USD) to 500 Khs (about 5 USD). Such fees tend to hinder children with disabilities from accessing health care because they are high especially for parents of such children who may be poor, and coming from a disadvantaged background. The KNCHR reported that this may be one of the reasons why there is no comprehensive statistical data on persons with disabilities because some parents may shy away from accessing health care services for their children. In addition, the commission reported that the process of registration was very long taking about a year or more and it was taking place only in Nairobi, Kenya.

⁴⁴⁸ Kenya National Commission on Human Rights (KNCHR), supra 444, p. 34.

⁴⁴⁹ See the South African Constitution, Section 27 (1) of; Section 27 (2) of the South African constitution requires the State to put in place legislation which will enable the progressive realization of the right to health services.

According to Section 11 (3) of the Children’s Act, 2005, of South Africa “[a] child with a disability (...) has the right not to be subjected to medical (...) practices that are detrimental to his or her health, well-being or dignity”.⁴⁵⁰ Section 13 of the Children’s Act gives children with intellectual disabilities the right to have information on their health care. Here every child with intellectual disabilities has the right to “have access to information on health promotion and prevention and treatment of ill health and disease (...)”; to “have access to information regarding his or her health status”; and to “have access to information regarding the causes and treatment of his or her health status”.⁴⁵¹ The information that will be provided to children with intellectual disabilities must be given in appropriate format “accessible to children, giving due consideration to the needs of disabled children”.⁴⁵²

Additionally, “[t]he National Health Act, 2003 regulates national health and provides uniformity in respect of health services nationwide by establishing a national health system which encompasses both the public and private providers of health services.”⁴⁵³ One of the objects of the act includes protecting, fulfilling, respecting, and promoting the rights of children with intellectual disabilities.⁴⁵⁴

3.3.2. A focus on work by CSOs

Sunshine association is a non-profit organization in South Africa which helps children with intellectual, developmental, and physical disabilities.⁴⁵⁵ This organization has been chosen

⁴⁵⁰ See South Africa’s Children’s Act, 2005, Section 11 (3) ; The General Principles guiding the implementation of the Act stipulates that “[a]ll proceedings, actions or decisions in a matter concerning a child must protect the child from unfair discrimination on any ground, including on the grounds of health status or disability of the child (...)”, See Section 6 (2) (d); All medical health services at primary level in the public sector in South Africa are free. See Committee on the Rights of Persons with Disabilities, Initial reports of State parties due in 2009, South Africa, 24 November, 2015.

⁴⁵¹ Ibid, Section 13.

⁴⁵² Ibid, Section 13.

⁴⁵³ Committee on the Rights of Persons with Disabilities, *supra* 56, par. 263, p. 49.

⁴⁵⁴ See Section 2 (c) (iv) of the National Health Act, 2004, South Africa; The Act places an obligation on the Minister of Health to prioritise research objectives on the health needs of children with intellectual disabilities. See Section 70 (1) (2)(d)

⁴⁵⁵ In 2016, the organization celebrated its 40th Anniversary. To sustain the organization’s operations, it holds fundraising campaigns to raise funds and to establish relationships with donors. Corporate donations and

because it has been in operation for more than 40 years in South Africa helping children with disabilities, and because of its unwavering commitment to its goals this has resulted into an increment in government funding.⁴⁵⁶ The organization offers an early intervention programme to children with intellectual disabilities from as early as 18 months.⁴⁵⁷ Additionally, the association offers therapeutic services to children with intellectual disabilities aged between 18 months to 7 years old through the help of a physiotherapist, social worker, nutritionists, and speech therapists from students at the University of Witwatersand in South Africa, one of the best universities in Africa.

3.3.3. An analysis of the Legislation vis-à-vis CRC and CRPD Standards.

The disparity between urban and rural health provision in South Africa is significant, with the dominance of poor health services being provided in rural areas than in the urban areas. These inequalities are also prevalent in the private and public hospitals – with public hospitals compounded by poor health services in the country.⁴⁵⁸ The country has recorded significant improvements in accessing health care because of free primary health care, however, “nearly a

fundraising ventures are the organizations biggest sources of income. The South African government is a contributor to its finances. The organization received donations of about 2.5 million rands in 2015 (about 140,000 United States (U.S) dollars) and 635 thousand rands (about 47,000 U.S. dollars) in 2016. Available from <https://www.sunshine.org.za/about.html> (Accessed on 30/09/2017).

⁴⁵⁶ Ibid

⁴⁵⁷ It offers training courses to parents, professionals and care-givers who handle children with intellectual disabilities. It also works with various volunteers after successfully completing a structured screening process, and thereafter they are specifically trained in the sunshine model and the SMART (Strive Towards Achieving Results Together). The SMART has been in existence for 15 years and works with children who are operating developmentally under the age of three years. The association carries out its early intervention programmes at Craighall, Eldorado Park and Elsburg (Germiston).

⁴⁵⁸ The South African Alternate Report Coalition reported that “only 53 % of medical practitioners and 36 % of specialists work in the public sector. 47 % of South Africa’s children live in rural areas, yet rural provinces experience significant shortages of nurses and medical practitioners”. See South African Alternate Report Coalition, Alternate Report to the UN Committee on the Rights of the Child in response to South Africa’s Combined 2nd, 3rd, and 4th Periodic Country Report on the UN Convention on the Rights of the Child, October 2015, par.182, p. 24; An estimated 63 % of general practitioners work in the private sector, and this sector absorbs about 62 % of the national health expenditure in South Africa, providing health services to a population of about 7 million people – whilst the public sector absorbs about only 38 %, providing for about 35 million people. See Keegan Kautzky and Stephen M. Tollman, ‘A perspective on Primary Health Care in South Africa’, p. 24, *South African Health Review*, 2008, Health Systems Trust.

quarter of children still travel more than 30 minutes to reach a health facility, and transport costs can lead to life threatening delays”.⁴⁵⁹

There is also a lack of qualified personnel to handle children with intellectual disabilities, and a shortage of medicines.⁴⁶⁰ The delivery of Primary Health Care (PHC) is also undermined by the emigration of trained medical personnel.⁴⁶¹

A report by the South African Alternate Report Coalition indicated that the Eastern Cape Province is one of the provinces experiencing shortages of staff and other essential drugs.⁴⁶²

The crisis in the health care system in the Eastern Cape is not because of the legacy of the apartheid regime, but a failure in democracy. Prevalent corrupt practices by public officials in the province has been at the expense of the health care system. An investigation by the Special Investigation Unit in 2013 reviewed that 800 million rands (about USD 80 million) had been stolen over a period of 18 months and no arrests had been made.⁴⁶³

Additionally, the “[p]rocurement of medicine nationally focuses on adults and often fails to consider children’s needs,” as such “[p]harmacists therefore manipulate adult medicines and this unlicensed usage may put children at risk”.⁴⁶⁴ Information on children with intellectual

⁴⁵⁹ See South African Alternate Report Coalition, supra 310; 90 per cent of South Africans live within a radius of 7 Km of the nearest public clinic, with an estimated two-thirds living within 2 Km. Those who are closest to many of these public health facilities often have a high income, and those with the lowest income are usually farthest from them (about 10 Km). The implications of this are that the poor parents and or guardians will constantly find it hard to access health facilities for their children with intellectual disabilities because of the long distances between communities and public health facilities. The probability of a child having a “road to health” card drops lineally with distance from a public health facility. This card is an important comprehensive child health monitoring tool (such as the immunization record which plays an important part in preventing disability in children). See Zoe McLaren, Cally Ardington and Murray Leibbrandt, Distance as a barrier to health access in South Africa, pp. 6 – 12, *Working Paper Series No. 97*, 2013, Southern Africa Labour and Development Research Unit.

⁴⁶⁰ The African Child Policy Forum, *Children with Disabilities in South Africa: The Hidden Reality*, 2011, Addis Ababa, p. 37; See South African Alternate Report Coalition, supra 310, par. 185, p. 25.

⁴⁶¹ See Keegan Kautzky and Stephen M. Tollman, supra 458, p. 25.

⁴⁶² See South African Alternate Report Coalition, supra 310, par. 185, p. 25; See Treatment Action Campaign (TAC) and Section 27, ‘Death, and Dying in the Eastern Cape. An investigation into the collapse of a health system’, p. 16 - 26, 2013, TAC, Section 27, South Africa.

⁴⁶³ Ibid (TAC and Section 27) p. 16 - 26.

⁴⁶⁴ See South African Alternate Report Coalition, supra 310, par. 200, p. 26.

disability is in inaccessible formats which limits the parent's understanding of the medical condition that the child is experiencing.⁴⁶⁵

Early detection mechanisms are essential in the health system to allow prevention of disability in children. The Department of Women, Children and People with Disabilities reported that “early detection does not appear to be foremost among health care priorities for children in South Africa and there is (...) no national screening programme being implemented”.⁴⁶⁶ There is a shortage of medical personnel who are specialists in the assessment of children.⁴⁶⁷ This may result in “(...) false reassurances and inaccurate information being given to caregivers (...)”.⁴⁶⁸

Discriminatory practices are prevalent in most health facilities in the country, and as such are in desperate need of “[m]easures of accountability of support staff, health professionals, managers and administrators”.⁴⁶⁹ Lack of access to health care facilities has been further perpetuated by negative attitudes from nursing staff.⁴⁷⁰ “Also of concern are allegations of malpractice and incompetence on the part of medical professionals, resulting in primary or secondary disability”.⁴⁷¹

⁴⁶⁵ Department of Women, Children and People with Disabilities, Baseline Country Report to the United Nations on the Implementation of the Convention on the Rights of Persons with Disabilities in South Africa, 17th April 2013, par. 269, p. 50, Republic of South Africa.

⁴⁶⁶ Department of Women, Children and People with Disabilities, UNICEF, Department of Social Development, *Children with Disabilities in South Africa: A situation analysis 2001 – 2011*, 2012, Pretoria, p. 40.

⁴⁶⁷ Ibid, p. 77; About 47 % (1, 444) of the 3,074 clinics in South Africa reported that they do not have visits from Doctors. See Department of Health, National Health Care Facilities Baseline Audit, *National Summary Report*, 2012, p. 31, Health Systems Trust, Pretoria.

⁴⁶⁸ Ibid, p. 78.

⁴⁶⁹ A “National Audit of health Care Establishments established that there was a poor compliance with ministerial priority areas such adequacy of waiting times (68%), cleanliness (50%), patient safety (34%), and positive and caring attitudes (30%)”. See South African Alternate Report Coalition, supra 310, par.187, p. 25.

⁴⁷⁰ Ibid, par. 195, p. 26; Positive and caring attitudes, a vital ministerial measure by the Department of Health, scored a 30%. This is a poor score which has implications on the quality of service offered at most of the public health facilities. See more Department of Health, supra note 467, pp. 1 – 2.

⁴⁷¹ Department of Women, Children and People with Disabilities, UNICEF, Department of Social Development, supra 466, p. 78.

3.4. CRC and CRPD Standards Regarding the Right to Health.

3.4.1. Positive steps by States in achieving the right to health for children with intellectual disabilities as per CRC and CRPD standards.

To reach children with intellectual disabilities even in the most remote rural areas in South Africa, the government embarked on the re-engineering of its PHC delivery system. This re-engineering process aims at moving away “the clinic – or hospital-based model to a community-based model”.⁴⁷² An important aspect of this new delivery system aims at emphasizing on the importance of PHC by improving the “prevention aspect which has been neglected in favor of curative care”.⁴⁷³ In other words, “[i]t repositions a curative, individually based oriented system towards a proactive, integrated and population-based approach to service delivery, based on municipal ward-based primary health care outreach teams”.⁴⁷⁴

For South African children with intellectual disabilities to enjoy their right to health, community health workers are the link between the community clinic and the household to which the child belongs. This is done by bringing health services to the community – giving a boost to early identification and implementation of the intervention.⁴⁷⁵ The delivery of health services to community households helps to overcome barriers in accessing health care such as transport and time costs, and long distances between health facilities and the communities. Using the newly developed “Road to Health” booklets, it has become easier for PHC medical personnel to monitor developmental milestones and to refer children with developmental delays to higher level health facilities for specialist treatment.⁴⁷⁶

⁴⁷² Ibid, p. 89.

⁴⁷³ Ibid, Pretoria, p. 89.

⁴⁷⁴ P. Sodo and A Bosman, Progress of the municipal ward-based primary healthcare outreach teams in Vhembe, Limpopo Province, p. 18, *Strengthening Health Systems* 2017; 2 (1): 18 – 22, Pretoria.

⁴⁷⁵ Department of Women, Children and People with Disabilities, UNICEF, Department of Social Development, supra 466 p. 89.

⁴⁷⁶ See Thein Win, An Assessment of the ‘road-to-health-booklet’ based on knowledge/perceptions of the clinic nurses and conduct a record review of the completion of the booklets”, July 2016, Masters Thesis, University of Witwatersrand, Johannesburg.

A significant positive outcome from this programme is that services carried out by the Ward Based PHC outreach teams reaches recipients, and thus reduces the burden of transport and time costs – most importantly, it reduces the burden of walking long distances to access health services for children with intellectual disabilities especially in rural areas.

A study by Sodo and Bosman reviewed that “[a] total of 804, 538 households were reached by 151 [outreach teams] in 97 wards since the inception of the intervention”, which started towards the end of 2011 in Vhembe district.⁴⁷⁷ However, the programme faces some challenges such as lack of resources in terms of stationery, lack of transport to visit households, and lack of equipment batteries.⁴⁷⁸ This shows the poor planning and a lack of budget for the Ward Based Outreach Teams. A professional nurse, who is also a team leader for the outreach teams, is not always present during the household visits because they do not have the time and due to gross shortage of staff at health facilities.⁴⁷⁹ This affects supervision and may cause poor programme outcomes. There is also “a lack of a link between community-based services and services offered by fixed health facilities”.⁴⁸⁰

3.4.2. Drawbacks in achieving the right to health in State Parties as Per CRC and CRPD standards.

According to Zambia’s National Health Strategic Plan, 2011 – 2015 “[i]t is (...) estimated that in urban areas, approximately 99% of households are within 5 Kilometres of a health facility, compared to 50% in rural areas”.⁴⁸¹ Some of the factors which has led to this situation include “geographical challenges and poor state of transport and communication infrastructure,

⁴⁷⁷ P. Sodo and A Bosman, *supra* 474, p. 22; A total 23, 539 visits had been conducted to children below the age of 5 years.

⁴⁷⁸ *Ibid.*, p. 22.

⁴⁷⁹ *Ibid.*, p. 20.

⁴⁸⁰ *Ibid.*, p. 18; this lack of linkage between the services being carried out by the outreach teams and the fixed health facilities risks compromising the quality of care that would be provided at these facilities. Such a fragmented system could also affect the operation and service delivery of health care.

⁴⁸¹ Ministry of Health, National Strategic Plan 2011 – 2015, p. 12, Lusaka, Zambia.

particularly for rural areas”.⁴⁸² Additionally, there is unfair distribution of health infrastructure and health workers in the health system in Zambia because efforts tend to focus more on urban areas than in rural areas, where there is a shortage of these health structures and personnel.⁴⁸³ Other drawbacks in the health facility include shortages of much needed drugs and other medical supplies (...).⁴⁸⁴

There is a serious shortage of medical personnel in the health sector in Zambia which tends to affect the quality of health care services being provided at health facilities.⁴⁸⁵ “There are three main problems, namely the absolute shortage of health workers, inequities in the distribution of health workers and skills-mix, which all favour urban areas, than rural areas”.⁴⁸⁶ A review of the country’s National Health Strategic Plan, 2006 – 2010, showed that there was an increment in the total number of health workers from 23, 176 in 2005 to 29, 533 in 2009.⁴⁸⁷ However, this was only a representation of a 57 per cent of the required 51, 414 health workers.⁴⁸⁸ With a shortage of health workers, and there inequitable distribution in the country, the quality of health care services in rural areas is compromised. In fact, “[t]he situation is so severe that there are still a number of health facilities in the rural areas, which are run by unqualified staff or only one qualified staff”.⁴⁸⁹

The adoption of the 2010 Kenyan constitution “introduced a new governance framework with a national government and 47 counties”.⁴⁹⁰ This was a move away from the centralized system

⁴⁸² Ibid, p. 12.

⁴⁸³ Ibid, p. 12.

⁴⁸⁴ Ibid, p. 12.

⁴⁸⁵ Ibid, p. 22.

⁴⁸⁶ Ibid, p. 22.

⁴⁸⁷ Ibid, p. 22.

⁴⁸⁸ Ibid, p. 22.

⁴⁸⁹ Ibid, p. 23.

⁴⁹⁰ Catherine Barker, Aaron Mulaki, Daniel Mwai and Arin Dutta, Devolution of Health Care in Kenya: Assessing County Health System Readiness in Kenya: A review of the Selected Health Inputs, p. 1., July 2014, USAID (Kenya), PEPFAR. Available from https://www.healthpolicyproject.com/pubs/479_KenyaPETSCountyReadinessFINAL.pdf (Accessed 27/11/2017).

of government which had been in place since the county's independence in 1963. One of the aims of devolution is to ensure that services are brought closer to the people as counties tend to manage the delivery of services.⁴⁹¹ However, "there have been challenges in [accessing] health care services for [children with disabilities] at the local hospital where district hospitals are understaffed, under-budgeted and do not stock the medicine needed by persons with disabilities (...)"⁴⁹²

There are also concerns as to whether counties are ready to deliver services as per timeline set by the Transition Authority (TA).⁴⁹³ A research carried out by the USAID and President's Emergency Plan for AIDS Relief (PEPFAR) in 2013/2014 reviewed that "[h]ealth facilities are unequally distributed across the 47 counties"⁴⁹⁴ "Densely populated Mombasa and Nairobi have 134 and 124 health facilities per 100 square kilometers, respectively, but far fewer facilities per 10,000 people (2.9 and 2.4, respectively)"⁴⁹⁵ As such, these figures may indicate that these counties "may have a sufficient number of facilities for the population, but patients must travel long distances to reach them"⁴⁹⁶ Counties such as Tana River, Mandera, and Bomet with few facilities per 10,000 people and per 100 square kilometers "may have limited capacity to care for everyone in their catchment area" and "[p]eople seeking health care in these counties are likely inconvenienced by travel time and distance to health facilities"⁴⁹⁷

The setbacks in the South African health system have been well documented which have negatively affected the realization of the right to health for children with intellectual disabilities. The deplorable state of the health system in the Eastern Cape Province, an area where Nelson

⁴⁹¹ See Constitution of Kenya, 2010, Fourth Schedule, Nairobi, Kenya.

⁴⁹² United Disabled Persons of Kenya, *supra* 268, p.40.

⁴⁹³ Catherine Barker, Aaron Mulaki, Daniel Mwai and Arin Dutta, *supra* 490, p. 1. 27/11/2017).

⁴⁹⁴ *Ibid*, p. 2.

⁴⁹⁵ *Ibid*, p. 3.

⁴⁹⁶ *Ibid*, p. 3.

⁴⁹⁷ *Ibid*, p. 3.

Rolihlahla Mandela the country's first President came from, has been described by activists as "broken, inhumane and collapsed" where "accountability is nonexistent".⁴⁹⁸ The health crisis in the province is not because of the unequal regime by the apartheid government, it is a failure of democracy. In 2013, "the national Auditor General's annual check of the financial statements showed that over the last decade "tens of million of rands are lost each year through a mix of deliberate fraud, improper oversight, and poorly managed supply chain systems".⁴⁹⁹ These mismanagements in the health sector have been at the expense of the well-being of the population in the province.

Conclusion

This chapter has explored the CRC and CRPD standards regarding the right to health for children with intellectual disabilities. It should be noted that, being healthy is not merely the absence of illness or disease, rather it encompasses a variety of factors such as the well-being in the physical, social, and mental aspects of each person. The right to health for children with disabilities is enshrined under Article 24 of the CRC and Article 25 of the CRPD. Article 24 of the CRC gives States the duty to provide quality health care, paying keen attention to underserved areas; to reduce infant and child mortality; to develop the primary health care system; and to provide information on health issues in formats that would be easily understood by persons with disabilities. For example, this would entail providing health information in large print. Article 25 of the CRPD gives States the duty of providing health services without discrimination because of a person's disability. Since the right to health is an economic right, this brings in the aspect of progressive realization stipulated under Article 4 (2) of the CRPD. As such, States must take the necessary steps to ensure that this right is achieved as per

⁴⁹⁸ IRIN, Healthcare in South Africa's Eastern Cape Collapses, 2013, Available from <http://www.irinnews.org/analysis/2013/09/23> (Accessed 27/11/2017)

⁴⁹⁹ Ibid.

available resources. The State must put in place a timeframe, formulate a strategy and monitor progress of the plan which must be implemented. For example, building infrastructure and training of health workers is a State duty which cannot be immediately realized, but they can over a period. The realization of the right to health for children with disabilities is important in the prevention of further or secondary disabilities, and it helps in fulfillment of other human rights such as the right to education.

Chapter Four – Findings and Recommendations

4.0. Introduction

This chapter aims at highlighting the salient findings that the previous chapters have explored relating to some best practices that are being employed in Zambia, Kenya, and South Africa regarding the right to education and health for children with disabilities. Thereafter, a section on the recommendations to Zambia will follow. The focus of this entire thesis has been to offer recommendations to the Zambian government based on findings (best practices) being implemented regarding right to education and health for children with intellectual disabilities.

4.1. Findings; Best Practices

This thesis has helped to highlight that children with intellectual disabilities have rights under international human rights law. “The right to education for children with disabilities has been addressed directly and indirectly by ‘soft’ (that is, non-binding) and binding international law”.⁵⁰⁰ In 1948, the UDHR’s Article 26 gives everyone the right to education. This was later followed by other non-binding proclamations such as the U.N. Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1993 and the Salamanca Statement in 1994. “The Salamanca Statement and Framework for Action clearly introduced the concept of ‘inclusion’ in education for persons with disabilities”, however, “(...) [this was]

⁵⁰⁰ Bronagh Byrne, *supra* 94, p. 235.

morally rather than legally binding upon States”.⁵⁰¹ The CRC was the first internationally binding covenant to prohibit discrimination because of disability and it introduced rights specifically targeting children with disabilities.⁵⁰²

Article 24 of the CRPD establishes the right to inclusive education for persons with disabilities. According to Bronagh Byrne, she stipulates that the aims of inclusive education should meet three elements;

Firstly; the full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms, and human diversity; secondly, the development by people with disabilities their personality, talents, and creativity, as well as their mental and physical abilities, to their fullest potential; and finally, to enable people with disabilities to participate effectively in a free society.⁵⁰³

It should be noted that, no attempt was made to define the term ‘inclusion’ under Article 2 of the CRPD. On the other hand, guidance has been offered by stipulating the aims which encompasses such an education system, that is, “to state that children with disabilities should not be excluded from the general education system on the basis of disability, and that they should receive support required within the general education system to facilitate their effective participation”.⁵⁰⁴ As such, “[t]his would appear to signify a positive approach to inclusion; one wherein the presumption is in favour of education in mainstream settings, with the provision of support to ensure that education really is inclusive and not reduced to mere integration”.⁵⁰⁵

In Sub-Saharan Africa, South Africa is known to be one of the leaders when it comes to the implementation of progressive policies. It was the second country in Africa to ratify the CRPD and it has completed its first reporting cycle as per stipulations under Article 35 of the CRPD. Inclusive education was prescribed very early on in South Africa in 2001 through the DBE’s

⁵⁰¹ Andrea Broderick, *supra* 73, p. 235.

⁵⁰² Bronagh Byrne, *supra* 94, p. 235; See CRC Article 2 and 23.

⁵⁰³ *Ibid*, p. 240-41; See CRPD Article 24 (1)

⁵⁰⁴ *Ibid*, p. 241.

⁵⁰⁵ *Ibid*, p. 241.

White Paper 6.⁵⁰⁶ According to the Education White Paper 6 “[f]ull service schools (...) are schools (...) that will be equipped and supported to provide for the full-range of learning needs among all [the] learners”.⁵⁰⁷ The establishment of these schools will be through the guidance of South Africa’s Schools Act, enacted in 1996. The impetus behind the building of full-service/inclusive schools in South Africa is because the government, through the DBE, wants to eliminate the traces of the apartheid regime which were still prevalent in special needs education.⁵⁰⁸ During the Apartheid regime, “special schools were (...) organized according to two segregating criteria, race and disability”, as a result, “schools that accommodated white disabled learners were extremely well-resourced, whilst few schools that accommodated black disabled learners were systematically under resourced”.⁵⁰⁹ To repeat, the establishment of full-service/inclusive schools aims at eliminating the discriminatory nature of the apartheid regime which is still present in the education sector. As of 2015, the country has 715 full-service/inclusive schools.⁵¹⁰

It should be noted that, the establishment of full-service/inclusive schools does not imply that special schools in South Africa will be totally phased out. The Education system in the country will comprise of; ordinary schools, for pupils that require low levels of support; full-service/inclusive schools, for those pupils that need moderate support; and special schools, for those pupils with disabilities requiring high levels of support.⁵¹¹ Some of the special schools will be turned into resource centres to support ordinary and full-service schools.⁵¹²

⁵⁰⁶ Department of Education, Education White Paper 6: Special Needs Education, July 2001, Pretoria, Republic of South Africa.

⁵⁰⁷ Ibid, p. 22.

⁵⁰⁸ Department of Education, ‘What is an Inclusive Education and Training system?’ p. 9., Education White Paper 6: Special Needs Education, July 2001, Pretoria, Republic of South Africa.

⁵⁰⁹ Ibid, p. 9.

⁵¹⁰ Presentation by Mathanzima Hubert Mveli Acting Deputy Director General at the Department of Basic Education, Progress Report on Inclusive Education and Special Needs Education, Portfolio on Basic Education Meeting, 30th May 2017. Slide No. 9, Available at <http://pmg-assets.s3-website-eu-> (Accessed 18/09/2017).

⁵¹¹ Department of Education, supra 508, p. 10.

⁵¹² Ibid, p. 10.

The inefficiencies of the Education White Paper 6 have been highlighted in Chapter two of this thesis. To repeat, the South African High Court in *Western Cape Forum for Intellectual Disability v. Government of the Republic of South Africa* stipulated that White Paper 6 did not cover children with profound and severe intellectual disabilities.⁵¹³ The implementation process was ineffective because it employs a 20 year implementation plan, as such, these children would only be accommodated in 2021.⁵¹⁴

Apart from the Western Cape High Court finding that the State had violated the rights of children with severe and profound intellectual disabilities, such as, the right to basic education, human dignity, equality and protection from degradation. The High Court ordered the South African government to address the needs of children with severe and profound intellectual disabilities by providing “affordable access to a basic education of an adequate quality” and to ensure “training of persons to provide education for children who are severely and profoundly intellectually disabled”.⁵¹⁵ The government has made progress since the High Court’s decision. In 2011, it established the Inter-Departmental Forum assigned the task to draft progress reports of the High Court order. Some of the progress that has been recorded at the national level include the completion of the Draft Policy Framework and Learning Programme for children with profound and severe intellectual disabilities.⁵¹⁶

The right to education and the right to health are inter-linked. For a person to attain an education, he or she has to be in a healthy state and to live a healthy life, education plays an important role because it equips a person with knowledge on how to live a healthy life, for example, through information imparted from teachers.

⁵¹³ *Western Cape Forum for Intellectual Disability v. Government of the Republic of South Africa and Government of the Western Cape*, supra note 63, par. 18, 28, 52 (2)

⁵¹⁴ *Ibid*, par. 18, 28, 52 (2)

⁵¹⁵ *Ibid*, par. 52 (2).

⁵¹⁶ Department of Education, supra 349, p. 22 – 23.

One of the ways the South African government decided to strengthen its health sector was by ensuring that it developed a much stronger PHC system. This has become dubbed as what is called as the Re-Engineering of the PHC in South Africa. The initiative focuses on four main elements which includes; increasing life expectancy; combating HIV/AIDS and decreasing the burden of disease from Tuberculosis (T.B); strengthening health system effectiveness; and decreasing maternal and child mortality.⁵¹⁷ The focus of this thesis has been based on the last two main areas. The vision of re-engineering the PHC system in South Africa was developed in 2010, and launched in 2011. This initiative is based on the Brazilian model of health care. “Brazil was able to improve health outcomes by inter alia expanding the role of community agents working in teams with health professionals in designated catchment areas”.⁵¹⁸

The PHC re-engineering system in South Africa adopts a three-stream approach to the delivery of health services. This is done through Municipal Ward-Based PHC Outreach Teams, School Health Services and District-Based Specialist Teams. “PHC re-engineering repositions a curative, vertical, individually oriented system to a proactive, integrated, and population-based approach to service delivery, based on municipal ward-based primary healthcare outreach teams that include community health workers and home-based carers”.⁵¹⁹ Each outreach team is linked to a PHC facility through a professional nurse who is also the team leader.⁵²⁰ Each ward should have at least one outreach team targeting 1,500 households per year.⁵²¹ Team members are delegated services, and they are not employed on full-time basis for Ward-Based Outreach Team purposes.⁵²²

⁵¹⁷ Yogan Pillay and Peter Barron, The implementation of PHC re-engineering in South Africa, p. 1, a summary of the *Provincial Guidelines for the Implementation of the Three Streams of PHC Re-Engineering*, 2012, Available from <https://www.phasa.org.za/wp-content/uploads/2011/11/Pillay-The-implementation-of-PHC.pdf> (Accessed 27/11/2017)

⁵¹⁸ Ibid, p. 1-2

⁵¹⁹ P. Sodo and A Bosman, *supra* 474, p. 22.

⁵²⁰ Ibid, p. 22.

⁵²¹ Ibid, p. 22.

⁵²² Ibid, p. 22.

School health services provide health services in schools such as screening of learners at the earliest times in their school careers, and priority should be given to those schools which are the poorest in a region. District-Based Specialist Teams consist of a team of experts such as a PHC nurse, a paediatrician and a paediatric nurse. All the three streams must work together to ensure better health outcomes for persons in South Africa.

Before 2011, health officials in South Africa used “the Road To Health Card (RTHC) [as] an essential monitoring tool for under five (5) child” developments in public health facilities countrywide.⁵²³ The use of these cards proved to be an important element in observing child health and monitoring of child developments. With the emergence of re-engineering the PHC, came a shift towards the use of the Road To Health Booklets (RTHB) because they are seen as being able to detect childhood development problems early.⁵²⁴

Proper use of the RTHB allows for the “early detection” of childhood disability which “leads to early diagnosis” and intervention.⁵²⁵ The RTHB contains information on the growth of the child, immunization records, developmental screening, and oral health. Other benefits include; assisting and guiding nurses with referral decisions; it is a “comprehensive child health monitoring tool”; and it provides a “clear scope” with comprehensive information it contains, thus, a useful guiding tool.⁵²⁶

The use of the newly developed RTHB has come with its challenges amongst doctors, nurses, and other health personnel. Some of these challenges include a lack of completion of the booklet because it consumes a lot of time to complete, limited note taking space, and it includes confidential information.⁵²⁷

⁵²³ See Thein Win, *supra* 476, p.2.

⁵²⁴ *Ibid*, p.2.

⁵²⁵ *Ibid*, p.3.

⁵²⁶ *Ibid*, p.28.

⁵²⁷ *Ibid*, p.6.

4.2. Recommendations to Zambia

This thesis has shown that children with intellectual disabilities are human rights holders, and that they are not just mere objects of charity provisions. It has also highlighted how much Zambia, Kenya, and South Africa comply with the international human rights standards as stipulated in the CRC and CRPD regarding the protection and promotion of the rights to education and health for children with intellectual disabilities. Additionally, this thesis has given an overview of the work some of the progressive NGOs in the three countries are undertaking in helping children with intellectual disabilities to enjoy their human rights. NGOs play a vital role in championing the rights of children with intellectual disabilities, and they help to fill in the service gaps left by the government. The following are some of the recommendations which the Zambian government must undertake to offer more protection to the rights of children with disabilities.

- The Zambian government needs to collect more data on the situation of persons with disabilities. The current literature does not have comprehensive data on the situation of persons with disabilities in the country. The coming national census in 2020 is a good opportunity to carryout this task.
- 2017 marks 7 years since the State ratified the CRPD. The initial report was supposed to be submitted in 2012, two years after ratifying the Convention. There is an urgent need for the country to submit its initial report on the situation of persons with disabilities in the country. This will give an opportunity to citizenry, NGOs and DPOs and other interested stakeholders to offer inputs on how best the State can meet the needs of persons with disabilities. This will also be an opportunity to criticise the State for some of its failings in protecting the rights of persons with disabilities based on what it will report, and from evidence using shadow reports. It will also be an opportunity to collect important data on the situation of persons with disabilities.

- The State needs to start making progress towards establishing inclusive schools which should accommodate persons with disabilities, such as children with intellectual disabilities. Arguably, it can be stated that the physically disabled persons are to some extent accommodated in mainstream schools because in most cases this group of people need only some adjustments to the building structures and walkways to be accommodated. But what happens to children with intellectual disabilities, who may need more than just adjusting the infrastructure? Eliminating discrimination in communities should start from a very young age, and the school environment can help to facilitate that through an inclusive education system.

Conclusion

Children with intellectual disabilities are one of the most marginalized groups in society. One of the reasons why this has been the case is because little is known about intellectual disability. In Africa, some of these children are hidden away because the family is ashamed or fears that they will be discriminated against by other members of the communities because people perceive such children as being demon possessed. This is certainly not the case. Children with intellectual disabilities can become active members of the society, and contribute to its growth. Thus, creating an inclusive society will help to appreciate diversity and eliminate negative attitudes which discriminate against children with intellectual disabilities.

The CRC was the first international human rights convention to prohibit discrimination because of disability and it highlighted that children with intellectual disabilities have rights to health and education. The coming of the CRPD affirmed the recognition of rights for persons with disabilities. Today, it well known knowledge that persons with disabilities are human rights holders. As it has already been established throughout this thesis, countries such as Zambia, Kenya and South Africa have ratified both Conventions and the necessary legislation has been

put in place to protect the rights of children with intellectual disabilities. However, inadequacies or failures are still prevalent when it comes to protecting the rights of children with intellectual disabilities. Most of these failures are due to poor managements, negative attitudes towards persons with disabilities, selfishness (as with the case of the rampant corruption in the Eastern Cape Province in South Africa), and a lack of vision by some politicians.

Unquestionably, the rights to education and health are important rights in ensuring that children with intellectual disabilities develop, live better and more full-filling lives. The right to education is paramount in ensuring that children with intellectual disabilities become active members in the communities they live. Education helps to unlock other fundamental human rights. It is through getting an education that a person, disabled or not, will know about the benefits of being healthy. Education imparts information to disabled children with life-long lessons that can help them overcome day-to-day struggles. However, this thesis has shown that this right is still far from being realized for children with intellectual disabilities in Zambia, Kenya, and South Africa. Long distances, lack of appropriate curriculum suitable to meet the needs of children with intellectual disabilities, payment of school fees (even when countries such as Zambia and Kenya have a FPE policy in place), a lack of assistive devices and personnel, and governments favoring special schools over inclusive school continue to prevent children with intellectual disabilities from realizing their right to inclusive education.

Similarly, the right to health and education are inter-linked, and as such this thesis has helped to highlight the importance of these rights by exploring some of the best practices that are being employed to help children with disabilities realize them. When a disabled child is fully enjoying their right to health, it becomes easier to prevent diseases and prevent secondary disabilities because they are constantly being monitored by health personnel every time they visit the clinic/health centre. Unfortunately, this thesis has highlighted that the right to health is still far

from being realized for children with disabilities in the countries that have been mentioned. Long distances, a serious shortage of medicines appropriate for children, corruption, lack of well-trained staff on disability issues, and poor work culture are recurring happenings in all the three countries, as such, hampering children with intellectual disabilities from realizing their right to health.

Interestingly, this thesis has helped to highlight that it has not been all gloomy in the protection of the right to education and health for children with intellectual disabilities. Some South African schools are being turned into full-service/inclusive schools. As of 2015, the country has 715 full-service/inclusive operating in all its nine (9) provinces. This should be a sign of hope that inclusion for children with intellectual disabilities can be achieved through strong political will, and a supportive population which is fighting to end segregation and discrimination. Segregation and discrimination were a common feature during the apartheid regime, and this continued in the special education section. To remedy the state of things, the government decided to come up with the Education White Paper 6 to foster the implementation of inclusive schools. South Africa's Schools Act guides the implementation of these schools. This White Paper 6 was based on work which took 5 years to accomplish, that is from 1996 to 2001. Despite its flaws, which were well highlighted especially in the *Western Cape Forum for Intellectual Disability v. Republic of South Africa*. The initiative is a progressive one and it should be picked up by other African countries, of course after polishing it up and making the necessary adjustments. For example, the 20-year implementation plan needs to be re-visited and adjusted to make it more flexible to changes in the society.

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