

African Disability Rights Yearbook 2017

The *African Disability Rights Yearbook* aims to advance disability scholarship. Coming in the wake of the United Nations Convention on the Rights of Persons with Disabilities, it is the first peer-reviewed journal to focus exclusively on disability as human rights on the African continent. It provides an annual forum for scholarly analysis on issues pertaining to the human rights of persons with disabilities. It is also a source for country-based reports as well as commentaries on recent developments in the field of disability rights in the African region.



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African Disability Rights Yearbook 2017

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EDITORIAL

The editors of the *African Disability Rights Yearbook (ADRY)* are pleased to announce the publication of the fifth volume of the *ADRY*.

Section A of this volume features seven articles by: Mirriam Nthenge on early childhood development and education for children with disabilities in Kenya; Bernadette Malunga, Ngeyi Ruth Kanyongolo, and Ngcimezile Mbano-Mweso on access to justice of children with disabilities in defilement cases in Malawi; Zita Hansungule and Trynie Boezaart on socio-economic rights of children with disabilities in South Africa; Faraaz Mahomed and Michael Ashley Stein on de-stigmatising psychosocial disabilities in South Africa; Magnus Mfoafo-M'Carthy and Jeff Grischow and on mental illness, stigma and disability rights in Ghana; Mark Mostert and Martha Weich on a framework for addressing trafficking of body parts of persons with albinism; and Abdallah Possi and Ally Possi on the intersection between identity and anti-discrimination measures for protecting persons with albinism. The last two articles, which focus on albinism, stem from papers presented at a conference on albinism that was convened in 2016 by the Centre for Human Rights, University of Pretoria.

Section B contains reports on two countries: **Djibouti** by Djibril Ismail Cher; and **Madagascar** by Isambilo Rabearison-Andrianjara.

Section C contains two commentaries by: Elizabeth Kamundia on the intersection between right to the highest attainable standard of mental health and article 25 of the CRPD in selected African countries; and Damalie Naggita-Musoke on East African disability rights developments.

The 2017 volume ends with a book review of Elizabeth Barnes's *The minority body: A theory of disability*. The book is reviewed by Charles Ngwena.

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SECTION A: ARTICLES

*Miriam Nthenge****Summary**

The focus of this article is access to early childhood development and education (ECDE) by children with disabilities in Kenya. In general, ECDE has received minimal protection, if any, under international human rights law, including in the UN Convention on the Rights of Persons with Disabilities. The article argues that despite the gap in the international human rights framework on the rights of children with disabilities to access ECDE, domestically the Basic Education Act of 2013 provides an enabling framework to safeguard this right. To this end, the article argues that equality and non-discrimination, which underlie basic education law, provide a stronghold for advocating and implementing ECDE for children with disabilities in Kenya.

1 Introduction

Education is an empowerment and multiplier right. Access to quality education enables one to profit from other rights and is a prerequisite for individuals to have control over their lives.¹ It is through education that individuals develop their human potential, sense of dignity and self-worth as well as their mental and physical abilities.² Education builds a pathway for one to claim and advocate one's rights. For instance, it facilitates the acquisition and enhancement of skills for one to enjoy one's right to work.

* LLM (National University of Ireland, Galway); Open Society Foundation Disability Rights Scholar 2014/2015. The author would like to thank Dr Shivaun Quinlivan, Sarah Hofmayer and Elizabeth Kamundia for their constructive feedback.

1 F Coomans 'Clarifying the core elements of the right to education' <http://aihr-resourcescenter.org/administrator/upload/documents/core.pdf> (accessed 11 November 2016).

2 Arts 24(1)(a), (b) & (c) Convention on the Rights of Persons with Disabilities (CRPD).

M Nthenge 'The Basic Education Act of 2013 as a tool for advancing early childhood development and education for children with disabilities in Kenya' (2017) 5 *African Disability Rights Yearbook* 3-24 <http://doi.org/10.29053/2413-7138/2017/v5n1a1>

Education also facilitates effective participation in political life. Furthermore, it broadens an understanding of proceedings of day-to-day activities, including information on leisure activities and norms governing society. Formal education is a systematic process where transition from one level is preceded by another. The significance of these levels is justified by skills gained at preceding stages as tools for advancing to the next level. The article focuses on one of the levels – early childhood development and education (ECDE). This level plays a crucial role in laying a foundation in education. However, the protection of early childhood development and education under both domestic and international human rights law remains uncertain.³

The article focuses on access to early childhood education by children with disabilities in Kenya. The central argument of the article is that, although early childhood education is not strongly protected in the normative international human rights framework, the Basic Education Act of 2013 provides a framework for advancing ECDE for children with disabilities in Kenya. Against this backdrop, the article attempts to answer the following questions: to what extent the Basic Education Act of 2013 provides a framework for safeguarding and promoting access to early childhood education for children with disabilities in Kenya; and what opportunities exist in Kenya's framework, and specifically in its blue print plan Vision 2030, to make access to early childhood education by children with disabilities a living reality. The structure of the article builds on these questions, and is divided into four sections. Section one begins by operationalising key terms used in the article and providing an overview of the general normative framework on the right to education. Section two introduces the education system in Kenya and legal tools on the right to education for children with disabilities in general. The section closes with an overview of treaty bodies' comments to Kenya on access to ECDE. Section three narrows down to the Basic Education Act of 2013. An in-depth analysis of relevant provisions on ECDE is conducted. In light of this, the section examines the way in which the relevant provisions of the law may be utilised to seek judicial remedy and to advocate access to ECDE by children with disabilities. The section goes further to examine opportunities for implementation, with a specific focus on one of the flagship projects on education under the Medium Term Plan (2013-2017).⁴ Section four provides a conclusion and highlights challenges that could be resolved in future research.

3 KD Bieter *The protection of the right to education by international law, including a systematic analysis of article 13 of ICESCR* (2006) 137.

4 Kenya Vision 2030 2007 http://www.vision2030.go.ke/?page_id=3319 (accessed 23 August 2015).

2 Operationalisation of terms and overview of the normative framework on the right to education - International and regional

The United Nations (UN) Educational, Scientific and Cultural Organisation (UNESCO) defines early childhood care and education as the period from birth to eight years of age.⁵ The UN Committee on Rights of the Child (CRC Committee) adopts a similar definition. General Comment 7 on implementing child rights in early childhood⁶ defines early childhood as ‘all young children at birth throughout infancy, during the preschool years as well as during the transition to school’.⁷ However, in its reference to ECDE as the term used in Kenya’s policies, the article narrows down to pre-primary education. The Basic Education Act of 2013 (Act) defines pre-primary school as ‘education imparted to a child of four to five years before joining level one in primary school’.⁸

Additionally, for clarity in understanding, the article draws a distinction between inclusive education, integrated education and special education. The CRC Committee defines inclusive education as ‘a set of values, principles and practices that seeks meaningful, effective, and quality education for all students, that does justice to the diversity of learning conditions and requirements not only of children with disabilities, but for all students’.⁹ General Comment 4 of the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) on the right to inclusive education adopts a similar definition with additional elements.¹⁰ The CRPD Committee recognises partnership, support to teachers and monitoring as essential to inclusive education. The General Comment further defines segregated or special education as ‘provision of education in separate environments designed to respond to a particular or various impairments, in isolation from students without disabilities’.¹¹ Integrated education is defined as ‘a process of placing persons with disabilities in existing mainstream educational institutions, and requiring them to adapt and accommodate to a pre-determined environment’.¹² A common practice in integrated education includes isolated units for persons with

5 <http://www.unesco.org/new/en/education/themes/strengthening-education-systems/early-childhood/> (accessed 23 August 2015).

6 CRC Committee General Comment 7 (2005): Implementing child rights in early childhood, 20 September 2006, CRC/C/GC/7/Rev.1

7 As above.

8 Sec 2 Basic Education Act 2013.

9 CRC Committee General Comment 9 (2006): The rights of children with disabilities, 27 February 2007, CRC/C/GC/9.

10 CRPD Committee General Comment 4 (2016) art 24: Right to inclusive education, 2 September 2016, CRPD/C/GC/4; see also R Riser *Implementing inclusive education: A commonwealth guide to implementing article 24 of the UN Convention on the Rights of Persons with Disabilities* (2012) 47.

11 CRPD Committee (n 10 above) para 11.

12 As above.

disabilities in the mainstream school environment who transition after a certain period, depending on how they can cope with the mainstream environment.

2.1 Role of early childhood development and education

ECDE has been described as the foundation for subsequent learning. It is the period of remarkable physical and cognitive development and to 'children with disabilities it is key in enabling them to be in an inclusive environment'.¹³ Evidence demonstrates that experiences during the first years of growth enhance or inhibit the realisation of an individual's potential in future life. The CRC Committee corroborates this argument. It underscores the implementation of children's rights in early childhood as an effective way to help prevent personal, social and educational difficulties during middle childhood and adolescence.¹⁴

At the national level, the national early childhood development policy framework normatively acknowledges the benefits of investing in early childhood education for children with disabilities. The policy recognises that such investment allows early identification and intervention, and therefore ensures that children with disabilities maximise their talents.¹⁵ Early assessment coupled with intervention provide relevant information to families and teachers, especially about the support needs of the child that will optimise his or her learning potential.¹⁶

Access to quality ECDE by children with disabilities enhances their potential. At pre-school level, children are granted opportunities to learn to co-operate, develop fine motor skills, develop languages and opportunities to take responsibility and make choices.¹⁷ Teachers are expected to support children's sense of self-worth and encourage creativity. Inclusive ECDE for children with disabilities, therefore, will demand a recognition of differences and embrace diversity, hence the need to provide necessary accommodations and modifications to promote inclusion. This includes early training in orientation, mobility skills and alternative communications.

Stimulating early childhood education also enhances placement, retention and academic performance for children with disabilities. Bryant

13 UNESCO (n 5 above); Salamanca Statement and Framework for Action on Special Needs Education (1994), para 6; CRC Committee (n 6 above).

14 CRC Committee (n 6 above) para 8.

15 Ministry of Education *National early childhood development policy framework* (2006) sec 1.4(a).

16 UNESCO Policy Brief on Early Childhood Inclusion of Children with Disabilities: The early childhood imperatives N 46/ April-June 2009/REV; S Philpott 'Too little, too late? The CRPD as a standard to evaluate South African legislation and policies for early childhood development' (2014) 2 *African Disability Rights Yearbook* 51.

17 Ministry of Education *Early childhood development service standard guidelines* (2006).

and Maxwell argue that children with disabilities who have been placed in inclusive early intervention groups are less often placed in special education and retained in a grade compared to those who have not.¹⁸ The Inclusive Early Childhood Service System Project (IECSS) argues that ECDE is more effective than schools at connecting family support, community development, and child development as integrated and equally important outcomes of inclusive practice.¹⁹ Early intervention, therefore, remains a prerequisite to inclusive education for persons with disabilities. The Convention on the Rights of Persons with Disabilities (CRPD) underscores inclusive education,²⁰ as does the Salamanca Statement and the Framework for Action on Special Needs Education (1994).²¹

Flipping the coin to the economic side, the benefits of early intervention are immeasurable. Heckman argues that early intervention for children with disabilities not only helps to reduce the achievement gaps and the need for special education, but also promotes economic efficiency.²² An analysis of global experience of children with disabilities in schools indicates that key challenges facing inclusive education include a lack of accessibility, stereotyping, un-adapted curriculums and a lack of reasonable accommodation.²³

The inclusion of children with disabilities right from the beginning of the education system minimises some of these challenges. Having all children learning together teaches children to value diversity, builds social capital and lays the foundation for inclusive communities.²⁴ With regard to planning and availing necessary tools for education, schools are more likely to avail an inclusive environment at the onset. States, therefore, have to choose between providing adequate interventions in early stages or paying more in the future when phasing out segregated education in line with the standards set by the CRPD.²⁵

18 D Bryant & K Maxwell 'The effectiveness of early intervention for disadvantaged children' in M Guralnick (ed) *The effectiveness of early intervention* (1997) 23-46.

19 Inclusive Early Childhood Service Project 'Policy Brief No 2: A submission to the Day of General Discussion on the Right to Education for Persons with Disabilities' March 2015 <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGDontherighttoeducationforpersonswithdisabilities.aspx> (accessed 27 August 2015).

20 Art 24(1) CRPD.

21 Sec 2.

22 JJ Heckman 'The economics of inequality: The value of early childhood education' (2011) 35 *American Educator* 31.

23 See Concluding Observations to initial reports of States Parties to the CRPD http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5 (accessed 27 August 2015).

24 Inclusion International 'Submission to the Committee on the Rights of Persons with Disabilities: Article 24: Implications of the implementation for the people with intellectual disabilities' (2015) <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx> (accessed 17 September 2016).

25 CRPD (n 2 above).

2.2 Normative frameworks on the right to education – International and regional

The right to education is safeguarded in different international human rights instruments, namely, the Universal Declaration of Human Rights (Universal Declaration);²⁶ the International Covenant on Economic, Social and Cultural Rights (ICESCR);²⁷ the UN Convention on the Rights of the Child (CRC);²⁸ and the CRPD.²⁹ Regionally, the African Charter on Human and Peoples' Rights (African Charter),³⁰ the African Charter on the Rights and Welfare of the Child (African Children's Charter),³¹ the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (African Women's Protocol)³² and the African Youth Charter³³ safeguard the rights to education of persons with disabilities.

Specific emphasis on persons with disabilities is laid in articles 11(3) and 13 of the African Children's Charter. Article 13 of the Children's Charter obliges state parties to take special measures to ensure that gifted, female and disadvantaged children have equal access to education. This is further elaborated on in the guidelines on implementation of economic, social and cultural rights in the African Charter which calls for inclusive free and compulsory education for children with disabilities.³⁴ More recently, the African Commission on Human and Peoples' Rights (African Commission) published the Draft Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (Draft Disability Protocol).³⁵ Article 12 of the Draft Disability Protocol explicitly refers to the rights to education of persons with disabilities, emphasising that persons with disabilities should not be considered uneducable or untrainable.

A running thread in all these instruments is the right to free and compulsory primary education. However, an explicit reference to early childhood education as an early intervention measure is missing, including in the CRPD. The drafters of the CRPD overlooked this particular issue,

26 Art 26 Universal Declaration.

27 Art 13 ICESCR.

28 Art 28 CRC.

29 Art 24 CRPD.

30 Art 17 African Charter.

31 Art 11 African Children's Charter.

32 Art 12 African Women's Protocol.

33 Art 13 African Youth Charter.

34 African Commission on Human and Peoples' Rights 'Guidelines on implementation of economic, social and cultural rights in the African Charter on Human and Peoples' Rights' http://www.achpr.org/files/instruments/economic-social-cultural/achpr_instr_guide_draft_esc_rights_eng.pdf (accessed 5 September 2015).

35 African Commission on Human and Peoples' Rights Draft Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities, http://www.achpr.org/files/news/2016/04/d216/disability_protocol.pdf (accessed 11 June 2016).

specifically in article 24, despite proposals during the negotiations to explicitly include early childhood and pre-school education.³⁶ It is to be noted that the CRPD does emphasise early intervention in relation to the right to rehabilitation and the right to health.³⁷ The recommendations to state parties by the CRPD Committee also lack explicit guidance regarding early intervention under article 24. Instead, the Committee adopts a more general approach of recommending inclusive education at all levels. In cases where recommendations are targeting specific levels, the CRPD Committee explicitly makes reference to primary, secondary and tertiary education.³⁸ Specific recommendations are only notable in the Concluding Observations of state parties such as Austria, where the CRPD Committee urges the state party to ensure inclusive education from kindergarten to secondary education.³⁹

Nonetheless, recent developments by the CRPD Committee reflect a positive shift. In its General Comment 4 on article 24,⁴⁰ the Committee underscores early detection, identification and access to services for pre-school children, together with the provision of support and training to parents and caregivers of young children with disabilities.⁴¹ The CRPD Committee, thus, encourages state parties to invest in inclusive pre-school education in light of the clear evidence of the benefits to children as well as the enhanced likelihood that attendance at pre-school results in greater acceptance into local community schools.⁴²

At the regional level, the African Commission guidelines to state parties on the implementation of economic, social and cultural rights clearly interpret the right to education to include access to pre-primary education.⁴³ However, the guidelines in subsequent paragraphs fail to elaborate on pre-school.

Contrary to the aforementioned instruments, the Standard Rules on Equalisation of Opportunities for Persons with Disabilities (Standard Rules)⁴⁴ explicitly make reference to pre-primary education. Rule 6 reminds states to give special attention to very young children with disabilities and pre-school children with disabilities.⁴⁵ While they remain

36 UN Enable 'Chairs Draft Elements of a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities' (2004) <http://www.un.org/disabilities/default.asp?id=1423> (accessed 11 June 2016).

37 Arts 25(b) & 26 CRPD.

38 CRPD Committee Concluding Observations, Mexico CRPD/C/MEX/CO/1; CRPD Committee Concluding Observations, China CRPD/CHN/CO/1.

39 CRPD Committee Concluding Observations, Austria, CRPD/C/AUT/CO/1 para 40.

40 CRPD Committee (n 2 above) para 67.

41 Para 67.

42 As above.

43 African Commission (n 34 above) para 71.

44 UN General Assembly 'Standard Rules on the Equalisation of Opportunities for Persons with Disabilities' 85th Plenary Meeting 20 December 1993, A/RES/48/96.

45 Standard rules (n 44 above) paras 5(a) & (b).

non-binding, the Standard Rules have arguably become a norm of *jus cogens*.⁴⁶ Therefore, Rule 6 read together with article 24 of the CRPD remains key in the promotion of access to early childhood education by learners with disabilities. One can also argue that article 26 of the CRPD on habilitation and rehabilitation to some extent addresses early intervention in school for children with disabilities. It obligates state parties to the CRPD:⁴⁷

to take appropriate measures to enable persons with disabilities to attain and maintain maximum independence ... and full inclusion and participation in all aspects of life, specifically in the areas of ... education and social services, in such a way that these services and programmes begin at the earliest possible stage and are based on the multidisciplinary assessment of individual needs and strengths.

The Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW)⁴⁸ also reminds state parties to ensure equality of access by men and women to all levels of education, including pre-primary. Article 10(a) provides:

States shall take measures to ensure ... the same conditions for career and vocational guidance, for access to studies and for the achievement of diplomas in educational establishments of all categories in rural as well as in urban areas; this equality shall be ensured in pre-school, general, technical, professional and higher technical education, as well as in all types of vocational training.

Early intervention is recognised in other declarations, including the Salamanca Statement on Access to Special Education (1994),⁴⁹ which called on states to invest greater effort in early identification and intervention strategies.⁵⁰ The Dakar Framework for Action 2000 also recognises the need to expand and improve comprehensive ECDE, especially for the most vulnerable and disadvantaged children.⁵¹ Globally, ECDE is becoming an integral strand of discussions on the right to education. In the current 2030 Agenda for sustainable development,⁵² state parties commit to provide inclusive and equitable quality education

46 Preamble para (f) CRPD.

47 Art 26(1) CRPD.

48 Art 10(a) CEDAW.

49 United Nations Educational, Scientific and Cultural Organisation 'The Salamanca statement on framework for action on special needs education' (adopted by the World Conference on Special Needs Education: Access and quality, Salamanca, Spain, 7-10 June 1994).

50 Standard rules (n 44 above) sec 3(6).

51 Dakar Framework for Action: Education for All: Meeting our Collective Commitment (adopted by the World Education Forum, Dakar, Senegal, 26-28 April 2000).

52 UN General Assembly 70/1 Transforming our world: The 2030 Agenda for Sustainable Development (Resolution adopted by the General Assembly on 25 September 2015)A/RES/70/1 <https://sustainabledevelopment.un.org/index.php?menu=1300> (accessed 9 February 2016).

at all levels, including early childhood education.⁵³ Hence, while ECDE does not enjoy adequate protection in binding international norms, the correlation between early intervention, inclusive education and being included in the community⁵⁴ remains unequivocal. The obligation to fulfil this right, therefore, remains inexcusable for state parties.

It is essential to note that Kenya is party to the aforementioned instruments⁵⁵ and has endorsed international declarations on education, as discussed in this section. These treaties, therefore, form part of the laws of Kenya in line with article 2(6) of the Constitution of Kenya⁵⁶ and can be used before court when seeking judicial remedy.⁵⁷

3 Background information on persons with disabilities, the education system and general legislative framework on the right to education in Kenya

According to the World Disability Report 2011, persons with disabilities constitute 15 per cent of the general population.⁵⁸ In Kenya, statistics indicate that persons with disabilities constitute 4,6 per cent of the general population, which translates to 1,7 million.⁵⁹

Kenya has an 8-4-4 education system, which translates to eight years for primary school level, four years for secondary school level and four years for higher education.⁶⁰ Domestically, the rights to education of persons with disabilities are embodied in both mainstream and disability-specific legislation. The Persons with Disabilities Act (PDA) safeguards the right to education and prohibits the denial of admission of a person with a disability to any course of study on the basis of a disability.⁶¹ The right to education is also recognised as a constitutional right in article 53(1)(b) of the Constitution of Kenya, which entitles every child to free and

53 As above.

54 Arts 19, 24 & 26 CRPD; T Chataika et al 'Access to education in Africa: Responding to the United Nations Convention on the Rights of Persons with Disabilities' (2012) 27 *Disability and Society* 385 398.

55 See list of treaties ratified by Kenya http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Countries.aspx?CountryCode=KEN&Lang=EN (accessed 22 August 2015).

56 Art 2(6) of the Constitution of Kenya provides that '[a]ny treaty or convention ratified by Kenya shall form part of the law of Kenya under this Constitution'.

57 <http://kenyalaw.org/caselaw/> (accessed 22 August 2015).

58 World Health Organization (WHO) & World Bank *World report on disability* (2011).

59 National Co-ordinating Agency for Population and Development 'Kenya national survey for persons with disabilities: Preliminary report' (2008) <http://www.african.org/CBR%20Information/KNSPWD%20Prelim%20Report%20-%20Revised.pdf> (accessed 22 August 2015).

60 Ministry of Education 'Education for all: End of decade assessment (2001-2010)' http://www.unesco.org/new/fileadmin/MULTIMEDIA/FIELD/Nairobi/EFA_EDA_Report_2012_Web_Version_1_.pdf (accessed 22 August 2015).

61 Secs 18 & 19 Persons with Disabilities Act 4 of 2003.

compulsory basic education. The Basic Education Act of 2013, which gives effect to article 53(1)(b) of the Constitution, explicitly provides for the rights to education of children with disabilities. An in-depth analysis of the Act is provided in the next section.

While the PDA seems to remain unclear on inclusive education⁶² and has been critiqued for promoting segregated education, the Constitution, the supreme law in Kenya, provides a framework that may be used to promote inclusive education. It does so, first, by prohibiting indirect or direct discrimination on the basis of disability.⁶³ Second, it provides that persons with disabilities have a right to access educational institutions integrated in the society that are compatible to their interests.⁶⁴ Third, it recognises the need for substantive equality by providing affirmative measures in education to redress historical disadvantages.⁶⁵ In summary, the general framework on the rights to education of persons with disabilities in Kenya draws its strength from the robust equality and non-discrimination provisions in the Constitution of Kenya, 2010.

The actual practice, however, has little to be desired. In 2002, Kenya introduced a free primary education policy and later, in 2008, introduced free day-secondary school education.⁶⁶ One of the gains of the policy is the affirmative action for children with disabilities who get extra allocation to the standard capitation for non-disabled children.⁶⁷ However, this has not adequately advanced access to inclusive education by the majority of children with disabilities. In its report on access to education by children with disabilities, the Kenya National Commission on Human Rights recommended a review of the free primary education programme to meet the needs of children with disabilities. The National Commission on Human Rights reiterated:⁶⁸

For these children, Free Primary Education (FPE) goes beyond the provision of desks, books and chalk to include boarding, transportation, health and specialised equipment and teaching-aids necessary to educate them effectively.

Additionally, due to existing stereotypes⁶⁹ and an overemphasis on literacy and numeracy as a form of testing academic competence⁷⁰ in

62 Sec 19 PDA (n 61 above).

63 Art 27(4) Constitution of Kenya.

64 Sec 54(1)(b) PDA.

65 Sec 56(b) PDA.

66 Ministry of Education (n 58 above).

67 Every child is allocated Kshs 1020 (the equivalent of \$12), and a child with a disability gets an extra Kshs 2000 (\$23) to cater for tuition and other school requirements.

68 Kenya National Commission on Human Rights *Objects of pity or individuals with rights: The right to education for children with disabilities* (2007).

69 Kenya National Commission on Human Rights *From norm to practice: A status report on implementation of rights of persons with disabilities* (2014).

70 Equal Rights Trust & Kenya Human Rights Commission *In the spirit of harambee: Addressing discrimination and inequality in Kenya* (2012) 131.

mainstream schools, children with disabilities have been forced to go to special boarding schools.⁷¹ Statistics indicate that in total Kenya has 1 882 primary and secondary special needs schools.⁷² The majority of these schools are located far away from the childrens' homes, and parents are forced to pay a boarding fee.⁷³ These extra costs have raised concerns at the treaty level with the CRC Committee, who requested Kenya to provide details of the hidden costs of education of children with disabilities.⁷⁴

These challenges are further confirmed by statistics provided in Kenya's state report to the CRPD Committee. According to the state report, only 67 per cent of persons with disabilities were reported to have achieved primary education, while only 19 per cent had secondary education, with most attending special schools at pre-school and primary level. Only 39 per cent attended regular pre-school, and 37 per cent attended regular primary school respectively.⁷⁵ From these statistics it is clear that most children with disabilities lay their foundation in a segregated environment. In addition, the statistics clearly indicate that, despite affirmative action, children with disabilities are not accessing education equally to their non-disabled peers. Unequal access to services has been interpreted as indirect discrimination.

In *Autism Europe v France*,⁷⁶ the European Committee of Social Rights observed:⁷⁷

Indirect discrimination may arise by failing to take due and positive account of all relevant differences or by failing to take adequate steps to ensure that the rights and collective advantage that are open to all are genuinely accessible by and all.

Subsequently, the Committee held that the fact that the proportion of children with autism being educated in either general or specialist schools was much lower than in the case of other children constituted a violation of article 15(1) of the European Social Charter on taking necessary

71 CRPD Committee Concluding Observations in relation to the initial report of Kenya 4 September 2015, CRPD/C/KEN/CO/1 <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx> (accessed 17 September 2016).

72 CRPD Committee Consideration of reports submitted by state parties under article 35 of the Convention: Initial reports of state parties due in 2010, Kenya 28 July 2014, CRPD/C/KEN/1 <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx> (accessed 17 September 2016); Republic of Kenya 'Combined 8th-11th periodic report on the African Charter on Human and Peoples' Rights, November 2014 <http://www.achpr.org/search/?c=7&q=kenya> (accessed 17 September 2016).

73 Kenya National Commission on Human Rights (n 68 above).

74 CRC Committee List of issues in relation to the combined 3rd to 5th periodic reports of Kenya, 15 July 2015, CRC/C/KEN/Q/3-5; CRC Committee Concluding Observations to Kenya on 3rd, 4th and 5th periodic reports of Kenya, 2 February 2016, CRC/C/KEN/CO/3-5 <http://www.ohchr.org/EN/HRBodies/CRC/Pages/CRCIndex.aspx> (accessed 17 September 2016).

75 CRPD Committee para 176.

76 (1996) ECSR.

77 Complaint 13/2002, *Autism Europe v France* (n 76 above).

measures to provide education for children with disabilities. The Committee also held that there was a violation of section 17(1) of the European Social Charter regarding the provision of sufficient and adequate services, whether alone or read in combination with article E on non-discrimination of the revised European Social Charter.

Similarly, the CRPD Committee raised concern over unequal access to services. In its review of the initial state report of Denmark, for example, the Committee raised its concern over unequal access to the complaints system of children with disabilities receiving different hours of support. The CRPD Committee reiterated:⁷⁸

The Committee is concerned at reports that children in need of more than 9 hours of special education per week may submit a complaint to the Special Education Board, unlike children in need of fewer than 9 hours of special education per week who cannot submit a complaint to an independent authority regarding a lack of adequate educational support.

The CRPD Committee recommended amending the legislation to ensure that all children with disabilities can submit a complaint to an independent authority if they do not receive adequate educational support.⁷⁹

The central argument of the article paper is that normatively, the principle of equality and non-discrimination, as embodied in both mainstream and disability-specific laws, including in the Basic Education Act, can be utilised to effectively safeguard access to early childhood education. This argument is further analysed in the next section, where the article discusses the extent to which the Act can promote access to ECDE by children with disabilities in Kenya.

3.1 Treaty bodies on access to early childhood education in Kenya

In its interaction with various treaty bodies, both at the regional and international level, Kenya has received various recommendations with regard to its commitment to guarantee access to early childhood education.

In considering Kenya's initial report, the African Committee of Experts on the Rights and Welfare of the Child (African Children's Committee) lauded Kenya for constantly increasing its budget allocation

78 CRPD Committee Concluding Observations, Denmark, CRPD/C/DEN/CO/1 para 54.

79 Kenya National Commission on Human Rights (n 68 above) para 55.

for early childhood education.⁸⁰ Nonetheless, the Children's Committee expressed concern over the low number of children accessing early childhood education, highlighting that 65 per cent of children aged between three and six years had no access to pre-primary school facilities.

At the international level, an analysis of the CRPD Committee's Concluding Observations to state parties indicates a lack of explicit and conclusive guidance on access to early childhood education by children with disabilities.⁸¹ Conversely, the CRC Committee has expressed its concern on this issue. In its Concluding Observations, the CRC Committee urged Kenya to improve and strengthen early detection and treatment services.⁸² The CRC Committee further encouraged the inclusion of children with disabilities into the regular educational system and their inclusion in society.⁸³ It urged Kenya to increase the financial allocation given to children with disabilities in schools, taking into account the specific needs of every child.

Specifically on ECDE, the CRC Committee urged Kenya to re-examine the best way of implementing the free primary education policy, due to its effect on enrolment in ECDE.⁸⁴ The Committee further called for an increased budget allocation, particularly in pre-primary, primary and secondary education.⁸⁵ In its most recent list of issues, the CRC Committee requested Kenya to provide data on the number of children benefiting from the early childhood development programmes.⁸⁶ Ultimately, the fact that availability, affordability and accessibility of ECDE services have raised concerns clearly indicates the crucial role played by ECDE towards inclusive education.

The next section examines how the Basic Education Act of 2013 provides a framework of enhancing access to ECDE as an early intervention approach to inclusive education.

80 African Committee of Experts on the Rights and Welfare of the Child 'Recommendations and observations to the government of Kenya by the African Committee of Experts on the Rights of the Child concerning the initial report on the implementation of the African Charter on the Rights and Welfare of the Child' SA 2590, art 11, Education.

81 CRPD Committee Concluding Observations to state parties http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5 (accessed 5 September 2015).

82 CRC Committee Consideration of reports submitted by state parties under Article 44 of the Convention: Concluding Observations: Kenya, 44th session, 19 June 2007, CRC/C/KEN/CO/2 http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Countries.aspx?CountryCode=KEN&Lang=EN (accessed 5 September 2015).

83 As above.

84 As above.

85 As above.

86 As above.

4 Basic Education Act of 2013 – A new dawn?

The Basic Education Act of 2013 gives effect to article 53(1)(b) of the Constitution on free and compulsory basic education.⁸⁷ Critics of the Act have described it as ‘one step forward and two steps back’, especially due to its emphasis on segregated education as opposed to inclusive education.⁸⁸ However, it is to be noted, specifically with regard to access to education by persons with disabilities, that the Act is the first education statute to explicitly refer to ECDE, including access to ECDE by persons with disabilities.⁸⁹ Against this background, the next section examines how the Act can facilitate access to pre-primary school by children with disabilities. It does so by examining the following main issues: definitional aspects; equality and non-discrimination as a guiding principle; implementation of the Act; and prohibition of inhumane treatment of children with disabilities in educational settings.

4.1 Definitional aspects

The legal interpretation of terms remains of prime importance in the construction of obligations and entitlements. For instance, in its review of state party reports, the CRPD Committee has consistently called upon states to review their definition of discrimination to include reasonable accommodation and a shift from the medical model definition of disability to the social model.⁹⁰ The emphasis of a broad definition is to ensure the legal recognition of denial of reasonable accommodation as a form of discrimination on the basis of disability, hence the right to a remedy.

With regard to the interpretation of terms, the Act adopts a broad definition of basic education to include pre-primary education and adult education. It defines basic education as ‘educational programmes offered and imparted to a person in an institution and includes adult basic education and education offered in pre-primary educational institutions and centres’.⁹¹ It further defines pre-primary education as ‘education imparted to a child of four or five years before joining level one in primary school’.⁹² Primary school is defined as ‘education imparted to a child who

87 Preamble Basic Education Act 2013.

88 W Aseka & AS Kanter ‘The Basic Education Act of 2013: Why it is one step forward and two steps back for children with disabilities in Kenya’ (2014) 2 *African Disability Rights Yearbook* 50.

89 Kenya National Commission on Human Rights (n 66 above)15.

90 CRPD Committee Concluding Observations to Cook Island CRPD/C/COK/CO/1, paras 5 & 7; CRPD Committee Concluding Observations to Czech Republic CRPD/C/CZE/CO/1 para 7; CRPD Committee Concluding Observations to Ecuador, CRPD/C/CE/CO/1 para 8.

91 Sec 2 Basic Education Act 2013.

92 As above.

has completed pre-primary school'.⁹³ Article 53(1)(b) of the Constitution accords to every child the right to free and compulsory basic education.

Two issues arise from the above definitions: first, the question of whether pre-primary school is now free.⁹⁴ The second question is whether pre-primary education is compulsory as seen in the definitions of basic education. With regard to these two issues (whether pre-primary school is now free and compulsory), the County Early Childhood Education Bill 2014 clarifies that 'every child has a right to free and compulsory early childhood education'.⁹⁵ If enacted, the Early Childhood Education Bill, read together with the Act, will provide a framework for furthering access to early childhood education at the county level. Scholars corroborate this argument. To illustrate, in his article Murunga interprets the inclusion of pre-primary education in the definition of basic education as an opportunity to influence the implementation of ECDE at county level.⁹⁶

In practice, specifically relating to the two issues flagged out, an observation is made in Kenya's report to the African Commission. Kenya reports:⁹⁷

The government recognises the significant social and economic payoffs derived from investment in Early Childhood Development and Education (ECDE) including overcoming children educational disadvantages for poor children, supporting parents ... Previously investment in this area has been left mostly to the household, private sector and religious organisations. Since 2012, the processing of capitation grants to support ECDE with a budget of Kshs 1.6 billion to about 19 000 public ECDE centres with 1.4 million children commenced.

Hence, the government is taking concrete steps towards realising free and compulsory education at pre-primary level. Although not conclusively, one can argue that the government's shift of commitment to ECDE is predicated by an interpretation of basic education as it is provided for in the law.

93 As above.

94 Ministry of Education 'Education for All End of Decade Assessment' (2001-2010) http://www.unesco.org/new/fileadmin/MULTIMEDIA/FIELD/Nairobi/EFA_EDA_Report_2012_Web_Version_1_.pdf (accessed 9 September 2015).

95 County Early Childhood Education Bill 2014 <http://kenyalaw.org/kl/fileadmin/pdfdownloads/bills/2014/CountyEarlyChildhoodEducationBill2014.pdf> (accessed 17 September 2016).

96 J Murunga 'Devolving early childhood development education in Kenya: Policy challenges and opportunities' (2015) 3 *International Journal of Education and Research* 611.

97 CRC Committee Consideration of reports submitted by state parties under article 44 of the Convention: Combined 3rd, 4th and 5th periodic report of state parties due in 2012, Kenya 30 March 2015, CRC/C/KEN/3-5 http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Countries.aspx?CountryCode=KEN&Lang=EN (accessed 9 September 2015).

4.2 Equality and non-discrimination as a guiding principle

The second issue to be examined is the guiding principles. Section 4 of the Act provides for the guiding principles, which are fundamental in interpreting the substantive provisions of the Act. The Act, among other principles, is anchored in free and compulsory basic education for every child, equality and non-discrimination, and equality of education standards, including the medium of instruction to every child in public school. Other principles include the encouragement and protection of the marginalised, persons with disabilities and those with special needs and, finally, the provision of appropriate human resources, funds, equipment, infrastructure and related resources to meet the needs of every child in basic education.⁹⁸

Incontrovertibly, the principles under section 4 of the Act are centred on equality and non-discrimination. The Act, however, does not explicitly refer to reasonable accommodation. The Basic Education Regulations 2015 resolve this dilemma. It obliges all basic education institutions⁹⁹ to provide reasonable accommodation¹⁰⁰ to children with disabilities.¹⁰¹ These principles are indispensable when assessing the quality of pre-school education for children with disabilities.

From one perspective, it is about the application of the law across the board, regardless of the service provider, as long as services are open to the general public.¹⁰² In the case of ECDE for children with disabilities, therefore, it is an evaluation of whether children with disabilities equally access quality services in both public and private schools. A specific element to consider in examining whether children with disabilities equally access quality education services is to assess the provision of reasonable accommodation, which requires immediate realisation.¹⁰³ The CRC Committee draws the attention of states to potential discrimination in access to quality services for young children, especially where health,

98 Secs 4(a), (b), (f), (g), (s) & (u) Basic Education Act 2013.

99 The institution of Basic Education and Training is defined to include pre-primary school, primary or secondary school, an adult education institution and a middle-level college.

100 Although the Basic Education Regulations 2015 do not define reasonable accommodation, the CRPD, which forms part of Kenya's law, in line with art 2(6) defines reasonable accommodation. Kenya has also been urged to define reasonable accommodation in its legislation. Concluding Observations of Kenya, CRPD/C/KEN/CO/1 para 10(b).

101 Basic Education Regulations 2015, sec 25(a).

102 Art 4(1)(e) CRPD.

103 JE Lord & R Brown 'The role of reasonable accommodation in securing substantive equality for persons with disabilities' doi: 10.2139/ssrn.1618903 (accessed 12 September 2015); Report of the Office of the United Nations High Commissioner for Human Rights (OHCHR) 'Thematic study on the rights of persons with disabilities to education' 18 December 2013, A/HRC/25/29; CRPD Committee Consideration of reports submitted by state parties under article 35 of the Convention on the Rights of Persons with Disabilities, Spain, 19 October 2011, CRPD/C/ESP/CO/1 para 44.

education, welfare and other services are not universally available and are provided through a combination of state, private and charitable organisations.¹⁰⁴ The provision of ECDE in Kenya is a combination of efforts by the state and the private sector. Research indicates that in the past most ECDE providers have not taken into consideration the needs of children with disabilities.¹⁰⁵ Kenya should adopt a holistic approach in the operationalisation of equal access to ECDE by children with disabilities. This should encompass a monitoring mechanism, funding, data disaggregation of the number of children with disabilities accessing ECDE in both the private and public sector and an awareness campaign to combat stereotypes and prejudices.

4.3 Implementation

In accordance with the Fourth Schedule of the Constitution of Kenya, Part III of the Act devolves pre-primary education.¹⁰⁶ The County Education Board, together with the county government, is obliged to oversee the operation and management of pre-primary education.¹⁰⁷ In addition, the county government is obliged to report annually to the Cabinet secretary on the progress of education.¹⁰⁸ Part IV of the Basic Education Act obligates the Cabinet secretary to implement free and compulsory basic education, including establishing pre-primary, primary and secondary schools within a reasonably accessible distance within a county.¹⁰⁹ The use of 'shall' in both clauses places a mandatory obligation on government to provide free and compulsory education.¹¹⁰

Part IV further prohibits the charging of tuition fees; the denial of admission to school on different grounds, including disability; places a mandatory responsibility on parents to cause admission to a child; and criminalises the failure to fulfil this duty.¹¹¹ Part VI on special needs education obligates the Cabinet secretary to establish and maintain public special schools, including pre-primary, primary and secondary schools.¹¹²

From these legislative provisions, four main observations may be made in relation to access to pre-primary education, both in special and inclusive environment. The first observation is that the Basic Education Act encourages the community-based service provision approach, which

104 CRC Committee para 12.

105 Ministry of Education 'Task force on the re-alignment of the education sector to the Constitution of Kenya 2010, towards a globally competitive quality education for sustainable development' Task force report (2012).

106 Ch 11 Constitution of Kenya.

107 Sec 18(a) Basic Education Act 2013.

108 Sec 18(k) Basic Education Act 2013.

109 Secs 28(1) & (2) Basic Education Act 2013.

110 As above.

111 Secs 29, 30 & 34 Basic Education Act 2013.

112 Sec 44 Basic Education Act 2013.

promotes social inclusion.¹¹³ This is a very positive step compared to past experiences. Kamundia observes that the lack of accessible schools in the community has forced children with disabilities to opt for boarding schools far away and being separated from their families at a tender age.¹¹⁴

The second observation is that the Basic Education Act safeguards choice; the law prohibits the denial of admission to any school on the basis of disability. The non-rejection clause reinforces the provisions of the CRPD¹¹⁵ to which Kenya is a party. The Office of High Commissioner for Human Rights (OHCHR) observes that non-rejection clauses require immediate realisation and are applicable on an individual basis and should not be subjected to reasonability tests.¹¹⁶ Further, the OHCHR calls for an end to the rejection of students in mainstream schools and urges states instead to provide appropriate support to facilitate their inclusion.¹¹⁷ In its review of Sweden, for instance, the CRPD Committee raised its concern over the refusal of admission to certain pupils with disabilities on the grounds of organisational and economic hardship.¹¹⁸ The Committee urged Sweden to guarantee the inclusion of all children with disabilities in the mainstream education system and to provide the necessary support.¹¹⁹ Similarly, in its recommendation to Kenya, the CRPD Committee urged Kenya to 'immediately adopt a non-rejection policy for children with disabilities enrolling in regular schools and to provide reasonable accommodation'.¹²⁰

The third observation is that the Basic Education Act creates a mandatory responsibility on the Cabinet secretary, in consultation with the County government, to establish pre-primary schools. This responsibility is broadly interpreted to include all the resources that ensure the efficient and effective running of a learning institution. It is to be noted, however, that these responsibilities exist in a new system of devolved government which, as alluded to earlier, has the primary responsibility of the implementation of pre-primary education. As a new regime of governance, devolution is under test. While some counties have set up structures and are effectively running, others are still struggling.¹²¹ With regard to the implementation of ECDE, the National Education Sector Plan recognises

113 Art 19(c) CRPD.

114 E Kamundia 'Choice, support and inclusion: Implementing article 19 of the CRPD in Kenya' unpublished LLM dissertation, National University of Galway-Ireland, 2010 88.

115 Art 24(2)(a) CRPD.

116 OHCHR (n 103 above).

117 As above.

118 CRPD Committee Concluding Observation to Sweden CRPD/C/SWE/CO/1, para 47.

119 CRPD Committee Concluding Observation to Sweden (n 118 above) para 48.

120 CRPD Committee Concluding Observation to Kenya, CRPD/C/KEN/CO/1 para 44 (b).

121 M Laibuta 'Implementing devolution in Kenya: Challenges and opportunities two months on' <http://www.constitutionnet.org/news/implementing-devolution-kenya-challenges-and-opportunities-two-months> (accessed 11 November 2016).

that regional inequalities have negatively impacted on universal access to ECDE with some counties, specifically those from the northern region of Kenya recording the lowest percentage.¹²² To close existing gaps, the National Education Sector Plan calls on counties to expand the budget allocation for ECDE, and to train parents and teachers on enhancing care and education for younger children.¹²³ To ensure accountability and compliance, the development of a partnership with parents, civil society, in particular representative organisations of persons with disabilities and oversight authorities such as human rights institutions, is an indispensable element.

The CRPD obligates states to involve and consult persons with disabilities and representative organisations in the development and implementation of legislation and policies related to their issues.¹²⁴ Joint efforts between counties and representative organisations of persons with disabilities will be necessary to support the setting up of inclusive pre-primary schools. The independent monitoring framework, which includes the National Gender and Equality Commission and the Kenya National Commission on Human Rights, should also monitor the extent to which counties are complying with this obligation and identifying areas for harmonisation with universal education standards.¹²⁵

The fourth observation is that the Basic Education Act creates a mandatory responsibility of parents to ensure the admission of children to schools and criminalises the failure to fulfil this duty. For many children with disabilities, this is a shield – a shield to protect them from prejudices and stereotypes propagated within the family. These stereotypes have been used to justify denying children with disabilities the right to education.¹²⁶

Teachers recounted instances where they had to literally go to find children locked away by parents who saw no value in educating a child with disability. Many parents viewed such children as unproductive members of society or as ‘victims’ to be hidden.

The Act further puts a monitoring measure as a reinforcement mechanism to the mandatory responsibility of enrolling children with disabilities in school. It obligates the Cabinet secretary and the county Board on education to ensure completion and retention of children in school. It further calls for submissions of an annual report by the county

122 Ministry of Education, Science and Technology ‘National Education Sector Plan, Volume one: Basic Education, programme rationale and approach 2013/2014-2017/2018, para 18 <http://www.globalpartnership.org/fr/download/file/45908> (accessed 15 June 2016).

123 Ministry of Education, Science and Technology (n 122 above) para 19.

124 Art 4(3) CRPD.

125 Arts 33(2) & (3) CRPD. See also Draft Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Persons with Disabilities <http://www.achpr.org/news/2016/04/d216/> (accessed 15 June 2016).

126 Kenya National Commission on Human Rights (n 66 above) 37.

governments to the national government on achievements of each academic year. The monitoring mechanism coupled with the parental responsibility to ensure admission of children with disabilities is a safeguard to keep up-to-date information on the extent to which children with disabilities are accessing education.

4.4 Prohibition of inhumane treatment of children with disabilities in education settings

The final observation is the prohibition and criminalisation of acts of torture, cruel, inhuman or degrading treatment, whether physical or psychological of children with disabilities in education settings.¹²⁷ Research indicates that children with autism are disproportionately subjected to practices that deprive them of their liberty in schools. This is usually conducted on the account of dangerousness to oneself or others.¹²⁸ Reports indicate that children with autism are locked in cages or in isolation rooms during episodic moments. Prolonged restraint amounts to torture. This provision, therefore, may be interpreted as a safeguard to protect children with disabilities from being subjected to inhumane practices. It also provides a ground for parents as equal participants in education to question any measure taken against their children, which does not reflect the best interests of the child.

Finally, the Basic Education Act obligates the County Education Board to commission education-related research. This is paramount especially in relation to pre-primary education. Education assessment and resource centres play a critical role of assessing children and placing them in schools. For a very long time, these centres have remained understaffed and underfunded, and there is little information on how to improve their efficiency.¹²⁹ This includes adopting a multifaceted approach of assessing children's needs for support to be in an inclusive environment as opposed to the traditional medical model of identification to be placed in a special school. Research, therefore, constitutes one of the elements towards effective and efficient education assessment centres.

5 Opportunities for implementation

In 2008, Kenya adopted a blue print plan¹³⁰ as a strategy towards the implementation of the Millennium Development Goals (MDGs) under

¹²⁷ Sec 36(1) Basic Education Act 2013.

¹²⁸ E Macdonald 'Cage for autistic child at Canberra School: A shocking wake-up call' <http://www.watoday.com.au/comment/cage-for-autistic-child-at-canberra-school-a-shocking-wakeup-call-20150909-gjictu.html> (accessed 9 September 2015).

¹²⁹ Kenya National Commission on Human Rights (n 60 above.)

¹³⁰ Kenya's Vision 2030 <http://www.usaid.gov/sites/default/files/documents/1860/3%29%20Vision%202030%20Abridged%20version.pdf> (accessed 9 September 2015).

three main pillars: the political pillar, the social pillar and the economic pillar. Education falls under the social pillar. Under the current medium term programme (MTP2), the mainstreaming of ECDE is under the flagship projects for implementation.¹³¹ The goals include a review of the ECDE policy framework; the establishment of ECDE resource centres in 47 counties; and the provision of capitation grants with adjustments for children with disabilities enrolled in public ECDE centres.¹³² Further, the Sustainable Development Goals (SDGs) represent an opportunity for implementation of inclusive ECDE for children with disabilities. The SDG message to leave no one behind seeks to ensure that the targets are met for all peoples and segments of society, including persons with disabilities. Kenya, therefore, will be required to put in place measures to ensure inclusive and equitable early childhood education.

6 Proposals for future research and conclusion

Finally, the article poses two challenges for future research: First, the Act provides that pre-primary education is education provided for children between the ages of four and five years. The standard period of early childhood development and education according to UNESCO is birth to eight years. The question of what happens to children with disabilities before four years poses the challenge of whether the age of four to five is enough for early intervention in relation to the education of children with disabilities. Of specific concern here is birth registration and how this affects subsequent stages of learning, especially because of the primacy of documentation in registering in the education system. This begs the question of what possible ways the government can use to ensure that children between the ages of birth to four are not left out in early interventions as the success of the intervention between ages four and five depends on prior interventions.

Second, how free is free education for children with disabilities at all levels? The Basic Education Act provides that no tuition fee shall be charged to any pupil. Access to education requires a multi-dimensional approach. Availability as a core element of education is a broad aspect more than just affordability and, for learners with disabilities, especially persons with high support needs, this requires taking a step further to the provision of necessary support such as assistive devices, dietary provisions and health checks, especially for children of tender age. The challenge here for pre-primary education, as enshrined in the Act, is how proper dietary provisions and early intervention measures such as rehabilitation will be

131 Ministry of Devolution and Planning 'Second medium term plan 2013-2017: Transforming Kenya pathway to devolution, socio-economic development, equity and national unity' (2013) <http://www.usaid.gov/sites/default/files/documents/1860/1%29%20Second%20Medium%20Term%20Plan%202013%20-%202017.pdf> (accessed 9 September 2015).

132 As above.

achieved at school and family level, given the indirect relationship between poverty and persons with disabilities. Should the government enhance social protection programmes to families of children with disabilities?

In conclusion, the article argues that the Basic Education Act does provide a legal pathway of promoting pre-primary school for children with disabilities in Kenya. The Act and the SDGs¹³³ reinforce one another. The Act can offer guidance for the implementation of pre-primary education for children with disabilities, while the SDGs can contribute to the realisation of this right. Moving from paper to practice, therefore, requires adequate funding which should be earmarked at county budgeting, keeping up-to-date statistics which will assist in planning and adopting universal design as a way of dealing with accessibility challenges. The effective development and implementation of ECDE will also require effective participation and the involvement of disabled persons' organisations and representative organisations of children with disabilities, hence the need for partnership between civil society and parents. Additionally, the monitoring framework under article 33(2) of the CRPD should monitor the extent to which counties are promoting access to ECDE by children with disabilities.

133 See Goal 4 on education.

CHAPTER 2

ACCESS TO JUSTICE OF CHILDREN WITH DISABILITIES IN DEFILEMENT CASES IN MALAWI

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Summary

The sexual abuse of children with disabilities is a serious problem in society requiring responses tailored to meet their unique needs. In most cases such abuses remain unreported and, if reported, the children face many challenges to access justice within the criminal justice system. This article aims at examining in detail the legal treatment of cases involving children with disabilities in defilement offences in Malawi. The article will attempt to answer the question of whether Malawi respects the rights to access justice of children with disabilities, provided for in various international instruments as well as in local statutes, including article 13 of the CRPD and section 41 of Constitution of Malawi. The right to access justice refers to the ability of people to seek and obtain a remedy through formal and informal justice institutions, and in conformity with human rights standards. The article analyses the ability of children with disabilities in defilement offences to seek and obtain a remedy through formal institutions of justice. The article further analyses the legal and social barriers available to children with disabilities in defilement cases to access the formal systems and structures of the law. In so doing, the article examines four components of the right to access justice as areas of focus, namely, access to information; legal representation; a child's ability to participate in legal proceedings; and the availability of appropriate training of relevant professionals in the field of criminal justice. It is argued that, achieving access to justice for children with disabilities requires comprehensive social and legal support, as well as a constant analysis of legal structures in place that make it more difficult for children with disabilities in defilement cases to be empowered by the law.

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1 Introduction

Although sexual abuse of children is outlawed in almost all countries with severe criminal penalties, it persists as a significant global problem violating the fundamental human rights of children.¹ The abuse takes different forms, including defilement, also known as statutory rape, a common sexual offence in Malawi. Defilement is defined as having sexual intercourse with a girl below the age of 16 or a person suffering from a mental disability with or without her consent.² The seriousness of the offence cannot be overemphasised as it is committed against children who are among the most vulnerable persons in society. The threat of contracting HIV and other sexually-transmitted diseases makes the offence even more damaging to young children, and its negative effect is more pronounced in children with disabilities.³ Other studies have revealed that children with disabilities are at greater risk to suffer sexual abuse and other forms of abuse that negatively impact their enjoyment of human rights on an equal basis with other children.⁴ Further, studies have shown that there has been an increase in sexual abuse cases against children in sub-Saharan Africa.⁵ For instance, according to World Vision Malawi, the sexual abuse and exploitation of women and children have continued to rise to unprecedented numbers posing challenges to the protection, well-being, survival and development of children.⁶ Although there are currently no studies in Malawi providing substantial information on or quantifying the additional vulnerability to sexual abuse of children with disabilities,

- 1 UNICEF 'Sexual violence against children' (2015) http://www.unicef.org/protection/57929_58006.html (accessed 2 March 2016); Centres for Disease Control and Prevention 'Prevalence of sexual violence against children and use of social services – Seven countries, 2007-2013' (2015) 64 *Morbidity and Mortality Weekly Report* 565-569; M Stoltenborgh et al 'A global perspective on child sexual abuse: Meta-analysis of prevalence around the world' (2011) 16 *Child Maltreat* 79-101.
- 2 Secs 138 & 139 Penal Code Act 22 of 1929 (amended 2010). See also *Republic v Goliati* [1971-72] African Law Reports (Malawi Series) 251, where the court established that a child of 13 years was incapable of giving consent to sexual activity. See also *Republic v William John* Criminal Cause 13 of 2009 affirming this position. Defilement differs from rape as provided in the law in the sense that defilement occurs when a person performs an unlawful sexual act on a girl who is incapable of consenting to the act (ie below 16 years of age or with a mental disability), while rape is committed by a person who has sexual intercourse with a girl or woman capable of consenting (ie older than 16 years) without her consent.
- 3 See generally M Higgins & J Swain *Disability and child sexual abuse: Lessons from survivors' narratives for effective protection, prevention and treatment* (2010); I Hershkowitz et al 'Victimization of children with disabilities' (2007) 77 *American Journal of Orthopsychiatry* 629-635.
- 4 African Child Policy Forum (ACFP) *Children with disabilities in Africa: Challenges and opportunities* (2011).
- 5 K Lelor 'Child sexual abuse in sub-Saharan Africa: Child protection Implications for development policy makers and practitioners' (2005) in Development Research Briefings 3, Centre for Development Studies, University College of Dublin, <http://arrow.dit.ie/cgi/viewcontent.cgi?article=1001&context=aaaschslrep> (accessed 8 February 2017).
- 6 World Vision Malawi 'Children's rights in Malawi' (2010) http://lib.ohchr.org/HRBodies/UPR/Documents/session9/MW/WVI_WorldVisionInternational.pdf (accessed 9 February 2017).

elsewhere studies have revealed a strong association between disability and child maltreatment.⁷ This indicates that children with disabilities are significantly more likely to experience abuse than their peers who are not disabled.⁸ This can be attributed to a number of reasons, including the myth that sexual intercourse with a girl with a disability cures HIV and AIDS.⁹ A report by the Malawi Human Rights Commission revealed that there was a belief in some quarters that men who are HIV positive or suffering from AIDS will get cured if they sleep with a young girl or a girl with a disability.¹⁰ Such myths have threatened the lives of children with disabilities as they are more likely to be sexually abused due to their vulnerable state.¹¹ States need to take measures to ensure the full and equal enjoyment of all human rights and fundamental freedoms by children with disabilities. One such measure is to strengthen the capacity of the criminal justice system to facilitate the right to access justice for victims with disabilities in defilement cases. Children's access to justice, as defined by United Nations (UN), is 'the ability to obtain a just and timely remedy for violations of rights as put forth in national and international norms and standards (including the Convention on the Rights of the Child)'.¹² The Economic and Social Council's Guidelines on Justice in Matters involving Child Victims and Witnesses of Crime provide good practices, standards and principles relevant for effective criminal justice for children with disabilities in defilement cases.¹³ These guidelines require that both legal and social support must be established to enhance the role of child victims in the justice process.

The article examines the legal and social supports that are in place to assist disabled victims of defilement offences in accessing justice before courts of law. The article begins by delimiting the scope of the study and the methodological approach undertaken after this brief introduction. This is followed by an overview of the legal framework protecting children from sexual abuse in Malawi. The international standards and guidelines on access to justice are then explained and, using four main identified areas in ensuring access to justice for children with disabilities in defilement cases,

- 7 See L Jones *et al* 'Prevalence and risk of violence against adults with disabilities: A systematic review and meta-analysis of observational studies' (2012) 380 *Lancet* 899-907; EM Lund & J Vaughn-Jensen 'Victimisation of children with disabilities' (2012) 380 *Lancet* 867-869.
- 8 K Stalker & K McArthur 'Child abuse, child protection and disabled children: A review of recent research in child abuse review' (2012) 21 24-40.
- 9 F Kisanga 'Child sexual abuse in urban Tanzania: Possibilities and barriers for prevention' unpublished PhD thesis, University of Umea, 2012 6.
- 10 Malawi Human Rights Commission 'Malawi human rights 2015 Report' <https://www.state.gov/documents/organization/252913.pdf> (accessed 9 February 2017).
- 11 H Brown 'Sexual abuse of children with disabilities' in Council of Europe *Protecting children from sexual violence – A comprehensive approach* (2011)103-117.
- 12 UN Common Approach on Justice for Children (2008) 4 https://www.essex.ac.uk/armedcon/story_id/UNCOMMON.pdf (accessed 20 September 2008).
- 13 UN Economic and Social Council (ECOSOC) *UN Economic and Social Council 2005/20: Guidelines on justice in matters involving child victims and witnesses of crime*, 22 July 2005, E/RES/2005/20, <http://www.refworld.org/docid/468922c92.html> (accessed 8 August 2017).

the findings from interviews are discussed and analysed. The last section concludes and makes recommendations.

2 Objectives and methodology

The main objective of the article is to examine access to justice for children with disabilities as victims of defilement offences on issues pertaining to access to information, legal representation, a child's ability to participate in legal proceedings and the availability of appropriate training of relevant professionals in the justice field. The rationale was to uncover barriers affecting access to justice in the criminal justice system of children with disabilities. The article employed a human rights-based approach as its methodology.

A human rights approach involves asking what human rights aspects are affected by the issue under examination.¹⁴ This approach assisted in determining whether the Malawian Constitution and other legislation in Malawi are in line with international standards prescribed in human rights instruments in protecting children with disabilities from sexual abuse. The approach, therefore, assisted in assessing whether the Malawian government is fulfilling its duty under international human rights law to promote and protect the rights of children with disabilities. It also looks at the duties and responsibilities of duty bearers and assesses whether they have the knowledge, authority and resources to enforce the law.

The article used various methods of obtaining information, which mainly involved a documentation review. The main method used was desk review, which involved the reading of materials relating to the topic of study, such as court records, international law instruments, books, court decisions, statutes and journal articles, among others. The desk review was supplemented with individual interviews and observations. A total of 21 interviews were conducted using face-to-face interaction. Key informants, who included officials in various institutions directly involved with the prosecution of defilement offences against children with disabilities, such as police prosecutors and judicial officers, among others, were also targeted.

The interviews were conducted at two magistrate's courts in the Blantyre district of Malawi, specifically at the Blantyre Magistrate's Court and at the Soche Child Justice Court. Blantyre Magistrate's Court was selected as it is the centre of all magistrate's courts in the southern region of Malawi; it has more magistrates and is well resourced compared to other

14 See generally P Uvin 'From the right to development to the rights-based approach: How "human rights" entered development' (2007) 17 *Development in Practice* 597; P Gready 'Rights-based approaches to development: What is the value-added?' (2008) 18 *Development in Practice* 735.

magistrate's courts in the region. The Soche Child Justice Court was chosen because of its specialisation in children's cases. Before conducting the interviews, consent was sought from officials of the two courts and other organisations visited who granted permission to interview relevant respondents to the research. Further, consent was also sought from each respondent interviewed and the respondents were assured that the information obtained was only for academic purposes.

3 The offence of defilement

The Malawian Constitution,¹⁵ as supreme law of the land, has guaranteed children protection against sexual abuse by protecting them against any treatment that is likely to be harmful to their health, or to their physical, mental or spiritual or social development.¹⁶ The defilement of children with disabilities forms part of sexual abuse and, therefore, may be categorised as treatment that is harmful to the wellbeing of a girl child. The Constitution has also specifically provided for the right to equality and prohibition of discrimination on the basis of disability in section 20. Further protection against the sexual abuse of children with disabilities can be found in section 24 of the Constitution, which provides for the rights of women, including the right not to be discriminated against on the basis of gender and status. It requires legislation to be passed to eliminate customs and practices that discriminate against women, particularly practices that, among other things, promote or perpetuate sexual abuse. Malawi also passed the Gender Equality Act in 2013, which legislates against discrimination on the basis of sex and prohibits a person from treating another person less favourably than he or she would treat a person of his or her own sex.¹⁷ This is partly in response to the fact that most victims of sexual abuse in Malawi are women and girls and the fact that cultural beliefs, practices and stereotypes contribute to the prevalence of such offences.¹⁸

The Penal Code in Malawi provides for the offence of defilement of girls in two provisions. The first is section 138 of the Code, which defines the general offence of defilement as applying to any person who unlawfully has carnal knowledge of a girl under the age of 16. This provision applies to all girls, including those with disabilities. The offence carries a maximum penalty of 14 years' imprisonment. The Code also proscribes defilement specifically as regards women and girls with mental disabilities in section 139. The section provides that a person who has or attempts to have sex with a female 'idiot or imbecile' commits the offence of defilement of an idiot or imbecile. The maximum penalty for this offence,

15 Republic of Malawi Constitution Act 20 of 1994.

16 Sec 23(4)(c) Malawian Constitution.

17 This is also provided for in sec 20(1) of the Constitution.

18 World Vision Malawi (n 6 above) 3.

similarly, is 14 years' imprisonment. This section, according to Justice Mzikamanda in *Kanyinji v Republic*, is meant to 'protect mentally deranged girls or women'.¹⁹ The terms 'idiot' and 'imbecile', although linked with psychology and intelligence with an IQ test, should be replaced with more appropriate terms as they are debasing and derogatory.²⁰ The naming of a person as an imbecile or idiot gives a negative perception of the victim and it takes away from the seriousness of the offence. The law should best refer to persons with such disabilities as persons with intellectual disabilities as opposed to names that promote stigma and discrimination.

Further, by treating girls with mental disabilities separately from those without disabilities and other types of disabilities, it may be argued that section 139 of the Penal Code is discriminatory. As indicated above, both sections on defilement provide for the same penalty for the offences. Therefore, there seems to be no good reason to have a separate section to protect children with mental disabilities other than to stigmatise them by calling them imbeciles and idiots. This negative perception in the law is shared by some personnel in the justice system. Some personnel have no understanding of issues relating to disability and usually have a negative perception of people with mental disabilities, labelling them as 'people of unsound mind' or people who are 'insane' and who should be placed in their own category and not be treated as equals with others.²¹

In my years of service, I have never come across cases of children with disabilities. What I have dealt with is defilement of imbeciles but that is not a disability; such persons are just insane.

A perception such as the one above further victimises children with disabilities and it is essential that the law should not encourage such negative attitudes, as these attitudes may result in the unequal treatment of children with disabilities, especially mental disabilities, and children without disabilities. The former would thus be disadvantaged as they would not be accorded special attention and treatment before the law to enjoy equal protection as guaranteed in article 5 of the of the Convention on the Rights of Persons with Disabilities (CRPD).²²

In addition, sections 138 and 139 can be faulted for failing to protect male children with disabilities from defilement offences. The sections

19 [2008] MWHC 237 241. See also *Republic v Peter Jasi* Confirmation Case 1026 of 1994; *Republic v Andreyo William* Confirmation Case 565 of 1994.

20 M Rapley *The social construction of intellectual disability* (2004) 32; MJ Tassé 'What's in a name?' (2013) 51 *Intellectual and Developmental Disabilities* 113-116. See also generally L Salvador-Carulla et al 'Intellectual developmental disorders: Towards a new name, definition and framework for "mental retardation/intellectual disability" in ICD-11' (2011) 10 *World Psychiatry* 175-180.

21 Police prosecutor at the Child Justice Court.

22 Convention of the Rights of Persons with Disabilities GA Res. 61/611, adopted on 13 December 2006, entered into force on 3 May 2008, which states that all persons are equal before the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

specifically mention the offence of defilement against girls, excluding boys from the protection of the provisions. This is a serious omission as boys with disabilities are also much more vulnerable to sexual abuse by adults. Other countries in the region have changed the defilement offence and made it gender-neutral so that both girls and boys are protected.²³

4 Conceptualising access to justice of children with disabilities as victims of the offence of defilement

Access to justice is a fundamental right in itself and an essential prerequisite for the protection and promotion of all other human rights.²⁴ As a concept, access to justice for children with disabilities requires the legal empowerment of the children to be able to obtain a just and timely remedy for violations of their rights.²⁵ Access to justice guarantees the speedy and fair administration of justice accompanied by appropriate support for children with disabilities as victims of the offences through, among other things, access to relevant information, legal and other services for counselling and social assistance/support and the right to participate in criminal trials where relevant and appropriate.²⁶ Article 13 of the CRPD provides for the rights of access to justice of persons with disabilities. The article provides that states shall ensure effective access to justice for persons with disabilities on an equal basis with others, which shall include the provision of procedural and age-appropriate accommodations to ensure the effective participation of persons with disabilities in legal proceedings.²⁷

The Malawian Constitution has also provided for the right to access justice for its citizens, and stipulates in section 41 that every person shall have a right of access to any court of law for final settlement of legal issues and a right to an effective remedy by a court of law for acts violating his or her rights and freedoms as granted by the Constitution. Malawi passed a Disability Act in 2012 that has translated almost all the rights provided in the CRPD into local context. It is surprising to note that the Disability Act has not legislated on the right to access justice. This is a serious omission given the difficulties people with disabilities have in accessing justice at all levels.

23 See, generally, J Thompson *Rape sentencing study: Statutory sentencing for rape, defilement and sexual assault in East, Central and Southern Africa* (2012).

24 UN Office of the High Commissioner for Human Rights (OHCHR) 'Access to Justice for Children'. Report of the UN High Commissioner for Human Rights (2013) 3 UN General Assembly, A/HRC/25/35.

25 See UN Common Approach on Justice for Children (n 12 above) 4. Legal empowerment involves strengthening their capacity to exercise their rights, either as individuals or as members of a community.

26 OHCHR (n 24 above) 3-4.

27 Art 13 CRPD.

The complexity of the justice system requires that children, especially children with disabilities who are also victims of defilement, be accorded special guarantees or reasonable accommodation to ensure access to justice. Reasonable accommodation has been defined in article 2 of the CRPD as

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 of all human rights and fundamental freedoms.

The obligation of reasonable accommodation entails that persons or entities need to make certain modifications or adjustments to allow persons with disabilities to fully participate in the relevant sphere of life.²⁸ In terms of the right of access to justice of children with disabilities in defilement cases, four main aspects that would require reasonable accommodation may be isolated in the criminal justice system, namely, access to information; legal representation; a child's participation in proceedings; and training of personnel.²⁹

4.1 Access to court facilities and information

Article 9 of the CRPD focuses on accessibility and stipulates that state parties shall take appropriate measures to ensure that persons with disabilities have access on an equal basis with others, among other things, to buildings and other indoor and outdoor facilities.³⁰ Further, under article 4 state parties have an obligation to provide accessible information to persons with disabilities about mobility aids, devices and technologies. This right is provided for at the national level in section 8 of the Malawi Disability Act, which states that the government shall ensure the attainment of a barrier-free environment that enables persons with disabilities to have access to public buildings. The state is also mandated to develop sign language as a national language, among others. However, the research noted that children with disabilities who are victims of defilement offences have challenges in accessing justice in the courts of law in a number of areas, as follows:

4.1.1 Access to legal information

The provision of legal information poses another barrier for children with disabilities in accessing justice. The two courts that were under study had

28 European Commission 'Reasonable Accommodation for Disable People in Employment' (2016) http://ec.europa.eu/justice/discrimination/files/reasonable_accommodation_in_employment_final2_en.pdf (accessed 22 December 2016).

29 These aspects are drawn from the good practices established by the OHCHR. See OHCHR (n 24 above) paras 18-53.

30 Sec 9(1)(a) CRPD.

no translated legal materials suitable for different types of disabilities. Further, the lack of legal materials was compounded by an absence of legal personnel trained to work with children with disabilities. Prosecutors reported that this problem was much more evident when working with children with intellectual disabilities. The prosecutors reported that in cases where the only available witness is the victim with an intellectual disability, such cases often end in acquittal. This is so because it is difficult for prosecutors to get information from the child whom they have no expertise to work with. This leads to insufficient information being tendered before the court, which cannot reach the standard required in criminal offences of convicting an accused person beyond a reasonable doubt.³¹

Children with visual and speech disabilities are also affected due to communication challenges. Neither the Blantyre Magistrate's Court nor the Child Justice Court has trained personnel to assist in interacting with children with visual and speech disabilities. These courts also have no trained staff knowledgeable in sign language interpretation, and it is difficult to communicate with children who have a disability in relation to speech. Prosecutors reported that in such cases they consult with organisations working with persons with disabilities or relatives of the child with a disability to help them with communication. However, one magistrate said that this approach had its own challenges:³²

When we have cases of children with a speech disability, we most of the times rely on their guardians to help us with communication. However, we are not always sure that what the guardian is communicating to the court is what the child is really saying. This compromises the course of justice. An ideal situation would have been our own court interpreters communicating with the child and the court but that is not happening at the moment as we have no trained court interpreters in that area.

Further, neither of the two courts has any legal information translated into braille, and one may conclude that children with visual disabilities are denied access to legal information that may be helpful in their case. From the above, therefore, it is very clear that the state has not respected its obligation under the CRPD to provide information, communication and other services³³ such as signage in braille and forms of live assistance and intermediaries, including guides, readers, professional sign language interpreters, to facilitate accessibility to court buildings for persons with disabilities to ensure proper communication and their access to information.³⁴ Such neglect has robbed children with disabilities of their rights to access courts of law and, more importantly, of their rights to

31 Information from a female prosecutor at Blantyre magistrate's court.

32 A magistrate at the Child Justice Court.

33 Art 9(1)(b) CRPD.

34 See also art 21 of the CRPD.

access an effective remedy before courts of law as provided in section 41 of the Malawian Constitution.

4.1.2 *Physical access*

First, mere physical access to the court building poses a challenge to children with disabilities. For example, it was reported at the Blantyre Magistrate's Court that persons with disabilities, especially children, find it difficult to access the court building as it was not built with disabled persons in mind. The building has a number of storeys, and it was reported that in cases where a person with a physical disability was involved, the court had to move to the ground floor and if it could not be moved, the disabled person had to be carried to the upper floors.³⁵

Though this is a new building, it was not built having regard of persons with disabilities. There is a lift that does not work so if there is a person with a disability, the court has to move to the ground floors or the person must be carried on someone's back to the upper floors.

This is a violation of article 9 of the CRPD and has an impact on other rights of persons with disabilities. Among other things, such a challenge in physical access has the potential of discouraging defilement victims with disabilities from pursuing the matter. It also takes away the dignity of the person who is physically challenged who has to be carried to access the buildings of the court. It should be noted that the Federation of Disability Organisations in Malawi (FEDOMA) also did an access audit of the Blantyre Magistrate's Court and found that the court building was not disability-friendly.³⁶

In the case of *Esthe Muller v DoJCD and Department of Public Works*, a wheel chair-bound trial lawyer brought a case against the South African government as she could not access court house buildings. South Africa conceded that the failure to provide proper access was a form of unfair discrimination and committed to rendering the court buildings accessible.³⁷

The above shows that the Malawian government has failed to ensure physical access to courts of law for persons with disabilities, in particular children who are victims in defilement cases. The state can be taken to task for its failure to honour obligations under the CRPD, as was done in the case of *Esthe Muller* above.

35 Clerk at Blantyre Magistrate's Court.

36 Information from a project officer at The Federation of Disability Organisations in Malawi (FEDOMA).

37 J Lord et al 'Prospects and practices for CRPD implementation in Africa (2013) 1 *African Disability Rights Yearbook* 111.

4.2 Legal representation

In all criminal offences in Malawi, the state is considered the aggrieved party: All criminal cases are prosecuted by the state through the office of the Director of Public Prosecutions (DPP) and the Malawi police service. Private practitioners can only prosecute criminal offences after obtaining consent from the DPP.³⁸ In defilement cases relating to children with disabilities, it was discovered that it was mostly police prosecutors who handled these cases in the magistrate's court. All the prosecutors interviewed stated that they had never received any training in relation to the prosecution of cases involving children with disabilities. Most of them reported having challenges in relating with the victims, and said that their lack of expertise affected the outcome of these cases. Article 7 of the CRPD directs state parties to consider the best interests of the child in all actions involving children with disabilities,³⁹ and to have no specialised or trained prosecutors or lawyers to assist these children in legal proceedings does not constitute acting in the best interests of children with disabilities. This is so because the complexity of the justice system makes it difficult for children to access justice. Children are often unaware of their rights and the existence of legal services. Therefore, access to justice for children, especially those with disabilities, depends on the support provided by their parents or legal representatives. The absence of legal aid to children with disabilities can expose them to multiple forms of stigmatisation and discrimination. Children with disabilities need access to appropriate free or subsidised legal assistance to effectively engage with the legal system.⁴⁰

Section 72 of the Child Care, Protection and Justice Act⁴¹ provides that a local government authority shall keep a register of children with disabilities within its area of jurisdiction and give assistance to these children whenever possible in order to enable the children to grow up with dignity among other children and to develop their potential and self-reliance. This article argues that allowing children with disabilities to be represented by prosecutors who are not specialists in disability law or rights is not in conformity with section 72 of the Act and other laws protecting the rights of children with disabilities.

4.3 Children's participation in legal proceedings

Article 12 of the CRPD provides for the rights of persons with disabilities to recognition everywhere as persons before the law. State parties are mandated to recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. This includes the provision

38 Sec 76 Criminal Procedure and Evidence Code, Cap 08:01 of Laws of Malawi.

39 Art 7(3) CRPD.

40 See generally OHCHR (n 24 above).

41 Act 22 of 2010.

of appropriate measures that persons with disabilities may require in exercising their legal capacity. Article 7(3) states that states shall ensure that children with disabilities have the right to express their views freely on all matters affecting them and that their views should be given weight in accordance with their age and maturity on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise this right. Further, section 23(1) of the Malawian Constitution provides that children, regardless of the circumstances of their birth, are entitled to equal treatment before the law.

Children's participation in court proceedings is an empowering experience especially if they are mature.⁴² It affirms their dignity by being treated as individuals and also affirms their equality in society and under the law.⁴³ It may also be essential to ensure that justice is served as their testimony may provide the necessary evidence to secure a conviction. However, there are many concerns about child participation in court, especially when the child has a disability, as the court environment by its nature is hostile and unfavourable to children.⁴⁴ It may involve long waiting periods, and the content of the proceedings in sexual offences by nature is traumatising and uncomfortable.⁴⁵ The court, therefore, has a duty to provide the necessary support and means of participation to children with disabilities in defilement cases so as to ensure effective access to justice. As vulnerable witnesses, there must be special measures and other reasonable accommodations according to the personal needs of the child.⁴⁶ It is necessary that the court and all criminal justice staff be provided with guidance on how particular impairments and disabilities can manifest themselves in court proceedings if effective access to justice is to be guaranteed.⁴⁷

The interviews revealed that children with disabilities rarely take part in the proceedings of their cases, whether as victims or offenders. It also revealed that there were no support, adjustments or aids necessary to ensure such participation. Such support would include the necessary professional experts to assist with the particular disability the child has and ensure effective participation. The required adjustments may include modes of speaking and methods of communication. The court had no such

42 See generally I Ross et al 'Child participation in court' <http://www.law.umich.edu/centersandprograms/pcl/ljohnsonworkshop/Documents/Child%20Participation%20in%20Court.pdf> (accessed 19 September 2015).

43 See ECOSOC (n 13 above).

44 Ross (n 42 above) 9-10.

45 See H Firth et al 'Psychopathology of sexual abuse in young people with intellectual disability' (2001) 45 *Journal of Intellectual Disability Research* 244-252; S Gail et al 'Testifying in a criminal court: Emotional effect on child sexual assault victim' (1992) 57 *Monographs of the Society for Research in Child Development* 1-159.

46 J Talbot 'Fair access to justice? Support for vulnerable defendants in the criminal courts' (2012) Prison Reform Trust Briefing Paper, <http://www.prisonreformtrust.org.uk/portals/0/documents/fairaccesstojustice.pdf> (accessed 19 September 2015).

47 Talbot (n 46 above) 4.

special measures to assist children with disabilities or any person with disabilities who needed to participate in proceedings.

As noted above, a few cases do go through the system, but among these few, the main barrier to their participation is the communication difficulty, resulting in them being viewed as unreliable, not credible or not capable of giving evidence. One prosecutor explained this challenge as follows:

Taking a statement from a child with mental disability for instance is difficult. They keep repeating themselves and are sometimes incoherent. If this is the case, we rather choose not to put them in the witness's box but tender their statement recorded at the police station as evidence and rely on other witnesses to testify in court.

The choice not to use the child in such a trial may be influenced by considerations such as that, as a witness the repetitiveness may require patience on the part of the judge to hear the full testimony from the child, and also the time factor. If both are in short supply, this may work to the disadvantage of the prosecution's case. As will be elaborated further below, the judicial officers are not conversant with the needs of persons with disabilities, let alone their rights. Reasonable accommodation is not a principle one can rely on in such matters.

Further, the incoherence may undermine the prosecution's case as the child may be perceived as an unreliable witness due to a lack of appreciation of the disability and its effects on the child. This was confirmed by one of the senior magistrates interviewed, who stated:

Persons with disabilities are treated as normal people when they testify in a criminal trial. If the disability is regarding mental capacity, unless there is evidence other than of that witness, there is no way proof beyond reasonable doubt can be attained. This is because during testimony, such a witness may change the story many times and not present credible evidence.

In another interview, a court clerk at a specialised court for children also revealed the difficulty in communication where children with disabilities are involved in court proceedings, stating:

It is difficult when a child with a disability has to appear in court and has no guardian or relative escorting them ... We had a 16 year-old girl, who was both deaf and mute in the court one time but had no guardian with her. With no sign language interpreter, the case was only able to continue because the girl was able to read and write. A clerk would write down a question for her to respond by writing back the answer. Otherwise we would have not continued with the case because we have no means to support children with disabilities. But where there is support from the family, it makes it easy. On one occasion a boy with a physical and mental disability and also suffering from epilepsy accused of rape was able to speak and defend himself with the help and

support of his father. He was however found guilty and convicted of the offence.

This reliance on family members is generally discouraged if justice is to be served as their own knowledge and opinion may influence the communication. It is preferable when necessary professionals are available to support the children and necessary aids and technology are also available to ensure reasonable accommodation.

All these factors amount to a violation of the rights of children with disabilities to meaningfully participate in the administration of justice. It is absolutely necessary that courts make provision for special measures for children with disabilities so that they can contribute equally to the administration of criminal justice. The special measures will reduce the stresses associated with the court environment and provide a means for the child to give his or her best evidence. In countries like the United Kingdom, there are not only routine or systematic procedures in place for identifying the particular support needs of such witnesses, but statutes have also been adopted to provide the necessary legal guarantees.⁴⁸

6 Training of personnel

Article 13(2) of the CRPD provides that state parties shall promote appropriate training for those working in the field of administration of justice, such as the police, in order to ensure effective access to justice for persons with disabilities. According to article 4 of the CRPD, state parties have an obligation to promote the training of professionals and staff working with persons with disabilities.

The lack of knowledge was overwhelming in the justice system, from senior to junior officers. 'What laws? I am not aware of any laws on disability rights.' This was the response given when the acting lead magistrate was asked what laws on disability were made available to magistrates in the courts of Malawi. Not only is there a lack of knowledge of laws on disability rights, but also a lack of knowledge on how to work with children or adults with disabilities and a lack of knowledge of the legal concerns faced by persons with disabilities.

For instance, the study conducted found that persons working with children with disabilities in defilement offences, such as magistrates, prosecutors and parents, have no access to information on disability, in general, and specifically on laws and rights of children with disabilities.⁴⁹

48 The Youth Justice and Criminal Evidence Act 1999 defines such witnesses as vulnerable and provides for special measures for assistance or adjustments.

49 Principal Magistrate at Blantyre Magistrate's Court.

At this court we treat all cases equally. Justice sees no face. Children with disabilities are subjected to the same laws applicable to all other children. I am not aware that there is a Disability Act in Malawi, if I have never seen the Act and am not aware of these developments what more of a magistrate in the villages.

Statements such as the above clearly indicate that legal personnel in the justice system who should have been on the forefront protecting the rights of children with disabilities have no access to information on disability to enable them to adjudicate matters in a fair manner.

Further, it was revealed that none of the court clerks, police prosecutors and victim support unit officers had received any training whatsoever on these matters. Very few magistrates had been trained in disability rights. Such a gap in legal knowledge on disability rights and law can adversely affect the legal protection of the human rights of children with disabilities.⁵⁰ However, it is to be noted that the Faculty of Law at the University of Malawi, which trains most of the professional magistrates, has recently introduced a module in disability rights as a component of the Human Rights course in the year 2012.

7 Conclusion

The article discussed access to justice as it relates to children with disabilities in defilement offences. It has been found that the criminal justice system is lacking in terms of facilitating the enjoyment of this right by children with disabilities. Among other things, the courts are not accessible due to a lack of accessible structures, legal information, communication, participation in the proceedings by child victims, and the lack of training of personnel in the system. For access to justice of children with disabilities to be achieved, the courts have to become more open, flexible and responsive to children with disabilities. Malawi is also duty bound to protect and promote the rights of children with disabilities, as it has ratified the CRPD, which provides for access to justice for persons with disabilities.

50 S Ortoleva 'Inaccessible justice: Human rights, persons with disabilities and the legal system' (2011) 17 *ILSA Journal of International and Comparative Law* 281-319.

THE SOCIO-ECONOMIC RIGHTS OF
CHILDREN WITH DISABILITIES IN
SOUTH AFRICA: A COMPARISON
BETWEEN THE AFRICAN CHARTER ON
THE RIGHTS AND WELFARE OF THE
CHILD AND THE CONVENTION ON THE
RIGHTS OF PERSONS WITH DISABILITES

Zita Hansungule and Trynie Boezaart***

Summary

International law plays an important role in the promotion and protection of the socio-economic rights of children with disabilities. International law bolsters the mechanisms used to keep states accountable in the fulfilment of their obligations. This article discusses two international law instruments, namely, the African Charter on the Rights and Welfare of the Child and the Convention on the Rights of Persons with Disabilities, with the aim to examine how they provide for and protect the socio-economic rights of children with disabilities in the South African context and, by implication, children in the African context as a whole. Socio-economic rights place a duty on states to ensure that all people have access to the basic necessities of life, which include education, health care, food and water. Access to these and other services ensures that children with disabilities, like all other children, grow and develop in a manner that is cognisant of their specific needs and best interests. The discussion takes the form of a focused comparison of the two instruments, through which similarities and differences will be highlighted. The discussion further points out the different ways in which these instruments could reinforce the protection provided in national law to ensure that the socio-economic rights of children with disabilities in South Africa are protected and promoted.

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1 Introduction

Children with disabilities constitute the majority of children in South Africa who are in need of special protection and services to ensure their maximum development and inclusion in different spheres of society.¹ These protections and services are provided in different ways, including through the protection and promotion of a number of socio-economic rights. The article acknowledges the important role international law plays in the protection and promotion of socio-economic rights. International law bolsters and backs the mechanisms used to keep South Africa accountable in the fulfilment of its obligations. The mechanisms referred to in this instance are the Constitution and legislation² that contain South Africa's obligations and ways in which these obligations are to be carried out.

The international law instruments that will be the focus of the article are the African Charter on the Rights and Welfare of the Child (African Children's Charter)³ and the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD).⁴ The African Children's Charter is identified as the human rights instrument developed to meet the contextual needs of children in Africa. As such, it includes children with disabilities in South Africa. The CRPD is identified as the recently-ratified human rights instrument that focuses specifically on the rights of persons with disabilities, including children with disabilities.⁵ Both these instruments have an important role to play in ensuring the protection and promotion of the socio-economic rights of children with disabilities in South Africa. The article aims to provide a focused comparison of the two instruments to highlight the similarities and differences between the instruments. It will also point out the different ways in which these instruments could reinforce the national protections utilised to ensure the protection and promotion of the socio-economic rights of children with disabilities in South Africa.

1 Department of Women, Children and Persons with Disabilities, Department of Social Development and United Nations Educational, Scientific and Cultural Organisation (UNESCO) *Children with disabilities in South Africa: A situation analysis 2001-2011* (2012) 11-12.

2 These include the Children's Act 38 of 2005; the Schools Act 84 of 1996; and the Social Assistance Act 13 of 2004.

3 The African Charter on the Rights and Welfare of the Child was adopted July 1990, OAU Doc.CAB/LEG/ 24.9/49 (entered into force 29 November 1999).

4 The United Nations Convention on the Rights of Persons with Disabilities was adopted by the United Nations General Assembly on 13 December 2006 and opened for signature in March 2007.

5 This article will refer to children with disabilities and not persons with disabilities when it discusses the provisions of the CRPD and its implementation. This is done to highlight the fact that children with disabilities form part of the wider group of persons with disabilities who benefit from the CRPD in the same way and, in some cases, more than adult persons with disabilities.

2 Socio-economic rights in the South African context

Socio-economic rights place a duty on the state to ensure that all its members have access to the basic necessities of life, such as education, health care, food, water, shelter as well as access to housing.⁶ Access to these rights and/or services ensures that members of society are able to fully enjoy their other inter-related rights, such as the right to human dignity, equality, non-discrimination, expression and political participation.⁷

Socio-economic rights are set out and protected in the South African Constitution. Some of these rights, and specifically those that will be the focus of the article, are contained in sections 26 and 27 of the Constitution. Section 26 provides, among other things, that everyone has the right to adequate housing. It places a responsibility on the state to take reasonable legislative and other measures to progressively realise this right within its available resources. Section 27 provides that everyone has the right to have access to health care, food, water and social security, as well as social assistance if they cannot support themselves and their dependants. The state must take reasonable legislative and other measures within its available resources to ensure the progressive realisation of each of these rights. These rights are applicable to ‘everyone’, including children with disabilities.

Children, including children with disabilities, have additional socio-economic rights set out in section 28(1)(c) of the Constitution. This section provides that ‘[e]very child has the right ... to basic nutrition, shelter, basic health care services and social services’. Section 28(2) goes on to provide that the best interests of a child should be considered paramount in all matters concerning the child. This section does not contain the ‘available resources’ and ‘progressive realisation’ limitations similar to the sections 26 and 27 rights. This also applies to the section 29(1)(a) right to basic education.⁸ This has resulted in the conclusion that children have ‘immediate and effective access’ to the services and resources protected therein.⁹ This is especially true as far as children who are in the care of the state or in alternative care are concerned.¹⁰

6 J Brickhill & N Ferreira ‘Socio-economic rights’ in I Currie & J de Waal (eds) *The Bill of Rights handbook* (2013) 564.

7 *Government of the Republic of South Africa v Grootboom* 2001 (1) SA 46 (CC) para 23; Brickhill & Ferreira (n 6 above) 564.

8 Sec 29(1)(a) of the Constitution provides, *inter alia*, that ‘everyone has the right to a basic education’.

9 S Liebenberg *Socio-economic rights: Adjudication under a transformative constitution* (2010) 234.

10 *Centre for Child Law v MEC for Education, Gauteng* 2008 (1) SA 233 (T) paras 2271-J.

Despite these commendable constitutional protections, currently there exists no jurisprudence or legislation that ‘gives substance to the meaning of socio-economic rights’ or minimum core.¹¹ International law and regional law, therefore, are very important as they provide guidance on the content of socio-economic rights and ways in which to measure progress in the implementation thereof.¹² In this regard, it is important to note a constitutional obligation imposed by in section 39(1)(b) of the Constitution, which provides that ‘[w]hen interpreting the Bill of Rights, a court, tribunal or forum must consider international law’. The Constitutional Court has recognised that ‘[i]nternational agreements and customary international law provide a framework within which ... [the Bill of Rights] can be evaluated and understood’.¹³

3 An overview of the African Charter on the Rights and Welfare of the Child

The African Children’s Charter has been signed and ratified by 41 African

11 P Proudlock ‘Children’s socio-economic rights’ in T Boezaart (ed) *Child law in South Africa* (2009) 292-302-303. See also M Pieterse ‘Coming to terms with judicial enforcement of socio-economic rights’ (2004) 20 *South African Journal on Human Rights* 406-407; D Blitchitz ‘Giving socio-economic rights teeth: The minimum core and its importance’ (2001) 119 *South African Law Journal* 484. The Constitutional Court has declined to be drawn into making decisions on the ‘minimum core’ applicable to socio-economic rights in South Africa. In *Mazibuko & Others v City of Johannesburg & Others* 2010 (3) BCLR 239 (CC); 2010 (4) SA 1 (CC) paras 59-60, the Constitutional Court was of the view that ‘[f]ixing a quantified content might, in a rigid and counter-productive manner, prevent an analysis of context. The concept of reasonableness places context at the centre of the enquiry and permits an assessment of context to determine whether a government programme is indeed reasonable ... [O]rdinarily it is institutionally inappropriate for a court to determine precisely what the achievement of any particular social and economic right entails and what steps government should take to ensure the progressive realisation of the right. This is a matter, in the first place, for the legislature and executive, the institutions of government best placed to investigate social conditions in the light of available budgets and to determine what targets are achievable in relation to social and economic rights.’ Statements of a similar nature were made in *Government of the Republic of South Africa & Others v Grootboom & Others* 2001 (1) SA 46; 2000 (11) BCLR 1169 para 32 and in *Minister of Health & Others v Treatment Action Campaign & Others (No 2)* 2002 (5) SA 721; 2002 (10) BCLR 1033 para 38. However, it could be argued that judicial precedent on the fulfilment and implementation of socio-economic rights has, over the years, in an indirect manner, started the process of determining the minimum core of socio-economic rights in the Constitution. Eg, in relation to children’s socio-economic rights, a number of judgments have discussed what it means to have access to basic education. Judgments have found that it includes the provision of educator and non-educator posts (*Centre for Child Law v Minister of Basic Education & Others* [2012] 4 All SA 35); the provision of school furniture (*Madzodzo & Others v Minister of Basic Education & Others* 2014 (3) SA 441 (ECM)); the provision of textbooks (*Section 27 & Others v Minister of Education & Another* 2013 (2) SA 40 (GNP) and *Minister of Basic Education v Basic Education for All* [2016] 1 All SA 369 (SCA); 2016 (4) SA 63 (SCA)).

12 Proudlock (n 11 above) 292.

13 *S v Makwanyane & Another* 1995 (6) BCLR 665; 1995 (2) SACR 1 paras 36-7, as quoted in Currie & De Waal (n 6 above) 146.

countries, including South Africa.¹⁴ Nine countries have signed but not yet ratified the Children's Charter, and four countries have neither signed nor ratified it.¹⁵ The African Children's Charter arose as a result of frustration felt by African countries towards the UN Convention on the Rights of the Child (CRC) which was a product of a number of compromises that had to be made to ensure consensus among states with different backgrounds.¹⁶ Provisions that would have adequately covered issues peculiar to the African context were not sufficiently addressed.¹⁷ For example, the CRC failed to deal with the following issues distinct to the African context:

- the disadvantages that the girl child experiences in the African context;
- widespread practices in the African context such as female genital mutilation and circumcision;
- the important role, responsibilities and duties that the African context gives to the family and community in the upbringing of children; and
- the socio-economic conditions that African children experience and are exposed to that affect their survival.

The African Children's Charter was developed in order to ensure that the CRC was given specific application¹⁸ in the African context.¹⁹ A more specific explanation of why the Children's Charter came about, with the above frustrations in mind, is that it was the result of a desire by African states to deal with and address challenges peculiar to African children.²⁰ This is recognised in the Preamble to the Charter, which states:

NOTING WITH CONCERN that the situation of most African children remains critical due to the unique factors of their socio-economic, cultural, traditional and developmental circumstances, natural disasters, armed conflicts, exploitation and hunger, and on account of the child's physical and mental immaturity he/she needs special safe guards and care.

14 African Commission on Human and Peoples' Rights 'Ratification table: African Charter on the Rights and Welfare of the Child' <http://www.achpr.org/instruments/child/ratification/> (accessed 6 March 2016). South Africa ratified the African Children's Charter on 7 January 2000.

15 As above.

16 F Viljoen 'The African Charter on the Rights and Welfare of the Child' in Boezaart (n 11 above) 335; BD Mezmur 'The African Children's Charter versus the UN Convention on the Rights of the Child: A zero-sum game?' (2008) 23 *South African Public Law Journal* 3-7; A Lloyd 'A theoretical analysis of the reality of children's rights in Africa: An introduction to the African Charter on the Rights and Welfare of the Child' (2002) 1 *African Human Rights Law Journal* 12-15.

17 F Viljoen 'Supra-national human rights instruments for the protection of children in Africa: The Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child' (1998) 31 *Comparative and International Law Journal of Southern Africa* 205.

18 As above.

19 Mezmur (n 16 above) 6.

20 Viljoen (n 17 above) 205.

The African Children's Charter is an embodiment of the acknowledgment that 'each region, with its unique culture, traditions and history, is best placed to handle and resolve its own human rights situation'.²¹ The importance of the Charter (and other regional instruments) is cemented by the UN General Assembly which affirms that regional instruments that ensure the protection and promotion of human rights could make a major contribution to the effective enjoyment of human rights.²²

In addressing African peculiarities and other concerns, the African Children's Charter aims to accomplish the goal of ensuring that the African child receives care for his or her health and physical, mental, moral and social development.²³ This is achieved by taking into account the virtues of the child's cultural heritage and historical background.²⁴

4 An overview of the Convention on the Rights of Persons with Disabilities

The CRPD entered into force on 3 May 2008.²⁵ Thirty-four African countries, including South Africa, have ratified the Convention.²⁶ The working group that developed the CRPD consisted of delegates from seven African countries, which included Cameroon, Comoros, Mali, Morocco, Sierra Leone, South Africa and Uganda.²⁷

The CRPD was developed to ensure the existence of an internationally-affirmed document that articulates the manner in which human rights and freedoms apply specifically to persons with disabilities, including children.²⁸ The CRPD is essentially a comprehensive and integral international human rights instrument that has been developed to promote and protect the rights and dignity of persons with disabilities.²⁹ It is the mechanism that ensures redress of the profound social disadvantage

21 Viljoen (n 17 above) 205-206.

22 Mezmur (n 16 above) 5.

23 Preamble African |Children's Charter.

24 As above.

25 United Nations 'Convention on the Rights of Persons with Disabilities' <http://www.un.org/disabilities/default.asp?id=150> (accessed 9 March 2016).

26 J Lord & MA Stein 'Prospects and practices for CRPD implementation in Africa' in C Ngwenya et al *African disability rights yearbook 2013* (2013) 98-99. South Africa ratified the CRPD on 30 November 2007; see https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en (accessed 7 March 2017).

27 The working group was established by an *ad hoc* committee created by the UN General Assembly to analyse the possibility of developing a convention dealing with the rights of persons with disabilities. The working group's mandate was to elaborate on a draft text of the Convention (see A Palacios & M Walls 'Changing the paradigm – The potential impact of the United Nations Convention on the Rights of Persons with Disabilities' in J Allain & S Mullally *The Irish yearbook of international law* (2006) 130).

28 Palacios & Walls (n 27 above) 100.

29 Preamble to the CRPD.

that persons with disabilities experience despite the existence of various other human rights instruments.³⁰

The CRPD affirms a number of important principles that ensure the protection and promotion of the rights of persons with disabilities. These principles also guarantee the full enjoyment of the human rights and fundamental freedoms of persons with disabilities without discrimination.³¹ Disability is understood as an evolving concept resulting from the interaction with attitudinal and environmental barriers that hinder the full and effective participation in society by persons with disabilities on an equal basis with others.³² The CRPD acknowledges that discrimination on the basis of disability is a violation of the inherent dignity and worth of the human person.³³

5 A comparison between the protection of socio-economic rights entrenched in the African Children's Charter and the CRPD

The African Children's Charter and the CRPD have both been formulated to protect particularly vulnerable groups of people, namely, African children and persons with disabilities, who historically did not enjoy sufficient protection through international instruments. This was the case despite the fact that the international instruments applied to them equally as to other people. The general international instruments, however, did not meet their special needs in the same way the African Children's Charter and the CRPD do. What follows is a comparative examination of the Children's Charter and the CRPD and how they provide for the protection and promotion of the socio-economic rights of African children with disabilities, focusing on children in the South African context. The discussion begins with the foundational principles that apply in all circumstances, including those relating to socio-economic rights.

5.1 Foundational principles and provisions in the African Children's Charter and the CRPD specifically relating to children with disabilities

The African Children's Charter and the CRPD are both based on foundational principles that guide the interpretation and application of these instruments. They also contain provisions that relate specifically to children with disabilities, which are highlighted in the next sections.

30 As above.

31 As above.

32 As above.

33 As above.

5.1.1 African Charter on the Rights and Welfare of the Child

Gose identifies four foundational provisions or pillars that the Children's Charter is based upon, namely, non-discrimination; the best interests of the child; the right to survival and development; and the right of the child to participate in matters concerning his or her well-being.³⁴ Gose describes these as the 'soul' of the instrument.³⁵

Article 3 of the African Children's Charter contains the non-discrimination clause which provides as follows:

Every child shall be entitled to the enjoyment of the rights and freedoms recognised and guaranteed in this Charter irrespective of the child's or his/her parents' or legal guardians' race, ethnic group, colour, sex, language, religion, political or other opinion, national and social origin, fortune, birth or other status.

One immediately notes that the article does not include disability as a prohibited ground of discrimination.³⁶ Despite the fact that the article applies to all children, including children with disabilities, one cannot but lament the fact that the African Children's Charter did not take advantage of the unique opportunity to affirm the importance of the rights and freedoms of children with disabilities.³⁷ Nevertheless, the article's relevance to all children, including children with disabilities, ensures that children with disabilities should not be discriminated against in their claim to the socio-economic rights set out in the Children's Charter. In addition to the article applying to all children, the inclusion of the phrase 'other status' is an indication of the fact that the list provided is not an exhaustive one and that, therefore, recognition should be given to 'other forms of differential treatment that cannot reasonably and objectively be justified'.³⁸ This would include discrimination against persons with disabilities that would impair the recognition, enjoyment or exercise of their rights.³⁹

Article 4 of the African Children's Charter provides for the best interests of the child, and states that the best interests of the child should be the primary consideration in all actions affecting the child, which includes

34 M Gose *The African Charter on the Rights and Welfare of the Child* (2002) 17. The CRC Committee identified these principles as foundational principles to the implementation of the CRC as well (see General Guidelines regarding the form and content of initial reports to be submitted by States Parties under art 44, para 1(a) of the Convention: 19/10/30 CRC/C/5 [13]).

35 Gose (n 34 above) 17.

36 H Combrinck 'The hidden ones: Children with disabilities in Africa and the right to education' in J Sloth-Nielsen (ed) *Children's rights in Africa: A legal perspective* (2008) 310.

37 As above.

38 General Comment 20 Non-discrimination in economic, social and cultural rights (art 2 para 2 of the International Covenant on Economic, Social and Cultural Rights) E/C.12/GC/20 (2 July 2009) paras 15 & 27.

39 As above.

children with disabilities. State parties, therefore, should mould their laws and policies with the best interests principle in mind.⁴⁰ This, in essence, would mean that states must be cognisant of the best interests and special needs of children with disabilities, particularly in their formulation of laws and policies aimed at meeting the needs of persons with disabilities, including laws and policies relating to socio-economic rights.⁴¹ Article 4 states that the best interests of the child must be of primary consideration. The use of the definite article 'the' elevates the influence the principle has over other considerations.⁴²

Article 4(2) provides for the rights of children, including children with disabilities, to participate in matters concerning his or her well-being. Article 4(2) also provides that a child who is capable of communicating his or her own views should be provided the opportunity to do so in judicial and administrative matters affecting him or her. The views can be expressed directly by the child or through an impartial representative. Article 4(2) further provides that the child's views must be taken into consideration by the relevant authorities. The child is placed in the position of an active participant who has an opportunity to, in one way or another, influence decisions taken in matters involving him or her.⁴³

This article has limitations, such as the fact that the phrase 'who is capable of communicating his or her views' is restrictive in that this ability may relate to age, level of education and the ability to communicate verbally or to write.⁴⁴ This does not take into account children who can communicate, not in the traditional manner, but through other means such as body language.⁴⁵ This is especially unaccommodating for children with disabilities whose only means of communication are in ways other than speaking or writing, such as sign language.

The article is further limiting as it only provides for children's views to be expressed in judicial and administrative proceedings and not in other forums or spaces that affect children, such as the family environment. This is restrictive in the area of socio-economic rights, as children with disabilities should be able to express their views, life experiences and needs when laws and policies on socio-economic rights are being formulated, without any restrictions. Article 7 seems to be a redeeming characteristic as it allows children, therefore also children with disabilities, to freely express their opinions in all matters. However, article 7 also contains the limitation that only children who are capable of communicating their views can express their opinions.

40 Gose (n 34 above) 26; Lloyd (n 16 above) 17.

41 As above.

42 As above.

43 Viljoen (n 16 above) 338.

44 Gose (n 34 above) 124; Viljoen (n 16 above) 338.

45 As above.

Article 5 of the African Children's Charter provides for the right to survival and development. Article 5(2), which is important for purposes of this article, places the obligation on states, to the maximum extent possible, to ensure the survival, protection and development of the child. One of the ways in which article 5(2) could be interpreted is that states are placed under the obligation, among other things, to ensure the protection and provision of socio-economic rights, as this is one of the ways of making sure that children survive, grow and develop in the best manner possible. This especially includes children with disabilities. The limitation of this right, namely, the fact that states are given the option to do this to the maximum extent possible, could mean that states may argue that, because of scarce resources, they are not able to ensure that socio-economic rights are fully protected.⁴⁶

Article 13 of the African Children's Charter, which deals specifically with the protection necessary to ensure the advancement of the rights of children with disabilities, is linked to these foundational pillars for children with disabilities. Article 13(1) of the Children's Charter provides that children with disabilities have the right to special measures of protection to meet their physical and moral needs. These special measures of protection must be provided under conditions that respect their dignity and promote self-reliance and active participation in their communities.⁴⁷ Article 13(2) of the African Children's Charter details the special measures that states must undertake in order to comply with article 13(1).⁴⁸ Article 13(2) provides as follows:

State parties to the present Charter shall ensure, subject to available resources, to a disabled child and to those responsible for his care, of assistance for which application is made and which is appropriate to the child's condition and in particular shall ensure that the disabled child has effective access to training, preparation for employment and recreation opportunities in a manner conducive to the child achieving the fullest possible social integration, individual development and his cultural and moral development.

The article makes the assistance to be provided subject to available resources.⁴⁹ However, the Children's Charter only requires that the circumstances of the child's special situation be taken into account. The Charter does not go into as much detail as the CRC where in articles 23(2) and (3) it is provided that the circumstances of the parents or the caregivers must be taken into account and that services must be provided free of charge where possible.⁵⁰ The fact that the African Children's Charter does not state that the circumstances of the parents or caregiver be taken into account could allow for services to be extended to a larger group of

46 Gose (n 34 above) 44.

47 As above.

48 Gose (n 34 above) 90.

49 As above.

50 Art 13(2) African Children's Charter; arts 23(2) & (3) CRC; Gose (n 34 above) 90.

children than the CRC covers, whose parents or caregivers could care for them without state assistance.⁵¹ The list of services to be provided does not include education, health care services and rehabilitation which are provided for in the CRC.⁵²

5.1.2 *Convention on the Rights of Persons with Disabilities*

Article 3 of the CRPD sets out the foundational provisions or pillars of the CRPD as indicated below:

- (a) respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- (b) non-discrimination;
- (c) full and effective participation and inclusion in society;
- (d) respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- (e) equality of opportunity;
- (f) accessibility;
- (g) equality between men and women;
- (h) respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

For purposes of this article, only three of the above will be dealt with, namely, respect for inherent dignity; non-discrimination; and respect for the evolving capacities of children with disabilities. These pillars have been described as the 'moral compass' of the CRPD.⁵³

Respect for the inherent dignity of all human beings, including children with disabilities, requires that all treatment and interaction be carried out in a manner that is respectful and shows concern.⁵⁴ Respect for the inherent dignity of all must filter into how all other human rights, including socio-economic rights, are applied and interpreted.⁵⁵ Bassler notes the importance of respect for inherent human dignity by stating the following:

[Respect for inherent dignity] means that people must be treated as ends in themselves, first as people and only then as people with particular characteristics. For people with disabilities this means asking the question about whether the treatment or interaction is predicated on preserving and

51 As above.

52 Art 23(3) CRC.

53 R Kayees & P French 'Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 *Human Rights Law Review* 27.

54 Currie & De Waal (n 13 above) 251.

55 As above.

protecting the moral worth of the individual, not some idea about the person's disability ...⁵⁶

The African Children's Charter does not contain a provision specifically requiring respect for inherent dignity. Therefore, in this regard the CRPD plays a very important role. The CRPD ensures that the inherent dignity of children with disabilities is placed at the forefront of actions purporting to protect and provide services to these children. The promotion and protection of the socio-economic rights and the resultant formulation of laws and policies as well as the provision of services to children with disabilities must be buttressed by respect for the inherent dignity of such children.

Article 5 of the CRPD touches on equality and non-discrimination of persons, including children with disabilities. The article, among other things, provides that all persons are equal before and under the law and are entitled to equal protection by and benefit of the law without having to suffer any discrimination. States bear the responsibility to prohibit all forms of discrimination on the basis of disability and to guarantee to all persons with disabilities equal and effective protection against all forms of discrimination. In order to fulfil their obligations, states must take all appropriate steps to ensure that reasonable accommodation is provided. Finally, article 5 recognises that it may be necessary to take specific measures to hasten or achieve the equality of persons with disabilities. It notes that this will not be considered discrimination under the CRPD.

This clause differs from article 3 of the African Children's Charter. It applies specifically to persons with disabilities and, therefore, captures the protection needs of children with disabilities more clearly. It does not list the grounds on which a person should not be discriminated against, but broadens the scope of protection by stating that all discrimination on the basis of disability is prohibited. Read with article 3 of the Children's Charter, this would offer stronger protection to children with disabilities in South Africa, as there would be the recognition that children with disabilities should not be discriminated against because they are children or on the basis of their disability.

Article 5 of the CRPD places the responsibility on states to ensure equality and non-discrimination, while article 3 of the African Children's Charter does not specifically mention who is responsible for ensuring that children are not discriminated against. The Children's Charter focuses on the child as the rights bearer, whereas the subject in the provision of the CRPD is the state.⁵⁷

56 LA Basser 'Human dignity' in MH Rioux et al (eds) *Critical perspectives on human rights and disability law* (2011) 36.

57 Gose (n 34 above) 18.

It may be argued that the African Children's Charter offers broader protection against discrimination in the sense that it is not only the state that has the duty of non-discrimination, but everyone that the child comes into contact with. The CPRD, on the other hand, focuses only on the state as duty bearer.

Article 5 of the CRPD recognises that specific measures may need to be implemented to accelerate ensuring the equality of persons, including children with disabilities, and that this will not be considered discrimination. This is especially important in the context of socio-economic rights, where children with disabilities are often in a worse position than other children in their access to socio-economic rights.⁵⁸ Article 3 of the African Children's Charter makes no mention of this.

The inclusion of respect for the evolving capacities of children with disabilities in article 3 of the CRPD is ground-breaking as children with disabilities often have been seen to have little or no capability or competence to learn and develop themselves.⁵⁹ Article 3 ensures that steps are taken to equip children with disabilities with the ability to develop the capacity for learning, developing and decision making, something that is possible through the socio-economic right to education.⁶⁰ This also is not specifically contained in the African Children's Charter. A combined reading of the Children's Charter rights and the CRPD, therefore, ensures the comprehensive protection of children with disabilities.

As in the case of the African Children's Charter, linked to the pillars, the CRPD contains a provision that deals specifically with children with disabilities in article 7. Article 7 provides:

- 1 State parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
- 2 In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

58 See, eg. *Western Cape Forums for Intellectual Disability v The Government of the Republic of South Africa* 2011 (5) SA 87 (WCC), where children with severe and profound intellectual disabilities (that is, having IQ levels of 20-35 and less than 20 respectively) were not provided with education by the state. The children had to rely on services provided by centres run by non-governmental organisations. The centres were also unable to cater for all children with severe and profound intellectual disabilities. The state only provided subsidies to these centres. These subsidies were not sufficient to meet the children's educational needs and were far less than that given to other children.

59 B Byrne 'Minding the gap? Children with disabilities and the United Nations Convention on the Rights of the Persons with Disabilities' in M Freeman *Law and childhood studies* (2011) 427; UNICEF 'Using the human rights framework to promote the rights of children with disabilities: Discussion paper – An analysis of the synergies between CRC, CRPD and CEDAW' (2009) 15.

60 Byrne (n 59 above) 427-428.

- 3 State parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right.⁶¹

First, one immediately notes that, unlike the African Children's Charter, which states that the best interests of the child should be *the* primary consideration, the CRPD provides that the best interests of the child shall be *a* primary consideration in matters affecting the child. The formulation of the CRPD is unfortunate,⁶² as it weakens the influence of the best interests principle, and incurs the risk that other values could prevail over the best interests of children with disabilities.⁶³

Second, article 7(3) of the CRPD states that children with disabilities have the right to express their views freely on all matters affecting them. It does not, as in the case of the African Children's Charter, place a restriction on how this expression of views is to be executed. The CRPD's protection of children's participation, therefore, is broader than that provided for in the Children's Charter.

5.2 Socio-economic rights included in the African Children's Charter and the CRPD

The above discussions have clearly defined children with disabilities, like all children, as rights bearers of various human rights, including socio-economic rights, whose rights are independent of the societies and families they come from.⁶⁴ This acknowledges the fact the children with disabilities are 'distinct members of the moral community with distinct interests [and needs] who are appropriately viewed as self-originating sources of valid moral claims with an equal moral status'.⁶⁵

A comparative enquiry will now be carried out on some of the socio-economic rights provided to children with disabilities as distinct rights bearers by the African Children's Charter and the CRPD. This is done to highlight the similarities in and differences between the instruments and the ways in which they can complement and support each other in the furtherance of the socio-economic rights of children with disabilities in South Africa. This is important as socio-economic rights ensure that children with disabilities have access to their basic needs for survival, growth and development.⁶⁶ Three socio-economic rights will be dealt

61 Art 7 CRPD.

62 This formulation in the CRPD is similar to that provided for in art 3(1) of the CRC.

63 Byrne (n 59 above) 429.

64 A Nolan *Children's socio-economic rights, democracy and the courts* (2014) 7.

65 As above.

66 Gose (n 34 above) 81.

with, namely, the right to education; the right to health and related rights; and the right to social security.

5.2.1 Right to education

The African Children's Charter recognises the right to education in article 11, which places an obligation on state parties to promote and protect access to education. Article 11(1) states that every child has the right to education. Article 11(2) sets out the aims of education, which include the promotion and development of children's personalities, talents and mental and physical abilities to the fullest potential; the fostering of respect for human rights and fundamental freedoms set out in African regional and international instruments; the promotion of children's understanding of primary health care; and the preservation and strengthening of positive African morals, traditional values and cultures. Article 11(3) sets out the obligations placed on state parties, which include the provision of free and compulsory basic education and the implementation of special measures in respect of female, gifted and disadvantaged children, to ensure equal access to education for all sectors of the community.

The CRPD recognises the right of children with disabilities to education in article 24. Article 24(1) of the CRPD states that the right to education must be realised on the basis of non-discrimination and equal opportunity. It provides that an inclusive education system must be ensured at all levels. This reiteration and affirmation of the need for and importance of non-discrimination and equality in the context of education is important for children with disabilities as it ensures that the educational environment is one that is free of discrimination, and affirms the specific needs that children with disabilities have and the different ways they are able to contribute. This is not contained in the African Children's Charter and, therefore, it is very important that the two instruments are read together when dealing with the rights of children with disabilities to education.

The aims of education are also set out in article 24(1) of the CPRD. Among others, these include the full development of human potential, a sense of dignity and self-worth, as well as the strengthening of respect for human rights, fundamental freedoms and human diversity; the development by persons with disabilities of their personalities, talents and creativity, as well as their mental and physical abilities, to their fullest potential; and enabling persons with disabilities to effectively participate in a free society. These aims, although in some ways similar, are different in the sense that they are formulated to apply specifically to persons with disabilities. It should, therefore, be read in conjunction with the aims set out in the African Children's Charter, as this will ensure that children with disabilities receive the most out of their education in the South African context.

Article 24(2) contains the obligations on state parties to ensure that the right to education is fully realised. States should ensure that persons with disabilities are not excluded from receiving education on the basis of disability, and that children with disabilities are not excluded from receiving free and compulsory basic education. This is similar to article 11(3) of the African Children's Charter, which also provides for free and compulsory basic education. However, article 24(2) goes further and provides that inclusive, quality and free education should be accessed by persons with disabilities on a basis of equality with others. The distinct requirements of children with disabilities should be reasonably accommodated, and support should be provided in the education system in order to facilitate effective education. In order to make the most of academic and social development, effective individual support measures must also be provided.

Further provisions on the right to education contained in the CRPD (and not in the African Children's Charter) are detailed in articles 24(3) and 24(4) of the CRPD. Article 24(3) sets out the measures states parties must employ in order to ensure that persons with disabilities learn life and social development skills that will facilitate full and equal participation in education and their communities. These measures include:

- facilitating the learning of braille, alternative script, augmentative and alternative models, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
- facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community; and
- ensuring that the education of persons, and in particular children, who are blind, deaf or deaf and blind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximise academic and social development.

Article 23(4) provides that in order to ensure that the right to education is realised for persons with disabilities, the teachers employed, including teachers with disabilities, should be proficient in sign language and/or braille. Professionals and staff that work at all levels of education should also be trained, among others, in disability awareness, the use of appropriate means of communication and educational techniques and materials to support persons with disabilities.

The provisions supporting the right to education in the African Children's Charter and the CRPD clearly indicate that the CRPD elaborates on the right in more detail than the Children's Charter.⁶⁷ The more detailed provisions of the CRPD are aimed at ensuring that states

67 Save the Children *See me, hear me: A guide to using the UN Convention on the Rights of Persons with Disabilities to promote the rights of children* (2009) 108.

understand what the right to education means for children with disabilities and what their responsibilities are in this regard.

A comprehensive and well-rounded approach to the application of both the African Children's Charter and the CRPD should be carried out with the aim to ensure that children with disabilities in the South African context and African context in general have unhindered access to education. This is important for disabled children in South Africa, as it is reported that close on 500 000 children with disabilities do not attend school and that hundreds of thousands who are in school have fallen behind.⁶⁸ These alarming figures are linked to a number of shortcomings in the education system, such as that children with disabilities face discriminatory attitudes and admission practices⁶⁹ as they try to access mainstream or special public schools,⁷⁰ and that children with disabilities are exposed and vulnerable to violence and abuse.⁷¹

Another shortcoming in the South African education system is that children with disabilities who attend public schools, particularly special schools, often do not receive quality education.⁷² A number of issues that have been identified that affect the quality of education children with disabilities are exposed to include the standard of curriculum delivery in special schools; a lack of requisite and specialised skills on the part of teachers to adapt teaching practices; poor provision of learner and teacher support material; unequal distribution of educators to schools catering for children with disabilities; and a lack of accessible transport.⁷³ All these challenges, and many others, affect the ability of children with disabilities to acquire –

essential learning tools (such as literacy, oral expression, numeracy and problem solving) and the basic learning content (such as knowledge, skills, values, and attitudes) required by human beings to be able to survive, to develop their full capacities, to live and work in dignity, to participate fully in development, to improve the quality of their lives, to make informed decisions, and to continue learning. The scope of basic learning needs varies

68 Human Rights Watch *Complicit in exclusion: South Africa's failure to guarantee an inclusive education for children with disabilities* (2015) 2.

69 School governing bodies and principals often make arbitrary decisions about whether they will accommodate children with disabilities. Children with, among others, intellectual disabilities, multiple disabilities and autism are often on the receiving end of these decisions. Human Rights Watch (n 68 above) 2.

70 Human Rights Watch (n 68 above) 2-3.

71 Human Rights Watch 2; J Bornman 'Accessing justice via key role players: A view from South Africa' in DN Bryen & J Bornman (eds) *Stop violence against people with disabilities* (2014) 46-48.

72 Human Rights Watch (n 68 above) 2; Department of Basic Education 'Report on the implementation of education: White Paper 6 on inclusive education – An overview for the period 2013-2015' (2015) 34-53.

73 Department of Basic Education (n 71 above) 34-53.

with individual countries and cultures, and inevitably, changes with the passage of time.⁷⁴

The African Children's Charter and the CRPD should be used to keep the South African government accountable in its obligation to address the above challenges and ensure better access to education for children with disabilities.

5.2.2 Health and health-related rights

It has been acknowledged that access to health care services is a challenge for children with disabilities in South Africa.⁷⁵ This needs to be addressed in a manner compliant with international law as articulated, inter alia, in the African Children's Charter and the CRPD. The challenges faced include the following:

a lack of access to the physical environment, lack of access to information in accessible formats; discriminatory and negative attitudes toward persons with disabilities displayed by health and support personnel; a lack of appropriately trained and skilled health personnel concerned with disability ... inaccessible and unaffordable transport, particularly in rural and impoverished communities.⁷⁶

In order to address the above barriers to access health care services, the provisions of the African Children's Charter and the CRPD must be implemented as a matter of urgency. The Children's Charter contains provisions relating to health and health services in article 14, which in article 14(1) begins by providing that every child should enjoy the best attainable state of physical, mental and spiritual health. The CRPD, in article 25, provides that state parties have the responsibility to recognise the right of persons with disabilities to enjoy the highest attainable standard of health without discrimination. States are further required to ensure that all appropriate measures are taken to ensure that persons with disabilities have access to health services, including health-related rehabilitation that is gender sensitive. The African Children's Charter provides for the 'best attainable' state of health, while the CRPD mentions the 'highest attainable' standard of health. This differentiation in expression does not seem to result in any major difference.⁷⁷ However, the CRPD does re-affirm that access to health must not be hindered by discrimination, something the Children's Charter fails to do.

74 UNESCO 'World declaration on education for all and framework for action to meet basic learning needs' (1990) art II.

75 Department of Women, Children and Persons with Disabilities 'Baseline country report to the United Nations on the implementation of the Convention on the Rights of Persons with Disabilities' (2013) 50.

76 As above.

77 Gose (n 34 above) 82. Gose compares the African Children's Charter and the CRC (art 24(1)) which has the same wording as the CRPD.

The African Children's Charter differentiates between physical, mental and spiritual health, while the CRPD does not contain such differentiation. In making this differentiation, the Children's Charter ensures that there is no ambiguity regarding the meaning of health and, instead, broadens the concept of health.⁷⁸ The CRPD states that health services must be gender-sensitive highlighting women's issues and, in this case, issues of the girl child, which the Children's Charter does not do.⁷⁹ The CRPD also refers to the provision of rehabilitation services to persons with disabilities. This is particularly important for children with disabilities who are in need of rehabilitation services for their continued development and growth.

Article 14(2) of the African Children's Charter provides that state parties must take certain steps to pursue the full implementation of the right to health. These measures, among others, include a reduction in the infant and child mortality rate; the provision of necessary medical assistance and health care to all children, with an emphasis on developing primary health care services; the provision of adequate nutrition and safe drinking water; the use of appropriate technology, within the framework of primary healthcare, to combat disease and malnutrition; and measures to ensure that parents, children, community leaders and community workers are informed of and supported in the use of basic knowledge of child health and nutrition. All these special measures take cognisance of the context in which African children, and in this instance children with disabilities, find themselves, and aim to meet the needs of children in these contexts.

The CRPD complements the protection granted to children with disabilities by the African Children's Charter by requiring state parties to the CRPD to implement certain measures aimed at targeting the specific needs of children with disabilities. These are set out in article 25 and include the following: providing the same range, quality and standard of free or affordable health care and programmes as provided to other persons; and providing health services specifically needed by persons with disabilities, which include early identification and intervention and services aimed at minimising or preventing further disabilities. This is of particular importance to children with disabilities who would benefit from early identification and intervention.⁸⁰ Article 25 also requires state parties to provide health care services as close as possible to the communities where the children with disabilities find themselves, and to prevent the

78 As above.

79 Apart from its reference in art 14(2)(e) to appropriate health care for expectant and nursing mothers and its reference in art 11(3)(e) to the obligation of state parties to take special measures in respect of female children in the promotion of the right to education.

80 Save the Children (n 67 above) 122.

discriminatory denial of health care or health services, food and fluids on the basis of disability.

It is interesting to note that neither the African Children's Charter nor the CRPD contains a limitation clause stating that the right to health is to be provided to the maximum extent possible or within the available resources.⁸¹ This, therefore, could result in a 'higher level of protection, and result in constant pressure on the state ... to further the full achievement of the right'.⁸²

5.2.3 *Right to social security and social assistance*

Children with disabilities often find themselves in contexts of extreme poverty which make them 'vulnerable to infection, and less likely to have resistance to illness or access to healthcare. They are more likely to lack clean water and sanitation, and are more exposed to accidents.'⁸³ This is also the case in the South African context.⁸⁴ One way of addressing poverty and its effects is through the provision of social security grants to assist in the provision of basic economic and social needs.⁸⁵

Unfortunately, the African Children's Charter does not contain a provision on the right to social security or even the right to an adequate standard of living.⁸⁶ There is no provision directing the state to provide such needed assistance to children with disabilities.⁸⁷ This omission has been described as 'extremely disturbing', particularly in the African context.⁸⁸

Article 28 of the CRPD provides some cure as it contains a provision on an adequate standard of living and social protection. Here, the CRPD recognises the fact that children with disabilities require a larger income to assist them to develop and grow adequately.⁸⁹ Therefore, article 28 places specific obligations on state parties.⁹⁰

Article 28(1) of the CRPD places an obligation on state parties to recognise that children with disabilities have a right to an adequate

81 Gose (n 34 above).

82 As above.

83 Save the Children (n 67 above) 124. See also World Bank *Convention on the Rights of Persons with Disabilities: Its implementation and relevance for the World Bank* (2007) 15.

84 Save the Children (n 67 above) 124.

85 S Rosa & M Dutschke 'Child rights at the core: The use of international law in South African cases on children's socio-economic rights' (2006) 22 *South African Journal on Human Rights* 231.

86 Gose (n 34 above) 120; Rosa & Dutschke (n 85 above) 231; A Skelton 'Girls' socio-economic rights in South Africa' (2010) 26 *South African Journal on Human Rights* 145.

87 Skelton (n 86 above) 145.

88 Gose (n 34 above) 120.

89 Save the Children (n 67 above) 126.

90 As above.

standard of living which includes access to adequate food, clothing and housing as well as the continuous improvement of their living conditions. States must ensure that this right is promoted without any discrimination on the basis of disability. Article 2 of the CRPD defines ‘discrimination on the basis of disability’ in the following manner:

any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms ...

Article 28(2) places the obligation on state parties to ensure that the social protection of children with disabilities is recognised and enjoyed without discrimination on the basis of disability. To accomplish this, states must take certain measures which, among other things, include the following: ensuring equal access to clean water and appropriate and affordable services, devices and other assistance to meet disability-related needs; and ensuring access to social protection programmes and poverty reduction programmes. States must also ensure that children with disabilities living in poverty enjoy financial assistance to cover disability-related expenses.

6 Oversight of the implementation of the African Children’s Charter and the CRPD

The implementation of both the African Children’s Charter and the CRPD is overseen by monitoring bodies established by the instruments. The African Committee of Experts on the Rights and Welfare of the Child (African Children’s Committee) was established by the African Children’s Charter to promote and protect the rights and welfare of the child.⁹¹ State parties to the Children’s Charter are required to report to the Children’s Committee on the measures they have adopted to give effect to the Children’s Charter and the progress made in the enjoyment of the rights in the Charter.⁹² The Committee on the Rights of Persons with Disabilities (CRPD Committee) was established by the CRPD.⁹³ State parties that have ratified the CRPD are required to submit to the Committee reports on measures taken to give effect to their obligations under the CRPD.⁹⁴

91 Art 32.

92 Art 43.

93 Art 34.

94 Art 35.

6.1 African Committee of Experts on the Rights and Welfare of the Child

In 2013 the South African government submitted its initial report to the African Children's Committee highlighting measures taken to further its obligations under the African Children's Charter.⁹⁵ The report was considered by the Children's Committee, which produced Concluding Observations. The Concluding Observations set out a number of observations on the manner in which the African Children's Charter is being observed in order to protect children's rights. The following was said with regard to the rights of children with disabilities:

- The African Children's Committee noted a number of challenges in efforts made to realise the rights of children with disabilities, including inadequate disaggregated data; barriers to accessing of facilities and social services; poor quality of services to children with disabilities such as rehabilitative services; inadequate integration of the social model in various policies and practices; and limited monitoring frameworks. It recommended that efforts to realise the rights of children with disabilities in line with the African Children's Charter be strengthened.⁹⁶
- The African Children's Committee recommended that South Africa take all necessary measures to ensure the realisation of inclusive education. Such measures must take into account the individual educational needs of children; must cater for children's specific needs by re-evaluating curricula, incorporating special needs education in training of teachers and other personnel involved in education; and providing and improving basic infrastructures suitable to children with disabilities.⁹⁷
- The African Children's Committee urged South Africa to improve the effective implementation of laws, policies, and practices through capacity building and training, that promote substantive equality of children in general, including children with disabilities.⁹⁸
- The African Children's Committee recommended that South Africa provide for care and dependency grants for children with disabilities.⁹⁹

The Concluding Observations challenge and place a responsibility on the South African government to improve services and assistance rendered to children with disabilities and to remove barriers that hinder children with disabilities from fully developing their potential. South Africa recently submitted its second country report to the African Children's Committee

95 Republic of South Africa (2013) 'South Africa's Initial Country Report on the African Charter on the Rights and Welfare of the Child – Reporting Period: January 2000 – April 2013'.

96 African Committee of Experts on the Rights and Welfare of the Child (2014) 'Concluding Recommendations by the African Committee of Experts on the Rights and Welfare of the Child on the Republic of South Africa Initial Report on the Status of Implementation of the African Charter on the Rights and Welfare of the Child' para 50.

97 Para 53 African Children's Committee.

98 Para 21 African Children's Committee.

99 Para 41 African Children's Committee.

(for the period May 2013 to May 2016) providing updated information and data on the implementation of policies and legislation on the protection and promotion of children's rights in line with the African Children's Charter. It will be interesting to see how the Committee interacts with this report, particularly in light of its 2014 Concluding Observations.

6.2 Committee on the Rights of Persons with Disabilities

South Africa recently submitted its initial country report to the CRPD Committee.¹⁰⁰ The report acknowledges that

[c]hildren with disabilities remain extremely vulnerable to exclusion, abuse and inequality, particularly in impoverished communities. This is because of failures in the service delivery system, persistent harmful traditional beliefs associated with disability, lack of access to relevant information by parents and families, lack of effective early identification and intervention across sectors for young children, lack of equal access to compulsory education, failure of the judicial system to protect children with disabilities, as well as failure to ensure justice where abuse has occurred, and inadequate training for caregivers working with children with moderate to severe intellectual and/or severe physical disabilities.¹⁰¹

The CRPD Committee is yet to issue Concluding Observations on South Africa's report. It is hoped that the Committee will engage rigorously with the report and produce Concluding Observations that can be used for the improved protection and implementation of the rights of children with disabilities by the state and for advocacy by non-state actors.

7 Conclusion

The African Children's Charter and the CRPD differ but have similar ways of providing protection to children with disabilities. They both have a common goal, which is to provide the most comprehensive and effective protection to children with disabilities. This is borne out by the fact that they require children with disabilities to be treated as rights bearers with dignity and respect, in a non-discriminatory manner that takes into account their views and their best interests.

As regards socio-economic rights, the African Children's Charter appears to provide some of these protections in a general sense, understandably so, since it aims to protect a large group of children, namely, children in the African context. The CRPD, which focuses mainly on persons with disabilities, including children, delves deeper into the

100 Committee on the Rights of Persons with Disabilities consideration of reports submitted by state parties under article 35 of the Convention: Initial reports of state parties due in 2009: South Africa CRPD/C/ZAF/1 (24 November 2015).

101 Para 378 CRPD.

needs of children with disabilities and how the human rights system can promote, protect and assist in the provision of these needs.

Taken together in an interpretively comprehensive manner, the African Children's Charter and the CRPD complement each other in the protection they provide to children with disabilities in South Africa and the broader African context. These two instruments, when viewed as mechanisms aimed at achieving a common goal, may be used to bring substance and content to the socio-economic rights of children with disabilities provided for by national law. South Africa is duty bound to ensure that the rights, including socio-economic rights, of children with disabilities are protected and fulfilled as provided for by both the African Children's Charter and the CRPD.

Faraaz Mahomed and Michael Ashley Stein***

Summary

Stigma and associated discrimination against persons with psychosocial disabilities constitute a considerable barrier to the realisation of the highest attainable standard of health in South Africa, Africa, and further afield, constituting a significant human rights violation. This situation is evidenced and exacerbated by mental health as a whole remaining under-prioritised in law, policy and resource allocation. States parties to the Convention on the Rights of Persons with Disabilities (CRPD) have a duty to address stigma and discrimination through awareness raising and education. Some important commitments have been made in this respect, particularly at the policy level in South Africa. Nevertheless, and as demonstrated by tragic recent events, effective implementation remains lacking. This article lays out the obligations incumbent upon the South African government to address stigma and discrimination on the basis of psychosocial disability as a public health and human rights imperative by examining positive duties incorporated into international instruments and domestic law and policy. It further considers the role of political de-prioritisation of mental health and how this constitutes stigma of a systemic nature, using case law and examples of research and best practice from South Africa, Africa generally, and beyond. We conclude that South Africa is failing to meet its obligations to persons with psychosocial disabilities, and recommend that positive duties be emphasised in potential disability-specific legislation; high-level political commitment and co-ordination is

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secured for mental health; the CRPD's independent monitoring requirement is urgently fulfilled; and contextually-relevant interventions are crafted with the active participation of persons with psychosocial disabilities and their representative organisations.

1 Introduction

The World Health Organization (WHO) estimates that over 450 million people worldwide live with psychosocial disabilities,¹ a figure some experts believe to be a severe under-approximation.² Empirical certainty is especially challenging in South Africa where the overall accuracy of disability statistics has been the subject of significant debate due to unreliable, inconsistent and, at times, possibly biased measuring and reporting methods.³ Moreover, pervasive stigma and discrimination relating to persons with psychosocial disabilities in that state remain neglected by law and policy makers notwithstanding an urgent need to eliminate those prejudices and their consequences. Specifically, despite law and policy provisions that obligate South Africa to educate the public on psychosocial disabilities, and to undertake those education initiatives as part of a broader effort to prioritise mental health, no real progress has been made in the development and rollout of national awareness and stigma-reduction activities. As a consequence, mental health as a whole remains domestically de-prioritised and under-researched.

The article examines the need to address mental health stigma and its ramifications as human rights violations and public health challenges in the context of South Africa's broader obligation to ensure the full realisation of the rights of persons with psychosocial disabilities. In doing so, we consider the state's obligations under the Convention on the Rights of Persons with Disabilities (CRPD), and especially its domestic duties as encompassed in the Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA),⁴ the Draft National Disability Rights Policy (NDRP),⁵ and the National Mental Health Policy and Strategic Framework 2013-2020 (NMHPF).⁶

We argue that addressing stigma is both a public health and a human rights concern that is inadequately accounted for in existing laws and

- 1 WHO 'Mental disorders affect one in four people' http://www.who.int/whr/2001/media_centre/press_release/en/ (accessed 25 July 2017).
- 2 D Vigo et al 'Estimating the true global burden of mental illness' (2016) 3 *Lancet Psychiatry* 171-178.
- 3 K Foskett 'Intellectual disability in South Africa' (2014) <http://www.includid.org.za/Downloads/South%20Africa%20and%20Intellectual%20Disability.pdf> (accessed 25 July 2017).
- 4 Act 4 of 2000.
- 5 Draft National Disability Rights Policy, *Government Gazette* 38471, 16 February 2015.
- 6 Department of Health *National mental health policy and strategic framework 2013-2020* (2013).

policies. Although some South African laws and frameworks make mention of stigma and discrimination on the basis of psychosocial disability, or explicitly require the state to take steps to address this problem, existing protections nonetheless remain insufficient. To illustrate: the Mental Health Care Act⁷ lacks any positive obligation to foster inclusivity, while the provisions of PEPUDA, consciously designed to promote equality through public education,⁸ have yet to be activated. Lack of adequate resourcing and attendant capacity building, likewise, forms a significant impediment to meeting existing stigma reduction objectives, despite their inclusion in instruments such as the CRPD, NDRP and NMHPF. This demonstrated systemic failure to prioritise mental health in law and policy implementation amounts to stigma in its own right.

To comply with the CRPD as well as its own domestic legislation and policies, South Africa must undertake further actions. These can include high-level state intervention and inter-departmental co-ordination, adopting disability-specific legislation, and strengthening (while also making accountable) the South African Human Rights Commission (SAHRC) in its designated role as the state's CRPD-compliant independent monitoring mechanism. Using lessons from the rest of Africa as well as further afield, we consider how these recommendations might be best implemented for the benefit of persons with psychosocial disabilities in South Africa. Throughout the article we advocate for an African perspective which recognises that specific needs exist for South African persons with psychosocial disabilities, and that any contextually-relevant interventions must take those needs into account by including the active participation and consultation of those individuals and their representative disabled peoples' organisations (DPOs).⁹

2 Global, African and South African perspectives on Addressing Stigma

Stigma on the basis of psychosocial disability is a significant source of social marginalisation as well as a cruel and pervasive affront to human rights and individual dignity.¹⁰ This prejudice can dehumanise those affected and cast them as ineligible for fundamental rights,¹¹ including

7 Act 17 of 2002.

8 Ch 5 of the Act relates to the promotion of equality through, among other means, public education.

9 JE Lord & MA Stein 'Prospects and practices for CRPD implementation in Africa' (2014) 1 *African disability rights yearbook* 97.

10 BD Robbins & HL Friedman 'Social justice, human dignity and mental illness: A psychological perspective informed by personalist ethics' in CV Johnson & HL Friedman (eds) *The Praeger handbook of social justice and psychology* (2014) 67 71-72.

11 A Dhanda & T Narayan 'Mental health and human rights' (2007) 370 *Lancet* 1197-1198.

rights of access to health care facilities that (ironically) can help ameliorate those very same stigmatised and impairing conditions.¹² Discrimination can also play a role in perpetuating or causing 'socially-induced stress', at once a product and a recapitulation of the original structural and institutional biases that result in psychosocial impairments.¹³ In this sense, stigma and discrimination constitute a cyclical phenomenon, further alienating and oppressing those who have already been alienated and oppressed.

False attributions that consider psychosocial impairments as the product of witchcraft, supernatural possession or 'feeble-mindedness' have been demonstrated to be particularly significant impediments to accessing mental health care on the African continent.¹⁴ This barrier is exacerbated by negative attitudes among health care workers and a dearth of adequate treatment options, which in combination reinforce harmful stereotypes by leaving psychosocial disabilities untreated.¹⁵ In South Africa, much like the rest of the continent, the role of stigma as a rights violation and as an impediment to accessing responsive care continues to greatly impede individuals from seeking support, care or treatment.¹⁶ Similarly, a lack of adequate information and training on mental health issues causes some health care workers to feel unable or unwilling to render services to persons living with psychosocial disabilities.¹⁷ The result is that psychosocial disabilities often go untreated, that communities exclude people who could live fulfilling and productive lives in those communities, and that mental health continues to suffer a 'lack of ownership' as a policy priority.¹⁸

Stigma also hinders progress toward developing laws and policies relating to mental health in African countries, including South Africa.¹⁹ Thus, although Ghana enacted mental health legislation, and South Africa promulgated the NMHPF, the lack of implementation of the respective statutes continues to bar progress in each of these countries.²⁰ Ghana, for example, despite the promulgation of a national Mental Health Act in 2012, has yet to implement the law or prioritise mental health care in

12 S Cooper et al 'Viewing Uganda's mental health system through a human rights lens' (2010) 22 *International Review of Psychiatry* 578-583.

13 C Nelson 'Of egg shells and thin skulls: A consideration of racism-related mental illness impacting black women' (2006) 29 *International Journal of Law and Psychiatry* 128.

14 B Saraceno et al 'Barriers to improvement of mental health services in low-income and middle-income countries' (2007) 370 *Lancet* 1164-1174.

15 P Bartlett et al 'Mental health law in the community: Thinking about Africa' (2011) 5 *International Journal of Mental Health Systems* 21-24.

16 CO Egbe et al 'Psychiatric stigma and discrimination in South Africa: Perspectives from key stakeholders' (2014) 14 *BMC Psychiatry* 191.

17 R Kakuma et al 'Mental health stigma: What is being done to raise awareness and reduce stigma in South Africa?' (2010) 13 *African Journal of Psychiatry* 118-120.

18 AJ Flisher et al 'Mental health policy development and implementation in four African countries' (2007) 12 *Journal of Health Psychology* 505-516.

19 MA Omar et al 'Mental health policy process: A comparative study of Ghana, South Africa, Uganda and Zambia' (2010) 4 *International Journal of Mental Health Systems* 24.

20 GH Walker 'Ghana Mental Health Act 846 of 2012: A qualitative study of the challenges and priorities for implementation' (2015) 49 *Ghana Medical Journal* 266.

practice due to a lack of financial, human, and political resources.²¹ The next part considers incumbent obligations by South Africa to ensure that stigma is addressed.

3 South Africa's obligations to address stigma

South Africa ratified the CRPD in 2007.²² Further to the Constitution of the Republic of South Africa,²³ the act of ratification bound the state to honour the treaty's mandates. Amongst these obligations are requirements enumerated in article 8(1) that states break down stigma and positively educate their populations on issues relating to disability.²⁴ This legal duty is worth citing in full. States are charged:

- a. To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
- b. To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
- c. To promote awareness of the capabilities and contributions of persons with disabilities.

The responsibilities in article 8 have a direct bearing on all obligations arising under the CRPD, because each of the treaty's provisions must be read horizontally and holistically, including the non-discrimination and equality provisions (article 5).²⁵ Obviously connected duties relating to individual articles include equal access to health (article 25); provisions which guarantee the right to education (article 24) and to work (article 27); and the mandate for inclusion in the community (article 19). Put another way, countering the impact of stigma makes it vitally easier for people with psychosocial disabilities to seek care, attend school and university, pursue employment that is fair and dignified, and live where and with whom they wish.²⁶ Hence, numerous intersecting rationales support states alleviating stigma and discrimination, and restoring the dignity and fundamental freedoms of persons with psychosocial disabilities.

In domestic South African law, section 10 of the Mental Health Care Act prohibits discrimination on the basis of mental health status, but

21 Walker (n 20 above) 272.

22 CRPD 'List of ratifying states and regional integration organisations' <http://www.un.org/disabilities/convention/signature.shtml> (accessed 25 July 2017).

23 Sec 231 Constitution of the Republic of South Africa, 1996.

24 P Bartlett 'Stigma, human rights and the UN Convention on the Rights of Persons with Disabilities' in W Gaebel et al (eds) *The stigma of mental illness: End of the story?* (2017) 209-226.

25 MA Stein 'Disability human rights' (2007) 95 *California Law Review* 75.

26 JK Burns 'Mental health and inequity: A human rights approach to inequality, discrimination and mental disability' (2013) 8 *Health and Human Rights Journal* 19.

imposes no penalties for its violation. nor does it incorporate positive duties and, instead, focuses largely on issues of legal capacity and institutionalisation.²⁷ Nevertheless, these elements of mental health law have a substantial role to play in improving the quality of life of persons with psychosocial disabilities. Indeed, in *De Vos*,²⁸ the Constitutional Court of South Africa characterised provisions allowing for the imprisonment of people with psychosocial disabilities prior to trial in terms reminiscent of ‘socially-induced stress’,²⁹ namely, that the practice ‘reinforces the stigma and marginalisation that people [living with psychosocial disabilities] are subjected to on a routine basis’.³⁰ Arguably, the same is true of involuntary institutionalisation which, while the subject of some necessary debate,³¹ has the potential to be routinely abused as well as abusive, thereby causing great harm, including unnecessary stigmatisation, in the process.³²

Similarly, as demonstrated in *Purohit & Another v The Gambia*,³³ the sole disability-related decision rendered by the African Commission for Human and Peoples’ Rights (African Commission), respect for the freedom of movement and association of people with psychosocial disabilities constituted a central component of the right to be free from discrimination itself. The Commission recognised that the right to appeal involuntary detention was essential for the assurance of the dignity of persons with psychosocial disabilities, while also asserting that laws which inadequately protected the rights of these persons constituted a failure to recognise their special needs and, therefore, amounted to discrimination.³⁴

3.1 Incorporating a positive obligation

Purohit likewise elaborated on the need for positive measures to integrate persons with psychosocial disabilities into society. The African Commission required The Gambia to ensure appropriate steps for inclusivity through law and policy designed to address discrimination and, in the process, advance associated rights such as the right to ‘a decent life, as normal and full as possible’.³⁵ Trenchantly, *Purohit* asserted the value of the right to health and required that its realisation be advanced positively

27 Sec 10 Mental Health Care Act (n 7 above).

28 *De Vos NO v Minister of Justice and Constitutional Development* 2015 (9) BCLR 1026 (CC).

29 Nelson (n 13 above) 128.

30 *De Vos* (n 28 above) para 46.

31 MC Freeman et al ‘Reversing hard-won victories in the name of human rights: A critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities’ (2015) 2 *Lancet Psychiatry* 844-850.

32 JE Lord & MA Stein ‘Contingent participation and coercive care: Feminist and communitarian theories consider disability and legal capacity’ in B McSherry & I Freckleton (eds) *Coercive care: Law and policy* (2013) 31.

33 (2003) AHRLR 96 (ACHPR 2003).

34 *Purohit* (n 33 above) paras 53-57.

35 *Purohit* para 61.

without 'discrimination of any kind'.³⁶ The decision, therefore, underscores the need for disability to be de-stigmatised in all spheres if discrimination is to be fully alleviated at individual, community, institutional and social levels. It also implies a positive and active state duty to seek a means of promoting inclusivity, whether in advancing the right to health care or in seeking to ensure access to the full spectrum of rights.³⁷

Aside from the Mental Health Care Act, no other form of disability-related legislation currently exists in South Africa. PEPUDA places a positive obligation on the state to promote the right to equality, including non-discrimination, on the basis of disability. Section 25(1)(a) of PEPUDA requires the state to 'develop awareness of fundamental rights' through, among other means, public information campaigns. Therefore, a significant obligation exists in respect of the promotion of the right to equality in South Africa, including through awareness raising and information dissemination. Yet this provision, along with the entire chapter of PEPUDA that deals with the promotion of the right to equality, remains in abeyance awaiting the signature into law of the President of South Africa, a situation that has persisted for over 17 years.³⁸

It is worth noting that two recent policy instruments have demonstrated a commitment to a rights-based approach to psychosocial disability and have included stigma reduction as part of these schemes. These policies, which emanated from different departments, are the National Disability Rights Policy (also known as the White Paper on the Rights of Persons with Disabilities), championed by a Directorate of the Department of Social Development (formerly the Department of Women, Children and People with Disabilities), which was approved in December 2015;³⁹ and the National Mental Health Policy and Strategic Framework 2013-2020, which is a product of the National Department of Health.⁴⁰ These are certainly important steps forward in the advancement of the rights of persons with psychosocial disabilities. Yet, as explored in the next section, notwithstanding considerable commitments on paper, the actual implementation of stigma reduction and public education initiatives have been less forthcoming.

36 *Purohit* para 84.

37 *Purohit* paras 78-81.

38 South African Human Rights Commission *Equality Round Table Report* (2015).

39 Draft National Disability Rights Policy (n 5 above); Western Cape Association for Persons with Disabilities 'Disability rights: A huge step forward' <http://www.wcapd.org.za/uncategorized/disability-rights-a-huge-step-forward/> (accessed 25 July 2017).

40 Department of Health (n 6 above).

4 Failure to address stigma

In 2013, South Africa issued its first progress report on the state's compliance with the provisions of the CRPD. The report noted in relation to article 8 that, despite awareness regarding the rights of disabled persons occupying a place of prominence in the state agenda, 'weaknesses in co-ordination, implementation and monitoring and evaluation have largely detracted from its effectiveness and impact'.⁴¹ This is a grim self-indictment of the inability of the South African government to mobilise resources and political will to support the rights of persons with disabilities. Two years later, South Africa's first periodic country report to the Committee on the Rights of Persons with Disabilities (the treaty body tasked with oversight of the CRPD) outlined a handful of activities aimed exclusively at officials in government departments as evidence of progress towards meeting the objectives of article 8.⁴² Such an approach belies the fact that the CRPD requires a much broader and societal approach to raising awareness and reducing stigma, and demonstrates that the country is failing to meet these obligations.

That South Africa has made numerous commitments to the reduction of stigma on the basis of psychosocial disability is indeed noteworthy. Yet, the lack of sound implementation and appropriate resourcing for such initiatives is amply borne out by the meagre advances reported in the country's CRPD report. Among the challenges identified in meeting this need is the lack of available resources to ensure sound implementation. Research conducted in 2009 assessed that 'there are not currently resources available for education to reduce stigma'.⁴³ Six years later, Marais and Petersen examined the extent of the country's implementation of the NMHPF, and found that resource allocation remained a challenge. Also contributing to administrative malaise was a lack of political impetus:

The mental health policy framework does not provide sufficient guidance on how stigma should be addressed, with provincial and district level respondents not being aware of any specific anti-stigma programmes for mental health and variations between provinces in terms of prioritising addressing stigma.⁴⁴

41 Department of Women, Children and People with Disabilities, South Africa *Baseline country report to the United Nations on the implementation of the Convention on the Rights of Persons with Disabilities* (2013).

42 Department of Social Development *First periodic country report on the United Nations Convention on the Rights of Persons with Disabilities* (2015).

43 M van der Merwe 'Psychiatry in distress: How far has South Africa progressed in supporting mental health?' <http://www.dailymaverick.co.za/article/2015-07-15-psychiatry-in-distress-how-far-has-south-africa-progressed-in-supporting-mental-health/#.WCkejUrLIW> (accessed 25 July 2017).

44 DL Marais & I Petersen 'Health system governance to support integrated mental health care in South Africa: Challenges and opportunities' (2015) 9 *International Journal of Mental Health Systems* 1-21.

The lack of political knowledge, will or co-ordination that these authors refer to as stumbling blocks translates directly into an absence of political impetus to destigmatise mental health, regardless of the formal legal obligations and policy commitments to do so. While the promulgation of both the NDRP and the NMFPH illustrates that there is nominal political will to ensure that the rights of people living with psychosocial disabilities are advanced, this has not translated into the actual implementation of stigma reduction activities. Put another way, 'mental health is a priority on paper but not in practice'.⁴⁵ This failure speaks to a broader neglect – and essentially stigmatisation of its own kind – of psychosocial disability as an area for legal, political and administrative action, as illustrated further below.

5 Realising the obligation to address stigma

Notwithstanding public political commitments by South Africa to ameliorate stigma arising from psychosocial disability, a considerable and glaring gap exists as far as implementation is concerned. Ultimately, weak rights enforcement is not isolated to stigma reduction since mental health more generally remains a neglected issue country-wide, remaining 'low on the public sector agenda'.⁴⁶ Experts thus point to the entrenched stigmatisation of psychosocial disability as a primary 'excuse for inaction',⁴⁷ and among 'the chief obstacles' to improving mental health care.⁴⁸

The marginalisation of mental health as a public health or human rights concern is well illustrated by the fact that less than 5 per cent of South Africa's health budget is expended on assisting people with mental health needs.⁴⁹ In comparison with countries such as Zambia and Uganda, where less than 1 per cent of national budgets are expended on mental health, this proportion seems relatively generous. Nonetheless, the figure illustrates a very telling point about an urgent need for parity if care provision is to match the burden of disease relating to mental health.⁵⁰ *Purohit* may be instructive in this regard as well, with the African Commission encouraging states parties to the African Charter on Human and Peoples' Rights (African Charter) 'to take concrete and targeted steps, while taking full advantage of its available resources, to ensure that the

45 Walker (n 20 above).

46 AA Herman et al 'The South African stress and health (SASH) study: Twelve-month and lifetime prevalence of common mental disorders' (2009) 99 *South African Medical Journal* 339.

47 United States Department of Health and Human Services Substance Abuse and Mental Health Services Administration *Mental health: A report of the surgeon-general* (1999) 3.

48 S Sturgeon 'Stigma and marginalisation: Structural violence and the impact on mental health' (2012) 48 *Social Work* 58 61 (citing Sartorius).

49 H Jack et al 'Closing the mental health treatment gap in South Africa: A review of costs and cost-effectiveness' (2014) 7 *Global Health Action* 10.

50 Omar et al (n 19 above) 26-28.

right to health is fully realised in all its aspects without discrimination of any kind'.⁵¹ Commentators interpret this to mean that mental health should comprise a significant proportion of the health budget, and that the failure to do so constitutes discrimination against those affected by psychosocial disability.⁵²

Indeed, the under-prioritisation of mental health in South Africa is a pervasive problem, as evidenced by the lack of reliable data. This problem has more recently proven to be deadly. Between March and December 2016, 94 psychiatric patients died after having been removed from institutionalised care and placed in unlicensed community settings which were found by the South African health Ombud to be 'unstructured, unpredictable and sub-standard' in what came to be known as the Gauteng Mental Health Marathon Project (GMHMP).⁵³ These transfers occurred after subsidies for institutionalisation had been cancelled due to an apparent lack of funds⁵⁴ and because of 'selective interpretation' of the NMHPF⁵⁵ which, in an effort to comply with article 19's enshrinement of the right to live in the community, calls for a systematic process of de-institutionalisation.⁵⁶ Instead, what occurred was a 'chaotic' process of transferring patients to under-resourced facilities with untrained staff.⁵⁷ This is clearly contrary to the state's obligations in terms of the CRPD, and calls into question not only the commitment of the South African government to address stigma and foster awareness of mental health in society, but more pointedly the commitment to recognise and prioritise mental health needs altogether.

The next part considers some potential formal and institutional remedies that can have the effect of addressing what amount to gross failures on the part of the state to meet its obligations.

6 Addressing South Africa's failure to meet its commitments

The CRPD, PEPUDA, NDRP and NMHPF evidence South Africa's binding legal obligations for reducing stigma towards and promoting the rights of individuals with psychosocial disabilities. The state has also made various other commitments through which it has expressed its intention to

51 *Purohit* (n 33 above) para 84.

52 M Anyidoho 'The right to health for mental health patients: African Commission' (2004) 1 *Housing and ESC Rights Quarterly* 4.

53 Office of the Health Ombud *The report into the circumstances surrounding the deaths of mentally-ill patients* (2017).

54 M Raborife 'Too many unanswered questions about Esidemeni 37' <http://www.news24.com/SouthAfrica/News/too-many-unanswered-questions-about-esidimeni-37-20161028> (accessed 25 July 2017).

55 Office of the Health Ombud (n 53 above) 1.

56 As above.

57 Office of the Health Ombud (n 53 above) 2.

meet these obligations. Therefore, it would be incumbent upon the South African government to consider the numerous challenges already identified and how these may be engaged with and alleviated. The following is an exploration of the mechanisms through which the advancement of public education and reduction of stigma relating to psychosocial disability might be accomplished.

6.1 Emphasising mental health in policy and budgeting

Although we emphasise the significance of stigma reduction in relation to psychosocial disability, a broader issue that should also be addressed is the neglect of mental health as a public health concern. These challenges form part of the same larger and more systemic problem,⁵⁸ with social attitudes and public health policies coalescing to marginalise persons with psychosocial disabilities in numerous intersecting ways.⁵⁹ For instance, stigma obstructs the rehabilitation of individuals with psychosocial disabilities through de-prioritisation or a lack of co-ordination. Half of all African countries remain without a mental health policy, signalling that psychosocial impairment is a marginalised area of concern across the continent.⁶⁰ Similarly, the formulation of policies that subsequently remain unimplemented represents another form of de-prioritisation. It should, therefore, be noted that, while addressing stigma in public arenas requires one form of intervention, the prioritisation of mental health can in itself serve to alleviate stigma and, therefore, must be considered in the policy process alongside awareness-raising initiatives.

Emphasising mental health as an area of policy priority will require questioning the 'lack of ownership' identified by scholars⁶¹ and ensuring that this is addressed through the clear designation of officials whose mandate is the promotion of mental health in their respective policy agendas. This is particularly important for South Africa in the Departments of Health, Finance and Social Development, where issues of resourcing and budget constraints have been identified as impediments. Ensuring that mental health is advocated for within these institutional structures can significantly alter this situation, with a stronger emphasis being placed on the needs of those with psychosocial disabilities as a matter of regularity in all aspects of governance.

The continued neglect of mental health as a concern evidences stigma across institutions, and can be alleviated through the appointment of a task

58 United States Department of Health and Human Services (n 47 above); Omar et al (n 19 above); Walker (n 20 above).

59 PW Corrigan et al 'Structural levels of mental illness stigma and discrimination' (2004) 30 *Schizophrenia Bulletin* 481-491.

60 J Ssebunya et al 'Developing a national mental health policy: A case study from Uganda' (2012) 9 *PLoS Med* 10.

61 Flisher et al (n 18 above).

force advocating its prioritisation in government departments while centrally co-ordinating these efforts. This can have the effect of ensuring that mental health is given the necessary priority and also that psychosocial disability is made visible – is understood and demystified. Visibility, in turn, can have a significant impact in improving awareness,⁶² whether at the level of local communities and health establishments or, indeed, nationally, including amongst law makers themselves.

Inter-departmental co-ordination and the dovetailing of activities undertaken by the Departments of Health, Finance and Social Development can significantly advance what amounts to a common goal across ministries. Recognising that these departments place a significant emphasis on the advancement of the rights of persons with psychosocial disabilities, it seems reasonable to suggest that an inter-ministerial mechanism be implemented to harmonise unenforced schemes currently contained in NDRP and NMHPF. Considering that one of the barriers to addressing stigma has been identified as the insufficient allocation of resources,⁶³ avoiding duplication and resource pooling can significantly aid in the achievement of outcomes that advance both public health aspirations and disability rights objectives. Such a mechanism, therefore, requires high-level engagement in its composition. Clearly, the participation and input of other ministries, such as the Department of Justice and Correctional Services, the Department of Basic Education and others, is likewise needed.

6.1.1 Disability rights legislation concordant with the CRPD

Cabinet approval of the NDRP signals a significant shift in the desire to see the rights of persons with psychosocial disabilities realised. Still, the passage from White Paper status to the formulation of a Bill, and eventually a National Disability Rights Act, has significant advantages. Flynn, for example, notes that an impediment to the advancement of the rights of persons with disabilities in South Africa through policy has been the lack of enforcement and accountability mechanisms, which may be legislated for.⁶⁴ Similarly, Byrnes suggests that the provisions of the CRPD require specific legislation in order to meet the need for harmonisation of national laws with the Convention because of the numerous areas covered, ranging from issues of legal capacity to child protection and the prohibition of torture. As such, he suggests, the mere inclusion of a non-discrimination

62 R Warner 'Fields of intervention' in Gaebel et al (n 24 above) 435-450.

63 Herman et al (n 46 above).

64 E Flynn *From rhetoric to action: Implementing the UN Convention on the Rights of Persons with Disabilities* (2011).

provision or 'reading in' of disability into existing instruments, such as the Mental Health Care Act, is not likely to be sufficient.⁶⁵ Instead, an approach which addresses all disabilities in a manner that recognises the scale and the range of challenges faced would be preferable.

With regard to stigma reduction, an important advantage of legislation is the legal obligation placed on the state to promote the rights of persons with psychosocial disabilities. This is particularly important because of the fact that the promotional mandate incorporated in PEPUDA remains inactive. Such apathy has contributed to a lack of accountability on the part of the South African government to rigorously and diligently undertake initiatives aimed at the promotion of the right to equality.⁶⁶ While it is clear that there may be some need for greater elucidation of the relationship between proposed legislation and PEPUDA, there has been no indication that the latter will reach the stage of implementation. Further, the recent introduction of seemingly parallel pieces of legislation, such as the Women's Empowerment and Gender Equality Bill,⁶⁷ suggests that the political will to see Chapter 5 reach fruition may be lacking.

However, perhaps more importantly, articles 4(1)(a)-(e) of the CRPD recognises the need for harmonisation and appropriate auditing of existing legislative mechanisms in order to identify what gaps exist in the current legal framework and how the state may go about rectifying them.⁶⁸ The Department of Social Development has already embarked upon such a review, although the outcome is as yet unclear.⁶⁹ A comprehensive process that considers what specific needs exist and how legislation can best aid in the advancement of fundamental rights is a necessary first step. However, it must be followed by the development of legislation which places a specific emphasis on the obligation of the state to address stigma on the basis of psychosocial disability through, among other means, rights promotion, awareness raising and inter-departmental co-ordination.

Few states explicitly set forth measures to be undertaken to reduce stigma and promote the rights of persons with disabilities in their domestic legislation. Malaysia's Persons with Disabilities Act of 2008, and Bangladesh's Rights and Protection of Persons with Disabilities Act of 2013, however, provide useful guidance in respect of addressing stigma

65 A Byrnes 'Disability discrimination law and the Asian Pacific region. Paper for the UNESCAP, social development division for the Asia-Pacific region' http://www.unescap.org/files/documents/PUB_CRPD-Paper-III-Andrew-20110121.pdf (accessed 25 July 2017).

66 L Vetten 'Submission to the Portfolio Committee on women, children and people with disabilities on the Women Empowerment and Gender Equality Bill [B50-2013]' <http://pmg-assets.s3-website-eu-west-1.amazonaws.com/submissionwegebillparliament.pdf> (accessed 25 July 2017).

67 As above.

68 Byrnes (n 65 above).

69 Personal communication with official from the Department of Social Development, 26 November 2016.

through legislative mechanisms. Each of these laws uses national and district co-ordination committees to advise relevant government structures and to engage in awareness raising and information dissemination.⁷⁰ Such a model provides avenues for participation and oversight by persons with disabilities, while maintaining governmental implementation and resourcing obligations.

Even so, further concretising legislation can significantly enhance impact through, for example, the establishment of a stigma-reduction working group made up of public education experts who can report back on an annual basis to the Parliamentary Portfolio Committee on Women, Children and People with Disabilities. Such an approach has an added advantage of creating permanent structures with the dedicated purpose of advancing promotional objectives. Nor must such an approach be limited to the proposed legislation. It could draw upon the work of the NMHPF, to name an example, in ensuring that CRPD-guided and informed work is accurately motivated, implemented and monitored. Legislation and policy can be periodically evaluated for concordance with the CRPD, utilising a human rights assessment to examine mental health frameworks in Africa. Because currently no country on the continent (or indeed, the globe) is as yet fully compliant with the provisions of the CRPD, continuous examination can significantly aid in moving progress on this challenge.⁷¹

6.2 Research and capacity building

Stigma reduction is a relatively well-researched topic in the developed world, with numerous systematic studies illustrating that improving education, reducing social distance and intelligently targeting key stakeholders (such as healthcare workers) can have significant benefits.⁷² Yet, similar research in the developing world has only recently emerged.⁷³

70 Malaysia Persons with Disabilities Act, 2008; Bangladesh Rights and Protection of Persons with Disabilities Act, 2013.

71 N Drew et al 'Mental health law in Africa: Analysis from a human rights perspective' (2013) 12 *Journal of Public Mental Health* 10.

72 S Evans-Lacko et al 'The state of the art in European research on reducing social exclusion and stigma related to mental health: A systematic mapping of the literature' (2014) 29 *European Psychiatry* 382-389; D McDaid 'Countering the stigmatisation and discrimination of people with mental health problems in Europe' http://ec.europa.eu/health/archive/ph_determinants/life_style/mental/docs/stigma_paper_en.pdf (accessed 25 July 2017) 12-14.

73 A Alem et al 'Community-based mental health care in Africa: Mental health workers' views' (2008) 7 *World Psychiatry* 54; N Monteiro et al 'Policy perspectives and attitudes towards mental health treatment in rural Senegal' (2014) 8 *International Journal of Mental Health Systems* 9; J Crabb et al 'Attitudes towards mental illness in Malawi: A cross-sectional survey' (2012) 12 *BMC Public Health* 541; A Kapungwe et al 'Attitudes of primary health care providers towards people with mental illness: Evidence from two districts in Zambia' (2011) 14 *African Journal of Psychiatry* 290.

The relative successes of the Time to Change campaign in the United Kingdom⁷⁴ and Like Minds, Like Mine in New Zealand⁷⁵ provide important guidance in respect of the deconstruction of negative and false attributions. They also point out the need for private sector co-operation and the use of a variety of avenues for stigma reduction, including creative arts productions and the introduction of 'peer workers'.⁷⁶

Nonetheless, importing programmes from the global north wholesale without an acknowledgment of resource differentials and the specific contextual factors that lead to stigma and discrimination in the African context is not an appropriate solution. More empirically-grounded research is needed on the manner in which stigma can be combated, particularly in South Africa, where historically there have been a number of short-lived interventions that were not replicated or evaluated for their efficacy.⁷⁷ Similarly, awareness of mental health issues in many South African communities remains poor and requires targeted intervention aimed at literacy.⁷⁸ International models, many of which have been long-lasting and have undergone evaluation for their efficacy, can certainly be of significant utility,⁷⁹ but this must necessarily be accompanied by localised investigation.

Key obstacles to addressing public attitudes are the combined lack of evidence-based methods aimed at mitigating negative perceptions; an absence of capacity to carry out such initiatives once devised; and adequate policy co-ordination aimed at implementation.⁸⁰ The South African government, therefore, must accurately capture the capacity needs associated with goals contained in the NDRP and NMHPF if these programmes are to bear fruit. Addressing skills shortages as well as capital needs is likely to be an important consideration in the translation of political rhetoric into changes in actual lived experiences. It also is important to note that a significant amount of expertise already exists in the form of South Africa's DPOs and their umbrella body, the African Disability Forum, comprising DPOs from across the continent.⁸¹ The state, therefore, should ensure an approach that makes use of the expertise housed within these organisations to guide appropriate research functions and to inform the design and rollout of stigma-reducing activities.

74 C Henderson et al 'The time to change programme to reduce stigma and discrimination and its wider context' in Gaebel et al (n 24 above) 339-356.

75 R Cunningham et al 'Like minds, like mine: Seventeen years of countering stigma and discrimination against people with experience of mental distress' in Gaebel et al (n 24 above) 263-288.

76 Henderson et al (n 74 above); Cunningham et al (n 75 above).

77 Kakuma et al (n 17 above) 118-120.

78 Egbe et al (n 16 above).

79 H Stuart 'What has proven effective in anti-stigma programming?' in Gaebel et al (n 24 above) 497-514.

80 Marais & Petersen (n 37 above).

81 International Disability Alliance 'African Disability Forum' (2017) <http://www.internationaldisabilityalliance.org/african-disability-forum> (accessed 25 July 2017).

South Africa's State Institutions Supporting Democracy – commonly referred to as Chapter 9s, and including the SAHRC and the Commission for the Protection and Promotion of Cultural, Religious and Linguistic Communities – also have a particularly important role to play in the realisation of the rights of persons with psychosocial disabilities. In terms of the Constitution and its enabling legislation, the SAHRC bears a clear mandate to promote the advancement of human rights, including those related to the community of persons with disabilities.⁸² Therefore, it is incumbent upon the government of South Africa and the SAHRC itself to ensure that this promotional mandate is fully carried out in respect of the rights of persons with psychosocial disabilities as well.⁸³

6.3 A (South) African perspective on stigma

As noted above, a considerable need exists for further investigation into stigma on the basis of psychosocial disability in South Africa and on the continent. This, in turn, requires that interventions, policies and laws must recognise the specific context in which they operate and seek to ensure relevance.⁸⁴ In the context of evolving mental health law, policy and practice, 'Africa presents particular challenges and opportunities'.⁸⁵ Among the unique structural factors experienced by the region are the significant shortage of specialised mental health professionals and the fact that, with the possible exception of South Africa, the institutionalisation of persons with psychosocial disabilities has not been a common occurrence.

In 2014, persons with psychosocial disabilities, non-governmental organisations (NGOs), policy makers, academics, research funders and service providers from Eastern, Western, Southern and Northern Africa and further afield, adopted the Declaration on Mental Health in Africa (Africa Declaration), a framework that broadly defines an agenda for serving the needs and advancing the rights of persons with psychosocial disabilities throughout the continent.⁸⁶ Sub-titled 'Moving to implementation', the pronouncement is worth quoting at length:

82 Sec 181 South African Constitution; South African Human Rights Commission Act 40 of 2013.

83 It is worth noting that an oversight function exists in relation to the SAHRC, whereby annual reporting to the Parliamentary Portfolio Committee on Justice and Correctional Services is required. Therefore, there is ample scope for ensuring that the SAHRC meets its promotional obligations and for holding the institution to account. To date, this has not been the case.

84 MA Stein & JE Lord 'Forging effective international agreements: Lessons from the UN Convention on the Rights of Persons with Disabilities' in J Heymann & A Cassola (eds) *Making equal rights real: Taking effective action to overcome global challenges* (2012) 27.

85 Bartlett (n 24 above) 21.

86 AS Daar et al 'Declaration on mental health in Africa: Moving to implementation' (2014) 7 *Global Health Action* 24589.

In communities in which persons with psychosocial disabilities live, and even in the health care system, the affected persons, their families, and caregivers are frequently stigmatised and experience social exclusion and discrimination; and it is often assumed that little can be done to address their circumstances. However, a growing body of scientific evidence shows that much can be done for treatment, at moderate additional costs, and with significant economic benefits to countries, while at the same time reducing suffering and improving, and often saving, the lives of those who are affected.⁸⁷

The Africa Declaration goes on to state that although challenging, the African health system may also present an opportunity for task, resource and knowledge sharing.⁸⁸ Regional and national efforts aimed at addressing stigma on the basis of psychosocial disability and advancing the rights of disabled persons generally, therefore, will need to recognise the specific challenges and opportunities that their context presents.

Meanwhile, in February 2016, the African Commission adopted the Draft Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (African Draft Disability Protocol).⁸⁹ This instrument adds renewed impetus to efforts to ensure the mainstreaming of the rights of persons with disabilities into regional frameworks. It contains a specific non-discrimination provision, including what might be construed as a promotional mandate. Article 3, paragraph 3 of the African Draft Disability Protocol requires states parties to 'take steps to ensure that specific measures, as appropriate, are provided to persons with disabilities in order to promote equality and eliminate discrimination'. Yet, the article does not actually require states parties to advance rights through educative mechanisms, thus not fully recognising the need for societal shifts rather than merely the introduction of 'specific measures'. Therefore, it remains to be seen whether any explicit emphasis on the African context and the particular challenges faced by Africans with disabilities will be incorporated into the instrument. First published for comment in 2014,⁹⁰ the Draft Disability Protocol has not yet been finalised and there have been criticisms regarding its lack of contextual relevance.⁹¹ The instrument has also been critiqued for its under-emphasis on psychosocial disabilities, a state which is hoped will be rectified as the final version nears completion, adoption and, most importantly, resource allocation.⁹²

87 As above.

88 As above.

89 African Commission on Human and Peoples' Rights 'Draft Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa' http://www.achpr.org/files/news/2016/04/d216/disability_protocol.pdf (accessed 25 July 2017).

90 L. Nkatha Murungi & E. Durojaye 'The sexual and reproductive health rights of women with disabilities in Africa: Linkages between the CRPD and the African Women's Protocol' (2015) 3 *African Disability Rights Yearbook* 3-30.

91 Personal communication with official from the Department of Social Development, 4 February 2017.

92 As above.

The marginalisation of psychosocial disability within continent-wide initiatives is also instructive for South Africa, where context-specific narratives and culturally-unique taboos likewise prevail. Despite the integration of a rights-based lens in the NDRP and NMHPF, an emphasis on specific sociocultural barriers to accessing care, and a focus on community and family-level stigma are not clearly captured. This is despite the fact that cultural, racial, gendered, ethnic, religious and traditional taboos play a significant part in the stigmatising process in South Africa.⁹³ Both societal stigma and self-stigma are informed by the context in which they occur, and will require interventions that reflect these contextual concerns if they are to be effective.⁹⁴ It, therefore, is imperative that a significant component of the research elaborated upon above considers the need for culturally-relevant methods of integrating persons with psychosocial disabilities and pay due mind to the specific opportunities characteristic of the African and South African context.⁹⁵ Civil society and DPOs – including the South African Federation for Mental Health, MindFreedom South Africa and the Pan-African Network of People with Psychosocial Disabilities – will have a central role to play in this process, bringing with them knowledge of conditions that government may very well not be exposed to. Their contributions, which in any case are required by article 4(3) of the CRPD, should be valued and encouraged.⁹⁶

6.4 Independent monitoring of implementation

A key innovation of the CRPD is its commitment to accountability and effective monitoring of outcomes through the inclusion of a provision in article 33(2) which requires the designation or strengthening of an independent monitoring mechanism (IMM).⁹⁷ The IMM plays a significant role in ensuring that the rights of persons with disabilities are advanced by functioning as a comprehensive evaluator of laws and policies across government departments, and by assessing the societal impact of these schemes.⁹⁸ A considerable role thus exists for IMMs in seeking to ensure that the provisions of the CRPD are adequately and diligently implemented. Article 33(3) further and explicitly requires that persons with

93 CO Egbe 'Experiences and effects of psychiatric stigma: Monologues of the stigmatisers and the stigmatised in an African setting' (2015) 10 *International Journal of Qualitative Studies on Health and Well-Being* 27954.

94 As above.

95 Bartlett (n 24 above) 21.

96 It is noted, as an illustrative example, that advocacy and reporting on the GMHMP were due to efforts by the Pan-African Network of People with Psychosocial Disabilities after government, courts, parliament, and the SAHRC declined to act.

97 MA Stein & JE Lord 'Monitoring the Committee on the Rights of Persons with Disabilities: Innovations, lost opportunities, and future potential' (2010) 31 *Human Rights Quarterly* 689.

98 G de Beco 'Article 33(2) of the UN Convention on the Rights of Persons with Disabilities: Another role for national human rights institutions?' (2011) 29 *Netherlands Quarterly of Human Rights* 87.

disabilities are equal participants in the monitoring process and that the state ensures the input of civil society and DPOs in such a practice. While South Africa has committed to the implementation of article 33 in an effort to promote transparency and accountability, the formal designation or strengthening of an IMM has not yet materialised.⁹⁹ This amounts to a failure on the part of the state to meet its obligations in terms of the CRPD and requires urgent rectification if South Africa is to be said to be meeting its responsibilities.¹⁰⁰

With regard to stigma reduction and the broader prioritisation of mental health, the IMM can play a significant role, not least in examining barriers to the implementation of existing policy objectives and lacunae in law which continue to result in the marginalisation of persons with disabilities. Monitoring the rollout of awareness-raising campaigns, providing training to DPOs and self-advocates, and ensuring regular and accountable meetings of the task force proposed above could also be important functions for the IMM. This, of course, requires substantial commitment on the part of the state to ensure adequate resourcing and capacitation of the mechanism, whether it takes the form of being housed in an existing institution such as the SAHRC (as is the case with countries such as Germany and Denmark), or whether it results in a broader conglomeration of bodies under an umbrella mechanism co-ordinated as an IMM (akin to Austria's Independent Monitoring Committee).¹⁰¹ In either instance, the significant upscaling of resources and technical expertise is needed for the IMM to be fit for purpose.

While these interventions are not the only actions needed to ensure that stigma relating to psychosocial disability is addressed in South Africa, they will go a long way in domesticating the provisions of international law into the country's legal landscape and, in the process, ensuring that mental health receives the visibility necessary to be addressed comprehensively and consistently. The provisions of the CRPD suggest that these interventions are the minimum threshold required for South Africa to meet its obligations, rather than being the 'ceiling' for which the state must strive, meaning that the emphasis must also be placed on an approach that is sustainable and that will be augmented as needed.

99 Personal communication with official from the South African Human Rights Commission, 27 November 2016.

100 Because the SAHRC Act of 2013 incorporates a mandate to monitor South Africa's compliance with international instruments, the argument was made that there was not a need for formal designation but that there was still a need for strengthening as per the CRPD.

101 UNHCHR *Study on the implementation of article 33 of the UN Convention on the Rights of Persons with Disabilities in Europe* (2013).

7 Conclusion

A study of the effects of stigma and concomitant discrimination relating to psychosocial disability in South Africa noted two major effects on those affected, namely, 'being unable to lead normal lives and a worsening state of health of the service user'.¹⁰² These outcomes violate human rights protections, are personally harmful, unnecessary and deeply troubling. They represent a failure to integrate people with psychosocial disabilities into broader South African society, and a clear failure to adequately protect persons with disabilities from discrimination and marginalisation as required by the CRPD.¹⁰³ The South African government is aware of this situation, and appears at least nominally committed to its alleviation. This is significant, and the development of both the NDRP and NMHPF is an important development. Nevertheless, it is through implementation that their progress will be judged.

The Africa Declaration notes the 'urgent need to address stigma, social exclusion and discrimination' as crucial for contributing to quality of life improvements for persons with psychosocial disabilities; further, that the broad community of stakeholders 'must play a major role in bringing about these positive changes'.¹⁰⁴ This is indeed a very significant recognition in its own right. Crucially, however, it is accompanied by an important acknowledgment of the 'urgent need for political vision, commitment, and leadership at the highest level to encourage national dialogue on mental health'.¹⁰⁵ Governments should take the lead, while working with and supporting an inclusive, cross-sectoral, multi-stakeholder approach that can effectively engage with and remedy conditions and social circumstances that enable or reinforce stigma and discrimination against persons with psychosocial disabilities.

We echo the Africa Declaration's call for commitment and action. This requires not only that government enact sound policies, following on the lead of the NDRP and NMHPF, but also strong and accountable institutions and adequately-resourced bureaucracies to carry them out. In the wake of the GMHMP, South Africa must commit never again to fail those living with psychosocial disabilities. Addressing stigma is one step it can and should take without delay.

102 Egbe et al (n 16 above) 6.

103 Arts 4(1)(a)-(e)CRPD.

104 Daar et al (n 86 above).

105 As above.

CHAPTER 5

MENTAL ILLNESS, STIGMA AND DISABILITY RIGHTS IN GHANA

Magnus Mfoafo-M'Carthy and Jeff D Grishow***

Summary

Ghana has recently received much attention for human rights abuses against persons with mental illnesses in traditional 'fetish' and Christian prayer camps. Evidence has surfaced of Ghanaians with mental illnesses being forced against their will to attend the camps only to be physically abused, forcibly isolated and even chained to trees. Not only do these practices reveal a high level of stigma, but they also contravene the spirit and intention of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Despite the fact that Ghana has ratified in the CRPD and passed a new Mental Health Act in 2012, there has been little reaction in the country towards the harsh treatment of patients with mental illnesses at the camps. Lately, however, Ghanaian disability activists have started to take up their cause, protesting the camps as sites of human rights abuses. Starting with the example of one of these activists, also a camp survivor, the article investigates the potential of a human rights framework as a tool for improving the delivery of mental health services in Ghana.

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1 Introduction

In October 2014, the Christian Health Association of Ghana released a film on stigma and mental health to raise awareness about human rights abuses faced by Ghanaians with mental illnesses. The film narrates the story of Doris Appiah Danquah, whose experience with manic depression forced her out of university and into a series of ‘healing’ camps between the late 1970s and early 1990s. In 1978, Danquah earned a place in the Medical School of the Ghana’s premier university, the University of Ghana, after posting top marks at the prestigious Achimota High School in Accra. Her studies did not last long. Shortly after arriving on campus, Danquah began to feel a ‘deep sadness and a deep fear’. She wanted to be alone, skipped classes and struggled mightily as her dream of a medical degree began to slip away. Eventually Doris was diagnosed with manic depression, and her parents realised that she would not be able to complete university without treatment. The University gave her a three-year leave of absence to recover and return to the programme. What followed, however, was 22 years of being moved from institution to institution as Danquah’s family searched in vain for a solution. The first choice was the Accra Psychiatric Hospital, located in the country’s capital. However, the hospital’s psychiatrist turned Doris away, informing her parents that her condition was ‘simply who she was’; that nothing could be done medically; she would never recover, and Doris and her family would have to accept her condition.¹

Desperate to find a cure, Doris’ family tried a series of traditional fetish shrines and Christian prayer camps, believing that her condition had a spiritual cause and that ‘Doris’s depressed soul had escaped from the world of reality and needed to be persuaded back home’.² Doris’s father initially took her to a famous fetish shrine called Akonedí at Larteh in the eastern region of the country. In Larteh, the traditional healers prescribed to Danquah herbs mixed with gin and administered by a caregiver who also helped to dress and bathe her. This placement ended when the caregiver lashed Doris with a belt, catching her eye with the hook, after she had told him that she intended to escape to Accra. Having heard about the beating, Doris’s father moved her to another fetish shrine, the Nana Ntia shrine at Gomoah Fete in the central region.³

This visit also failed and the family moved her to a Christian prayer camp in Kumasi. Treatment at the prayer camp included forced fasting and an ‘intensive routine of prayers and casting away [of] demons’.⁴ Ms

1 DA Danquah ‘Still I arise: The story of Ms Doris Appiah Danquah’ (Christian Health Association of Ghana, 2014), <https://vimeo.com/109473357>, (accessed 1 August 2016).

2 As above.

3 As above.

4 As above.

Danquah recounts that she was beaten by camp officials for challenging the truth of the Bible. When she resisted the beatings, she was chained, for days at a time despite the elements, rain or shine; she was released only to bathe and then chained again. One night, the drunk brother of the pastor came to Ms Danquah and hit her with a gin bottle before shackling her. Camp staff also chained her up after unsuccessful escape attempts. She eventually escaped successfully and found herself roaming the streets. Her family found her and sent her to another prayer camp, this time in a remote area past Zebilla in the northern part of the country. Once again Danquah escaped and, according to her account, she decided to return home and heal herself. Gradually she started feeling better and eventually returned to university, graduating with a nursing degree. Recently, Doris found work as the director of an orphanage, and she acts as a strong advocate for the rights of Ghanaians with mental illnesses.⁵

Doris Danquah claims that she experienced many forms of stigma during her years of involuntary treatment. Many people blamed her for her illness, telling her that the depression was a punishment from God for past wickedness or evil acts. Maybe, others said, she had taken someone's husband or was a witch who killed her children. Whatever the precise belief, she was told that her manic depression was a divine punishment for her sins because she 'didn't serve God well'.⁶ When she found herself alone on the streets, some people gave her food or money but still expressed deep prejudices. In one example, Ms Danquah recounted that some children gave her a few coins to buy food but threw the plate into a fire after she had finished eating. This seemed to have been a common practice, and Ghanaian psychiatrist Dr Gordon Donnir, who was interviewed along with Danquah in 2014, attributes this to the belief that mental illness is contagious and can be transmitted through direct contact with the 'infected' person. In Dr Donnir's opinion, these actions show that individuals diagnosed with a mental illness are the most stigmatised of any disabled group in Ghana.⁷

What should we make of Doris Danquah's narrative in *Still I arise*?⁸ As Nepveux and Beiticks observe, there is a tendency for disability documentaries to present Western, neo-colonial narratives of disability that portray disabled Africans as inferior, passive and in need of Western charitable interventions.⁹ This is certainly the case in the two films they study – *Emmanuel's gift* (Ghana) and *Moja Moja* (Kenya) – and it certainly could be true of African-produced films such as *Still I arise* as Ghanaian perspectives such as Danquah's could be influenced by charitable/neo-

5 As above.

6 As above.

7 As above.

8 Danquah (n 1 above).

9 D Nepveux & E Smith Beiticks 'Producing African disability through documentary film: Emmanuel's Gift and Moja Moja' (2010) 4 *Journal of Literary and Cultural Disability Studies* 237-238 251-253.

colonial models and assumptions about disability. Nevertheless, we argue that *Still I arise* (Ms Danquah's story) is different in its emphasis on agency and personal efforts to free oneself from discrimination and stigma through self-healing. This is a story of the strength, perseverance and tenacity of a disabled individual, who takes back power after it was taken from her. It is also a story of rights, in that Ms Danquah talks openly about the violation of human rights in the prayer camps and (to a lesser extent) fetish shrines, and the need to enhance disability rights by changing attitudes towards disabled Ghanaians. In its insistence on rights for persons with mental illnesses as a precursor for self-healing and self-determination, Danquah's story hits on the core debates over the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) and mental health, and offers an excellent springboard for assessing the potential of the CRPD in light of Ghanaian conditions. First, however, we must address the issue of the validity of Danquah's claims.

2 Disability, mental illness and stigma in Ghana

Are Ms Danquah's claims valid in light of what we know about the prevalence and causes of stigma towards persons with mental illnesses in Ghana? Answering this for Ghana is complicated by the fact that many foreign non-governmental organisations (NGOs) and media outlets portray many African countries – and Africa generally – as particularly prone to stigma towards disability. Following Ahmedani, we define stigma with reference to Goffman and Dudley, whose definitions of stigma include attitudes that discredit individuals and discount their identities, as well as stereotypes that portray individuals or groups as inferior against societal norms.¹⁰ Using this definition, many popular reports paint a picture of Africa generally as particularly prone to stigma against disabled persons. At best, attitudes of stigmatising result in disabled persons being denied access to health care and education. At worst, they are hidden, locked away, abandoned or even killed. While the popular literature tends to make such pronouncements without solid evidence,¹¹ the weight of recent scholarly research – stimulated by the Movement for Global Mental Health launched in 2007¹² – does point to widespread stigma in Africa.

10 E Goffman *Stigma: Notes on the management of spoiled identity* (1963) 2-6; JR Dudley 'Confronting stigma within the services system' (2000) 45 *Social Work* 1; BK Ahmedani 'Mental health stigma: Society, individuals, and the profession' (2011) 8 *Journal of Social Work Values and Ethics* 2.

11 There are many reports making claims of disability stigma in Africa, often backed up by no real evidence. See eg Plan Togo <https://plan-international.org/where-we-work/africa/togo/about-plan/news/reducing-the-stigma-around-children-with-disabilities-in-togo/>; Advantage Africa <http://www.advantageafrica.org/topics>; Inclusion International <http://inclusion-international.org/inclusion-africa-2/>; Integrated Regional Information Networks (IRIN) <http://www.irinnews.org/report/90139/senegal-children-with-disability-when-stigma-means-abandonment>; *VOA News* 19 June 2012 <http://www.voanews.com/content/the-curse-of-childhood-disability-in-south-africa/1213185.html> (all websites accessed 20 September 2016).

12 <http://www.globalmentalhealth.org> (accessed 1 September 2016).

This research represents a significant shift in opinion over the past decade. Previously, many commentators assumed that stigma towards mental illness was low in Africa compared to that in other parts of the world. This perception was reinforced by a lack of research into stigma and mental illness in Africa. A survey of existing research conducted in 2006 found only 62 publications worldwide between 1990 and 2004 on beliefs and attitudes towards mental illness. The vast majority focused on European countries, and Ethiopia was the only African country on the list, represented by a single study on the north-western part of the country published in 1999.¹³ Since 2004 many more academic studies have appeared, most likely connected to the advocacy efforts of the Movement for Global Mental Health mentioned above. The more recent work has found evidence of widespread stigma towards mental illness in Africa. For example, researchers have found unexpected high levels of stigma towards persons with mental illnesses among Nigerian clergy and university students, towards persons with psychotic illnesses in South Africa, and in primary schools in Kenya.¹⁴ On a comparative level, one study concluded that stigma towards mental illness was worse in Cameroon than in Canada.¹⁵

In Ghana, a recent study of disability in Accra reveals evidence of widespread discrimination and stigma towards disabled Ghanaians generally, who are among 'Ghana's most excluded members of society'.¹⁶ Recent literature on mental illness in Ghana presents a similar picture of high levels of stigma, on four levels: within the family; in public settings; at the workplace; and among health service providers. At the family level, academic research points to high levels of discrimination and stigmatisation against family members with mental illnesses. In the community of Pantang in Accra, Dako-Gyeke and Asumang found that most of the patients had been deserted by their families (spouses, parents and children, among others), beaten up, molested, labelled as witches and accused of causing their own predicaments. They further found that that if

- 13 MC Angermeyer & S Dietrich 'Public beliefs about and attitudes towards people with mental illness: A review of population studies' (2006) 113 *Acta Psychiatrica Scandinavica* 169.
- 14 AO Adewuya & ROA Makanjuola 'Social distance towards people with mental illness amongst Nigerian university students' (2005) 40 *Social Psychiatry and Psychiatric Epidemiology* 868; AO Adewuya & ROA Makanjuola 'Social distance towards people with mental illness in Southwestern Nigeria' (2008) 48 *Australian and New Zealand Journal of Psychiatry* 394; NG Igbinomwanhia & JO Omoaregba 'The attitudes of clergy in Benin City, Nigeria towards persons with mental illness' (2013) 16 *African Journal of Psychiatry* 200; CO Egbe 'Experiences and effects of psychiatric stigma: Monologues of the stigmatizers and the stigmatized in an African setting' (2015) 10 *International Journal of Qualitative Studies on Health and Well-Being* 6-7; DM Ndeti et al 'Stigmatizing attitudes toward mental illness among primary school children in Kenya' (2016) 51 *Social Psychiatry and Psychiatric Epidemiology* 79.
- 15 KO St Louis & PM Roberts 'Public attitudes toward mental illness in Africa and North America' (2013) 16 *African Journal of Psychiatry* 131.
- 16 KL Geurts & SGMA Komabu-Pompeyie 'From "sensing disability" to *Seselelame*: Non-dualistic activist orientations in twenty-first century Accra' in S Grech & K Soldatic (eds) *Disability in the global south: The critical handbook* (2016) 295.

persons with mental illnesses were parents, their family members denied them access to their children on the grounds that the parents were dangerous and might harm the children.¹⁷ These findings have been corroborated by other research. In a study and focused on the three main psychiatric hospitals in Ghana (Pantang, Accra and Cape Coast), Barke et al found that mental health patients were discriminated against and stigmatised by their families, as some participants asserted that they did not feel comfortable living with persons with mental illnesses or who had a history of mental disorders. Among other things, participants claimed that the behaviour of mental patients was never predictable and, as such, they were dangerous and potentially harmful to family members.¹⁸

In a study in Ho in the Volta region, Tawiah found that people with mental health issues were discriminated against and stigmatised at the economic, social and psychological levels within their family settings. At the economic level, family members denied food and the basic necessities of life to relatives with mental disorders. This psychologically impacted them as it affected their self-esteem. Socially, some family members hid relatives with mental illnesses from the public, and verbally abused, ridiculed and mocked them at home.¹⁹ The consequences of the above types of abuse in family settings are devastating to the healing processes of Ghanaians with mental illnesses. At the very points where they need the most moral, social, financial and physical support, those who should be the most supportive tend to either abuse them or simply abandon them to their fate. As a result, mental patients always feel isolated and distant from their loved ones, and they develop a low self-esteem.²⁰ At the other end of the spectrum, several studies have found that some families discriminate against family members with mental illnesses through overprotection and excessive sympathy. For example, Thornicroft et al found that, even though family members of mental patients were supportive, the patients sometimes felt they were being overprotected and not given their independence to do certain things.²¹ Barke et al found that some members displayed an excess of sympathy to relatives with mental disorders. As with overprotection, 'over-sympathy' negatively affected the self-determination of Ghanaians with mental illnesses, often by blocking efforts to help them overcome or cope with their conditions. In many

17 M Dako-Gyeke & ES Asumang 'Stigmatization and discrimination experiences of persons with mental illness: Insights from a qualitative study in Southern Ghana' (2013) 11 *Social Work and Society International Online Journal* 5-8.

18 A Barke et al 'The stigma of mental illness in Southern Ghana: Attitudes of the urban population and patients' views' (2011) 46 *Social Psychiatry and Psychiatric Epidemiology* 1196-1198.

19 PE Tawiah 'Stigma and discriminations suffered by mental patients and their caregivers in the Ho municipality of Ghana' unpublished PhD thesis, University of Ghana, 2012 28-29.

20 Dako-Gyeke & Asumang (n 17 above) 5-6.

21 G Thornicroft et al 'Discrimination in health care against people with mental illness' (2007) 19 *International Review of Psychiatry* 113-114.

cases, excessive sympathy took the guise of pity and a lack of respect for family members with mental illnesses.²²

At the societal level, studies have found that it is usually the friends and neighbours of persons with mental illnesses who act in degrading ways towards them and, hence, reproduce discrimination and stigmatisation on a wider basis. For example, Barke et al reported that some participants wanted mental patients to be sent away and isolated from their communities or, at the very least, they refused to live nextdoor to someone known to suffer from a mental illness.²³ Dako-Gyeke and Asumang as well as Tawiah confirmed this finding when they discovered that persons with mental illnesses were deserted and shunned by their friends and neighbours. They also found a widespread aversion to marrying people with or who had a history of mental illness. When asked why they harboured these feelings, respondents across several studies accused mental patients of being harmful, dangerous and unpredictable in their behaviour.²⁴

Apart from the fact that people wished them to be isolated from general society or avoided their company, persons with a history of mental illness were also ridiculed and removed from groups or associations they initially belonged to before falling ill. For instance, a Ghanaian woman with a mental illness interviewed by Thornicroft et al said:

I used to be very influential in the local community, I was chair of the Education Committee, but I discovered that they don't involve me so much anymore ... I used to socialise in my community, then they would be looking at me in a funny way and for a couple of them, it's like you don't exist anymore.²⁵

Of the many community institutions, one might expect that formal churches or other religious organisations – as opposed to prayer camps – would be part of the public sphere where persons with mental illnesses would be embraced more warmly. However, the research that has been done suggests otherwise. For example, Thornicroft et al found that religious institutions also stigmatised and discriminated against their members with mental illnesses. One participant revealed that after she had narrated her ordeal to her church members as a form of testimony, they withdrew themselves from her, and she later regretted testifying to her church members because of the way they reacted towards her.²⁶

Perhaps worse than being removed from or shunned by civic associations, Dako-Gyeke and Asumang also found that that publicly-

22 Barke et al (n 18 above) 1196.

23 As above.

24 Dako-Gyeke & Asumang (n 17 above) 6; Tawiah (n 19 above) 28-29.

25 Thornicroft et al (n 21 above) 113.

26 Thornicroft et al 114.

identified mental health patients were labelled with derogatory language ('crazy,' 'lunatics', and so forth), and were often left to beg for food along the streets of urban centres in order to survive.²⁷ When people begin to label mental health patients as lunatics, mad or crazy, what is meant is that they are of no use to society any longer. However, the fact is that mental illness can be treated, and those who are suffering could be made responsible and their condition restored if people regard them the same as any other person suffering any other form of illness. However, because of negative public attitudes towards persons with mental illnesses, most mental health patients do not want to be known publicly and, thus, do not seek medical treatment from formal health institutions. Instead, stigma and discrimination often drive Ghanaians with mental illnesses to prayer camps and traditional healers for treatment.²⁸

Ghanaians with mental illnesses are also discriminated against and stigmatised in the workplace by prospective or current employers and colleagues. Employers often refuse to hire individuals with mental illnesses. That this practice may be common is illustrated by Barke et al, whose recent study reported that 77,2 per cent of mental health patients asserted that most employers will pass over their applications in favour of other candidates without mental health problems.²⁹ In other cases, respondents reported about being dismissed by employers if they developed a mental illness after having been hired. Some employers also admitted to believing that they would lose customers if they employed individuals with visible or known mental illnesses.³⁰ In addition to not being hired or being dismissed, Thornicroft et al reported that some employers would reduce the number of hours or days worked by employees with mental illnesses, although the respondents were not sure whether the employers did so because of discrimination or because they believed that it was for the good of the employee.³¹ At least one study added a gender dimension to workplace stigmatisation, finding that women reported more cases of discrimination than their male counterparts.³² In addition, multiple studies have revealed that co-workers as well as employers routinely stigmatised and discriminated against persons with mental illnesses. This includes general levels of discomfort working alongside a colleague considered to have a mental illness, as well as more active forms of stigmatisation in the form of humorous, degrading and derogatory comments, and accusations that a co-worker with a mental illness may be dangerous and cause harm to others.³³

27 Dako-Gyeke & Asumang (n 17 above) 8.

28 UM Read et al 'Local suffering and the global discourse of mental health and human rights: An ethnographic study of responses to mental illness in rural Ghana' (2009) 5 *Globalization and Health* 4 9; Tawiah (n 19 above) 26.

29 Barke et al (n 18 above) 1198.

30 Dako-Gyeke & Asumang (n 17 above) 9-10.

31 Thornicroft et al (n 21 above) 114.

32 Tawiah (n 19 above) 25.

33 Dako-Gyeke & Asumang (n 17 above) 6; Tawiah (n 19 above) 28-29.

The final level at which discrimination and stigmatisation take place is that of health service providers in both formal and informal settings. According to Human Rights Watch, health service providers discriminate against and stigmatise Ghanaians with mental illnesses by denying them food and medicine, refusing to provide them with adequate shelter, subjecting them to involuntary treatment, and physically abusing them in cruel, inhuman and degrading ways.³⁴ This corroborates with the findings of Thornicroft et al, who found one of their participants asserting that she had been forcibly held by a group of health personnel and given an injection against her will.³⁵ Human Rights Watch also established that nurses at times verbally abused and physically inflicted pain on patients with mental illnesses, especially when they were 'trying to escape, when they complained about pain, and when they failed to take medication, or for failing to follow hospital rules'.³⁶ Ghanaians with mental illnesses are treated in this way whereas others, such as malaria patients, are not, because persons with mental illnesses are stigmatised in the sense of being labelled and stereotyped as inferior or dangerous.

A common thread running through popular reports and academic studies on stigma in Ghana is the idea that mental illness is caused by supernatural forces. For instance, the BBC reported in 2010 that an increasing number of disabled African children were being accused of witchcraft.³⁷ Similarly, as part of a special series on children in South Africa, *Voice of America News* claimed that children with cerebral palsy were considered by some Xhosa families to be 'bewitched' by bad spirits.³⁸ More recently, the *Huffington Post* claimed:

The most frequently-stated causes of disability in Uganda and Africa at large include witchcraft; a curse or punishment from 'gods', anger of ancestral spirits, bad omens, reincarnation, heredity, incestuous relationships, and the misdemeanors of the mother. These misperceptions not only lead to stigma, but also to a belief that children with disabilities should be demonised.³⁹

NGO reports paint a similar picture. In a four-country survey, for example, Plan International stated that respondents from Togo, Sierra Leone, Niger

34 Human Rights Watch 'Like a Death Sentence': Abuses against persons with mental disabilities in Ghana (2012) 17.

35 Thornicroft et al (n 21 above) 114.

36 Human Rights Watch (n 34 above) 17.

37 British Broadcasting Corporation 'Rise in African children accused of witchcraft' (2010) <http://www.bbc.com/news/world-africa-10671790> (accessed 20 September 2016).

38 Voice of American News 'African children struggle with poor health care' 2012 19 <http://www.voanews.com/content/the-curse-of-childhood-disability-in-south-africa/1213185.html> (accessed 20 September 2016).

39 TK Davenock 'Not all disabled are created equal' *Huffington Post* 2015 http://www.huffingtonpost.com/tarita-karsanji-davenock/not-all-disabled-are-created-equal_b_8374510.html (accessed 20 September 2016).

and Guinea commonly said that mental illness often was ‘inflicted due to a “bad spirit”’, or was ‘a curse from God’.⁴⁰ In Ghana, an oft-quoted report by Human Rights Watch states that ‘disability is widely considered – even by persons with mental disabilities themselves – as being caused by evil spirits or demons’. As such, casting out evil spirits is an important part of the cure, and fasting in prayer camps is believed to facilitate this process.⁴¹ Ghanaian beliefs in spiritual causes of mental illness have been confirmed by systematic academic studies. For example, a team led by the respected disability scholar Ursula Read reported that many of the 67 interviewees – including persons with mental illnesses – attributed the illnesses to ‘evil spirits, sorcery and witchcraft’.⁴² These beliefs, combined with the pervasiveness of discrimination and stigma within the family, in public, at the workplace and among health service providers, result in family members often forcing Ghanaians with mental illnesses to attend fetish shrines or prayer camps for treatment.⁴³

3 CRPD and mental health

It is in the above contexts that we should consider the potential of the CRPD as a tool for combatting human rights abuses towards Ghanaians with mental illnesses. Opened for ratification in 2006, the CRPD has transformed the discussion of global disability and focused attention on human rights for disabled individuals in the majority world.⁴⁴ The champions of the CRPD are very optimistic about its potential, claiming that the Convention has produced ‘a paradigm shift in political conceptions of disability’,⁴⁵ which has triggered a new disability discourse capable of empowering civil society,⁴⁶ in turn making it possible to ‘legislate a belief change regarding persons with disabilities’.⁴⁷ One optimist goes as far as writing that the CRPD will lead to the removal of ‘societal barriers that create and reinforce disability’.⁴⁸ Others are not convinced. Pointing to the African context, Lang and Groce and their

40 S Coe *Outside the circle: A research initiative by Plan International into the rights of children with disabilities to education and protection in West Africa* (2013) 24.

41 Human Rights Watch (n 34 above) 7 16 17 26.

42 Read (n 28 above) 7.

43 Tawiah (n 19 above) 23.

44 ‘Majority World’ is the latest and arguably most accurate label for the world region formerly labelled ‘Third World’, ‘Developing World’ and/or ‘Global South’. C Barnes & A Sheldon ‘Disability, politics and poverty in a majority world context’ (2010) 25 *Disability and Society* 771-772.

45 H Mannan et al ‘Core concepts of human rights and inclusion of vulnerable groups in the United Nations Convention on the Rights of Persons with Disabilities’ (2012) 6 *ALTER – European Journal of Disability Research* 172.

46 P Harpur ‘Embracing the new disability rights paradigm: The importance of the Convention on the Rights of Persons with Disabilities’ (2012) 27 *Disability and Society* 1.

47 MA Stein & JE Lord ‘Future prospects for the United Nations Convention on the Rights of Persons with Disabilities’ in MA O’Donn & G Quinn (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian perspectives* (2009) 32.

48 DS Cobley ‘Towards economic participation: Examining the impact of the Convention on the Rights of Persons with Disabilities in India’ (2013) 28 *Disability and Society* 453.

colleagues have found that successful implementation has been hampered in Nigeria, Zimbabwe and Uganda by problems of governance (inadequate national disability laws, limited political will) and weaknesses within DPOs (underfunding, overwork, control by paternalistic urban elites). This is particularly disturbing because, to secure their rights, disabled individuals require more resources and support than non-disabled persons.⁴⁹ Similar problems have been identified in South Africa, Kenya and Ghana.⁵⁰ The problem is compounded when disabled persons lack the power, money and/or education to claim their rights.⁵¹ If this is the case, 'rights can do nothing but reinforce the status quo, as those left powerless can do nothing [but] make sporadic and/or symbolic claims'.⁵² By implication, unless a disabled individual gains support from a more powerful and/or wealthy patron, or perhaps moves up the social ladder, a rights-based approach actually may reproduce the marginalisation of disabled individuals in the majority world.⁵³ This effect may be worsened if communities in majority world settings have different conceptions of practices that Western law makers consider to be human rights abuses.⁵⁴ As we shall see below, the majority world beliefs about human rights – and in our case Ghanaian beliefs specifically – are especially applicable to questions about mental illness.

Of the CRPD's provisions, article 12 (mental capacity), article 14 (equality of liberty and security) and article 17 (physical and psychological integrity) relate most directly to mental health. As with the CRPD generally, these articles reflect the participation of DPOs in the drafting process. As a result, the CRPD privileges 'the values, preferences and life projects of (disabled persons)' and seeks to reorient legal regimes with this goal in mind.⁵⁵

49 R Lang et al 'Implementing the United Nations Convention on the Rights of Persons with Disabilities: Principles, implications, practice and limitations' (2011) 5 *ALTER – European Journal of Disability Research* 208-211; see also CJ Eleweke 'A review of the challenges of achieving the goals in the African Plan of Action for People with Disabilities in Nigeria' (2013) 28 *Disability and Society* 316-322.

50 M Heap et al "'We've moved away from disability as a health issue; it's a human rights issue": Reflecting on 10 years of the right to equality in South Africa' (2009) *Disability and Society* 858-859; BM Opini 'A review of the participation of disabled persons in the labour force: The Kenyan context' (2010) 25 *Disability and Society*; DM Nepveux 'Reclaiming agency, ensuring survival: Disabled Urban Ghanaian Women's Negotiations of Church and Family Belonging' (2006) 26 *Disability Studies Quarterly* [no pagination]; M Ssengooba et al "'Like a death sentence": Abuses against persons with mental disabilities in Ghana' Human Rights Watch Report 2012 82-83.

51 M Russell 'What disability civil rights cannot do: Employment and political economy' (2002) 17 *Disability and Society* 129.

52 DA Young & R Quibell 'Why rights are never enough' (2000) 15 *Disability and Society* 122.

53 R Malhotra 'Expanding the frontiers of justice: Reflections on the theory of capabilities, disability rights, and the politics of global inequality' (2008) 22 *Socialism and Democracy* 96-97.

54 Read et al 11-12.

55 S Wildeman 'Protecting rights and building capacities: Challenges to global mental health policy in light of the Convention on the Rights of Persons with Disabilities' (2013) 41 *Journal of Law, Medicine and Ethics* 58.

This approach rejects the medical model of disability put forward by non-disabled medical experts, which defines disability as an impairment and takes a charitable approach towards interventions designed to 'normalise' disabled bodies. In its place, the CRPD shifts the ground to the social model, which argues that disability is socially constructed by non-disabled actors. As expressed in the CRPD, the social model emphasises autonomy and self-determination in the pursuit of disability rights.⁵⁶ In relation to mental health, this priority informed the drafting of articles 12, 14 and 17 but, as we shall see, the drafting process was contentious and the results were ambiguous and not unproblematic.

Article 12 sets out the right of disabled persons to play an active role in decisions affecting their well-being. The article takes a very strong stance against substitute decision making, in which a person assumes decision making for another person without their consent. However, it permits supported decision making, whereby a person permits someone else to make their decisions, so long as safeguards are put into place to ensure true participation and consent in decision making.⁵⁷ However, the article does not set out how this may be achieved in practice, and there are no mechanisms to monitor safeguards or adjudicate disputes between disabled persons and the decision makers should they arise. Article 14 guarantees equality of liberty and security, including protection from arbitrary detention. According to this article, any form of detention solely based on disability without the consent of the disabled person is prohibited.⁵⁸ However, article 14 does not preclude preventive detention on other grounds, such as danger, if it is 'de-linked' from disability, and some governments, including that of Britain, have argued that preventive detention does not violate article 14 if it is justified by the risk posed to the disabled person or their community.⁵⁹ Article 17 sets out the right to 'physical and psychological integrity', which includes protection from compulsory medical treatment. However, it is very brief (only 23 words in total) because of disagreements and a lack of consensus during the drafting process. As a result, governments can (and have) argued that the CRPD allows for compulsory treatment as long as it does not include 'torture or inhuman or degrading treatment'.⁶⁰ While the UN Office of the High Commissioner for Human Rights (OHCHR) and the CRPD Committee disagree with this interpretation, it is nonetheless possible for governments to make the case.⁶¹

This brief discussion of articles 12, 14 and 17 raises several questions about the CRPD, mental health and disability rights. In the weakest case,

56 Wildeman (n 55 above) 59.

57 Wildeman 56-58.

58 P Bartlett 'The United Nations Convention on the Rights of Persons with Disabilities and mental health law' 2012 75 *Modern Law Review* 767-768.

59 Bartlett (n 58 above) 772 775.

60 Bartlett 756.

61 Wildeman (n 55 above) 57.

the CRPD leaves much room for interpretation, and its provisions related to mental health have been challenged by governments in the West, including those of Australia and Canada. In the strongest case, the CRPD calls for autonomy and self-determination for persons with mental illnesses and an end to involuntary treatment, coercive physical punishment and substitute decision making. But even the strongest case requires certain prerequisites, especially sufficient access to the resources needed to support decision making and autonomy. The Implementation Manual for the CRPD drafted by the World Network of Users and Survivors of Psychiatry (WNUSP) sums this up as follows:

Autonomy and self-determination are dependent on having sufficient access to resources so that economic and social coercion do not lead to decision making that does not reflect the person's own values and feelings ... Autonomy and self-determination are also dependent on the existence of meaningful alternatives related to the particular decision at issue.⁶²

Through their participation in the process of drafting the CRPD, persons with psychosocial and intellectual disabilities have introduced, in Wildeman's words, 'the emancipatory project of shifting mental health policy from its historical fixation on involuntariness and incapacity toward the relatively uncharted territory of supports'.⁶³ Wildeman supports this position in calling for the creation of 'supportive social systems (including access to material resources and a range of meaningful options)', which she believes 'are essential to the development and expression of autonomy'.⁶⁴ The reference to 'material resources' is consistent with the argument by the creators of the social model that economic development is a necessary precursor for disability rights. This, as we shall see in the next section, complicates the discussion of mental health rights in the Ghanaian context.

4 CRPD, mental health and Ghana

Against critics who dismiss the CRPD's approach as 'fantastical extensions of the social model to the point of denying the phenomenon of impairment', Wildeman argues that international agencies should use the CRPD as a basis for investigating the social supports required for achieving 'autonomy and active citizenship' based on the perspectives of

persons with psychosocial disabilities and also those with intellectual disabilities – including persons with direct experience of capacity determination or coercive interventions – across different cultural, social, and

62 Quoted in Wildeman (n 55 above) 59.

63 Wildeman (n 55 above) 60.

64 Wildeman 59.

national locations and across intersecting categories of discrimination including race, gender, and age.⁶⁵

Doris Danquah is one such person with direct experience of forcible confinement and involuntary treatment. As such, as Wildeman would argue, we should heed Danquah's call to confront human rights abuses at fetish shrines and prayer camps. At the national level, the first step would be for the Ghanaian government to rewrite its Mental Health Act to make it consistent with the CRPD's call for autonomy and self-determination. Interestingly, in 2012, the year in which Ghana ratified the CRPD, the Ghanaian government did pass a revision to its 1972 Mental Health Act. The 2012 Act addresses human rights, but it continues to permit involuntary treatment and substitute decision making. According to article 42, a third party may apply to a court to admit a person with a mental illness against their will, if there is a risk of self-harm or harm to others, or if it is believed that their condition will deteriorate significantly. Patients can be admitted either to an accredited facility under the Health Institutions and Facilities Act of 2011, or to an institution recognised by the Minister of Health.⁶⁶

The current Ghanaian Health Act clearly contravenes the spirit and intention of the CRPD. As a first, step, therefore, it would be reasonable to pressurise the government to revise the Act accordingly. This would at least provide a foundation for mental health advocates, such as Doris Danquah, to lobby for choice of treatment. However, even if the Ghanaian government were to change the Act, achieving the CRPD's ideals of self-determination and autonomy for persons with mental illnesses would face significant challenges. In the short term, it appears that the Ghanaian government is willing to collaborate with fetish priests and prayer camp leaders in the delivery of mental health care.⁶⁷ If this practice takes root, the fetish and prayer camps will remain part of the country's informal system of delivering mental health services, which – in light of the current Mental Health Act – would keep the door open to involuntary admissions without the consent of Ghanaians with mental illnesses. As such, activists, NGOs and other lobbyists could promote human rights and attempt to change attitudes. Some scholars appear to believe that this might be the best way forward, arguing that shrines and prayer camps can treat patients effectively if their leaders are taught to eliminate forcible confinement and abusive behaviour.⁶⁸ However, there is some evidence that many Ghanaians with mental illnesses accept the necessity of forcible confinement, including chaining, as a result of moral beliefs that place

65 Wildeman 60.

66 Secs 18 & 22 Ghana Mental Health Act 846 of 2012.

67 D Arias et al 'Prayer camps and biomedical care in Ghana: Is collaboration in mental health care possible?' (2016) 11 *PLoS ONE* 2-3.

68 A de-Graft Atkins 'Mental illness and destitution in Africa: A social-psychological perspective' in E Akyeampong et al (eds) *The culture of mental illness and psychiatric practice in Africa* (2015) 134-135 138.

community needs above individual needs.⁶⁹ Changing beliefs, therefore, might pose a formidable challenge in the short term.

As a long-term solution, social model advocates argue that economic development and equitable distribution of its proceeds are necessary precursors to disability rights, especially in the majority world.⁷⁰ This idea is present in the CRPD and it is implicit in the WNUSP's belief – quoted above – that persons with mental illnesses must have access to enough resources to eliminate 'economic and social coercion' that may force them to make decisions against their will.⁷¹ But would economic development automatically produce changes in culture and attitudes? This is a difficult question to answer. Current attitudes in Ghana towards mental illness and fetish shrines and prayer camps certainly are rooted in culture and society. But rather than being 'traditional' in the sense of having existed since time immemorial, they are instead rooted in historical changes connected to colonialism, development and modernity. During the colonial era 'witchcraft' and 'fetish cults' blossomed in Ghana in the context of the country's uneven integration into the world economic system. The Akonedi shrine, for example, where Doris Danquah spent her first episode of involuntary confinement, dates to the mid-1800s and emerged as an important healing shrine only during the leadership of the shrine priestess, Nana Ama Ansa, between 1927 and 1957.⁷² More obviously, Christian prophets date from colonial times, and they were connected to anti-witchcraft campaigns from the 1920s and 1930s. The preoccupation with witchcraft continued after independence and escalated with the boom in evangelical churches since the 1980s.⁷³ As such, these beliefs are not traditional in the sense of being timeless. Indeed, present forms of culturally-based stigma and discrimination towards persons with mental illnesses (and other disabilities) in Ghana are not mere primordial relics of an ancient past. On the contrary, they are expressions of Africa's uneven development and incorporation into the modern world. African cultural institutions and norms are not static, but instead have shifted and transformed over time in response to the challenges posed by uneven development, poverty, eroding social services and threats to community social cohesion. The lesson here is that, in order to nurture attitude changes, economic growth is not only necessary in a general sense, but it must be equitable as well as robust, reaching into rural areas and down to the village and community level.

69 Read et al (n 28 above) 10-12.

70 Barnes & Sheldon (n 44 above) 778-779.

71 Quoted in Wildeman (n 55 above) 59.

72 OA Boakyewa 'Nana Oparebea and the Akonedi Shrine: Cultural, religious and global agents' unpublished PhD thesis, Indiana University, 2014 48-49.

73 P Gifford 'A View of Ghana's new Christianity' in L Sanneh & JA Carpenter (eds) *The changing face of Christianity: Africa, the West, and the world* (2005) 84-85; TC McCaskie 'Anti-witchcraft cults in Asante: An essay in the social history of an African people' (1981) 8 *History in Africa* 137-138.

5 Conclusion

Numerous factors contribute to the stigmatisation of mental illness in Ghana. One problem is the cultural myth that attributes mental illness to curses, or the visitation of the sins of one's forefathers, or other forms of personal weakness. These beliefs justify the shunning of the victims and their treatment as second-class citizens. It also explains why people such as Doris Appiah Danquah are sometimes sent to consult fetishes or subjected to abuses in spiritual camps. Clearly, these practices have cultural foundations, and attitudes need to change. Some NGOs, such as Plan Togo, have initiated programmes towards this end. They believe that sensitisation is the key to ending stigma towards disabled persons, and this organisation is working to help parents and children to raise awareness of how important it is to integrate children with disabilities into education and the community.⁷⁴

However, is it enough to simply focus on educating and convincing non-disabled persons to shift their attitudes towards mental illness? Our analysis suggests that it is not. Instead, one should search for the underlying roots of these attitudes. In the case of Ghana, these roots are not simply traditional but rather tied to the country's historical experience with development and modernity, which has produced or strengthened certain 'traditional' narratives as opposed to others. In this sense, disability is socially constructed on the foundation of economic roots. Prior to or along with programmes to change attitudes, there must be programmes to deliver equitable economic growth in general, including growth for the non-disabled population and development that provides disabled persons with opportunities for productive activities, if they so choose. If this can be achieved, then disabled Ghanaians – including those with mental illness – might have more opportunities for social inclusion and more power for self-advocacy. In the long term, this could provide a basis for changing attitudes towards mental illness, including the attitudes of the leaders of fetish shrines and prayer camps.

Perhaps more importantly, in the short and medium term proceeds from growth and development should be directed to social supports, including programmes to strengthen the state's capacity to recruit medical professionals and deliver social services. This addresses a second problem related to overcoming stigma towards mental illness in Ghana: the lack of psychosocial approaches to treatment. Ghana's mental health system is overly dependent on medication, which can negate the effective treatment of persons with mental illnesses. But even where medicines are effective, Ghana's lack of psychiatrists and shortage of antipsychotic and

74 Plan Togo <https://plan-international.org/where-we-work/africa/togo/about-plan/news/reducing-the-stigma-around-children-with-disabilities-in-togo/> (accessed 20 April 2015).

psychotropic medications severely limit treatment options. As a result, the psychiatric hospitals are severely overcrowded and families are forced to explore alternative treatment through fetish shrines and prayer camps. In light of this situation, we believe that improving economic conditions and the capacity of the state to deliver medical services are necessary foundations for changing attitudes to reduce stigma. It is not a question of simply altering supposed traditions of stigma, discrimination and social exclusion.

The situation seems dire, but new developments in disability rights have allowed disabled activists to begin to combat stigmatisation and discrimination. After 22 years, Doris Danquah was able to go back to university to complete a nursing degree. She is now a strong advocate for the rights of persons with mental illnesses and, along with other activists, she is working to change social norms and public policies. Her story deserves a wide audience. She and other disabled Ghanaians need to be supported by changes in the material conditions of their societies. Economic growth, better social service provision and incentives to recruit more medical professionals would be a very good starting point.

CHAPTER 6

ALBINISM IN AFRICA: A PROPOSED CONCEPTUAL FRAMEWORK TO UNDERSTAND AND EFFECTIVELY ADDRESS A CONTINENTAL CRISIS

Mark P Mostert* and Martha M Weich**

Summary

Across Africa trafficking in albino body parts is far more complicated than might first be assumed, as this activity is merely the end result of a complicated process with origins far removed from the point of sale. The literature in this area tends to focus on either (a) the actual act of procuring and selling body parts; or (b) loosely-related and fairly vague reports of why this process flourishes. There is no extant overarching conceptual framework linking key underlying interrelated vectors that combine to drive severe exploitation of persons with albinism, (for instance, stigma; traditional and other cultural beliefs; the status and impact of authority figures; local, regional and national discrimination; the financial impact and economy of scale in trafficking body parts, and so forth). The absence of such a framework directly hinders proposing or implementing effective solutions, as these solutions are unlikely to succeed if they ignore the highly-symbiotic relationships among the undergirding vectors. Therefore, we propose an initial conceptual framework that unpacks crucial connections among related variables impacting trafficking in albino body parts in Africa, and then use the framework to suggest areas of emphasis to reduce and eliminate the trafficking of these body parts in Africa.

1 African context

Trafficking in human body parts is a persistent, intractable international problem and is a direct response to the ever-growing need for transplantable organs worldwide. However, there is an even more sinister set of circumstances in Africa: The trafficking in body parts of Africans with albinism for use as magical charms and in magical potions, in several countries, has reached crisis proportions.

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Exact statistics of albino killings, maimings and abductions are not currently available. However, these practices are likely to occur across most of the continent. A recent report indicated that in 25 African countries, there had been 185 killings and 297 survived attacks. African countries known to be involved in the trafficking of albino parts include Tanzania, Burundi, Kenya, the Democratic Republic of the Congo (DRC), Mozambique, Malawi, South Africa and Swaziland. Further isolated reports of killings and attacks have come from Benin, Botswana, Burkina Faso, Burundi, Cameroon, Côte d'Ivoire, the DRC, Egypt, Ghana, Guinea, Kenya, Lesotho, Malawi, Mali, Mozambique, Namibia, Niger, Nigeria, Rwanda, Senegal, South Africa and Swaziland.¹

Three brief representative examples suffice: Malawi, Kenya, and Burundi and, with attention to the apparent ground zero of trafficking in persons with albinism, Tanzania.

1.1 Malawi

Irinnews² recently reported that from early 2015 to May 2016 ritual killings of persons with albinism escalated in Malawi with 17 cases documented along with 66 abductions and other albinism-related crimes. The purpose of the murders and abductions was to sell body parts to witchdoctors and other practitioners of traditional medicine.

For example, a teenager with albinism watching a soccer match was abducted and later found dead without his hands and feet, which were allegedly sold to a dealer in Mozambique. Elsewhere, a 30 year-old woman was murdered, her breasts and eyes removed.³

1.2 Kenya

In Kenya, there have been at least 75 murders of children and adults with albinism since 2000. There is little information on murder and abduction attempts, but they are fairly widespread, especially in rural parts of the country. For example, in September 2015 three men attacked a 56 year-old home owner demanding money. When the victim refused, the attackers

1 Under the Same Sun 'Reported attacks of persons with albinism – Most recent attacks included' 18 September 2017 <http://www.underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%20extended%20version.pdf> (accessed 22 September 2017).

2 Irinnews 'Magic and murder: Albinism in Malawi' 5 August 2016 <https://www.irinnews.org/fr/node/256222> (accessed 22 September 2017).

3 Amnesty International 'Malawi: Stop ritual murders of people with albinism' 9 August 2016 <https://www.amnesty.org/en/get-involved/take-action/stop-albinism-killings-in-malawi/> (accessed 22 September 2017).

suggested they cut off a hand or ear to sell in neighbouring Tanzania.⁴ The victim was cut deeply several times around his ear and his arms before the assailants fled. Officials suggested that such attacks were a direct result of the government's crackdown on albino hunters in neighbouring Tanzania.⁵

1.3 Burundi

While Burundi is home to several thousand Africans with albinism, trafficking in body parts has until recently been fairly contained. However, as trafficking has increased in neighbouring Tanzania, and with the Tanzanian government's subsequent action to eradicate albino hunters, attacks are escalating in Burundi. For example, in 2012 six heavily-armed men attacked a group of children in their home. One child was kidnapped and later found dead without her arms and legs. There have been other reports of albino bodies being disinterred and mutilated. The last 10 years have seen 21 murders of persons with albinism; another 13 survived attacks; and several graves have been robbed of corpses of persons with albinism.⁶

1.4 The continental trafficking dynamo – Tanzania

While it is likely that trafficking in body parts occurs in many places across the continent, there is little doubt that 'ground zero' for the crisis is Tanzania. The current spate of killings began in October 2006, in and around the city of Mwanza on the shores of Lake Victoria, a region with the highest per capita number of witchdoctors in the country.

By 2008, the Tanzanian government responded in several high profile ways, including appointing a woman with albinism to the national parliament, banning all traditional healers and witchdoctors from practising their trade, and declaring the killing of persons with albinism a capital crime. Between 2006 and June 2016, there were 76 killings, 69 attack survivors, one abduction survivor, 17 grave robberies, and two failed grave robbery attempts.⁷

4 'Attackers in Kenya try to hack off body parts from albino for sale in Tanzania as polls near' *Mail and Guardian* 14 September 2015 <http://mgafrica.com/article/2015-09-14-attackers-in-kenya-try-to-hack-off-body-parts-from-albino-for-sale-in-tanzania-as-polls-near> (accessed 22 September 2017).

5 'Kenya's albinos moved away from Tanzania border amid witch doctor threat' *The Telegraph* 23 September 2015 <http://www.telegraph.co.uk/news/worldnews/africaandindianocean/kenya/11885641/Kenyans-albinos-moved-away-from-Tanzania-border-amid-witchdoctor-threat.html> (accessed 22 September 2017).

6 Under the Same Sun (n 1 above).

7 Amnesty International (n 3 above).

Given these scenarios, there is a need to understand how to ameliorate the problem. As a starting point, we suggest an explicit framework of contributing and intervention factors that impact persons with albinism from their immediate context through more distanced contexts and which merit attention if the trafficking crisis is to be effectively addressed.

What is currently available in the extant literature related to the plight of persons with albinism can be divided into contributing and intervention factors. Contributing factors are those that impact and shape the lives of persons with disabilities in a negative way. Intervention factors are those that seek to positively address the negative contributing factors.⁸ These factors are addressed below as part of a nested set of systems that lay out the proximity of these factors to any person with albinism.

Both contributing and intervention factors can occur in the immediate context of persons with albinism, or be further distanced from where they live their lives. However, whether in close proximity or further away, these factors are interrelated and nested to form a complex conglomerate of the world of persons with albinism.

A useful framework to set the contributing and intervention factors in context is provided by Bronfenbrenner.⁹

2 Bronfenbrenner

Bronfenbrenner describes a series of four distinct yet interrelated ecological settings when studying a subject, in this case persons with albinism and trafficking in body parts. Originally developed for ecological educational research, these settings serve the purpose of defining the space around the topic to be studied and, while these spaces are specific and circumscribed, they are both interrelated and nested to the one within the other. These settings are the microsystem; the mesosystem; the exosystem; and the macrosystem.

2.1 Microsystem

The microsystem is the immediate setting in which the object of the study, here persons with albinism, resides. This system contains the elemental factors of time, place, activity and role. Settings are defined as the places in which subjects engage in specific activities in specific roles (for instance, roles such as that of parent, teacher, son, daughter, and so forth).

8 M Mostert 'Stigma as barrier to the implementation of the Convention on the Rights of Persons with Disabilities (CRPD) in Africa' in C Ngwenya et al (eds) *African Disability Rights Yearbook 2016* 3.

9 U Bronfenbrenner 'The experimental ecology of education' (1976) 5 *Educational Researcher* 5.

2.2 Mesosystem

The mesosystem is a system of interrelated microsystems.

2.3 Exosystem

The exosystem is an extension of the mesosystem including wider social entities that influence the microsystem and mesosystem. Examples may include major societal institutions operating at the local/community level, such as the world of work, the neighbourhood, media, government agencies, communication, transport, social networks, and so forth.

2.4 Macrosystem

The macrosystem is the widest and broadest system, representing the larger cultural context such as economic and legal/political systems.

Based on previous work in this area that identified both contributing and interventions factors, we illustrate contributing and intervention factors in Bronfenbrenner's nested systems in Figure 2.

Figure 1: Bronfenbrenner's ecological systems

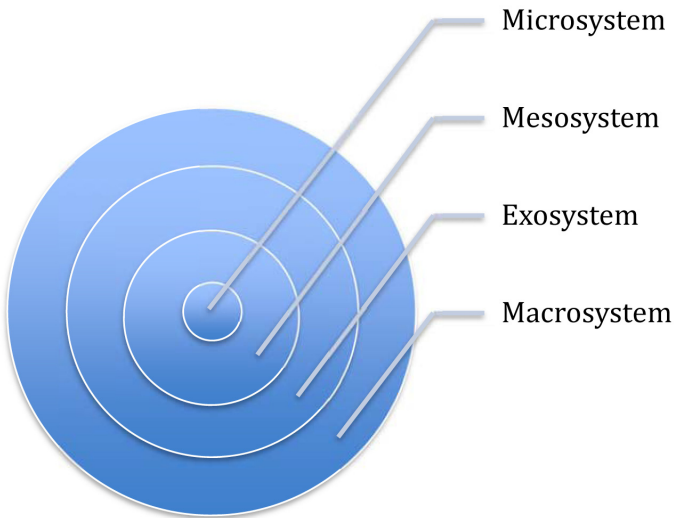
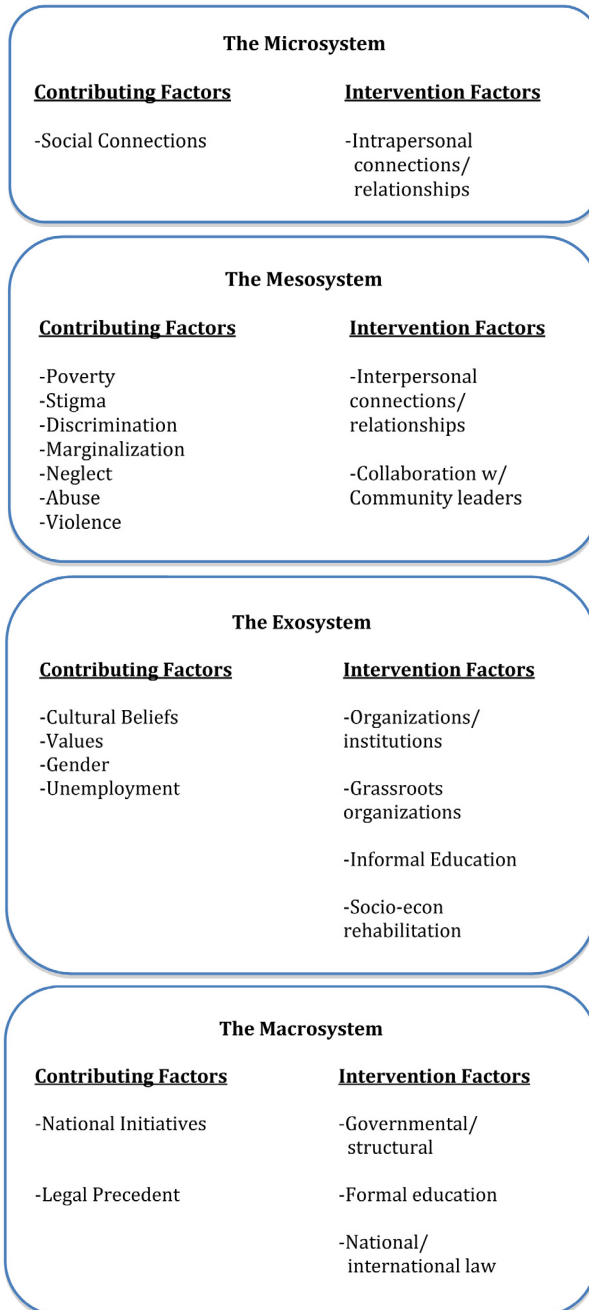


Figure 2: Bronfenbrenner's systems applied to PWA contexts



This representation makes it clear, according to the extant literature, where concentrations of support and assistance for Africans with albinism reside. In the microsystem, the most immediate of the four contexts, social connections and community issues around persons with albinism are apparently improved by relying on bettering intrapersonal reflections as a means of assimilating persons with albinism among their immediate social systems of family, friends and the immediate community, for example the village. In the next-closest context, the mesosystem, factors negatively contributing to persons with albinism, appear counterbalanced by attention to and the fostering of interpersonal relationships and involving community and other local leaders to reinforce the legitimacy of persons with albinism. At the next contextual locale, the exosystem, broader considerations around persons with albinism, again, mostly negative, are counteracted by the efforts of local organisations and institutions; grassroots outreaches; informal education; socio-economic rehabilitation; and advocacy for and by persons with albinism. Finally, the macrosystem, the farthest context from where persons with albinism reside, seeks to implement national initiatives and legal precedent via governmental strictures, formal education initiatives, and applications of national and international law.

Thus, all current contextual representations are focused on ensuring that persons with albinism are more fully included, respected, and granted their human rights as fully-inclusive members of their societies. Every resource noted above is aimed at combating a host of legitimate problems, but with scant attention to the crisis of kidnapping, killing and body part harvesting of persons with albinism, notwithstanding a very real general awareness about the trafficking crisis.

Below we describe the trafficking problem in terms of an entire trafficking cycle, its topography in relation to persons with albinism, and some basic approaches necessary to ameliorate the trafficking in body parts of persons with albinism in Africa.

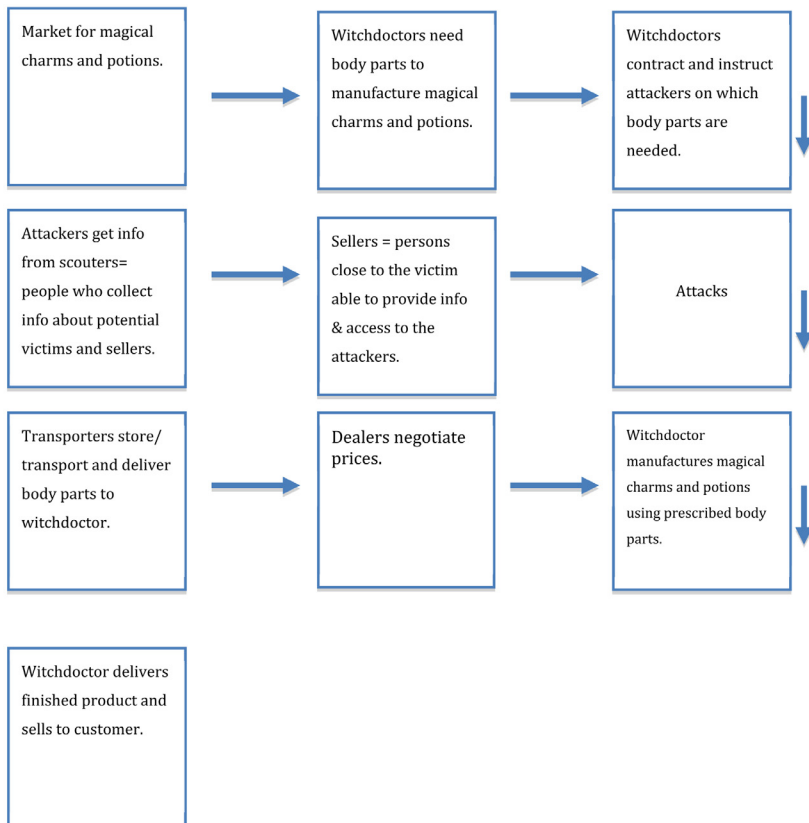
3 The problem

The trafficking in body parts of persons with albinism, economically, is a simple matter of supply and demand. If there were no demand for magical charms or potions, or the willingness of customers to pay exorbitant amounts of money for them, there would be little impetus for this grisly trade. However, the demand is very real and drives the trafficking market and its various players in a commercial trafficking cycle that is well established.

Thus, the entire trafficking process begins and ends with customers who demand charms and potions thought to contain magical qualities. Customers approach a witchdoctor who is the key catalyst setting the

process in motion. Depending on the customer's wishes, the witchdoctor will determine the body parts needed for the charm or potion and will then contract the attackers to procure the specific body parts. The attackers, however, need pertinent information about where they might acquire these body parts, that is, the location of persons with albinism. Attackers consult with scouters whose task it is to know where to find a suitable person with albinism and who the sellers are. Sellers are defined as those closest to the albinism victims who provide real-time information about where the victim may be found. Based on this information, the attack on the person with albinism is carried out and the relevant body parts procured. Transporters, who may or may not be the attackers, transfer the body parts to the witchdoctor after dealers have set or negotiated prices with both the transporters and the witchdoctor. Upon delivery to the witchdoctor, the magical charm or potion is manufactured and sold for profit to the customer. We refer to this process as the commercial trafficking cycle, appearing in Figure 3.

Figure 3: The commercial trafficking cycle¹⁰

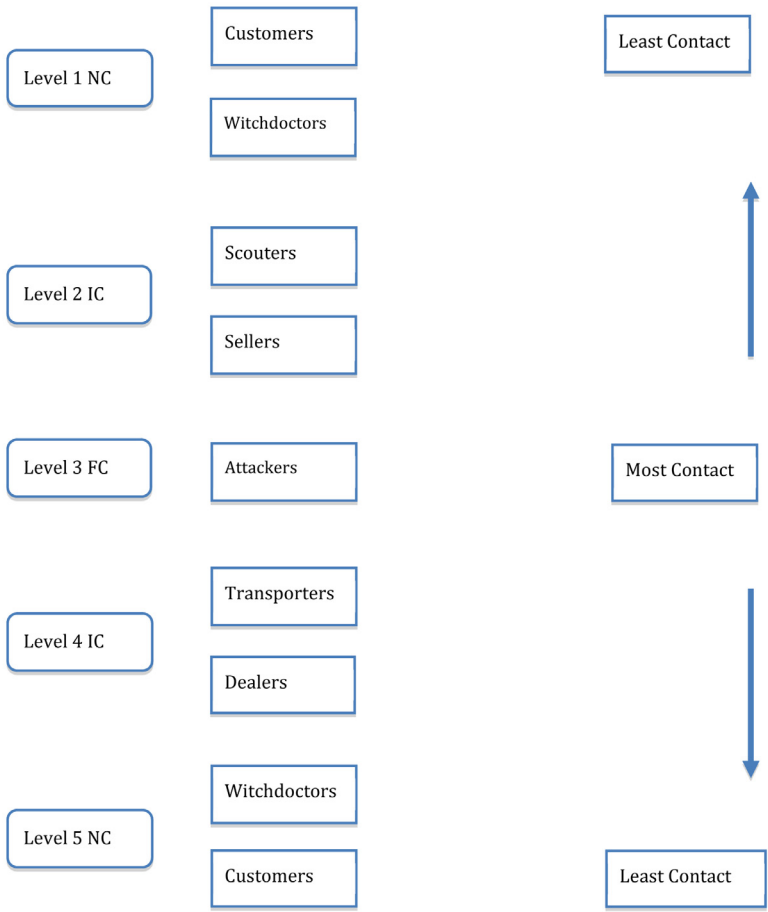


3.1 The commercial trafficking cycle and proximity

An often overlooked quality of Bronfenbrenner's nested systems is the obvious implication that, while nested, the systems are also topographically distanced the one for the other and, therefore from the subject being studied (in this case persons with albinism). That is, the closest system to the subject – here persons with albinism – is the microsystem, with the other three systems (meso-, exo- and macrosystems) being further away. It is this quality of proximity that may also be applied to the stakeholders in the commercial trafficking system to unpack contact between players and their distance closer to, or further from, the victim, as shown in Figure 4 as a series of proximity levels. At level 1, there is no contact (NC) between the victim with albinism and the customer and the witchdoctor. At Level 2, there is intermediate contact (IC) between the victim and scouters and sellers, who are immediately in the vicinity of the victim with albinism, the scouter having to know the immediate whereabouts of the person with albinism and the seller being a direct acquaintance of this person. Finally, in terms of proximity, full contact occurs when the assailants physically attack the person with albinism that results in either severe maiming or death as the ordered body parts are procured. Thereafter, proximity recedes in reverse order of that preceding the attack. Transporters of the body parts and dealers who are the middle men setting prices are classified as having intermediate contact seeing that they are in proximity to the person with albinism's body parts rather than the person with albinism themselves. Finally, to complete the process, the witchdoctors receive the body parts, manufacture what the customer ordered and the transaction is thereby completed. Here, neither party has any actual contact with the person with albinism.

10 J Bell 'Motivated by profit and witchcraft beliefs: East African networks target people with albinism' 2008 http://www.flinders.edu.au/ehl/fms/law_files/Criminal%20Justice/Motivated%20by%20profit%20and%20witchcraft%20beliefs_Burke.pdf (accessed 20 September 2016).

Figure 4: Trafficking commercial cycle and proximity



4 Solutions

Clearly, this state of affairs calls for immediate action at every level of society. The extant literature, however, as with the contributing and intervention factors discussed earlier, notes actions that are heavily weighted toward the protection of, and advocacy for, persons with albinism in the face of organ trafficking issues. These may also be placed within Bronfenbrenner’s nested systems and are amalgamated from suggestions in the literature.

At the level of the microsystem, the immediate setting, literature suggestions centre on how to protect, assist and provide advocacy for persons with albinism. At the level of the mesosystem, a related set of settings, the literature suggests that law enforcement entities have the capacity to detect organ trafficking, and that awareness of organ trafficking across the community be operationalised. At the level of the exosystem, the settings where social structures and institutions reside, suggestions include optimising co-operation among all entities involved in combating trafficking; the strengthening of local and national justice systems and jurisdictions; collecting and analysing data related to trafficking; and strategic advocacy efforts at the level of state institutions. Finally, at the level of the macrosystem, which encompasses cultural and other national institutions, the literature calls for co-operation between countries to eradicate trafficking; the application of international pressure; and the call for special rights for persons with albinism under national and international law.

What is clear is that these efforts, no doubt well intended, are scattered, often unrelated, and nowhere near as substantial and interconnected as they need to be to start making a difference to the lives of persons with albinism whose lives are threatened because of the procurement and trafficking of their organs. Here the question is ‘What are the forces needed to detect and destroy the commercial trafficking cycle in albino body parts?’

While victim protection/assistance and self-advocacy are no doubt helpful, they are not sufficient at the level of the microsystem. We suggest that other vectors be considered, as summarised in Figure 5.

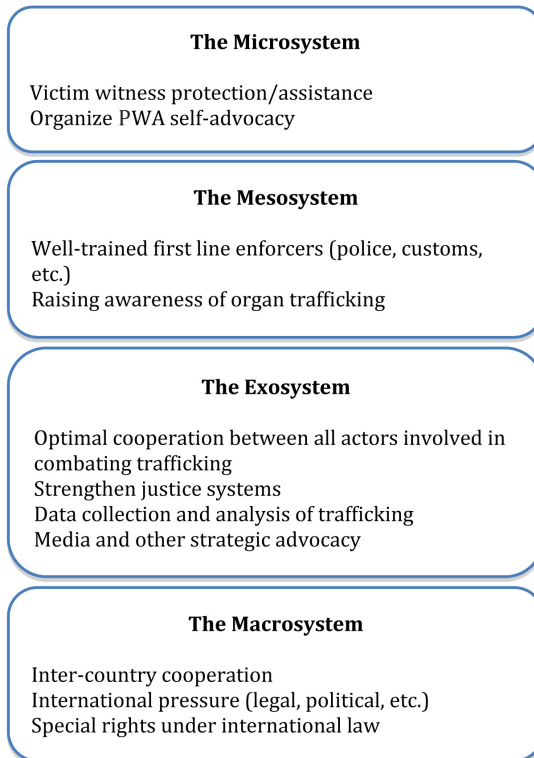
4.1 Protection

First, protection cannot be left to the local authorities that might be understaffed, perhaps corrupt and, perhaps because of negative perceptions, could be unco-operative in protecting persons with albinism. A culture of value, understanding, empathy and tolerance for persons with albinism must be established so that those closest to these persons are resolute in protecting them. Furthermore, strengthening these ties will make it more likely that potential perpetrators will be identified and reported to the authorities, thereby lessening the chances of an attack. Generally, in most African settings, the local community is much more immediate and invested in curbing crime, and of doing so proactively, than local law enforcement officials who, by definition, are almost always reactive. Second, knowing that a particular location is hostile to potential perpetrators may establish ‘safe zones’ where persons with albinism will at least be somewhat assured that there are places where they are less likely to be harmed.

4.2 Co-operation between citizens and law enforcement

In relation to the discussion directly above, it stands to reason that the greater the positive co-operation between citizens and law enforcement at any level, but especially at the local level, is crucial to deflecting perpetrators who will be more likely to know that such co-operation may lead to their apprehension. This co-operation, however, assumes that citizens trust law enforcement personnel and can be assured that their efforts will be dealt with efficiently and in the best interests of persons with albinism. It also assumes that law enforcement officers have received appropriate training about the plight of persons with albinism and are able to model tolerant behaviour to these persons within their jurisdiction.

Figure 5: Suggested vectors necessary to protect persons with albinism from attacks



4.3 Raising awareness

Here the issue of raising awareness is not only related to ignorance about persons with albinism, but specifically about the issue of albino organ trafficking. Generally, raising awareness is a herculean task given opposing societal, cultural and economic forces, and is perhaps much more of a challenge related to persons with albinism and organ harvesting. Awareness of the trafficking issue may be an even larger challenge given that it does not occur everywhere and, by its nature, is secretive. Concerted awareness campaigns would be needed to make every citizen aware of the trafficking issue and how to be alert for signs of possible collusion and attacks in their communities. In this day and age of electronic media, we suggest that there are a myriad of opportunities for advocacy efforts to be much more effective than in the past.

4.4 Operational co-operation between all parties

Co-operation between citizens and authorities at the local level is only the beginning of the huge challenge faced in getting everyone on the same page of the playbook. Law enforcement, the legal system, the community, political, local and regional leaders, and so forth, must all be able to interact in the best interests of persons with albinism generally in relation to the commercial trafficking cycle in particular. Given the enormity of this task, is it incumbent on governments to first acknowledge the challenges faced by their citizens with albinism, and then similarly in relation to the procurement and trafficking issue. This, undoubtedly, creates huge challenges for all concerned but it is crucial if the procurement and trafficking crisis is to be acknowledged, let alone effectively addressed.

4.5 Strengthening the justice system

As noted elsewhere, while every African justice system contains legal and other statutes related to maiming, abduction and trafficking, this is no guarantee that any crimes perpetrated against persons with albinism are automatically addressed. In this regard, there are arguments to be made that along with the overall strengthening of legal statutes protecting persons with albinism, law makers might be well served to specifically single out crimes against these persons as a special legal category with concomitantly more severe sanctions. This may take the form of special legal sanctions, such as hate crime legislation.

4.6 Data collection

In any endeavour, it is not possible to address a problem without understanding its cause, extent and sequelae. In this regard, there is virtually no data available anywhere in Africa or the extant literature

delineating the extent, depth and ramifications of the albino organ procurement and trafficking crisis. Without this data, any and all attempts at solving the problem will be weakened by not knowing in comprehensive detail the overall parameters of the crisis. It is not enough to simply understand that there is a commercial trafficking cycle without, for example, understanding the nuances of the cycle's moving parts, the forces at play influencing the cycle, the extent of the trafficking networks, why networks seem to exist in some places but not others, and so forth.

4.7 International aspects

There is little doubt that as the procurement and trafficking in organs of persons with albinism and others become clearer, it will be obvious that not all trafficking is local, but rather is regional and international. Thus, it will become increasingly necessary for regional and international co-operation to stem the tide and break the cycle. Of necessity, these levels of co-operation involve not only governments but also international agencies that have an interest in ending these crimes. This is a significant challenge for all parties concerned, especially seeing that at this level progress, no matter how co-operative, is usually very slow. Once there is some level of co-operation on the extent of the problem and how it should be addressed, then international pressure can be exerted on those countries that do not co-operate in eradicating these crimes or that are responsible for very slow or non-existent implementation of agreed-upon interventions. Finally, at the international level, there are currently efforts to grant persons with albinism special rights under international law, the aim being that once this is achieved, eradicating the crimes of organ procurement and trafficking will be more effectively addressed.

The abovementioned issues are certainly important, but they do not address the second obvious question we pose: 'What should be done when trafficking is uncovered and its players apprehended?'

We suggest, as a starting point, that the following be considered:

4.8 Judicial punishments

There is little doubt that the procurement of the organs of persons with albinism involves any number of serious crimes irrespective of the players' distance from the actual attack and organ procurement. Consequently, judicial punishment is a logical outcome should perpetrators be apprehended. Still, the issue is perhaps not as clear-cut as it should be. While all African countries have statutes that cover murder and kidnapping, and some specifically have statutes addressing organ procurement and trafficking, the intersection of these illegal acts with deep-seated social attitudes and stigma may play a significant part in how these punishments are adjudicated. For example, it is not unreasonable to

imagine members of law enforcement or even members of the judicial system perceiving the murder of persons with albinism as less heinous than that of other citizens, with concomitant discrimination in the delivery of verdicts and subsequent punishments. Furthermore, a major issue relates to the actual implementation of the law in this instance. For example, Tanzania, after the recent spate of killings of persons with albinism, instituted the death penalty for certain levels of perpetrators.¹² However, effective and efficient implementation of the law has been inconsistent at best for any number of legal, societal and national reasons. Currently, there is very little in the literature to suggest how law enforcement and the conviction of perpetrators can become more fully and consistently implemented country or continent-wide.

4.9 Rehabilitation

Most legal systems recognise that while punishment is a major aspect of the law, there is also the need, where possible, to rehabilitate convicted criminals while they are incarcerated or after they are released. This recognition, however, does not necessarily translate into rehabilitation programmes for offenders. In relation to persons with albinism and organ trafficking, a distinction needs to be made between rehabilitation to integrate offenders back into civil society and rehabilitation of attitudes and perceptions about persons with albinism. General rehabilitation programmes are few and far between in many African countries, and the literature shows no record of rehabilitation attempts related to perpetrators of trafficking in organs of persons with albinism.

4.10 Reconciliation

While less often acknowledged than judicial punishment and rehabilitation, reconciliation can be an effective tool in mitigating future animus and crime. For example, the *Gacaca* courts¹³ established in Rwanda after the 1994 genocide, aside from their justice-based applications, contained a significant element related to reconciling victims and perpetrators, especially when both parties continued to live in close proximity to each other. Similar elements were a visible part of South Africa's Truth and Reconciliation Commission¹⁴ when investigating the many atrocities of apartheid. While full and unconditional reconciliation may not always occur, reconciliation could be a significant vehicle for

12 *Mail and Guardian* (n 4 above).

13 T Hauschildt 'Gacaca courts and restorative justice in Rwanda' 15 July 2015 <http://www.e-ir.info/2012/07/15/gacaca-courts-and-restorative-justice-in-rwanda/> (accessed 15 September 2017).

14 L McLeod 'Reconciliation through restorative justice: Analysing South Africa's truth and reconciliation process' Spring 2015 <http://beyondintractability.org/library/reconciliation-through-restorative-justice-analyzing-south-africas-truth-and-reconciliation> (accessed 18 September 2017).

bridging the gap between perpetrators of albino organ trafficking and the families and loved ones of victims. Again, as with the Rwandan case, victims and perpetrators are likely to reside in close proximity and interact regularly in their communities. We were unable to uncover any reports of reconciliation programmes related to albinism victims and their perpetrators.

4.11 Reparations

The notion of reparations generally seeks to 'make whole', however imperfectly, those aggrieved by a crime. In some systems this takes the form of monetary or asset compensation; community service or prominent social statements of regret or acknowledgment; and the perpetrators' assumption of responsibility for the crime committed.

There is little doubt that the surviving loved ones of murdered persons with albinism suffer a great deal not only over the loss of their loved one, but in knowing how and why the victim was killed. While any form of reparation is hardly adequate to compensate for this horrific state of affairs, it might well go some way to assuaging the psychological and emotional wounds incurred by the crime.

4.12 Retraining

Appropriately, many have noted that albino organ procurement and trafficking is a lucrative business that rewards players at every stage of the commercial trafficking cycle. Typically, this is attached to arguments of poverty and high levels of unemployment, the general idea being that were better economic opportunities available, players would be less likely to engage in trafficking activities. This is problematic on two fronts. First, it is unlikely that in most African countries problems of poverty and unemployment will be solved in the near future and, second, even should employment be close to 100 per cent, it is unlikely that these jobs would be as lucrative as trafficking in albino body parts. On the other hand, however, there is little evidence either that poverty eradication and employment programmes could, even in some small way, mitigate this issue. The simple answer is that the entire set of issues related to how to deal with trafficking in body parts of persons with albinism remains largely unexamined and unaddressed.

5 Conclusion

The article laid out three crucial vectors related to the crisis of persons with albinism in Africa.

First, we noted that there currently exists a significant number of contributing and intervention factors nested within all aspects of African society that seek to address the challenges faced by persons with albinism. While this scenario is far from complete, and while many current interventions may or may not be effective, it is clear that the community of persons with albinism in some countries are being acknowledged and their issues addressed, however imperfectly. Here efforts need to be increased in terms of both intervention focus and efficacy to make the lives of PWA better on all counts. Furthermore, these efforts are significantly uneven. For example, efforts in Tanzania far outstrip efforts elsewhere to address not only the wellbeing of persons with albinism, but also to attempt to curb the commercial trafficking cycle. Not only must efforts continue in Tanzania, but they must be more seriously addressed wherever persons with albinism are found.

Second, we analysed the commercial trafficking cycle and noted the proximity of various players to the victim. It is important to articulate this cycle and proximity issues as a starting point for addressing how, eventually, it might be disrupted and eradicated. The cycle has only recently been articulated, and there is no evidence in the literature that we could find that addresses the cycle in its complexity and influence, let alone speculating on effective solutions. For example, virtually no attention is paid to players other than the attackers. While this focus is on its own terms necessary, it is not sufficient, as it is equally important to consider the entire set of players and how they (significantly) contribute to the procurement of organs of persons with albinism.

Third, we gathered from the literature what prophylactic efforts were available specifically targeting the safety of persons with albinism as potential victims for organ procurement and trafficking and how they were nested in proximity to these persons. What is clear in this regard is that current efforts are piecemeal and scattered; much more 'Band aid' solutions to immediate problems than an actual co-ordinated effort that addresses, at least, the albinism side of the trafficking issue. Clearly, the paucity of efforts here is a boon to those profiting from the commercial trafficking cycle in that they are usually able to easily circumvent whatever paltry efforts exist.

In sum, we acknowledge that the very real plight of persons with albinism is beginning to be noticed and addressed, albeit in a piecemeal and somewhat unco-ordinated way, but that at every level, from the person with albinism in an African village to the national and international structures that govern the globe, there is so far no measured, logical, sequenced approach to adequately protect and include Africans with albinism.

THE IDENTITY QUESTION VERSUS
APPROPRIATENESS OF LEGAL ANTI-
DISCRIMINATION MEASURES:
ENDORISING THE DISABILITY RIGHTS
APPROACH TO ALBINISM

Abdallah Possi and Ally Possi***

Summary

The marginalisation of persons with albinism has for years gone unnoticed. Recently various platforms have been used to combat reported harmful practices against persons with albinism, particularly in Africa. While it is currently accepted that albinism is a human rights agenda, the manner of its advocacy remains unresolved with respect to the 'appropriate legal approach' for protecting the rights of persons with albinism. When addressing this problem, two issues appear to be confused: identity (the 'who are we' question); and the appropriate legal anti-discrimination approach. Thus, the two issues are distinguished in this contribution by endorsing the 'appropriate legal anti-discrimination approach' in realising the rights of persons with albinism. It is worth noting that questions of identity are subjective and should not be confused with objective and empirical questions regarding the appropriate legal mechanisms designed to promote and protect the rights of a particular group. Without downplaying the significance of identity in the formation of the rights groups movement, which has proved vital to the development of human rights, this contribution argues that, while persons with albinism might have multiple identities, the 'disability rights approach', which is founded on the social model of disability that uses human rights as a path, is well placed to accommodate matters concerning the rights and equality of persons with albinism.

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1 Introduction

Recent human rights discourse has been dominated by debates seeking to adopt preferable solutions for realising the rights of persons with albinism. Indeed, albinism is now widely acknowledged to be a human rights concern. However, the latest approaches deployed to address this concern conflict with one another and, at times, overlap. The question of identity has emerged, as has uncertainty over the best approach to adopt in attempting to realise the rights of persons with albinism.

Before unpacking the main issues in this area of concern, a general understanding of albinism is important. It is a rare, non-contagious, genetically-inherited condition present at birth. It is found in both genders, regardless of ethnicity, and in all countries of the world. The condition results in a lack of pigmentation (melanin) in the hair, skin and eyes, causing vulnerability to the sun and bright light. As a result, most persons with albinism have varying levels of visual impairments (some may be legally blind) and are prone to developing skin cancer.¹ The medical approach to albinism is insufficient as it treats the condition as an illness or defect² – a ‘disease involving lack of pigmentation’.³

The prevalence of albinism varies across the world.⁴ It is estimated that one in every 20 000 persons in North America and Europe has some form of albinism, while the reported frequency in sub-Saharan Africa ranges from one in 5 000 to one in 15 000, with prevalence rates of one in 1 000 to one in 1 500 for selected populations.⁵ However, studies on the frequency of albinism often lack objectivity in their methodology or are incomplete, rendering the estimates guesses at best. According to World Health Organisation (WHO) estimates, there are tens of thousands of people living with albinism in Africa.⁶

Negative social perceptions are a major obstacle to the enjoyment of the right to equality and other human rights of persons with albinism.⁷ The literature reveals a long history of widespread acts of stigma against

1 HRC *Persons with albinism: Report of the Office of the United Nations High Commissioner for Human Rights* (2013) paras10 & 11.

2 J DiGennaro ‘Sex-specific characteristics as defences to criminal behaviour’ (1983) 6 *Criminal Justice Journal* 196; SAD Kanga ‘A call for a Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Persons with Disabilities in Africa’ (2013) 21 *African Journal of International and Comparative Law* 222; J Gillette ‘Pregnant and prejudiced: The constitutionality of sex and race-selective abortion restrictions’ (2013) 88 *Washington Law Review* 654.

3 S Scott ‘A new category of “colour”: Analysing albinism under Title VII and the Americans with Disabilities Act’ (1999) *The Journal of Gender, Race and Justice* 469.

4 HRC (n 1 above) para 14.

5 HRC *Report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism* (2016) para 15.

6 HRC (n 1 above).

7 M Mswela ‘The “evil albino” stereotype: An impediment to the right to equality’ (2013) 32 *Medicine and Media* 89-92.

persons with albinism in different places throughout the world,⁸ where they are viewed as inferior, bizarre and sinister,⁹ and often subjected to ridicule.¹⁰ There were even times when African Americans with albinism or those with vitiligo were exhibited in taverns, dime museums and circus sideshows.¹¹ The portrayal of albinism in some films and fiction has been viewed by activists to be mostly negative, and this supports and stimulates societal intolerance and discrimination against the group.¹² In some places, because of a lack of understanding about albinism, it is taken for granted that persons with albinism have perfect vision and, therefore, should not require assistance.¹³

The visibility of persons with albinism differs according to geographical location. In Western societies, where the populations are predominantly pale-skinned, persons with albinism often pass unnoticed, while in sub-Saharan Africa the condition is usually visible.¹⁴

In addition to the practical problems associated with albinism generally in Africa, an enduring challenge encountered by persons with albinism is the stigmatisation and ostracism they face.¹⁵ Such treatment is often associated with a web of myths pertaining to the condition, which myths usually have negative connotations.¹⁶ At the centre of all challenges confronting persons with albinism, women and children with albinism have always been most vulnerable in this regard. Children with albinism are at risk of abandonment, discrimination and exclusion¹⁷ because of the existence of harmful traditional practices of infanticide against them, as is

8 S Bucaro 'A black market for magical bones: The current plight of East African albinos' (2010) 15 *Public Interest Law Reporter* 2.

9 Scott (n 3 above) 521.

10 MK Possi 'Stigma and people with disability: A review of stigma attached to people with albinism' (1998) 13 *International Journal of Special Education* 82; MK Possi 'Gender and education of people with disabilities in Tanzania' (1996) 3 *Utafiti (New Series)* 83; .

11 CD Martin *The white African-American body: A cultural and literary exploration* (2002) 1.

12 Mswela (n 7 above) 81.

13 N Wan 'Orange in a world of apples: The voices of albinism' (2003) 18 *Disability and Society* 287.

14 C Baker et al 'The myths surrounding people with albinism in South Africa and Zimbabwe' (2010) 22 *Journal of African Cultural Studies* 169.

15 Bucaro (n 8 above) 2.

16 See; Possi (n 10 above); HRC (n 1 above) paras 15-18. The common myths associated with albinism include the following: 'A person with albinism is born of a white and an African parent'; 'albinism is a disease'; 'a person with albinism was conceived while a woman was menstruating'; 'albinism is contagious'; 'the lack of pigmentation of a child with albinism can be cured by traditional healers or herbalists'; 'the skin of children with albinism is delicate at birth but can be "toughened" by exposure to the sun'; 'a child with albinism is a ghost or a substitute for a proper child by spirits'; 'persons with albinism are sorcerers, or devils'; 'a person with albinism is a curse'; 'contact with persons with albinism will bring bad luck, sickness or death'; 'persons with albinism are considered to simply vanish (they do not die)'; 'persons with albinism are apes and a source of money'; 'people with albinism have the power of seeing in the dark'; 'pulling out the hair of a person with albinism brings good luck'; and 'sexual intercourse with a woman or a girl with albinism can cure HIV/AIDS'.

17 HRC (n 1 above) para 42.

commonly reported in some African communities.¹⁸ General problems of marginalisation in education and employment also affect persons with albinism.¹⁹ Their lack of education results in high unemployment rates which ultimately give rise to them experiencing the additional problems associated with low income and poverty. As a result, many persons with albinism in Africa cannot afford the cost of what they particularly need, such as proper sun screen lotions,²⁰ and, therefore, are at greater risk of developing skin cancer. The level of discrimination and the prevalence of myths have gone as far as ‘promoting’ the ritual killing of persons with albinism and the trade in their organs, the trafficking of their persons and the sale of children with albinism, often motivated by the myth that the ‘body parts of persons with albinism possess magical powers capable of bringing riches and power’.²¹

As stated above, while it is not in doubt that albinism currently is a human rights concern, the question of the ‘appropriate legal approach’ for realising the rights of persons with albinism appears not to have been conclusively answered. Thus, this contribution investigates the appropriate human rights approach for safeguarding the rights of persons with albinism and endorses the view that the disability rights approach appropriately accommodates matters concerning the rights and equality of persons with albinism.

This contribution contains six sections. The first is a general introductory section, which is followed by an assessment of the current international and regional approaches to protecting the rights of persons with albinism. The third section reveals some concerns surrounding the grounds of discrimination which have a bearing on advancing the rights of persons with this condition. The disability approach to albinism, which forms the central concern of this work, is analysed in section four. The approach endorsed still faces some challenges, which the article identifies in section five. Lastly, section six contains concluding remarks.

2 International and regional approaches to albinism

The second half of 2013 witnessed several landmark developments in advancing the rights of persons with albinism. International and regional human rights institutions took centre stage in this process. At the United Nations (UN), the Resolution on Attacks and Discrimination against

18 HRC para 43.

19 I Nzagi ‘Securing the rights of people with albinism in Tanzania mainland: The fight against social exclusion’ unpublished MA dissertation, International Institute of Social Studies, The Hague, 2009 34-35.

20 Nzagi (n 19 above) 36.

21 HRC (n 1 above) para 20.

Persons with Albinism²² was adopted by the Human Rights Council in June 2013. Later, in September 2013, the Office of the UN Human Rights Commissioner issued the Preliminary Report on Persons with Albinism.²³ Fourteen days after the publication of this report, the Human Rights Council adopted a Resolution on Technical Co-operation for the Prevention of Attacks Against Persons with Albinism.²⁴ Recent achievements at the UN were the proclamation of 13 June as the International Albinism Awareness Day;²⁵ the issuing of the Human Rights Council's Advisory Committee Report on a Study on the Situation of Human Rights of Persons with Albinism;²⁶ and the appointment of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism,²⁷ who issued her first report on 18 January 2016.²⁸

Amongst the steps taken by the African Union (AU) through the intervention of African human rights institutions were the adoption of the Resolution on the Prevention of Attacks and Discrimination against Persons with Albinism,²⁹ and a Declaration on Ending Discrimination and Violence against Girls in Africa.³⁰ There has also been an investigative mission with respect to the situation of children with albinism.³¹

While the Human Rights Council Resolution on Attacks and Discrimination against Persons with Albinism³² does not mention disability, the African Commission Resolution on the Prevention of Attacks and Discrimination against Persons with Albinism, which in many respects is similar to the UN Albinism Resolution, directly adopts a disability approach to albinism. Not only does the Albinism Resolution of the African Commission on Human and Peoples' Rights (African Commission) refer to article 18(4) of the African Charter on Human and Peoples' Rights (African Charter), which provides for the rights of persons

22 Resolution on Attacks and Discrimination against Persons with Albinism, Human Rights Council Resolution 23/13 of 2013.

23 HRC (n 1 above); United Nations Convention on the Rights of Persons with Disabilities, General Assembly Resolution A/RES/61/106 of 2006.

24 Resolution on Technical Co-operation for the Prevention of Attacks Against Persons with Albinism, Human Rights Council Resolution 24/33 of 2013.

25 Resolution on International Albinism Awareness Day, Human Rights Council Resolution 69/170 of 2014.

26 HRC *Report of the Human Rights Council Advisory Committee on the study on the situation of human rights of persons living with albinism* (2015).

27 Resolution on the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, Human Rights Council Resolution 28/6 of 2015.

28 HRC (n 5 above).

29 Resolution on the Prevention of Attacks and Discrimination against Persons with Albinism, African Commission on Human and Peoples' Rights Resolution 263 of 2013.

30 Addis Ababa Declaration on Ending Discrimination and Violence against Girls in Africa, adopted at the 22nd session of the African Committee of Experts on the Rights and Welfare of the Child, 5 November 2013.

31 Report on Investigative Mission on the Situation of Children with Albinism in Temporary Holding Shelters – Tanzania, African Children's Committee, 2016, <http://www.acerwc.org/investigation/> (accessed 24 June 2016).

32 Resolution 23/13 of 2013 (n 22 above).

with disabilities to special measures of protection in keeping with their physical or moral needs, but article 7 of the Albinism Resolution also invites its Working Group on Older Persons and People with Disabilities to include guarantees of the rights of persons with albinism in the envisaged Draft Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (African Disability Protocol). However, the Declaration on Ending Discrimination and Violence against Girls in Africa appears to treat albinism and disability as distinct issues, for example, when it requires member states to

take urgent and appropriate measures to support and provide for the needs of girls, particularly those in vulnerable circumstances, such as *girls with disabilities*, girls with *albinism*, girls in disasters ...

This kind of distinction (girls with disabilities and girls with albinism) appears four times in the declaration, which suggests that it was not accidental.

The latest international and regional developments set the stage for the adoption of the right approach to realising the rights of persons with albinism, while also raising relevant questions for consideration with respect to the appropriate approach. In fact, there are similarities between persons with albinism and those belonging to groups internationally accepted as minorities, or other groups that have suffered from marginalisation on whatever grounds. Nevertheless, it is necessary to study the situation and come up with a precise understanding of the phenomenon, since overgeneralisation runs the risk of obfuscating particular aspects of the condition that ought to be considered if real equality is to be realised. This makes it necessary to debate the appropriateness or otherwise of the disability approach to albinism. However, it is necessary first to determine how to categorise albinism as a cause of discrimination, which is done in the next section.

3 Albinism and the problem of categorising the basis of discrimination

While it is clear that persons with albinism experience marginalisation and discrimination, there seem to be some difficulties or contradictions in identifying the category into which they fall on the basis of discrimination. It appears that there are conflicting opinions as to how discrimination against persons with albinism should be dealt with, namely, whether the orthodox civil rights approach, based on colour (independently from the grounds of race and ethnic origin)³³ should be adopted, or the disability

33 Nzagi (n 19 above); Scott (n 3 above) 517.

rights approach.³⁴ A closer examination of the arguments for these approaches follows.

The Preliminary Report of the Office of the UN High Commissioner for Human Rights on the Attacks and Discrimination against Persons with Albinism called for further analysis and consultations to determine the category into which persons with albinism may fall and the basis for discrimination against these persons.³⁵ On the question of whether persons with albinism should be categorised as persons with disabilities, the Report noted:³⁶

In some of the written submissions received from associations working with persons with albinism, they are considered persons with disabilities. Others refer to discrimination on the ground of skin colour.³⁷

According to the Convention on the Rights of Persons with Disabilities (CRPD), persons with albinism could be considered persons with disabilities. According to information received, the laws of some states recognise albinism and the associated visual impairment as a disability. An additional review of the national legislation on disability needs to be conducted, and consultations with persons with albinism are required on the issue of self-identification.³⁸

The report also considered other grounds of discrimination that could be used to protect persons with albinism, such as race, minority status or 'other status', and stated:

The Committee on the Elimination of Racial Discrimination has not yet examined the issue of discrimination on the basis of colour with respect to persons with albinism.³⁹

The Independent Expert on minority issues has stated that '[p]eople living with albinism do not fall under the internationally accepted definition of minorities ... However, their stigma, the lifelong social exclusion and general discrimination they face is a similar experience to those vulnerable racial minorities because of their different skin colour.'⁴⁰

Organisations working with persons with albinism advocate for considering them as a group requiring special attention, as the discrimination and attacks they are exposed to are mainly rooted in erroneous beliefs and myths that must be addressed.⁴¹

34 M Mswela & M Nöthling-Slabbert 'Colour discrimination against persons with albinism in South Africa' (2013) 6 *South African Journal of Bioethics and Law* 27; Scott (n 3 above) 508.

35 HRC (n 1 above) para 77.

36 HRC para 77.

37 HRC para 77.

38 HRC para 78.

39 HRC para 80.

40 HRC para 81.

41 HRC para 83.

The Human Rights Council's Advisory Committee Report on a Study on the Situation of Human Rights of Persons with Albinism states *inter alia*.⁴²

Human rights challenges associated with albinism are multi-layered and are not currently being addressed in a comprehensive and sustainable manner by any human rights mechanism. In addition to the fact that they do not fall within the scope of the current definition of minorities, persons with albinism often suffer from poor eyesight and are prone to developing skin cancer, but cannot or would not want to be classified as persons with disabilities, as that would mean adding another layer of labelling and discrimination to which they may be subjected.

The Independent Expert's first report on albinism connects disability only with the visual impairment effects of albinism.⁴³ This is also the opinion of some in Europe and North America.⁴⁴ There is also the view that the problems with vision associated with albinism may not on their own be sufficient to constitute an impairment which substantially limits a major life activity.⁴⁵ Therefore, the 'perceived disability' approach has been proposed, which puts the focus on (another's) perception of the individual as 'disabled' without requiring the individual to view himself or herself as 'disabled'.⁴⁶

In an effort to determine the 'appropriate legal approach' to realising the rights of persons with albinism, conflicting views often emerge in relation to the question of identity as a construction of 'self' and the question of the appropriate legal anti-discrimination approach. This could be complicated by any attempt to 'universalise' albinism, thereby overlooking some issues, such as the evolving concept of disability. Much as issues of albinism cannot be 'universalised', the thesis of this contribution is that questions of identity are subjective and should not be weighed against objective and empirical questions regarding the appropriate legal mechanisms designed to promote and protect the rights of particular groups. This requires a closer look at identity, its formation and rejection, on the one hand, and the nature and purpose of legal terms, on the other.

The understanding of one's 'self' is a step forward in the development of group identity, which has been used as a political tool for marginalised

42 HRC para 59(f).

43 HRC paras 34-36.

44 See Scott (n 3 above) 516 and some of the responses to the HRC Advisory Committee's questionnaire (to States, NHRIs and NGOs) on the situation of human rights of persons with albinism, prepared pursuant to Resolution 24/33 of 2013 (n 24 above).

45 Scott (n 3 above).

46 Scott 517.

groups⁴⁷ such as persons with albinism. Every human being is aware of his or her individuality, and this awareness enables us to reflect on who we are, whom we choose to identify with, and what we choose to do as matters of choice, not compulsion.⁴⁸ Identity is empowering when self-ascribed, but can be delimiting when identity is ascribed to one by others.⁴⁹ Identity is a subjective experience and 'fluid', being subjected to the fluctuations of self and society;⁵⁰ and time, space and relationality are all important in identity formation and the achievement of a self-concept.⁵¹

People may accept or reject identities merely because of a variety of perceptions in their societies. For example, when disability identity is perceived as inferior, some persons with disabilities may try to conceal social markers of impairment to avoid the stigma of disability,⁵² and may feel the need to overcompensate for their impairments; that is, the need to succeed at levels higher than their colleagues without disabilities, which may lead to their developing a stressful lifestyle.⁵³ Others may try to shift the focus of their impairment through denial. This is what has been referred to as 'disability passing'.⁵⁴ In other words, the disability label may have offered some persons an opportunity to limit the freedom and independence of others, and a significant number of persons with disabilities may resolve to make everyone think that they do not have a disability,⁵⁵ or even develop negative attitudes towards others with disabilities in an effort to pass as 'normal'.⁵⁶ In the circumstances, certain persons with albinism may reject a particular identity such as a disability identity. This is not because they do not have an impairment, but because of the effects linked to societal perceptions that 'disability is a bad thing'.⁵⁷ Therefore, stigmatisation may have the result that some persons with albinism may internalise the harmful reactions that are generated by ignorance, cultural beliefs and myths, hence prompting a loss of self-esteem, which may possibly make them conclude that they have little to be proud of, either as persons with disabilities, in general, or as persons with albinism, in particular.⁵⁸ On the other hand, the shift from medical to social approaches to disability has situated disability as a 'valued concept'

47 CJ Johnstone 'Disability and identity: Personal constructions and formalised supports' (2004) 24 *Disability Studies Quarterly* <http://dsq-sds.org/article/view/880/1055> (accessed 22 September 2017).

48 MW Murugami 'Disability and identity' (2009) 29 *Disability Studies Quarterly* <http://dsq-sds.org/article/view/979/1173> (accessed 22 September 2017).

49 Johnstone (n 47 above).

50 As above.

51 Murugami (n 48 above).

52 JA Brune & DJ Wilson 'Introduction' in JA Brune & DJ Wilson (eds) *Disability and passing: Blurring the lines of identity* (2013) 1.

53 As above; Johnstone (n 47 above).

54 Brune & Wilson (n 52 above).

55 JA Brune 'The multiple layers of disability passing in life' in Brune & Wilson (n 52 above) 38.

56 Johnstone (n 47 above).

57 Consider some African societies where disability is perceived as a curse.

58 Mswela (n 7 above) 89-90.

in identity formation and, in this way, the adoption of a disability identity is seen as the 'reclaiming of the body' from approaches that have diminished the value of persons with disabilities.⁵⁹

When a particular concept is used in a legal sense, its meaning is not always subjected to an individual being's perceptions or desires. Any legal term in a statute serves a particular purpose in that statute. The concept of disability, for example, is capable of being construed in either the context of identity as above, or in the legal sense. Used in a legal context, it has a 'gate-keeping function' since it denotes the class of people entitled to special benefits, or those who qualify for reasonable accommodation and protection against discrimination.⁶⁰ To achieve this purpose, disability has to be objectively interpreted, as against disability as a subjective, individual (self)-construction. When it is construed with respect to the perception of self, disability may not necessarily produce the same results as when the term is used in a purely legal sense. It is also a fact that certain conditions may have 'multiple' identities and could well fit in with specific legal concepts defining particular groups. Where the same meaning is produced in both the subjective and objective construction of a particular concept, this should be more of a coincidence than a matter of pure logic.

This rejection of over-emphasising the construction of self in determining the basis of discrimination should not be construed as ignoring the significance of identity in the formation of a rights group movement and, for the purposes of this contribution, the 'albinism movement'. It is not in doubt that the recognition of one group in society by others comes about only with self-awareness within that group of its differences and strengths.⁶¹ The main point here is that identity issues and prohibited grounds of discrimination are not necessarily the same thing.

The perceived difficulty of defining the type of discrimination that occurs against persons with albinism, or the conflation of the question of identity as a construction of 'self' with the question of an appropriate approach to legal anti-discrimination measures, may well have arisen as a result of overlooking the potential of the disability approach to albinism, which is explored in the following section.

4 Disability approach to albinism

When contemplating the disability approach to albinism, one cannot ignore the complex relationship and, at times, the overlap, between the disability identity and the legal, human rights concept of disability.

59 Johnstone (n 47 above).

60 SR Bagenstos 'Comparative disability employment law from an American perspective' (2003) 24 *Comparative Labour Law and Policy Journal* 656.

61 <http://dsq-sds.org/article/view/343/433> (accessed 22 September 2017).

Furthermore, as there cannot be a universal legal definition of disability, it is inappropriate to narrow the definition and exclude any possibility of having some flexibility in interpreting the term. We expound the disability approach to albinism first by stating the extent to which disability as a matter of identity differs from disability in the legal context, and proceed to emphasise the broad concept of disability, considering the possibility of catering for albinism in domestic disability legislation. The disability approach to albinism is preferred, as this approach is better able to address the concerns of persons with albinism in Africa.

4.1 Coincidence of construction of self and a legal concept

As already stated, disability may be perceived as a matter of self-construct or as a legal construct, and an understanding of the difference between the two is vital to the general understanding of albinism as a disability, not only because of the concomitant visual impairment, but also because of the lack of pigmentation. However, there is a thin margin separating developments in disability identity and the current human rights approach to disability to be found in legal texts.

Disability as a matter of identity pervades the history of disability activism and scholarship.⁶² Persons with disabilities have the capability of constructing a self-identity not constituted in impairment but rather independent of it, and of accepting impairment as a reality that they live with without losing a sense of self.⁶³ The people in this group share a common history and experience of ‘oppression’ and a common bond of resilience,⁶⁴ the commonalities of which have produced a common way of expressing their shared experiences of negotiating disability in a world oriented largely for (and by) able-bodied people.⁶⁵ Disability identity, thus, is a political tool; and the legitimising language of the ‘politicised’ disability identity serves as a communicative tool that asserts that a marginalised disability group has equal rights in the larger society.⁶⁶

Disability identity has significantly influenced the approach of the CRPD⁶⁷ and disability legislation that rejects the medical approach to disability. The past legal definitions of disability were influenced by the medical or welfare approach to disability, in which the term ‘disability’ was used interchangeably with the term ‘impairment’ – a biological

62 C Kelly ‘Wrestling with group identity: Disability activism and direct funding’ (2010) 30 *Disability Studies Quarterly* <http://dsq-sds.org/article/view/1279/1307> (accessed 22 September 2017).

63 Murugami (n 48 above).

64 SE Brown ‘What is disability culture?’ <http://www.independentliving.org> (accessed 27 September 2017).

65 Johnstone (n 47 above).

66 As above.

67 General Assembly Resolution A/RES/61/106 of 2006 (n 23 above).

condition – or some functional characteristics, without reference to externalities such as stigma or the inaccessibility of the environment.

4.2 No universal definition of disability

The CRPD does not expressly define ‘disability’, but recognises it as ‘an evolving concept’, and states that ‘disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others’.⁶⁸ The reason for withdrawing the definition of disability was the disagreement in the *Ad Hoc* Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities with regard to whether or not the CRPD should include a definition of disability.⁶⁹ While, on the one hand, there was a concern that not including a specific definition of disability in the CRPD could lead to excluding persons with certain impairments,⁷⁰ on the other, an argument was raised that any disability would inevitably derive from the medical model, which would also lead to the involvement of some people and the exclusion of others.⁷¹ The view which seems to accord with the current approach is that the definition may change to make room for the inclusion of people who may not now be considered persons with disabilities⁷² and, furthermore, that any definition would also risk ignoring variations amongst societies – by ‘imposing a Western view of disability on non-Western cultural systems’,⁷³ or by compelling states to accept the existence in their societies of a large number of impairment groups not traditionally understood as persons with disabilities.⁷⁴ By not specifically defining disability, the CRPD enabled states and regions to contextualise disability issues within their realities.⁷⁵

Since the CRPD recognises attitudinal and environmental barriers as hindering the full and effective participation in society of persons with disabilities, it is evident that such barriers cannot be the same throughout the world, a fact which should make it understandable that some people

68 Preamble CRPD.

69 AS Kanter ‘The promise and challenge of the United Nations Convention on the Rights of Persons with Disabilities’ (2007) 34 *Syracuse Journal of International Law and Commerce* 291; R Kayess & P French ‘Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities’ (2008) 8 *Human Rights Law Review* 23.

70 Kanter (n 69 above) 292.

71 As above.

72 As above; AC Hendriks ‘Different definition – same problems – one way out?’ in ML Breslin & S Yee (eds) *Disability rights law and policy: International and national perspectives* (2002) 195.

73 Kanter (n 69 above) 292.

74 Kayess & French (n 69 above) 23.

75 EO Adebitan & YJ Job ‘Addressing the hotels facility and service needs of persons living with disabilities within Bauchi metropolis of Bauchi state, Nigeria’ (2014) Proceedings of the Multi-disciplinary Academic Conference on Sustainable Development Vol 2 No 1.

with certain forms of impairment may not be perceived as persons with disabilities in certain areas. Persons with albinism belong to one such category. A cross-cultural work in anthropology and disability studies has also highlighted the fact that the Western definition of disability does not necessarily clearly correspond to the way in which people define disability in other parts of the world.⁷⁶ This could explain not only the differences in the general perceptions across continents, but also the differences in the policy and legislative approaches regarding whether certain conditions, such as a lack of skin pigmentation, are sufficient to constitute an impairment necessary for the definition of disability in a particular jurisdiction.

In 2014, when responding to a questionnaire distributed by the Human Rights Council Advisory Committee, and particularly regarding the question of whether albinism is regarded as a disability, there were some notable differences in approaches or perceptions across countries, which could be attributed to a variety of factors in different countries. Responses from the human rights commissions of Malawi, Rwanda and South Africa⁷⁷ made it clear that persons with albinism are considered persons with disabilities in those countries. In countries such as Denmark, Spain, France and Germany, albinism was 'qualified' as a disability only with respect to visual impairment.⁷⁸ A similar view was expressed in China and Australia,⁷⁹ although there was also the view that there could be various categories for persons with albinism relating to non-discrimination laws on the basis of sensory impairment and physical appearance.⁸⁰

The responses to the questionnaire reinforce the view that perceptions of difference or the visibility of 'disability' attached to the skin are more frequent in places where albinism appears more visible, as in sub-Saharan Africa. In Nigeria, for instance, according to one non-governmental organisation (NGO), persons with albinism are considered 'the

76 G Brocco 'Labelling albinism: Language and discourse surrounding people with albinism in Tanzania' (2015) *Disability and Society* 1146.

77 Responses to the questionnaire (n 44 above) by the National Human Rights Organisations for Malawi, Rwanda and South Africa <http://www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/AttacksAgainstPersonsWithAlbinism.aspx> (accessed 24 June 2016).

78 Responses to the questionnaire (n 44 above) by the Danish Institute for Human Rights, Asociación española de Ayuda a Personas con Albinismo (Spain), Genespoir (France), and NOAH - Albinismus Selbsthilfegruppe Germany <http://www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/AttacksAgainstPersonsWithAlbinism.aspx> (accessed 24 June 2016).

79 Chinese Organisation for Albinism, Albinism Fellowship of Australia.

80 Responses to the questionnaire (n 44 above) by the Albinism Fellowship of Australia, <http://www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/AttacksAgainstPersonsWithAlbinism.aspx> (accessed 24 June 2016).

unfortunate lot who are ill-coloured'.⁸¹ An NGO in Germany presented a different picture.⁸²

Due to the fact that Germans are Caucasians, PWA often are not recognised [as persons with disabilities] by fellow citizens. This is due to two facts: lack of knowledge on albinism in the general population and the fact that their complexion (which may vary from white to strawberry-blond to light brown) does not differ too much from that of the other citizens.

There is growing recognition and acceptance in Africa that persons with albinism are persons with disabilities.⁸³ In a disabling society, so described because of the non-inclusion of persons with albinism, defining a certain person as a person with a disability constitutes a way for persons with albinism to explain to other individuals why they cannot do certain things which people without disabilities can do.⁸⁴ Their rights are violated on the basis of their disability status.⁸⁵ In addition to the negative social perceptions, the inaccessibility of basic requirements for persons with albinism, such as sunscreen lotions, proper skincare, large print information or magnifying glasses, has seriously contributed to the marginalisation of persons with albinism in sub-Saharan African countries. A tropical climate and the predominance of an agricultural economy means that the choices of employment opportunities of persons with albinism are limited, considering the susceptibility to skin cancer which may result from long-time exposure to sunlight. Under the circumstances, sunscreen and visual aids should be treated in the same way as wheelchairs and crutches for people with physical disabilities.⁸⁶

4.3 Albinism in domestic disability legislation

Generally, a human rights approach in disability legislation would mean that persons with albinism, especially in the African community, qualify for the protection and benefit of disability legislation. It would be difficult to sufficiently accommodate the issues of interest to persons with albinism in disability legislation where the definition of disability, for example, is focused on substantial limitations in obtaining employment or obtaining

81 As above.

82 Responses to the questionnaire (n 44 above) by the Albinismus Selbsthilfegruppe Germany, <http://www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/AttacksAgainstPersonsWithAlbinism.aspx> (accessed 24 June 2016).

83 J Burke et al 'Media analysis of albino killings in Tanzania: A social work and human rights perspective' (2014) 8 *Ethics and Social Welfare* 119.

84 Brocco (n 76 above) 1153.

85 Kamga (n 2 above) 230.

86 SH Braathen & B Ingstad 'Albinism in Malawi: Knowledge and beliefs from an African setting' (2006) 21 *Disability and Society* 610.

work,⁸⁷ which would mean that only certain persons with albinism qualified for the benefits of that legislation.

Many countries in Africa have ratified the CRPD. This has resulted in the enactment of new disability laws in some countries, which progress is expected to be emulated by other countries. In Tanzania, for example, the Persons with Disabilities Act⁸⁸ defines disability in relation to an individual to mean a loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical, mental or social factors. The Act also adopts a definition of a person with a disability like that of the CRPD, recognising a person with a disability to be 'a person with a physical, intellectual, sensory or mental impairment and whose functional capacity is limited by encountering attitudinal, environmental and institutional barriers'.⁸⁹ Also, the Zanzibar Persons with Disabilities (Rights and Privileges) Act⁹⁰ shifts from the medical approach to disability and, in addition, groups ultraviolet sun glasses and sun creams together with 'assistive devices and appliances'.⁹¹ Namibia, Zambia and Zimbabwe are also amongst the states with a non-medical definition of disability or a person with a disability,⁹² reflecting the CRPD's context, according to which a person with albinism should qualify as a person with a disability. Although there could be question as to the legal definition of a person with a disability under South African statutes, a recent study on the 'knowledge of disability rights and the social

87 Sec 2 of Disabled Persons (Employment) Act Cap 184 RE 2002 defines a person with disability (using the term 'disabled person') as 'a person who, on account of injury, disease or congenital deformity, is substantially handicapped in obtaining employment, or in undertaking work on his own account, of a kind which apart from that injury, disease or deformity would be suited to his age, experience and qualification'.

88 Persons with Disabilities Act 9 of 2010.

89 Persons with Disabilities Act (n 88 above) sec 3.

90 Persons with Disabilities (Rights and Privileges) Act 9 of 2006.

91 According to sec 29(1) of the Act, among the functions of the Zanzibar Disability Council is the provision of assistive devices, appliances, UV sunglasses and sun creams and other equipment to persons with disabilities to the maximum extent possible.

92 According to sec 1 of Namibia's National Disability Council Act 26 of 2004, disability is defined to mean 'a physical, mental or sensory impairment that alone, or in combination with social or environmental barriers, affects the ability of the person concerned to take part in educational, vocational, or recreational activities'. In Zambia, disability is legally defined as 'a permanent physical, mental, intellectual or sensory impairment that alone, or in a combination with social or environmental barriers, hinders the ability of a person to fully or effectively participate in society on an equal basis with others'. 'A person with disability is a person with a permanent physical, mental, intellectual or sensory impairment which, in interaction with various barriers, may hinder that person to fully and effectively participate in society on an equal basis with others' (Persons with Disabilities Act 6 of 2012 sec 2). In Zimbabwe, the law defines a 'disabled person' as being 'a person with a physical, mental or sensory disability, including a visual, hearing or speech functional disability, which gives rise to physical, cultural or social barriers inhibiting him from participating at an equal level with other members of society in activities, undertakings or fields of employment that are open to other members of society' (Disabled Persons Act 5 of 1992 sec 2).

encounters of students with disabilities in tertiary institutions' included persons with albinism as participants.⁹³ In 2010 there was a move to include 'albinism' in the legal definition of disability in Kenya,⁹⁴ although this move should be looked at in the context of the problem of defining disability in Kenya since, should a broader human rights definition of disability be adopted, it is not necessary to specifically list all kinds of impairments for the purpose of establishing that one's condition fits into any of the categories listed in the definition.⁹⁵

4.4 Weighing other non-discrimination approaches

Being marginalised and discriminated against is a common experience of persons with albinism in Africa, which they share with other marginalised groups. It is indeed possible, either because of the construction of the self, or the substantive nature of the anti-discrimination laws of certain jurisdictions, that persons with albinism could fall under different groups. It is for this reason that the discussion on albinism has involved other issues – notably issues of colour, of being in a minority, and of belonging to a particular social group. None of these issues can sufficiently address albinism issues in Africa, in terms of both visual impairment and a lack of skin pigmentation, in the manner the disability approach does.

4.4.1 Colour

There is no definition of 'colour' in human rights instruments. However, it is generally recognised that 'colour' implies skin colour.⁹⁶ Twenty-seven African constitutions identify 'colour' and 'race' as distinct prohibited grounds of discrimination,⁹⁷ whereas 25 African constitutions do not list

93 AK Tugli et al 'Knowledge of disability rights and the social encounters of students with disabilities in a tertiary institution in South Africa' (2014) 28 *Journal of Social Sciences* 147.

94 Persons with Disabilities (Amendment) Bill 2010.

95 See GO Onyango 'A socio-legal critique of the legal framework for the promotion of rights of persons with disabilities in Kenya' unpublished MA dissertation, International Institute of Social Studies, The Hague, 2012 23.

96 WJ Aceves 'Two stories about skin colour and international human rights advocacy' (2015) 14 *Washington University Global Studies Law Review* 563. .

97 Constitution of the Republic of Angola 2010 art 21(h); Constitution of Botswana 1966 art 15(3); Constitution of Burkina Faso 1991 art 1; Post-Transition Interim Constitution of the Republic of Burundi 2005 art 22; Constitution of the Arab Republic of Egypt 2014 art 21; Constitution of Eritrea 1997 art 14(2); Constitution of the Federal Democratic Republic of Ethiopia 1995 art 25; Constitution of the Republic of The Gambia 1997 art 33(4); Constitution of the Republic of Ghana 1992 art 12(2); Constitution of Kenya, 2010 art 27(4); Constitution of Lesotho 1993 art 18(3); Constitution of the Republic of Malawi 1994 art 20(1); Constitution of the Republic of Mali 1992 art 2; Constitution of Mauritius 1968, arts 3, 16(3) & (5); Constitution of the Republic of Mozambique 2004 art 39; Constitution of the Republic of Namibia 1990 art 10(2); Constitution of the Republic of Rwanda 2003 art 11; Constitution of Sierra Leone 1991 art 27(3); Constitution of the Federal Republic of Somalia 2012 art 11(3); Constitution of the Republic of South Africa, 1996 art 9(3); Transitional Constitution of

'colour' as a prohibited ground of discrimination.⁹⁸ Morocco and the Seychelles have adopted the 'classical' juridical equality stipulations by protecting the right of all to equality, but without mentioning any prohibited ground of discrimination.⁹⁹ The Tanzanian Constitution identifies 'colour' as a prohibited ground of discrimination, but does not include 'race' or 'ethnic origin' in the list,¹⁰⁰ suggesting that the term 'colour' could also be extended to cover race. However, using race as a proxy for colour poses some concerns of its own, since the two are in fact distinct phenomena,¹⁰¹ although they sometime overlap.¹⁰² This situation raises the following questions: Did the drafters of those constitutions that mention 'colour' as a prohibited ground of discrimination have persons with albinism in mind? Can the word 'colour', given the current situation, be extended to address albinism? Are persons with albinism in Africa stigmatised merely because of their colour?

Some have championed for 'colour/colourism' to be recognised as a distinct form of discrimination, which should cover persons with albinism, where the equality clause prohibits discrimination on the ground of colour independently from the grounds of race and ethnic origin.¹⁰³ As already stated, although the term 'colour' in human rights anti-discrimination

the Republic of South Sudan 2011 art 14; Interim National Constitution of the Republic of the Sudan 2005 art 31; Constitution of the Kingdom of Swaziland Act 2005 art 20(1); Constitution of the Republic of Uganda 1995 art 21(3); Constitution of Zambia Act 1991 art 40; and Constitution of Zimbabwe 2013 art 56(3).

- 98 Constitution of the People's Democratic Republic of Algeria 1989 art 29; Constitution of the Republic of Benin 1990 art 26; Constitution of Cameroon 1996 art premier; Constitution of the Republic of Cape Verde 1992 arts 1(2) & 24; Constitution of Central African Republic 2004 art 5; Constitution of the Republic of Chad 1996 art 14(i); Constitution of Comoros 2001 Preamble; Constitution of the Democratic Republic of the Congo 2006 arts 13 & 45; Constitution of the Republic of Djibouti 1992 art premier, arts 3 & 6; Constitution of the Republic of Equatorial Guinea 1991 art 15; Constitution of Gabon 1991 art 2; Constitution of the Republic of Guinea Bissau 1984 art 24; Constitution of the Republic of Guinea 1990 arts 1 & 8; Constitution of Côte d'Ivoire 2000 arts 17 & 30; Constitution of the Republic of Liberia 1986 art 11(b); Interim Constitutional Declaration 2011 art 6; Constitution of the Republic of Madagascar 1992 art 8; Constitution of the Islamic Republic of Mauritania 1991 art premier; Constitution of the Republic of Niger 1999 art 8; Constitution of the Federal Republic of Nigeria 1999 art 15(2); Constitution of the Republic of Congo 2002 art 8; Constitution of the Democratic Republic of São Tomé and Príncipe 1975 art 16(1); Constitution of the Republic of Senegal 2001 art premier; Constitution of Tunisia 1959 art 6. The Constitution was superseded by the Decree-Law 2011-14 on 23 March 2011, relating to the provisional organisation of the public authorities. The said decree does not contain a clear anti-discrimination provision. There have been negotiations for a new constitution. Constitution of the IVth Republic of Togo 1992 art 2. Morocco and the Seychelles have adopted the 'classical' juridical equality stipulations by protecting the right of all to equality, but without mentioning any prohibited grounds of discrimination. See Constitution of the Kingdom of Morocco 1996 art 5; Constitution of the Republic of Seychelles 1993 art 27(1).
- 99 See Constitution of the Kingdom of Morocco 1996 art 5; Constitution of the Republic of Seychelles 1993 art 27(1).
- 100 Constitution of the United Republic of Tanzania 1977 art 13(5). The same position reappears in the Proposed New Constitution 2014.
- 101 T Jones 'Shades of brown: The law of skin colour' (2000) 49 *Duke Law Journal* 1493; Aceves (n 96 above) 583.
- 102 Jones (n 101 above) 1493.
- 103 Mswela & Nöthling-Slabbert (n 34 above) 27.

discourse refers to skin colour,¹⁰⁴ it cannot be stated with certainty that the drafters had albinism in mind, and perhaps the insertion of colour as a prohibited ground of discrimination was an easy way of navigating through the complications associated with race/colour definitions. In explaining discrimination against persons with albinism, ‘skin colour matters’.¹⁰⁵ However, colour *per se* is not the cause of stigma directed at persons with albinism in Africa. Persons with albinism also face discrimination because of the impairments associated with the condition of albinism, such as photophobia; decreased visual acuity; extreme sun sensitivity; and skin cancer.¹⁰⁶ Therefore, colour alone, as a prohibited ground of discrimination, does not address the actual impairment consequences affecting the skin of persons with albinism. If colour were the main cause of stigma, the stigma directed at persons with albinism in Africa could also have extended to other ‘white’ persons, namely, persons of European origin in Africa.

4.4.2 *Minority*

Persons with albinism do not fall under the internationally-accepted definition of minorities, which is limited to national, ethnic, religious or linguistic minorities.¹⁰⁷ However, social attitudes toward persons with albinism are often similar to those experienced by other disability and minority groups.¹⁰⁸ It is for this reason that persons with albinism may be regarded as belonging to the ‘minority’ group – when the term is used in its generic form.¹⁰⁹ Used in its generic form, the term ‘minority’ then becomes too broad, and capable of including almost all marginalised groups. For example, viewed as a social construct, disability is a culturally-constructed minority identity,¹¹⁰ and persons with disabilities have been defined as the ‘largest minority’ in the world.¹¹¹

While the minority approach to albinism may be similar to the ‘disability rights approach’, in the sense that both approaches reject the medical conception of albinism/disability, the minority approach risks ignoring the specific ‘disability-related rights’ with respect to persons with albinism. At this point it is perhaps important to take note of the argument that achieving equality for persons with disabilities is a more complex and

104 Aceves (n 96 above) 563.

105 Aceves 583.

106 Mswela (n 7 above) 89 91.

107 United Nations Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities, General Assembly resolution 47/135 of 1992.

108 J Waugh ‘Social and emotional aspects of albinism’ <http://www.tsbvi.edu/seehear/winter99/albinism.htm> (accessed 4 October 2017).

109 A Fayoyin & N Ihebuzor ‘Advocacy for minorities in Africa: Issues and lessons in advancing the rights of albinos in Tanzania and osus in Nigeria’ (2014) *I Asia Pacific Journal of Research* 113.

110 Wan (n 13 above) 283.

111 See eg UN Enable *UN Convention on the Rights of Persons with Disabilities: Some facts about persons with disabilities* (2006).

difficult process than achieving equality for minorities.¹¹² In the circumstances, the impairment aspect of albinism makes it preferable to deal with it from a disability rights perspective. It may also be argued that the term 'minority' carries with it the same problems as the phrase 'a particular social group' (discussed immediately below), since it is so broad, and cannot in itself exclude persons with albinism from the 'disability' or 'other status' categories.

4.4.3 *A 'particular social group' or 'other status'*

Several African constitutions have the phrase 'other status' as a prohibited ground of discrimination. The term 'other status' envisages prohibited grounds of discrimination which are not clearly listed or addressed in the current international or regional instruments or domestic anti-discrimination laws. However, the phrase seems to be more a speculative than a practical tool, given the fact that most of the concrete policy or legislative measures aimed at addressing discrimination are focused on particular groups mentioned in the relevant laws.

Some could have attempted to classify persons with albinism as belonging to a particular social group.¹¹³ However, this expression is itself too broad to be useful, although it could be adequate to cover persons with disabilities¹¹⁴ or persons with albinism, where these groups of persons (or either of them) are not expressly covered in a particular legal or policy instrument.

Therefore, it follows that the expressions 'a particular social group' and 'other status' are unnecessarily expansive, and do not necessarily preclude persons with albinism from the protection of disability legislation. Relying solely on this approach may also lead to difficulties in ascertaining specific measures aimed at addressing the impairment aspects of albinism.

4.4.4 *Albinism and the question of intersectionality*

Intersectionality connotes that different identity categories can intersect and co-exist in the same individual in a way that creates a qualitatively different experience when compared with the experience of any of the characteristics separately.¹¹⁵ In this sense, intersectionality denies that

112 .T Shakespeare *Disability rights and wrongs* (2006) 65.

113 S Larson 'Magic, mutilation, and murder: A case for granting asylum to Tanzanian nationals with albinism' (2011) 2 25.

114 See United States Court of Appeals, 9th Circuit '*Tchoukhrova v Gonzales*' (2015).

115 B Smith 'Intersectional discrimination and substantive equality: A comparative and theoretical perspective' (2016) 16 *The Equal Rights Review* 73.

identity can be dissected into ‘mutually exclusive categories of experience and analysis’.¹¹⁶ Therefore, the grounds for discrimination should (in the appropriate circumstances) be defined in such a way that they reinforce one another.¹¹⁷ Therefore, a truly intersectional approach, for example, would state that the level of discrimination that a woman with albinism experiences is different from that faced by other women and distinct from that suffered by other persons with albinism. This is like stating that, because the CRPD covers albinism, the discrimination a woman with a disability experiences is different from that faced by other women and different from that suffered by other persons with disabilities. This article does not reject the notion of the intersectional nature of discrimination. Even within the larger disability group, it may be argued that only recently have there been louder voices for persons with albinism, meaning that the significance of intersectionality as regards albinism is that it exposes the differences in categories, including the disability category, bringing to attention the individuals at the intersections who are ignored by the current orthodoxy.¹¹⁸

The intersectional nature of discrimination is neither peculiar to persons with albinism, nor peculiar to persons belonging to any other ‘identities’. The core question in this article has been whether or not disability covers albinism, which we answer in the affirmative. Furthermore, the synergistic nature of intersectional discrimination requires one to identify some grounds of discrimination which, taken separately, would not seem to be discriminatory,¹¹⁹ and what these are with respect to albinism. Are persons with albinism discriminated against because of both colour and impairment? Which impairment – visual or a lack of skin pigmentation? Is it merely a question of colour or is the impact attached to the lack of skin pigmentation? These questions would take one back to the issues already covered in this article: visual issues which would require assistive devices, or an inability to work for long hours in the sun, which may require that workers with albinism be given reasonable office accommodation. Coupled with discrimination against the individual concerned, these factors are sufficient to constitute disability.

Intersectionality plays an important role in defining some unique instances of discrimination, but its overgeneralisation may lead to the incorrect assumption that intersectional discrimination is the only form of discrimination, or the only form of discrimination worthy of being addressed. This kind of assumption would create new and harmful

116 Smith (n 115 above) 76; D Schiek ‘Intersectionality and the notion of disability in EU discrimination law’ (2016) 53 *Common Market Law Review* 62.

117 As above.

118 Smith (n 115 above) 101.

119 S Fredman *Intersectional discrimination in EU gender equality and non-discrimination law* (2016) 28.

stereotypes, such as that all persons with albinism are victims of intersectional subordination.¹²⁰

4.5 Multiple identities and intersectionality not excluding the disability approach

Persons with albinism may have multiple identities, and there could be a number of suggestions regarding measures aimed at improving their human rights situation. Nevertheless, despite the multiple identity nature of albinism, the stigma surrounding albinism is not based purely on colour, and other seemingly broader descriptions or approaches to albinism, such as those attached to 'minorities' or 'particular social groups', sound as they may appear to be, may not be able to answer some specific issues of concern for persons with albinism in Africa. Therefore, it is important to recognise the fact that the impairment-related issues linked to albinism are fully covered under the CRPD and can be fully addressed under any domestic legislation following the CRPD model.

5 Potential challenges to the disability approach to albinism

The broad human rights approach to disability properly addresses albinism issues, especially in Africa, with respect to both visual impairment and skin pigmentation. However, there are still those who do not appear to fully appreciate the disability rights approach to albinism. This may be the case for a number of reasons, such as the continued existence of the vestiges of the medical approach to disability, weaknesses within the African albinism movement, and faulty attempts at universalising albinism, amongst others.

There are numerous policies and pieces of legislation in various countries that maintain the medical approach to disability, making it tedious to progressively address the concerns of albinism. For example, Uganda's definition of disability is tied to 'a substantial functional limitation of daily life activities'.¹²¹ Although there are some references to environmental barriers, the legislation contains the 'disability coding' which not only reflects the medical approach to disability but also excludes persons with albinism.¹²² Some other examples of the medical approach to

120 See T Makkonen *Multiple, compound and intersectional discrimination: Bringing the experiences of the most marginalised to the fore* (2002) 58.

121 Sec 2 of the Persons with Disabilities Act of 2006 defines disability as 'a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environment barriers resulting in limited participation'.

122 The codings which are in the First Schedule to the Act include, among others, 'skin diseases' and '[e]ye 'defects''. While albinism is not a disease, the visual issues are not the only challenges to persons with albinism. The codings exist for the purposes of determining 'whether an impairment has a substantial functional limitation of daily life

disability or the medical definition thereof can be seen in the disability legislation of Rwanda¹²³ and Sierra Leone.¹²⁴ In South Africa, although the Constitution as a whole is widely deemed (amongst some scholars) to be admirable, some uncertainties remain in defining persons with disabilities. Different pieces of legislation define disability for different purposes, such as employment and social security.¹²⁵ None of these definitions incorporates persons with albinism. In Ghana, the Persons with Disability Act¹²⁶ defines neither disability nor a person with a disability, making it problematic not only for persons with albinism who may seek to benefit from the said legislation, but also for other persons who may fall within the disability group. We take note, though, that the fact that the respective countries have ratified the CRPD is itself a progressive step towards a more inclusive approach to disability.

The medical approach to disability is likely to lead to persons with albinism being categorised as being 'impaired', which leads to stigmatisation and disempowerment. The construction of diametrically-opposed identities, the good against the bad, the strong against the weak, or the desirable against the undesirable, is fundamental to the oppression of persons with disabilities.¹²⁷ When this is the perception of disability amongst individuals with albinism, it is not possible to easily support the disability approach to albinism, since they too would perceive disability as a 'bad thing'. In other words, the rejection of the disability approach to albinism by some persons with albinism could well be caused by the fact that they too, perhaps unknowingly, also stigmatise persons with other forms of impairment.

The rejection of the disability approach to albinism by some individuals with albinism may influence them to look for a different way of characterising the nature or cause of discrimination against persons with albinism. When this happens in an environment where the African albinism movement lacks the ability to venture separately into the international arena, there is a risk of falling into the old trap of treating some conditions as universal from the perspective of Western rights movements. This observation should not be regarded as intended to

activities; or whether an impairment has a long-term effect on a person' (secs 4(1)(a) & (b) of the Persons with Disabilities Act (n 121 above)).

123 Law Relating to the Protection of Disabled Persons in General 1 of 2007.

124 Persons with Disability Act 3 of 2011 sec 2.

125 According to the Employment Equity Act 55 of 1998, 'people with disabilities' means 'people who have a long-term or recurring physical or mental impairment which substantially limits their prospects of entry into, or advancement in, employment'. According to the Social Assistance Act 13 of 2004, a person with a disability is one who is 'owing to a physical or mental disability, unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance'.

126 Persons with Disability Act 715 of 2006.

127 R Galvin 'The making of the disabled identity: A linguistic analysis of marginalisation' (2003) 23 *Disability Studies Quarterly* <http://dsq-sds.org/article/view/421> (accessed 22 September 2017).

discredit the tremendous efforts being made by some Western albinism rights activists who have worked tirelessly to promote the albinism agenda in the international human rights fraternity.¹²⁸ The point is that the weakness of the albinism movement in Africa has been the cause of inadequate dialogue amongst albinism organisations on the continent, a situation which has made it impossible to present a stronger albinism voice within the disability movement, even in jurisdictions where albinism is generally accepted as a disability. This has created the further possibility of developing the idea that the rights approach to albinism can be uniform and universalised.

6 Conclusion

A lack of pigmentation constitutes an impairment, which forms one part of the definition of a person with a disability. Despite the existence of this impairment, albinism is not universally characterised as a disability in legal terms. This alone must not prevent or discourage persons with albinism from pursuing their rights under the disability rights mechanism, considering the fact that even the term 'disability' itself does not have a universal definition. Thus, this contribution puts forward the view that in Africa, and probably in some other parts of the world, albinism can be legally construed as a disability with respect to both visual impairment and a lack of skin pigmentation. The task ahead is to ensure that the specific needs of persons with albinism are exhaustively addressed in future policies and programmes so as to cater for the full realisation of their rights.

128 Credit must be given to Under the Same Sun (UTSS), a Canadian-based organisation, also registered in Tanzania, as the only organisation for persons with albinism, which has been at the forefront campaigning internationally for the rights of persons with albinism. The organisation was registered in Tanzania shortly after the reports of the killings of persons with albinism had emerged.

SECTION B: COUNTRY REPORTS

RÉPUBLIQUE DE DJIBOUTI

*Djibril Ismail Cher**

1 Les indicateurs démographiques

1.1 Quelle est la population totale de la République de Djibouti?

Selon le dernier Recensement Général de la Population et de l'Habitat de 2009, la population djiboutienne est évaluée à 818 159 habitants.¹

1.2 Méthodologie employée en vue d'obtenir des données statistiques sur la prévalence du handicap en République de Djibouti. Quels sont les critères utilisés pour déterminer qui fait partie de la couche des personnes handicapées en République de Djibouti?

La République de Djibouti n'a pas encore effectué un recensement général de personnes handicapées. Cependant, la Deuxième Enquête Djiboutienne sur la Santé de la Famille (EDSF/PAPFAM2)² a produit les seules données statistiques disponibles sur le handicap. Cette étude de 2012, est loin d'être exhaustive puisque qu'elle n'a porté que sur un échantillon de 6233 ménages³ répartis sur l'ensemble du territoire national (capitale et 5 régions) tant en milieu urbain qu'en milieu rural. Le handicapé est défini par les enquêteurs comme « une personne ayant un empêchement physique ou mental ne lui permettant pas d'accomplir les tâches naturelles, compare à une autre personne du même âge et du même sexe et ce, pendant 6 mois ou plus ». De plus, l'enquête fait une distinction entre le handicap sévère et le handicap modéré sans pour autant expliciter ce critère de distinction.

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1 Article 1 du Décret N° 2010-0038/PR/MEFPCP portant publication des résultats du 2ème Recensement Général de la Population et de l'Habitat de 2009, Site Présidence.dj.

2 Direction de la Statistique et des Etudes Démographiques(DISED), Ministère de la Santé et Pan Arab Project for Family Health, Rapport Final EDSF/PAPFAM2, 2012.

3 Sur un total de 70160 ménages sédentaires répartis sur tout le pays et identifiés lors du recensement général de la population et de l'habitat de 2009. Voir ci-dessus n2, p146.

1.3 Quel est le nombre total et le pourcentage des personnes handicapées en République de Djibouti?

Les résultats de l'enquête EDSF/PAPFAM2 ont montré que 0.5% de la population de l'échantillon souffre d'un handicap sévère alors que 1% souffre d'un handicap modéré soit un total de 1.5%. Sachant que la population de la République de Djibouti est de 818 159 habitants en 2009, une extrapolation des résultats de l'échantillon à l'échelle de la population globale fait ressortir un nombre total de handicapés d'environ 12272 personnes.

1.4 Quel est le nombre total et le pourcentage des femmes handicapées en République de Djibouti?

Selon les résultats de l'échantillon, il n'y a pas de différence entre les hommes et les femmes (1.4% contre 1.5%),⁴ concernant la prévalence au handicap.

1.5 Quel est le nombre total et le pourcentage des enfants handicapés en République de Djibouti?

Le Ministère de la Femme et de la Famille vient de finaliser une enquête sur les enfants handicapés. Cependant, les résultats de cette étude ne sont pas encore été publiés.

1.6 Quelles sont les formes de handicap les plus répandues en République de Djibouti?

Il ressort de l'enquête que les formes de handicap les plus répandues sont respectivement le handicap visuel (47% des cas de handicap), suivi du handicap moteur (23%) et enfin du handicap auditif (17%).⁵ Il faudrait souligner que les enquêteurs ont évalué les autres handicaps à 13%, sans pour autant lister ces autres formes d'handicap. Enfin, il est précisé toutefois que les pourcentages sont calculés sur le total des cas d'handicap et non pas sur le total des handicapées, sachant qu'il y a des handicapés souffrant de plus d'un type d'handicap.

2 Obligations internationales

2.1 Quel est le statut de la Convention des Nations Unies relative aux Droits des Personnes Handicapées (CDPH) en République de Djibouti? La République de Djibouti a-t-il signé et ratifié la CDPH? Fournir le(s) date(s). La République de Djibouti a-t-il signé et ratifié le Protocole facultatif? Fournir le(s) date(s).

La République de Djibouti a ratifié, par les lois respectives N°67/AN/09/6^{ème} L et N°69/AN/09/6^{ème} L en date du 3 janvier 2010, la Convention des Nations Unies relative aux Droits des Personnes Handicapées (CDPH) ainsi que son Protocole Facultatif. La République de Djibouti a déposé les instruments de

4 Voir ci-dessus n2, p23

5 Voir ci-dessus n2, p24

ratification auprès du Secrétaire Général, dépositaire de la présente convention à la date du 18 juin 2012.⁶ Lors de l'adhésion à cette convention, la République de Djibouti n'a formulé la moindre réserve ni introduit une quelconque déclaration interprétative.

2.2 Si la République de Djibouti a signé et ratifié la CDPH, quel est/était le délai de soumission de son rapport? Quelle branche du gouvernement est responsable de la soumission du rapport? La République de Djibouti a-t-il soumis son rapport? Sinon quelles sont les raisons du retard telles qu'avancées par la branche gouvernementale en charge?

La République de Djibouti était tenue de soumettre son rapport initial dans un délai de deux ans après l'adhésion à la Convention soit à la date du 18 juillet 2014.⁷

En vertu de l'Arrêté N°2009-0322/PR/MJAP datée du 20 avril 2009, la soumission du rapport est dévolue au Comité intersectoriel chargé de la rédaction et de la soumission de rapports aux organes de traités. La coordination de ce Comité interministériel, est assurée par le Secrétaire Général du ministère de la justice. Effectivement, la République de Djibouti a soumis son rapport initial à la date du 02 février 2016.⁸ Le Comité Intersectoriel a souligné dans le rapport initial que l'Etat partie avait pris du retard dans la soumission du rapport sans pour autant en indiquer les raisons.⁹

2.3 Si la République de Djibouti a soumis le rapport au 2.2 et si le comité en charge des droits des personnes handicapées avait examiné le rapport, veuillez indiquer si le comité avait émis des observations finales et des recommandations au sujet du rapport de la République de Djibouti. Y'avait-il des effets internes découlant du processus de rapport liés aux questions handicapées de la République de Djibouti?

Le Comité des droits de personnes handicapées n'a pas encore examiné le rapport initial soumis par la République de Djibouti.¹⁰

2.4 En établissant un rapport sous divers autres instruments des Nations Unies, la Charte Africaine des Droits de l'Homme et des Peuples ou la Charte Africaine relative aux Droits et au bien-être de l'Enfant, la République de Djibouti a-t-il également fait mention spécifique du droit des personnes handicapées dans ses rapports les plus récents? Si oui, les observations finales adoptées par les organes statutaires ont-elles fait mention du handicap? Si pertinent, ces observations ont-elles été suivies d'effet? Etait-il fait mention des droits des handicapés dans le rapport de la Revue Périodique Universelle (RPU) des Nations Unies de la

6 Nations Unies, Collection des Traités https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_fr consulté le 24/04/2017

7 OHCHR http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?CountryCode=DJI&Lang=FR consultée le 24/04/2017

8 Comme ci-dessus n7

9 Rapport initial et périodique de la République de Djibouti, p5. http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fDJI%2f1&Lang=fr consulté le 24/04/2017

10 Comme ci-dessus n7

République de Djibouti? Si oui, quels étaient les effets de ces observations ou recommandations?

En effet, la République de Djibouti a fait mention du droit des personnes handicapées dans les rapports soumis aux organes de traités des Nations Unies et de l'union africaine.

Certaines observations finales ou recommandations adoptées ont également évoquées le droit de personnes handicapées.

• Comité de droits civils et politiques

Le comité n'a pas formulé de recommandations sur le droit des personnes handicapées bien que l'Etat Partie a mentionné dans son rapport l'inexistence d'établissements scolaires adaptés pour les enfants réfugiés, enfants de rue et les enfants handicapés.¹¹

• Comité de droits économiques, sociaux et culturels

Ainsi, le Comité a regretté, lors de l'adoption des observations finales, l'absence d'une législation interne définissant les droits de personnes handicapées et aussi l'indisponibilité de données fiables sur la jouissance par les personnes handicapées de droits économiques, sociaux et culturels.¹² A ce titre, il a été recommandé à l'état partie d'édicter une législation prévoyant de recours administratives et juridiques, de produire de données fiables sur l'exercice de droits économiques, sociaux et culturels de personnes handicapées et enfin de prendre de mesures concrètes en vue de leur faciliter l'accessibilité aux services publics. En outre, le Comité a jugé préoccupant le taux de chômage élevé parmi les personnes handicapées et a encouragé l'Etat Partie mettre en place de programmes favorisant l'insertion professionnelle de groupes marginalisés incluant les personnes défavorisées. Le Comité a déploré l'inexistence d'une législation sur la santé mentale ainsi que l'insuffisance de personnel qualifié et d'infrastructures spécialisés. Ainsi, il a été recommandé à l'Etat Partie de formuler une législation sur la santé mentale conforme aux normes internationales et ainsi améliorer l'accès aux soins par la mise en place de structures de santé adaptés disposant d'un personnel qualifié.

• Comité des droits de l'enfant

Le Comité a déploré que les enfants appartenant à des groupes vulnérables comme les enfants handicapés n'avaient pas tous accès à l'éducation, à la santé et à d'autres services sociaux. Ainsi, lors de l'adoption des observations finales du Comité,¹³ il a été recommandé à l'Etat Partie de prendre en considération le principe de non-discrimination en adoptant une stratégie globale d'élimination à l'égard de personnes vulnérables y compris les enfants handicapés.

Le Comité a également formulé un certain nombre de recommandations à l'Etat Partie portant sur les droits des enfants handicapés conformément aux Règles de Nations Unies pour l'égalité des chances des handicapés (résolution 48/96 de l'Assemblée générale) et de l'Observation générale numéro 9 du Comité des droits de l'enfant:

- Ratifier la convention relative sur les personnes handicapées et son protocole facultatif.

11 OHCHR, CCPR/C/DJI/I Rapport initial de la République de Djibouti, 2012. Accessible file:///C:/Users/CNDH/Downloads/G1244191%20(1).pdf

12 OHCHR, E/C.12/DJI/CO/1-3, Observations finales sur le rapport initial et le deuxième rapport périodique de Djibouti, 2013. Accessible file:///C:/Users/CNDH/Downloads/G1349994.pdf

13 OHCHR.org, file:///C:/Users/Djibril%20Ismail%20Cher/Downloads/G0844351.pdf, Consulté le 24/04/2017

- Prendre les dispositions pour adopter une législation spécifique sur le droit des handicapées.
 - Mettre en place de programmes spécialisés ainsi que les moyens humains et financiers nécessaires pour rendre effective le droit des enfants handicapés à l'éducation.
 - Multiplier les campagnes de sensibilisation sur les droits et besoins spécifiques des enfants handicapés et de favoriser leur insertion dans la société.
 - Fournir une formation professionnelle aux personnels de santé, aux travailleurs sociaux ainsi que les enseignants intervenant auprès des enfants handicapés.
- **Comité pour l'élimination de la discrimination à l'égard des femmes**
Le Comité a déploré, lors de l'adoption des observations finales,¹⁴ le manque de données tangibles sur la discrimination dont sont victimes les femmes âgées, les filles orphelines et vulnérables, les femmes réfugiées et migrantes ainsi que les femmes handicapées. De plus, il a été recommandé à l'Etat partie de favoriser l'éducation des filles et garçons handicapés en leur facilitant l'accès aux établissements scolaires ordinaires.

Le Comité a en outre appelé l'Etat Partie à adhérer aux instruments internationaux non encore ratifiés à la date de l'adoption des observations finales comme la convention relative aux droits de personnes handicapées (ratifié en 2010).

• **Comité contre la torture**

Le Comité dans ses observations finales¹⁵ a jugé regrettable le manque de données sur les garanties juridiques accordés aux personnes souffrant d'un handicap physique ou mental. Le Comité a également encouragé l'Etat partie à ratifier la Convention relative sur les droits de personnes handicapées.

• **Commission africaine des Droits de l'Homme et des Peuples**

La Commission a soulevé dans ses observations conclusives,¹⁶ le manque de données sur les conditions de détentions de personnes vulnérables y compris les personnes handicapées et sur le cas de l'unique centre de détention psychiatrique¹⁷ accueillant les personnes souffrant de troubles mentaux. La Commission a en outre regretté sur l'absence d'informations sur les mesures prises pour lutter contre les discriminations dont sont victimes les enfants souffrant de handicap.

La Commission a aussi mis en exergue l'absence de textes législatives pertinents pour protéger les droits de personnes handicapées et ainsi recommander de mettre en place de stratégies et autres mesures législatives appropriés. Enfin, la Commission a déploré le manque de données sur l'accès de personnes handicapées aux postes électives comme le parlement.

• **Examen Périodique Universel**

La République de Djibouti a mentionné dans son rapport son adhésion à la Convention relative sur le droit des personnes handicapées et le Protocole facultatif s'y rapportant. Ainsi, les Etats examinateurs ont à l'unanimité salué l'adhésion de Djibouti à la Convention. Le Nigeria a émis une recommandation encourageant l'Etat Partie à intensifier les efforts visant à protéger les personnes handicapées.

14 OHCHR.org, file:///C:/Users/Djibril%20Ismail%20Cher/Downloads/N1144158.pdf, Consulté le 24/04/2017.

15 OHCHR.org file:///C:/Users/Djibril%20Ismail%20Cher/Downloads/G1147991.pdf, Consulté le 24/04/2017.

16 ACHPR.org http://www.achpr.org/files/sessions/18th-ao/conc-obs/1-1993-2013/co_djibouti_init_comb_sr_fre.pdf Consulté le 24/04/2017.

17 En fait, il s'agit plutôt un local de la Prison de Gabode accueillant les prisonniers souffrant de troubles psychiques.

L’Egypte a quant à lui, recommandé à l’Etat partie de promouvoir l’éducation des personnes handicapées.

2.5 Y’avait-il un quelconque effet interne sur le système légal de la République de Djibouti après la ratification de l’instrument international ou régional au 2.4 ci-dessus?

La ratification de la convention n’a pas entraîné un effet positif sur le système légal. Il faudrait noter cependant que lors du dernier Atelier de Réflexion sur le handicap du 21-23 mai 2017 organisé par le Secrétariat d’Etat aux Affaires Sociales, il a été décidé d’édicter une législation spécifique pour la protection des personnes handicapées.

2.6 Les traités internationaux ratifiés deviennent-ils automatiquement loi nationale sous votre système légal? Si oui y’a-t-il des cas où les cours et tribunaux appliquent directement les dispositions du traité international?

L’article 70 de la Constitution djiboutienne, a consacré la primauté du traité sur la loi ordinaire. Rappelons que dans le système moniste en vigueur dans les pays francophones comme la République de Djibouti, les traités régulièrement ratifiés font partie intégrante du droit interne. Ces traités peuvent être invoqués auprès des juridictions nationales et les juges sont tenus d’appliquer directement les dispositions de la norme internationale dans la mesure où les traités régulièrement ratifiés ont, dès leur publication, une autorité supérieure à la loi. Toutefois, certains membres du Barreau de Djibouti déclarent invoquer constamment les instruments internationaux et régionaux ratifiés par la république de Djibouti mais qu’en revanche, les juges se contentaient d’appliquer la norme interne dans leurs jugements.

2.7 En référence au 2.4 ci-dessus, la Convention des Nations Unies relative aux Droits des Personnes Handicapées CDPH ou tout autre instrument international ratifié, en tout ou en partie, a-t-il été incorporé textuellement dans la législation nationale? Fournir les détails.

Il n’y a pas eu d’incorporation de la CDPH dans le corpus juridique interne. Il y a certes, une nécessité d’harmoniser la législation interne avec les dispositions du CDPH, même si l’applicabilité directe du traité ratifié est communément admise dans la doctrine juridique francophone.

3 Constitution

3.1 La constitution de la République de Djibouti contient-elle des dispositions concernant directement le handicap? Si oui énumérez les dispositions et expliquez comment chacune d’elles traite du handicap.

La constitution de la République de Djibouti ne contient aucune disposition concernant directement le handicap.

3.2 La constitution de la République de Djibouti contient-elle des dispositions concernant indirectement le handicap? Si oui énumérez les dispositions et expliquez comment chacune d'elles traite indirectement du handicap.

L'article 1 de la Constitution consacre le principe d'égalité et de non-discrimination en proclamant solennellement que « l'Etat assure à tous l'égalité devant la loi ». L'article 10 de la constitution dispose également que « tous les êtres humains sont égaux devant la loi ». Ce principe de non-discrimination consacré par la loi fondamentale est applicable à tous, y compris aux personnes handicapées.

La Constitution proclame également dans son préambule que les dispositions de la Déclaration Universelle des Droits de l'Homme et de la Charte Africaine des Droits de l'Homme et des Peuples (CADHP) font partie intégrante de la loi fondamentale. Ainsi, l'article 2 de la Déclaration Universelle des Droits de l'Homme proclame le principe d'égalité et de non-discrimination. Aussi, le paragraphe 4 de l'Article 18 de la CADHP consacre le droit de personnes handicapées à bénéficier de mesures de protection.

Eu égard à ce qui précède, il y a lieu de souligner que certaines dispositions pertinentes constitutionnelles (Constitution *stricto sensu* et Préambule) concernent indirectement le handicap.

4 Législation

4.1 La République de Djibouti a-t-il une législation concernant directement le handicap? Si oui énumérez la législation et expliquez comment la législation aborde le handicap.

Non.

4.2 La République de Djibouti a-t-il une législation concernant indirectement le handicap? Si oui énumérez la principale législation et expliquez comment elle réfère au handicap.

• **La loi du 05 juillet 1995 relative au Code Pénal¹⁸**

L'article 390 inclut parmi les formes de discrimination, celle basée sur le handicap. Cette disposition prévoit pour les personnes reconnues coupables de discrimination, une peine privative de liberté de 3 ans. L'article 514 réprime l'exploitation frauduleuse de la faiblesse ou de l'ignorance de certains groupes vulnérables comme les enfants ou des handicapés.

• **La loi du 31 Janvier 2002 sur le Code de la Famille¹⁹**

Selon l'article 166 du Code de la famille inclut parmi les causes de l'incapacité, la démence et la faiblesse d'esprit. Ainsi, cette disposition s'applique particulièrement aux handicapés souffrant de déficience mentale ou intellectuelle dont leur

18 Code pénal https://www.unodc.org/tldb/pdf/Djibouti_Penal_Code_Fr.pdf Consulté le 24/04/2017.

19 Code de la Famille <http://jafbase.fr/docAfrique/Djibouti/CodeFamille.pdf> Consulté le 24/04/2017.

incapacité pourrait être prononcée par une décision judiciaire susceptible de recours (Article 167 et 168). Ces dispositions constituant une restriction à l'exercice de la capacité juridique de personnes handicapées sont motivées par le souci de protéger leurs intérêts. En effet, ils seront assistés d'un tuteur pour la gestion de leurs biens. Et ainsi, les actes accomplis par les personnes souffrant de déficience mentale sans l'assistance du tuteur sont déclarés nuls (Article 178). Ces mesures de protection sont conformes à l'esprit de l'article 12 du CDPH qui encourage les Etats parties à prévoir des mesures d'accompagnement favorisant l'exercice de la capacité juridique de personnes handicapées.

- **La loi du 28 Janvier 2006 portant adoption du Code du Travail**²⁰

Article 117 consacre le principe de non-discrimination en matière d'emploi pour les personnes handicapées. Article 118 définit le travailleur handicapé comme « toute personne dont les possibilités d'obtenir ou de conserver un emploi, sont effectivement réduites par suite d'une insuffisance ou d'une diminution de ses capacités physiques ou mentales ». Il y a lieu de constater que le code du travail méconnaît le droit au travail pour les personnes handicapées, consacré par l'article 27 de la CDPH.

- **La loi du 3 Juillet 1999 portant orientation de la politique de la santé**²¹

Cette disposition législative prévoit l'accès à la santé pour tous (Article 2) et accorde une assistance spécifique aux groupes vulnérables incluant aussi les personnes handicapées (Article 4 et 5).

- **La loi du 10 Aout 2000 portant orientation du système éducatif djiboutien**²²

Cette loi reconnaît le droit à l'éducation pour tous (Article 4) et réaffirme que la scolarisation est gratuite (Article 16) et obligatoire de 6 à 16 ans (Article 14). Toutefois, une disposition exempte de cette obligation scolaire, les parents des enfants handicapés (article 4). Il y a lieu de remarquer que cette disposition législative adoptée avant la ratification par l'Etat Partie de la CDPH ne consacre pas explicitement l'insertion éducatif à tous les niveaux garanti aux personnes handicapées prévue par l'article 24 de la CDPH.

- **La loi du 27 Décembre 2007 relative à la prévention et la lutte contre le trafic des êtres humains**²³

Cette loi reconnaît que les personnes vulnérables (femmes, mineurs ou handicapés) sont les principales victimes du trafic humain (Article 1).

- **La loi du 5 Janvier 2014 sur l'Assurance Maladie Universelle**²⁴

Cette disposition législative a mis en place le Programme d'Assurance Sociale Santé (PASS) permettant aux groupes vulnérables comme les personnes handicapées le droit de bénéficier de la prise en charge de soins médicaux.

20 Code du Travail http://www.ilo.org/wcmsp5/groups/public/---ed_protect/---protrav/---ilo_aids/documents/legaldocument/wcms_126983.pdf Consulté le 24/04/2017

21 Loi 3 juillet 1999 portant orientation de la politique de la santé http://www.vertic.org/media/National%20Legislation/Djibouti/DJ_Loi_Orientation_Politique_Medicale.pdf Consulté le 24/04/2017.

22 loi du 10 Aout 2000 portant orientation du système éducatif djiboutien <http://www.education.gov.dj/index.php/service-juridique/36-dga/dhr/lois/183-loi-n-96-an-00-4emel-portant-orientation-du-systeme-educatif-djiboutien> Consulté le 24/04/2017.

23 Loi du 27 Décembre 2007 relative à la prévention et la lutte contre le trafic des êtres humains http://www.protectionproject.org/wp-content/uploads/2010/09/Djibouti_TiP-Law_2007.pdf Consulté le 24/04/2017.

24 Loi du 5 Janvier 2014 sur l'Assurance Maladie Universelle <http://www.droit-afrique.com/upload/doc/djibouti/Djibouti-Loi-2014-24-assurance-maladie-universelle.pdf> Consulté le 24/04/2017.

5 Décisions des cours et tribunaux

- 5.1 Les cours (ou tribunaux) de la République de Djibouti ont-ils jamais statué sur une question(s) relative au handicap? Si oui énumérez le cas et fournir un résumé pour chacun des cas en indiquant quels étaient les faits; la (les) décision(s), la démarche et l'impact (le cas échéant) que ces cas avaient entraînés.**

Non.

6 Politiques et programmes

- 6.1 La République de Djibouti a-t-il des politiques ou programmes qui englobent directement le handicap? Si oui énumérez la politique et expliquez comment cette politique aborde le handicap.**

Non.

- 6.2 La République de Djibouti a-t-il des politiques ou programmes qui englobent indirectement le handicap? Si oui énumérez chaque politique et décrivez comment elle aborde indirectement le handicap.**

Le Secrétariat d'Etat à la Solidarité nationale dont l'appellation a été changé en Secrétariat d'Etat chargé des Affaires Sociales (SEAS) lors du remaniement ministériel de Mai 2006, est le département en charge de la lutte contre la pauvreté et l'exclusion. De ce fait, cet organe a initié un programme de micro-crédits au profit des couches les plus défavorisées de la population djiboutienne. Ce programme a également ciblé les personnes vivant avec un handicap.

Le Programme d'Assurance Sociale Santé (PASS) introduit par la loi sur l'Assurance Maladie Universelle (AMU) du 05 janvier 2014, prévoit la prise en charge de frais médicaux aux groupes vulnérables, y compris les personnes handicapées.

Le Plan d'action Stratégique National pour l'Enfance à Djibouti (PASNED)²⁵ pour la période 2011-2015 avait pour objectif de permettre à tous les enfants incluant aussi les enfants handicapées, la libre jouissance de leurs droits fondamentaux en matière d'éducation, de santé etc.

25 PASNED(2011-2015) file:///C:/Users/Djibril%20Ismail%20Cher/Downloads/Plan%20d'Actions%20pour%20l'Enfance%202011-2015,%20Minist%C3%A8re%20Promotion%20de%20la%20Femme.pdf Consulté le 24/04/2017.

Le Schéma Directeur du Ministère de l'Éducation Nationale (2010-2019)²⁶ a identifié deux axes d'intervention portant respectivement sur les enfants en difficulté d'apprentissage et la scolarisation des enfants souffrant de handicap physique ou sensoriels.

7 Organismes en charge des personnes handicapées

7.1 En dehors des cours ou tribunaux ordinaires, la République de Djibouti a-t-il un organisme officiel qui s'intéresse spécifiquement de la violation des droits des personnes handicapées? Si oui décrire l'organe, ses fonctions et ses pouvoirs.

En dehors des juridictions ordinaires, il n'existe pas à ce jour en République de Djibouti d'organisme officiel s'intéressant spécifiquement aux violations de personnes handicapées.

7.2 En dehors des cours ou tribunaux ordinaires, la République de Djibouti a-t-il un organisme officiel qui, bien que n'étant pas spécifiquement en charge de la violation des droits des personnes handicapées s'y attèle tout de même? Si oui décrire l'organe, ses fonctions et ses pouvoirs.

La Commission Nationale des Droits de l'Homme (CNDH) dispose d'un mandat de protection des droits de l'Homme.²⁷ Il est en outre chargé du suivi de la mise en œuvre des organes de traités. Enfin, le Bureau de plaintes de la CNDH est compétent pour instruire les recours portant sur toutes violations des droits de l'Homme.²⁸

8 Institutions Nationales des Droits de l'Homme (Commission des Droits de l'Homme ou Ombudsman ou Protecteur du Citoyen)

8.1 La République de Djibouti est-il doté d'une Commission de Droits de l'Homme ou d'un Ombudsman ou d'un Protecteur du Citoyen? Si oui ses missions incluent-elles la promotion et la protection des droits des personnes handicapées? Si votre réponse est oui, indiquez également si la Commission de Droits de l'Homme ou l'Ombudsman ou le Protecteur

26 Schéma Directeur (2010-2019) file:///C:/Users/Djibril%20Ismail%20Cher/Downloads/2010-2019-Djibouti-Education-Sector-Plan.pdf par 40 et 41. Consulté le 24/04/2017.

27 Article 4 Loi n°59/AN/ 14/7ème L portant organisation et fonctionnement de la Commission Nationale de Droit de l'Homme (CNDH) <http://www.ilo.org/dyn/natlex/docs/ELECTRONIC/99841/119306/F24816027/DJI-99841.pdf> Consulté le 24/04/2017.

28 Article 5 Décret n°2015-210/PR/MJDH portant application de la loi n°59/AN/14/7ème L <http://www.ilo.org/dyn/natlex/docs/ELECTRONIC/99842/119308/F849115194/DJI-99842.pdf> Consulté le 24/04/2017.

du Citoyen de la République de Djibouti n'a jamais abordé des questions relatives aux droits des personnes handicapées.

La République de Djibouti a mis en place les institutions du Médiateur de la République (Ombudsman) et de la Commission Nationale des Droits de l'Homme (CNDH).

La République de Djibouti a mis en place les institutions du Médiateur de la République (Ombudsman) par la loi n°51 du 21 août 1999. Toutefois, cette institution ne dispose pas d'un mandat de protection des droits de l'homme.

La CNDH a été tout d'abord instituée par le décret n° 2008-0103/PR/MJAP du 23 avril 2008. Ensuite la loi n° 59/AN/ 14/7ème L du 20 juillet 2014 a été introduite dans le but de garantir l'indépendance de la Commission et ainsi la mettre en conformité avec les Principes de Paris.

La CNDH est dotée d'un mandat de promotion et de protection des droits de l'homme en vertu de la loi de 2014 qui a abrogé le décret de 2008 instituant la CNDH. La CNDH est également en charge du suivi de la mise en œuvre des instruments de droits de l'homme ratifiés par la République de Djibouti.²⁹ Le décret d'application qui a également édicté prévoit la mise en place de quatre sous commissions en charge d'un ou plusieurs instruments internationaux et régionaux de droits de l'homme. Précisément, c'est la deuxième sous-commission qui est chargé de surveiller la mise en œuvre de la Convention sur les droits de personnes handicapées.³⁰ A ce jour, la CNDH n'a pas reçu de plaintes sur un cas de violation de droits de personnes handicapées.

9 Organisation des personnes handicapées (OPH) et autres Organisations de la Société Civile

9.1 Avez-vous en République de Djibouti des organisations qui représentent et défendent les droits et le bien-être des personnes handicapées? Si oui énumérez chaque organisation et décrivez ses activités.

- **L'Association Vivre Plus Fort**

Cette association créée en 1988, est la première association ayant pour mission de sensibiliser les pouvoirs publics sur les droits des handicapés. Elle a également pour objet de s'atteler à l'insertion professionnelle des personnes handicapées en sensibilisant le patronat et la Chambre de Commerce. Cette association ayant plus de 500 adhérents, dispose d'un siège au centre-ville attribué par l'Etat. Elle a mis en place avec le soutien du Secrétariat d'Etat à la Solidarité Nationale un projet de micro finance au profit de personnes handicapées.

- **L'Association Action Handicap**

C'est une association créée en 2007, ayant plus de 300 adhérents et qui œuvre pour la promotion des personnes handicapées et la lutte contre la marginalisation des personnes vivant avec un handicap. Cette association a réalisé un certain nombre

29 Article 7 Loi n°59/AN/ 14/7ème L portant organisation et fonctionnement de la Commission Nationale de Droit de l'Homme (CNDH). Voir ci-dessus n27.

30 Article 2 Décret n°2015-210/PR/MJDH portant application de la loi n°59/AN/14/7ème L. Voir ci-dessus n28.

d'activités comme la sensibilisation le patronat sur le recrutement des personnes handicapées. Elle a aussi entrepris un plaidoyer en vue de favoriser l'accessibilité des personnes handicapées aux bâtiments publics. Cette association collabore avec l'International Disability Alliance et a d'ailleurs contribué au rapport alternatif soumis au Comité de Droits Economiques, Sociaux et Culturels par la Coordination de la Plateforme de la Société Civile Djiboutienne en 2013.³¹

- **L'Association Djiboutienne des Aveugles (ADDA)**

Créée en 2006, elle organise des activités de sensibilisation sur les droits de personnes aveugles ou malvoyants. Elle œuvre aussi dans l'accès de ces personnes malvoyants à l'éducation et à la santé.

- **L'Association des Blessés Invalides des Mines et Mutilés de Guerre**

Cette association créée en 2014 s'occupe de la réinsertion des mutilés de guerre blessés lors du conflit interne (1991-1994).

- **Association DEKA**

Cette association créée par une femme a pris l'initiative de mettre en place un refuge à plus de 70 personnes souffrant de handicap physique et mental.

- **Johanniter International**

Cette organisation non gouvernementale (ONG) en partenariat avec la Coopération Allemande a équipé un centre d'appareillage orthopédique mis en place au sein de l'hôpital Cheiko de Balbala. Ce centre est spécialisé dans la conception et la fabrication des prothèses, orthèses et chaussures orthopédiques pour personnes ayant un handicap physique.

- **Association de Femmes Handicapées**

Cette association créée en Mars de 2017 a pour objectif de favoriser l'insertion et l'autonomisation des femmes handicapées.

- **Fédération Djiboutienne d'Handisports**

Cette association fondée en mars 2017 vise à promouvoir le sport de compétition ou de loisirs pour les personnes présentant une déficience motrice, visuelle ou auditive. Elle est dirigée par Ali Mohamed Ali, le président de l'association Action Handicap.

9.2 Dans votre région, les OPH sont-elles organisées ou coordonnées au niveau national et/ou régional?

Depuis janvier 2017, toutes les organisations de personnes handicapées se sont regroupés autour d'une plateforme commune dénommée le Réseau National des Personnes handicapées (RNPH) a pour objectif de représenter les associations membres lors des consultations avec les organes étatiques et les partenaires au développement. Selon le président du RNPH Mr Idriss Moumin Abdi, ce réseau national projette de nouer un partenariat avec les OPH du monde entier et plus particulièrement avec ceux de la région de l'Afrique Orientale. En effet, il existe au sein des pays de l'Afrique de l'Est, un organe régional de coordination des OPH, la Fédération de Personnes Handicapés de l'Afrique de l'Est (Eastern Africa Federation of the Disabled).³² Cette organisation sous-régionale (EAFOD) a été

31 Rapport final Coordination de la Plateforme de la Société Civile Djiboutienne sur les Droits Economiques, Sociaux et Culturels 2013 http://tbinternet.ohchr.org/Treaties/CESCR/Shared%20Documents/DJI/INT_CESCR_NGO_DJI_15159_F.pdf Consulté le 29 Avril 2017.

32 Edan, Report on Workshop on advocacy for the promotion of rights and equalization of opportunities for persons with disabilities in Eastern Africa 6th, 8th December 2011 p29-30. http://www.edan-wcc.org/index.php/regions/item/download/37_af7480d156d908d687cf92b99c2d4da.

créée en 1993 à Kampala pour regrouper les réseaux nationaux des OPH de 14 pays dont Djibouti. Le siège de cette organisation est basé à Nairobi.

9.3 Si la République de Djibouti a ratifié la CDPH, comment a-t-il assuré l'implication des Organisations des personnes handicapées dans le processus de mise en œuvre?

Les OPH sont régulièrement invités à participer pour donner leurs points de vue aux conférences et séminaires organisés par le gouvernement. L'ensemble des OPH ont été conviés à exposer leurs recommandations lors de l'Atelier de Réflexion sur le Handicap organisé par le Secrétariat d'Etat aux Affaires Sociales.

9.4 Quels genres d'actions les OPH ont-elles prise elles-mêmes afin de s'assurer qu'elles soient pleinement intégrées dans le processus de mise en œuvre?

Les OPH ont participé activement à l'élaboration du rapport initial sur la mise en œuvre de la convention relative aux droits des personnes handicapées. Elles ont eu des réunions de travail avec les membres du comité intersectoriel de rédaction et de soumission de rapports sur la mise en œuvre des instruments des droits de l'homme.

9.5 Quels sont, le cas échéant les obstacles rencontrés par les OPH lors de leur engagement dans la mise en œuvre?

Une évaluation sommaire de la capacité organisationnelle des OPH montre certaines faiblesses. En l'absence d'un statut légal régissant les OPH, elles ont été créées en vertu de la loi Française de 1901 relative aux associations à but non lucratif encore en vigueur en République de Djibouti. La plupart ne disposent pas d'un siège pour se réunir excepté, l'Association « Vivre Plus Fort » et l'Association ADDA. Les adhérents sont en majorité de personnes vulnérables sans qualification professionnelle et vivant de la précarité. Elles n'ont pas les capacités techniques pour monter un projet et mobiliser des fonds de la part des partenaires au développement. Depuis une décennie, la visibilité médiatique des OPH se réduit aux interviews données à la presse écrite et audiovisuelle par leurs trois leaders³³ notamment, lors de la commémoration de la Journée internationale de Personnes Handicapées célébrée chaque année, le 3 Décembre. Enfin, ces OPH n'adoptent pas une approche proactive, laissant aux départements ministériels l'initiative de programmer les consultations sur la question du handicap.

9.6 Y'a-t-il des exemples pouvant servir de 'modèles' pour la participation des OPH?

Non.

9.7 Y'a-t-il des résultats spécifiques concernant une mise en œuvre prospère et/ou une reconnaissance appropriée des droits des personnes

33 Ali Mohamed Ali, le Président de l'association Action Handicap ; Idriss Moumin Abdi, le Président de l'association ADDA et Abdoukader Yacoub Mahamoud, l'ancien Président de l'association Vivre Plus Fort.

handicapées résultant de l'implication des OPH dans le processus de mise en œuvre ?

Non.

9.8 Votre recherche (pour ce projet) a-t-elle identifié des aspects qui nécessitent le développement de capacité et soutien pour les OPH afin d'assurer leur engagement dans la mise en œuvre de la Convention?

En premier lieu, il y a une nécessité de conduire une évaluation des structures des OPH dans le but d'analyser leurs forces et faiblesses. Aussi, elles doivent faire appel à une expertise externe en vue de formuler un plan stratégique et un plan d'action. Il est aussi indispensable de solliciter l'assistance technique de partenaires au développement en vue de bénéficier de programmes de renforcements de capacités. Enfin, un aspect qui doit mériter une attention particulière pour les OPH est la maîtrise des techniques du Lobbying dans l'objectif d'influencer les pouvoirs publics pour faire aboutir leurs projets.

9.9 Y'a-t-il des recommandations provenant de votre recherche au sujet de comment les OPH pourraient être plus largement responsabilisées dans les processus de mise en œuvre des instruments internationaux ou régionaux?

Les OPH doivent être représentés dans les organes en charge du suivi et de la mise en œuvre d'instruments de droits de l'homme ratifiés par la république de Djibouti notamment, le Comité Intersectoriel de rédaction et de soumission de rapports aux organes de traités et la Commission Nationale des Droits de l'Homme.

9.10 Y'a-t-il des instituts de recherche spécifiques dans votre région qui travaillent sur les droits des personnes handicapées et qui ont facilité l'implication des OPH dans le processus, y compris la recherche?

Les chercheurs du Centre de Recherches de l'Université de Djibouti (CRUD) et du Centre d'Etudes et de Recherches de Djibouti (CERD) n'ont pas à ce jour, conduit ou publié des études sur les droits de l'homme en général et le droit de personnes handicapées en particulier. Les institutions d'enseignement supérieur de la sous-région ne disposent point des centres de recherche se consacrant exclusivement aux droits de personnes handicapées.

10 Branches gouvernementales

10.1 Avez-vous de(s) branche(s) gouvernementale(s) spécifiquement chargée(s) de promouvoir et protéger les droits et le bien-être des personnes handicapées? Si oui, décrivez les activités de cette (ces) branche(s).

L'action publique en faveur des handicapés demande l'implication de plusieurs départements ministériels. Ainsi, le Ministère de l'Education Nationale et de la Formation Professionnelle s'efforce de faciliter pour les élèves handicapés l'accès à

l'éducation. Le Ministère de la Femme et de la Famille intervient dans la protection des enfants handicapés. Le Secrétariat d'Etat chargé des Affaires Sociales (SEAS) dirigée par Mme Mouna Osman Aden, joue un rôle de plus en plus prépondérant dans l'assistance et la protection de personnes handicapées. A ce titre, le SEAS, en partenariat avec le Réseau National de Personnes Handicapées (RNPH) a organisé un Atelier de Réflexion sur le Handicap du 21 au 23 Mai 2017. Parmi les recommandations figurent la mise en place d'une institution ou agence placée sous la tutelle du SEAS chargé de la protection de personnes handicapées ainsi qu'un mécanisme multisectoriel de coordination des politiques publiques en faveur de personnes handicapées.

11 Préoccupations majeures des droits de l'homme relatives aux personnes handicapées

11.1 Quels sont les défis contemporains des personnes handicapées en République de Djibouti? (exemple: Certaines régions d'Afrique pratiquent des tueries rituelles de certaines catégories de personnes handicapées telles que les personnes atteintes d'albinisme. A cet effet La Tanzanie est aux avant-postes. Nous devons remettre en cause les pratiques coutumières qui discriminent, blessent et tuent les personnes handicapées.

L'accès aux soins des personnes ayant un handicap mental constitue un défi majeur compte tenu du manque de personnel qualifié en psychiatrie. Pour une population estimée à environ un million de personnes, il n'y a qu'un seul médecin psychiatre qui exerce dans le seul service spécialisé de l'hôpital général Peltier situé dans la capitale. De plus, une nouvelle grille tarifaire prohibitive portant sur les soins hospitaliers constitue également un sérieux entrave à l'accès aux soins. Cela encouragerait les familles de ces personnes souffrant de déficience mentale de se tourner vers les thérapies traditionnelles. Il est fréquent aussi de voir de personnes souffrant de troubles psychiques vivant reclus et enchaînés dans leur chambre.

Le taux de pauvreté extrême et relative sont évalués respectivement 41,9% et 79,4%.³⁴ La pauvreté extrême affecte spécifiquement les groupes vulnérables comme les personnes handicapées. Ces derniers pour la plupart vivant de la mendicité, dorment dans la rue ou squattent les locaux du siège de l'association Vivre Plus Fort. C'est pour cette raison que les associations de personnes font un travail de plaidoyer auprès des pouvoirs publics et des fédérations des employeurs pour le recrutement de personnes handicapées.

La mobilité constitue un autre défi majeur pour ces personnes vulnérables. Plusieurs ont mis en exergue la difficulté de se procurer à titre gracieux de fauteuils roulants, unique moyen de locomotion dans la mesure où les transports en commun refusent de transporter les usagers handicapés. Ils prétextent que leurs bus n'ont pas de rampe d'accès pour les fauteuils roulants ou que les handicapés

34 DiSED, Profil de la pauvreté en République de Djibouti, Septembre 2012 p7. https://www.humanitarianresponse.info/system/files/documents/files/Profil%20de%20la%20pauvret%C3%A9%2012_Draft4.pdf.

mettent du temps pour monter ou descendre. Il arrive parfois que le fauteuil roulant d'une personne décédée soit récupéré par un autre handicapé.

11.2 Comment la République de Djibouti répond-t-il aux besoins des personnes handicapées au regard des domaines ci-dessous énumérés?

• Accès aux bâtiments publics

Rare sont les bâtiments publics disposant de rampes d'accès pour les fauteuils roulants. A ce titre, le Président de l'association ADDA avait interpellé le Président de la République sur cette question de l'accessibilité aux bâtiments publics et ce, lors du séminaire de l'Action Gouvernementale en 2009. Désormais, l'obtention du permis de construire pour tous les ouvrages publics est conditionnée à la prise en considération de l'accessibilité.³⁵

• Accès au transport public

En République de Djibouti, le système de transport public est inexistant. Le système de transport en commun en vigueur se limite aux bus et minibus appartenant à des particuliers travaillant à leur propre compte. Ces derniers choisissent à leur guise leur itinéraire en fonction de sa rentabilité. Certains quartiers de la banlieue de la capitale sont très mal desservis. De plus, les chauffeurs de bus et minibus circulant dans la capitale refusent systématiquement de transporter les personnes handicapées car n'étant pas équipés de rampe d'accès pour les fauteuils roulants. Cette discrimination en matière de transport pourrait être remédiée en cas de mise en place d'un système de transport public accessible aux personnes handicapées.

• Accès à l'éducation

Conformément aux recommandations des Etats Généraux de l'Education de 1999, La Loi d'Orientation du Système Educatif³⁶ édicté en 2000, proclame en son article 4 le droit à l'éducation pour tous les citoyens. La scolarisation est également rendu obligatoire pour les enfants âgés de 6 à 16 ans (Article 14). La gratuite de l'enseignement fondamental est garanti (Article 16). Toutefois, les parents ayant à leur charge des enfants handicapés ne pouvant poursuivre un cursus normal sont exemptés de l'obligation scolaire (Article 4). Ce texte législatif adopté avant l'adhésion de Djibouti à la CDPH ne mentionne pas explicitement la mise en place d'un cursus scolaire adapté aux personnes handicapées ni leur scolarisation dans les structures ordinaires. Toutefois, les parents souhaitant scolariser leurs enfants handicapés dans le cursus ordinaire rencontrent des difficultés pour les inscrire. Certains directeurs d'école arguant que les bancs de l'école ne sont pas adaptés pour les enfants handicapés. Cependant, cette lacune sera en partie remédiée par le décret du 12 mai 2011 portant création d'un service de la scolarisation des enfants à besoins spéciaux. Ce service est désormais opérationnel et il est dirigé par une personne non voyante en l'occurrence, le président de l'association ADDA. Ainsi, on peut noter la mise en place dans la capitale de deux structures éducatives adaptées aux enfants vivant avec un handicap. La première structure fondée en 2013 est située dans un bâtiment contiguë au siège de la commune de Ras Dika et accueille, 30 enfants malvoyants et 15 enfants atteints de retard mental congénital. La seconde structure fondée en 2004, est implantée dans les locaux. Du Centre de Protection de l'Enfance et accueille un total de 119 enfants. A Ali Sabieh, deux structures privées offrent un cursus adapté aux enfants trisomiques et les enfants sourds, accueillant un effectif total de 50 enfants.

35 Rapport initial et périodique de la République de Djibouti, p14. Voir ci-dessus n9.

36 Site officielle de la Présidence de la République de Djibouti <http://www.presidence.dj/texte.php?ID=96&ID2=2000-08-10&ID3=Loi&ID4=15&ID5=2000-08-15&ID6=n>.

- **Accès à la formation professionnelle**

La formation professionnelle est du ressort le Centre de Formation Professionnelle pour les adultes (CFPA). Autrefois, le CFPA était sous la tutelle du Ministère du Travail mais depuis 2011, il est dans les attributions du Ministère de l'éducation de Nationale et de la Formation Professionnelle. Le CFPA n'a pas ce jour, mis en place un programme de formation destiné aux personnes handicapées.

- **Accès à l'emploi**

Le taux de chômage est estimé à plus 60% de la population active.³⁷ Les personnes handicapées appartenant à la frange de la population la plus favorisée touchée par le chômage de masse. Le code du travail djiboutien de 2006 consacre en son article 17 le principe de non-discrimination en matière d'emploi. L'article 18 du code du travail définit le travailleur handicapé comme « toute personne dont les possibilités d'obtenir ou de conserver un emploi, sont effectivement réduites par suite d'une insuffisance ou d'une diminution de ses capacités physiques ou mentales ». Toutefois, il faut reconnaître que le code du travail édicté avant la ratification de la CDPH ne proclame pas le droit au travail de personnes handicapées consacré par l'article 27 de la CDPH. L'article 119 du code du travail prévoit la mise en place des mesures incitatives en cas de recrutements de travailleurs handicapés sauf que les décrets fixant les modalités d'application n'ont pas été encore édictés.

- **Accès à la détente et au sport**

La Fédération Djiboutienne d'Handisport est l'institution qui se charge d'offrir aux personnes handicapées des activités sportives de loisirs ou de compétitions. Cette fédération encourage ses adhérents à participer aux compétitions internationales comme les jeux para-olympiques. Le Secrétariat d'Etat à la jeunesse et aux sports met à la disposition des athlètes handicapés les infrastructures sportives publiques. Les activités culturelles sont restreintes dans la mesure où il n'y a plus dans la capitale aucune salle de cinéma, depuis la fermeture du Cinéma Odéon.

- **Accès à la justice**

Les personnes handicapées appartiennent à la frange de la population vivant dans la précarité. Ainsi, l'accès effectif de personnes handicapées à la justice mérite une attention particulière. Outre, l'accessibilité des tribunaux, l'aide juridictionnelle permettra aux personnes handicapées de saisir plus souvent les juridictions internes. L'aide juridictionnelle était limité auparavant aux affaires criminelles, il aura fallu attendre la loi de 2011³⁸ qui permet aux justiciables sans revenu de bénéficier d'une prise en charge partielle ou totale par l'Etat des honoraires d'avocats ou d'huissiers, à toutes les stades des procédures et ce, devant toutes les juridictions. En pratique, la procédure d'obtention de l'aide judiciaire est trop longue dans la mesure où le justiciable désirant bénéficier de l'aide judiciaire doit adresser une demande au Bureau d'aide judiciaire, dirigé par le Président de la Cour Suprême ou par un haut magistrat nommé par lui.

- **Accès aux soins de santé**

La loi du 3 juillet 1999 portant orientation de la politique de la santé et la loi du 05 juillet 2014 portant mise en place d'un système d'assurance maladie universelle prévoient de mesures spécifiques aux personnes handicapées et autres groupes vulnérables. Ainsi, l'article 3 de cette loi tout en mettant fin à la gratuité de soins de santé en vigueur, prévoient en même temps une obligation d'assistance en matière de soins aux personnes handicapées et autres groupes vulnérables. En outre, l'adoption de la loi sur l'Assurance maladie universelle (AMU) permet aux personnes handicapées de la gratuité de frais de consultations à travers le

37 Paul Roba, "Djibouti: Quelle situation politique" Note n° 287 - Fondation Jean-Jaurès - 20 novembre 2015 p3 <https://jean-jaures.org/sites/default/files/note-287.pdf>.

38 Loi n°136/AN/11/6ème L relative à l'aide judiciaire. <http://ilo.org/dyn/natlex/docs/ELECTRONIC/87845/100274/F745038514/DJI-87845.pdf>.

Programme d'Assurance Sociale de Santé. Cependant, les consultations en imagerie médicale comme l'échographie, la fibroscopie, le scanner ne sont pas pris en charge.³⁹ L'accès aux médicaments et l'hospitalisation à l'Hôpital Général Peltier (l'unique centre hospitalier de référence) ne sont pas également pris en charge même avec la carte de l'AMU.

11.3 La République de Djibouti accorde-t-il des subventions pour handicap ou autre moyen de revenue en vue de soutenir les personnes handicapées?

Quelques actions ponctuelles de distribution de denrées de première nécessité sont fournies aux personnes handicapées surtout lors du mois du Ramadan.

Cependant, il faudrait indiquer la subvention mensuelle de 15000Fd (85USD), accordé pas le Secrétariat d'Etat aux Affaires Sociales aux étudiants présentant un handicap moteur inscrits à l'Université de Djibouti.

11.4 Les personnes handicapées ont-elles un droit de participation à la vie politique (représentation politique et leadership, vote indépendant etc.) de la République de Djibouti?

Effectivement, l'article 5 de la constitution djiboutienne garantit à tous les citoyens djiboutiens majeurs (y compris les personnes handicapées), la libre jouissance de leurs droits civiques et politiques. La République de Djibouti a également ratifié en 2002, le Pacte International sur les Droits Civiles et Politiques qui accorde à tout citoyen le droit de jouir pleinement et sans discriminations de droits civiles et politiques.

Concernant la représentation politique, il y a lieu de constater que les personnes handicapées ne sont pas encore représentées au gouvernement mais on peut noter toutefois, l'élection d'un parlementaire non affilié à un OPH. Il s'agit précisément de Mr Abdillahi Bilal Kidar, un handicapé moteur équipé d'une prothèse, qui siège à l'Assemblée Nationale sans discontinuer depuis les élections législatives de 2003 soit 3 législatures (2003, 2008 et 2013).

11.5 Catégories spécifiques expérimentant des questions particulières/vulnérabilité:

• Femmes handicapées

Outre les garanties constitutionnelles et conventionnelles (Convention sur l'élimination de toutes les formes de discrimination à l'égard de Femmes, le Protocole de Maputo) portant sur la protection juridique des femmes en général, l'Etat partie n'a pas entrepris de mesures spécifiques protégeant les femmes handicapées.

• Enfants handicapés

La république de Djibouti a ratifié les instruments régionaux et internationaux relatif aux droits de l'enfant mais l'Etat partie n'a pas édicté une législation spécifique protégeant le droit des enfants handicapés. Cependant, le décret du 12 mai 2011 relatif à la création d'un service de scolarisation des enfants à besoins spéciaux a permis d'organiser de journées de sensibilisation sur l'éducation des

39 Article 22 Loi du 5 Janvier 2014 sur l'Assurance Maladie Universelle. Voir ci-dessus n24

enfants handicapées. La loi sur l'assurance maladie universelle permet une prise en charge médicale basique des enfants handicapés.

• **Prisonniers souffrant de déficience mentale**

Il existe de prisonniers mâles et femelles incarcérés à la prison civile de Gabode et souffrant de troubles psychiatriques. La prison dispose d'un personnel paramédical ainsi qu'un médecin généraliste affecté par la Ministère de la Santé sur la base d'un système de rotation. A ce jour, la prison ne dispose pas d'un médecin généraliste affecté à titre permanent.

Ainsi, ces prisonniers ne disposent pas de soins appropriés en raison du déficit en personnel qualifié en psychiatrie ou psychologie au sein de l'institution carcérale. Rappelant qu'il n'y a dans l'ensemble du pays qu'un seul médecin spécialisé en psychiatrie officiant dans le seul service de psychiatrie de l'Hôpital General Peltier (Hôpital de référence) situé dans la capitale. Enfin, la construction d'un hôpital psychiatrique est nécessaire pour prendre en charge tous les patients car le service spécialisé de l'hôpital Peltier ne dispose pas de places suffisantes pour les accueillir.

12 Perspective future

12.1 Y'a-t-il des mesures spécifiques débattus ou prises en compte présentement en République de Djibouti au sujet les personnes handicapées?

Lors du dernier Atelier de Réflexion sur le Handicap du 21-23 Mai 2017, plusieurs recommandations ont été formulées:

- Effectuer un recensement général sur les personnes handicapées.
- Mettre en place un mécanisme multisectoriel de coordination sur le handicap.
- Mettre en place une institution ou agence au sein du Secrétariat d'Etat chargé spécifiquement de promouvoir le droit des personnes handicapées.
- Célébrer une Journée Nationale du Handicapé Djiboutien et la création d'un Grand Prix du Chef de l'Etat sur les droits des personnes handicapés.
- Mettre en place de programmes de formation professionnels en faveur des handicapés.
- Former des formateurs spécialisés en langage de signe ou en braille.
- Favoriser la scolarisation des enfants souffrants de déficience mentale âgés de plus 16 ans
- Créer des structures éducatives spécialisées dans les 5 régions du pays.
- Favoriser la délivrance de cartes d'assurance maladie pour tous les handicapés.
- Favoriser la délivrance d'un carte d'invalidité assurant la gratuite de soins aux personnes handicapées.
- Assurer une formation aux professionnels de la sante dans la prise en charge spécifique de personnes handicapées
- Faciliter l'insertion professionnelle de personnes handicapées par la mise en place au sein de l'Agence Nationale de l'Emploi et de la Formation Professionnelle (ANEFIP) d'un bureau d'orientation en faveur de demandeurs d'emplois handicapés.
- Mettre en place un programme de micro-crédits ciblant les personnes handicapées désireux de créer une activité génératrice de revenu.

- Réaliser la mise en circulation de moyens de transport publics adaptés aux personnes handicapées.
- Sanctionner les chauffeurs de bus refusant de transporter les personnes handicapées
- Prévoir un quota pour l'accès aux logements sociaux en faveur des handicapés.
- Améliorer l'accessibilité aux bâtiments de l'administration, aux écoles et aux lieux de culte.

12.2 Quelles réformes légales sont proposées? Quelle réforme légale aimeriez-vous voir en République de Djibouti? Pourquoi?

En premier, il faudrait souligner l'existence d'un projet de décret⁴⁰ fixant un quota de recrutement de travailleurs handicapés en fonction de la taille de l'entreprise. Pour les entreprises employant un effectif compris entre 50 à 100 employés, le quota est fixe à 1%. Pour les entreprises employant un effectif compris entre 100 à 500 employés, le quota est fixe à 3%. Enfin, pour les entreprises ayant un effectif de plus de 500 employés, le quota est fixe à 5%.

- Ce projet de décret a été négocié entre les associations d'employeurs, les OPH ainsi que le syndicat des travailleurs. En cas d'adoption, ce texte réglementaire qui n'est pas encore en vigueur, aura certainement un effet bénéfique sur l'insertion professionnelle de travailleurs handicapés.
- Le code du travail en vigueur depuis 2006 mérite d'être amendé pour inclure des dispositions pertinentes sur les travailleurs handicapés et qui soient en conformité avec la CDPH.
- Eu égard au droit de participation politique des personnes handicapés, l'Etat partie devrait adopter un texte législatif favorisant la participation politique de personnes souffrant de déficience mentale.
- Dans le cadre de la mise en œuvre de la CDPH, l'Etat partie se doit de mettre en place une législation ambitieuse sur la question du handicap.
- L'Etat serait bien inspirée de légiférer en matière d'accès à la santé pour les personnes handicapées, en assurant la prise en charge gratuite de l'intégralité de frais médicaux (Consultations, examens complémentaires, hospitalisations; appareils orthopédiques, visuelles ou auditives, et médicaments etc.).
- La loi sur l'aide juridique devrait être amendée en vue de garantir explicitement la gratuité totale de tous les frais d'honoraires, d'huissiers ou d'expertises, pour les recours exercés par les personnes handicapées.
- Il serait loisible pour l'Etat partie de mettre en place une législation spécifique sur l'accès à l'éducation des enfants handicapés.
- Enfin, un texte réglementaire doit être édicté obligeant les promoteurs immobiliers à considérer l'accessibilité aux personnes handicapés pour tous les ouvrages publics.
- Il faudrait souligner que le Secrétariat d'Etat aux Affaires Sociales a entrepris de travaux d'élaboration de projets de lois et décrets en vue de mettre en conformité la législation interne avec les dispositions de la CDPH. Mais avant d'engager de réformes légales majeures sur la question, Il serait opportun d'attendre les observations finales et les recommandations du Comité du droit de personnes handicapées relatif au rapport initial de Djibouti.

40 Rapport initial et périodique de la République de Djibouti p31. Voir ci-dessus n9.

MADAGASCAR

*Isambilo Rabearison-Andrianjara**

1 Les indicateurs démographiques

1.1 Quelle est la population totale de Madagascar?

D'après l'INSTAT (Institut National de la statistique), en réponse à notre demande d'information au mois de juillet 2017, la population totale de Madagascar en 2016 est de 23 069 758, (vingt-trois millions soixante-neuf mille sept cent cinquante-huit).

1.2 Méthodologie employée en vue d'obtenir des données statistiques sur la prévalence du handicap à Madagascar. Quels sont les critères utilisés pour déterminer qui fait partie de la couche des personnes handicapées à Madagascar?

A l'heure actuelle aucune information n'est disponible à ce sujet car il n'y a pas de statistique officielle concernant les personnes handicapées à Madagascar.

En 2003, le Ministère de la Santé a effectué une enquête sur le handicap mais les chiffres fournis reposent sur des estimations. Comme le dernier recensement général date de 1993 les statistiques actuelles peuvent être biaisées. Il convient donc de traiter les chiffres disponibles avec beaucoup de précaution.

Pour information, le prochain recensement général inclura le handicap. La Plateforme des Fédérations des Personnes Handicapées de Madagascar (PFPH/MAD) a déjà été consultée sur ce point.

Selon la loi 97/044 du 02/02/98, Art. 2- L'expression « Personne handicapée » désigne toute personne qui présente une déficience congénitale ou acquise dans ses capacités physiques ou mentales et qui l'empêche d'assurer personnellement tout ou partie des nécessités d'une vie individuelle ou sociale normale.

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Quatre types de handicap sont officiellement reconnus à Madagascar:

- visuel
- auditif
- moteur
- psychique

Récemment, l'autisme auparavant assimilé au handicap psychique a été reconnu de manière consensuelle par les organismes malgaches concernés comme étant un type de handicap à part entière, c'est donc le cinquième.

1.3 Quel est le nombre total et le pourcentage des personnes handicapées à Madagascar?

Le Rapport mondial sur le handicap (2011) estime la prévalence des personnes en situation de handicap à 15%¹ à Madagascar soit 3 535 800 habitants en valeur absolue.

1.4 Quel est le nombre total et le pourcentage des femmes handicapées à Madagascar?

Nombre inconnu

1.5 Quel est le nombre total et le pourcentage des enfants handicapés à Madagascar?

Nombre total inconnu, estimation: 505.181, prévalence 5,5%.²

1.6 Quelles sont les formes de handicap les plus répandues à Madagascar?

La forme la plus répandue est le handicap visuel, prévalence 3,1%, vient ensuite le handicap moteur 2,8%, handicap auditif 1,8%, handicap mental 1,5% et handicap psychique 0,17%, par rapport à la population totale.³

2 Obligations internationales

2.1 Quel est le statut de la Convention des Nations Unies relative aux Droits des Personnes Handicapées (CDPH) à Madagascar? Madagascar a-t-elle signé et ratifié la CDPH? Fournir le(s) date(s). Madagascar a-t-elle signé et ratifié le Protocole facultatif?

La convention des Nations Unies relative aux droits des personnes handicapées a été signée le 25 septembre 2007. La loi autorisant sa ratification a été adoptée le 10

1 <http://www.amprmada.org/pages/congres/resumes-des-communications/page.html#7ozicjPFk2mZVRh0.99>.

2 Selon SITAN Book (2014) 95.

3 Voir Enquête MINSANP/OMS 2003).

Décembre 2014 et le dépôt d'instrument à la ratification a été effectué le 12 juin 2015 (loi 2014-031).⁴

La signature du protocole facultatif de la CDPH est en attente de la prochaine session ordinaire de cette année (2017).

2.2 Si Madagascar a signé et ratifié la CDPH, quel est/était le délai de soumission de son rapport? Quelle branche du gouvernement est responsable de la soumission du rapport? Madagascar a-t-il soumis son rapport? Sinon quelles sont les raisons du retard telles qu'avancées par la branche gouvernementale en charge?

Pour le rapport malgache, il faut se référer à l'article 35 de la Convention « chaque Etat partie présente ... un rapport détaillé ... dans un délai de 2 ans à compter de l'entrée en vigueur de la Convention pour l'Etat partie intéressé. Les Etats Parties présentent ensuite des rapports complémentaires au moins tous les 4 ans, et tous les autres rapports demandés par le Comité ».

Le comité interministériel de rédaction de rapport des droits de l'homme dirigé par le Ministère de la justice se charge de la rédaction du rapport. Le comité est composé du ministère des affaires étrangères, du ministère de la Justice, Police, Ministère de la santé, Min. Population, Ministère de l'Education nationale, ministère de la fonction publique, gendarme, ministère de la culture, Ministère de l'économie, Ministère des finances, Ministère de l'emploi, Ministère chargé de l'intérieur, avec les membres (4 représentants) de la société civile.

Madagascar est actuellement dans la phase de rédaction du rapport initial et envisage de le déposer cette année. Le délai de soumission du rapport initial étant de deux ans après la ratification, Madagascar est encore dans les temps.

2.3 Si Madagascar a soumis le rapport au 2.2 et si le comité en charge des droits des personnes handicapées avait examiné le rapport, veuillez indiquer si le comité avait émis des observations finales et des recommandations au sujet du rapport de Madagascar. Y'avait-il des effets internes découlant du processus de rapport liés aux questions handicapées à Madagascar?

Le rapport n'a pas encore été soumis.

Madagascar n'a pas encore de comité en charge des droits des personnes handicapées, le personnel de la direction des personnes handicapées du Ministère de la Population a émis des observations finales et des recommandations.

Ces effets internes le Ministère de la population cite, l'existence des programmes nationaux des personnes handicapées à Madagascar et la mise œuvre du programme de l'éducation inclusive.

2.4 En établissant un rapport sous divers autres instruments des Nations Unies, la Charte Africaine des Droits de l'Homme et des Peuples ou la Charte Africaine relative aux Droits et au bien-être de l'Enfant, Madagascar a-t-il également fait mention spécifique du droit des

4 cf (visite le 1 Juillet 2017).

personnes handicapées dans ses rapports les plus récents? Si oui, les observations finales adoptées par les organes statutaires ont-elles fait mention du handicap? Si pertinent, ces observations ont-elles été suivies d'effet? Etait-il fait mention des droits des handicapés dans le rapport de la Revue Périodique Universelle (RPU) des Nations Unies de votre Etat? Si oui, quels étaient les effets de ces observations ou recommandations?

Oui, les droits des personnes en situation de handicap sont mentionnés dans la Rapport Periodic Universel au point Q de la page 24.

2.5 Y'avait-il un quelconque effet interne sur le système légal de Madagascar après la ratification de l'instrument international ou régional au 2.4 ci-dessus?

La ratification de la CIDH devait s'assortir de la mise à jour du cadre légal (loi 97-044, son décret d'application et les 6 arrêtés) mais à ce jour cela n'a pas encore été fait.

2.6 Les traités internationaux ratifiés deviennent-ils automatiquement loi nationale sous votre système légal? Si oui y'a-t-il des cas où les cours et tribunaux appliquent directement les dispositions du traité international?

Oui, les cours et tribunaux peuvent directement appliquer les dispositions du traité international.

Selon l'article 137 de la Constitution: les traités ou accords régulièrement ratifiés ou approuvés ont, dès leur publication, une autorité supérieure à celle des lois, sous réserve, pour chaque accord ou traité, de son application par l'autre partie.

La loi 2014-031 autorisant la ratification de la CNDH est exécutée comme loi de l'Etat. La CNDH s'intègre donc automatiquement dans l'ordonnancement juridique interne.

2.7 En référence au 2.4 ci-dessus, la Convention des Nations Unies relative aux Droits des Personnes Handicapées CDPH ou tout autre instrument international ratifié, en tout ou en partie, a-t-il été incorporé textuellement dans la législation nationale? Fournir les détails.

Oui, dans la loi 2014-031 pour la CNDH, la Convention a été intégralement annexée à cette loi.

3 Constitution

3.1 La constitution de Madagascar contient-elle des dispositions concernant directement le handicap? Si oui énumérez les dispositions et expliquez comment chacune d'elles traite du handicap.

Le mot « handicap » ne figure pas une seule fois dans la Constitution.

3.2 La constitution de Madagascar contient-elle des dispositions concernant indirectement le handicap? Si oui énumérez les dispositions et expliquez comment chacune d'elles traite indirectement du handicap.

Il est juste mentionné dans le Préambule que « Madagascar...faisant siennes...la Charte internationale des droits de l'homme...l'élimination de toutes les formes d'injustice, de corruption, d'inégalité et de discrimination. »

4 Législation

4.1 Madagascar a-t-elle une législation concernant directement le handicap? Si oui énumérez la législation et expliquez comment la législation aborde le handicap.

Oui, loi 97-044 du 02 Février 1998 régissant les droits des personnes handicapées, son décret d'application et ses six arrêtés.

L'AFHAM, Association des Femmes Handicapées de Madagascar, a demandé à ce qu'une étude⁵ soit faite sur l'intégration professionnelle des Personnes En Situation de Handicap à Madagascar, menée par Madame Ketakandriana RAFITOSON.

Une partie de cette étude, répond à ses questions et sera donc retranscrite ici.

• La loi n°97-044:

Cette loi, promulguée en 1998, constitue le fondement du cadre légal régissant les droits des personnes handicapées à Madagascar. Elle comporte deux grands titres et plusieurs chapitres traitant, entre autres, des droits à la santé, des droits à l'éducation, des droits à la formation et à l'emploi et des droits sociaux des personnes handicapées.

En règle générale, les dispositions de la loi n°97-044 respectent les recommandations des textes internationaux. Un rôle prépondérant y est donné à l'Etat qui « incite », « favorise », « encourage » la promotion et la réalisation des droits des personnes en situation de handicap, et « assure » la prise de certaines

5 Rafitson K. *Etude sur l'intégration professionnelle des personnes en situation de Handicap à Madagascar*, 2016, AFHAM.p27.

mesures y liées. Même si l'utilisation du verbe « devoir » (en parlant de l'Etat) est largement plus fréquent dans le chapitre sur les droits à la formation et à l'emploi que dans les autres chapitres, l'impression générale dégagée par cette loi est qu'elle énonce des vérités générales dépourvues d'un véritable et sincère engagement en faveur des personnes en situation de handicap.

Le manque de concrétisation des mesures énoncées dans ce chapitre, mais aussi dans l'ensemble de la loi traduit ce manque flagrant de volonté politique. Les PESH elles-mêmes, interrogées au cours d'un atelier d'évaluation des impacts de la loi organisé par le Centre Sembana Mijoro (CSM) en 2009, trouvent que l'existence de ce texte n'a pas vraiment changé leur situation, même si elles reconnaissent qu'il a permis une évolution sensible de l'opinion publique et de la mentalité malgache à leur propos."

• **Le décret d'application:**

Ce décret porte application de la loi n°97-044 du 02 février 1998 et il est supposé marquer un engagement plus vif de l'Etat et de ses partenaires dans la protection et la promotion des droits des personnes handicapées à Madagascar.

Tout comme pour la loi, l'utilisation des termes « favorise », « peut », ou encore « encourage » ne reflète pas un réel engagement des autorités concernées en faveur de la protection et de la réalisation des droits des PESH.

Les dispositions relatives à l'éducation n'échappent pas à cette formulation évasive. L'un des exemples les plus frappants de ce manque d'engagement est l'article 19 du décret qui stipule que « L'éducation des personnes handicapées fait partie intégrante du système éducatif national, pouvant nécessiter la mise en place d'aménagements spécifiques à leur accueil, suivant les possibilités. » Il serait logique que l'Etat prenne des mesures concrètes et fasse, au nom de l'égalité des chances et des droits entre tous les citoyens, de l'accès des personnes handicapées à l'éducation une priorité, au même titre que le combat qu'il mène pour la scolarisation des personnes valides. L'article cité pose pourtant des limites claires quant aux actions que l'Etat pourrait prendre et il peut être supposé que l'appareil étatique justifiera toujours son manque de résultats en matière d'intégration scolaire des personnes handicapées par un manque de possibilités financières – ce qui serait exclu si la volonté politique se transformait en budgétisation, puis en programme.

En un mot, une révision de ce décret d'application doit aussi être programmée après l'harmonisation de la loi n°97-044 avec la CIDPH."

• **Les arrêtés interministériels:**

Il existe actuellement 6 arrêtés interministériels portant sur les droits des personnes handicapées à Madagascar. Il s'agit de:

- l'arrêté n° 23144/2004 du 2 décembre 2005 portant application des droits des personnes handicapées dans le domaine éducatif ;
- l'arrêté n° 23145/2004 du 27 décembre 2004 portant application des droits des personnes handicapées aux formations professionnelles et professionnalisantes ;
- l'arrêté n° 24665/2004 du 27 décembre 2004 portant application des droits des personnes handicapées en matière de santé ;
- l'arrêté n° 24666/2004 du 27 décembre 2004 portant application de la carte d'invalidité pour les personnes handicapées ;
- l'arrêté n° 24667/2004 du 27 décembre 2004 portant application des droits des personnes handicapées dans le domaine de l'emploi et du travail ;
- l'arrêté n° 24668/2004 du 27 décembre 2004 portant application des droits sociaux des personnes handicapées.

Même si les arrêtés interministériels pris en application de la loi n^o97-044 ont introduit dans la vie des PESH malgaches quelques changements mineurs – comme la possibilité d'utilisation de la carte d'invalidité dans les transports en commun dans certaines villes, il reste beaucoup à faire pour améliorer leur situation de façon radicale."

4.2 Madagascar a-t-elle une législation concernant indirectement le handicap? Si oui énumérez la principale législation et expliquez comment elle réfère au handicap.

Plusieurs législations malgaches intègrent la question du handicap. On pourrait cependant citer la loi n^o2003-044 du 28 juillet 2004 portant Code du Travail qui dans son chapitre III traite des Conditions particulières de travail de certaines catégories de travailleurs, à savoir les femmes, les enfants et les personnes handicapées.

« Article 105.- Aucune discrimination ne peut être faite en matière de travail ou d'emploi à égalité de capacité et d'aptitude entre les personnes valides et les personnes handicapées du fait de leur handicap. Les personnes handicapées ont droit au travail et à l'emploi, à l'égalité de chance et de traitement en matière d'apprentissage, de formation professionnelle et d'emploi.

Article 106.- Les personnes handicapées doivent jouir de toutes les infrastructures existantes, qu'elles soient publiques ou privées, en matière d'apprentissage et de formation professionnelle.

Article 107.- Toute entreprise ayant embauché un certain nombre de personnes handicapées bénéficie des mesures incitatives fixées par Décret pris après avis du Conseil National du Travail.

Article 108.- Il est créé auprès du Ministère chargé du Travail, une Institution chargée d'assurer la réinsertion professionnelle des personnes handicapées.

Article 109.- Un Décret pris après avis du Conseil National du Travail détermine la mission, l'organisation et le fonctionnement de ladite institution. »

5 Décisions des cours et tribunaux

Les cours (ou tribunaux) à Madagascar ont-ils jamais statué sur une question(s) relative au handicap? Si oui énumérez le cas et fournir un résumé pour chacun des cas en indiquant quels étaient les faits ; la (les) décision(s), la démarche et l'impact (le cas échéant) que ces cas avaient entraînés.

Selon le Collectif des Organisations des Personnes Handicapées et l'Association des Femmes Handicapées de Madagascar les tribunaux à Madagascar n'ont pas encore statué sur une question relative au handicap. Aucun cas ne leur a été présenté donc aucune décision.

Il faut cependant noter que les procédures exclues les personnes handicapées comme la difficulté d'avoir un interprète en langue des signes ou la difficulté pour les enquêteurs face à un sourd.

6 Politiques et programmes

6.1 Madagascar a-t-elle des politiques ou programmes qui englobent directement le handicap? Si oui énumérez la politique et expliquez comment cette politique aborde le handicap.

Oui, le Plan National d'Inclusion du Handicap (PNIH) pour la période de 2015-2019 dont l'objectif est d'accroître la participation sociale des hommes, femmes et enfants en situation de handicap dans le respect de leurs droits. Ce plan, signé en mars 2015, est un outil de programmation et un cadre de référence des interventions dans le domaine du handicap et vise à faciliter la mise en œuvre effective de la CIDPH. La mise en œuvre de ce plan – qui se base sur six axes sectoriels, à savoir, l'accès à l'éducation, la santé, l'emploi, le travail, les droits sociaux ainsi que l'accessibilité aux infrastructures et services de base – contribue à une meilleure autonomisation des personnes en situation de handicap, d'une moindre dépendance vis-à-vis de leurs familles et de la communauté; de lutter contre la pauvreté afin qu'elles contribuent au développement économique et socioculturel du pays.⁶ »

6.2 Madagascar a-t-elle des politiques ou programmes qui englobent indirectement le handicap? Si oui énumérez chaque politique et décrivez comment elle aborde indirectement le handicap.

Oui, un programme et deux politiques méritent d'être cités:

Le Programme Pays pour le Travail Décemment (PPTD) 2015-2019 dont le protocole a été signé 07 le Mai 2015, aborde le handicap sous l'angle de l'emploi. L'article 2, pose les deux axes prioritaires du PPTD: « Priorité 1: Favoriser l'accès des groupes vulnérables à l'emploi par le renforcement de leur employabilité et par la dynamisation des secteurs générateurs d'emploi. Priorité 2: Améliorer la productivité du travail par la promotion du dialogue social, le droit du travail et la sécurité sociale. » Le programme cible en priorité les groupes identifiés comme vulnérables⁷, incluant les enfants, les travailleurs de l'agriculture et de l'économie informelle, les personnes en situation de handicap, les chômeurs, les travailleurs de l'industrie extractive et du secteur maritime, et spécialement les jeunes et les femmes.⁸

La Politique Nationale de l'Emploi et de la Formation Professionnelle (PNEFP) promulguée en septembre 2015, englobe le handicap de manière transversale. En effet, la marginalisation des personnes en situation de handicap dans le secteur du travail est la conséquence directe d'un accès limité à l'enseignement et à la formation d'où les dispositions prises au sein de la PNEFP. Tout d'abord « La PNEFP, au regard des inégalités économiques et sociales, devra proposer des mesures permettant non seulement de les réduire mais surtout de les

6 Rafitson K. *Etude sur l'intégration professionnelle des personnes en situation de Handicap à Madagascar*, 2016, AFHAM. p38.

7 La vulnérabilité des sujets est mesurée à l'aide de trois principaux critères: l'exposition aux risques ou chocs, la sensibilité aux risques ou chocs, et la résilience, c'est-à-dire la capacité de retrouver la situation d'avant le choc.

8 Rafitson K. *Etude sur l'intégration professionnelle des personnes en situation de Handicap à Madagascar*, 2016, AFHAM. p34.

supprimer. Il s'agira notamment de : favoriser la redistribution des fruits de la croissance ; assurer l'accès à l'ETFP à toutes les couches sociales ; et favoriser l'embauche/emploi des personnes en situation de vulnérabilité (jeunes, femmes, personnes en situation de handicap, etc.). » Ensuite, selon « Les principes directeurs de la mise en œuvre de la PNEFP: vers une transformation socioéconomique du pays », il est affirmé que « La PNEFP doit améliorer l'accès et l'équité pour les groupes les plus marginalisés et notamment les jeunes dans les zones rurales, les personnes en situation de handicap et autres groupes vulnérables. »

La Politique Nationale de Prévoyance Sociale (PNPS) officiellement lancée en septembre 2015, dont l'objectif est de « Réduire de 15% le nombre de la population en situation d'extrême pauvreté. » traite du handicap parmi les cibles prioritaires de ses 4 axes stratégiques à savoir: l'augmentation du revenu des plus pauvres, l'amélioration de l'accès aux services sociaux de base, la protection et la promotion des droits des groupes spécifiques à risques et la consolidation progressive du régime contributif.

7 Organismes en charge des personnes handicapées

7.1 En dehors des cours ou tribunaux ordinaires, Madagascar a-t-elle un organisme officiel qui s'intéresse spécifiquement de la violation des droits des personnes handicapées? Si oui décrire l'organe, ses fonctions et ses pouvoirs.

C'est la Commission Nationale Indépendante des Droits de l'Homme (CNIDH) qui traite tout ce qui a rapport aux droits de l'Homme y compris les droits des personnes handicapées. A part les tribunaux elle peut ester en justice les cas de violation des droits des personnes en situation de handicap.

7.2 En dehors des cours ou tribunaux ordinaires, Madagascar a-t-elle un organisme officiel qui, bien que n'étant pas spécifiquement en charge de la violation des droits des personnes handicapées s'y attèle tout de même? Si oui décrire l'organe, ses fonctions et ses pouvoirs.

Oui, la CNIDH. C'est un organisme indépendant et apolitique chargé de la promotion et de la protection des droits de l'homme.

La Commission collabore et coopère avec les entités gouvernementales et non gouvernementales œuvrant pour la promotion et la protection des Droits civils, politiques, économiques, sociaux et culturels, ainsi qu'à la protection des groupes vulnérables dont les personnes en situation de handicap.

La Commission est habilitée à s'adresser directement au public ou par l'intermédiaire de tout organe de presse pour faire connaître ses actions et particulièrement pour rendre public ses avis et recommandations.

La Commission peut désigner certains de ses membres pour constituer en temps de besoin des groupes de travail chargés d'étudier les questions spécifiques et de lui présenter toutes recommandations utiles

8 Institutions Nationales des Droits de l'Homme (Commission des Droits de l'Homme ou Ombudsman ou Protecteur du Citoyen)

- 8.1 Madagascar est-il doté d'une Commission de Droits de l'Homme ou d'un Ombudsman ou d'un Protecteur du Citoyen? Si oui ses missions incluent-elles la promotion et la protection des droits des personnes handicapées? Si votre réponse est oui, indiquez également si la Commission de Droits de l'Homme ou l'Ombudsman ou le Protecteur du Citoyen de Madagascar à jamais abordé des questions relatives aux droits des personnes handicapées.**

Oui, la Commission Nationale Indépendante des Droits de l'Homme.

9 Organisation des personnes handicapées (OPH) et autres Organisations de la Société Civile

- 9.1 Avez-vous à Madagascar des organisations qui représentent et défendent les droits et le bien-être des personnes handicapées? Si oui énumérez chaque organisation et décrivez ses activités.**

Oui, il y en a plusieurs et elles sont aujourd'hui regroupées au sein de la Plateforme des fédérations des Personnes Handicapées de Madagascar (PFPH/MAD) dans le but de mieux coordonner les actions.

La PFPH/MAD regroupe 8 fédérations et 250 associations (mixte i.e. plusieurs types de handicap et spécifique i.e. un seul type) et est présente dans 20 régions sur les 22 de Madagascar. Elle travaille actuellement à intégrer les 50 autres associations restantes et mêmes celles nouvellement créées. Elle prévoit de créer de nouvelles branches dans la région Melaky et Anosy, seules régions de Madagascar où elle n'est pas encore présente.

- 9.2 Dans les pays de votre région, les OPH sont-elles organisées ou coordonnées au niveau national et/ou régional?**

Les organisations des personnes handicapées (OPH) sont coordonnées au niveau national grâce à la fédération.

Les OPH sont structurées comme suit: Les individus se regroupent au sein des associations, ces associations se regroupent au sein des fédérations et ces fédérations se regroupent au sein de la Plateforme des Fédérations des Personnes Handicapées de Madagascar.

9.3 Si Madagascar a ratifié la CDPH, comment a-t-elle assuré l'implication des Organisations des personnes handicapées dans le processus de mise en œuvre?

Madagascar est le 155^{ème} pays ayant ratifié la CIRDPH. Les OPH participent dans sa mise en œuvre à travers l'exécution de différents projets et aussi en collaborant avec les différents ministères en particulier, le Ministère de la Population, de la Protection Sociale et de Promotion de la Femme.

9.4 Quels genres d'actions les OPH ont-elles prise elles-mêmes afin de s'assurer qu'elles soient pleinement intégrées dans le processus de mise en œuvre?

La Plateforme des Fédérations des Personnes Handicapées de Madagascar ou PFPH/MAD dispose actuellement d'un pool de formateurs qui donne des formations sur la CIRDPH (Convention Internationale Relative aux Droits des Personnes Handicapées) aux différents organismes publics et privés. PFPH/MAD mène aussi des plaidoyers et des sensibilisations pour son application. Le ministère implique aussi la PFPH/MAD dans le processus de vulgarisation et d'application de la CIRDPH.

9.5 Quels sont, le cas échéant les obstacles rencontrés par les OPH lors de leur engagement dans la mise en œuvre?

Le principal obstacle pour les OPH, notamment la PFPH/MAD dans la mise en œuvre des actions est le remplacement fréquent des Directeurs et Responsables au sein des Ministères car à chaque fois il faut reprendre le processus depuis le début. Le manque de moyens financiers et de ressources humaines, et surtout l'absence de volonté de l'Etat sont aussi des problèmes majeurs.

9.6 Y'a-t-il des exemples pouvant servir de 'modèles' pour la participation des OPH?

La transformation du comité interministériel en Commission Nationale des Personnes Handicapées est un bon exemple de participation des OPH car ces membres sont les points focaux pour chaque ministère.

9.7 Y'a-t-il des résultats spécifiques concernant une mise en œuvre prospère et/ou une reconnaissance appropriée des droits des personnes handicapées résultant de l'implication des OPH dans le processus de mise en œuvre?

Oui, la ratification de CIRDPH en 2014 et l'établissement du plan National d'Inclusion de Handicap sont les fruits de la collaboration et de l'implication des OPH dans la mise en œuvre de la CIRDPH.

9.8 Votre recherche (pour ce projet) a-t-elle identifié des aspects qui nécessitent le développement de capacité et soutien pour les OPH afin d'assurer leur engagement dans la mise en œuvre de la Convention ?

Oui, les OPH ont besoin de renforcer leurs capacités en termes de plaidoyer auprès des autorités officielles, afin par exemple de réclamer la mise en conformité des

textes malgaches avec la CDPH, l'accessibilité des bâtiments administratifs, l'égalité des chances dans l'accès à l'emploi.

9.9 Y'a-t-il des recommandations provenant de votre recherche au sujet de comment les OPH pourraient être plus largement responsabilisées dans les processus de mise en œuvre des instruments internationaux ou régionaux?

D'abord, il faut que les OPH connaissent le contenu de ces instruments et leurs mécanismes de mise en œuvre au niveau national. Ensuite, les OPH doivent apprendre à travailler ensemble pour que leurs efforts ne soient pas éparpillés et produisent plus de résultats.

9.10 Y'a-t-il des instituts de recherche spécifiques dans votre région qui travaillent sur les droits des personnes handicapées et qui ont facilité l'implication des OPH dans le processus, y compris la recherche?

Il n'y a pas encore d'organismes de recherche proprement dites pour les personnes handicapées à Madagascar. Mais il y a Handicap International, UNFPA.

10 Branches gouvernementales

10.1 Avez-vous de(s) branche(s) gouvernementale(s) spécifiquement chargée(s) de promouvoir et protéger les droits et le bien-être des personnes handicapées? Si oui, décrivez les activités de cette (ces) branche(s).

La Direction des Personnes Handicapées et des Personnes âgées au sein du Ministère de la Population, de Protection Sociale et de Promotion de la Femme est la seule branche gouvernementale chargée spécifiquement de promouvoir et protéger les droits et bien-être des personnes handicapées.

11 Préoccupations majeures des droits de l'homme relatives aux personnes handicapées

11.1 Quels sont les défis contemporains des personnes handicapées à Madagascar? (exemple: Certaines régions d'Afrique pratiquent des tueries rituelles de certaines catégories de personnes handicapées telles que les personnes atteintes d'albinisme. A cet effet La Tanzanie est aux avant-postes. Nous devons remettre en cause les pratiques coutumières qui discriminent, blessent et tuent les personnes handicapées.

La mauvaise interprétation du handicap (fruit de la sorcellerie, héréditaire, etc.) a encore cours à Madagascar, à cause du faible niveau d'instruction. Ceci entraîne

l'exacerbation de la discrimination à tous les niveaux (école, emploi, etc.) et le faible taux d'intégration des personnes handicapées dans la société.

11.2 Comment Madagascar répond-t-elle aux besoins des personnes handicapées au regard des domaines ci-dessous énumérés?

Tous ces domaines sont régis par la loi 97-044 et ses textes d'application, ils sont théoriquement garantis mais il existe un fossé entre la théorie et la pratique

- Accès aux bâtiments publics: NUL
- Accès au transport public: il existe un arrêté là-dessus mais il n'est pas appliqué
- Accès à l'éducation: NUL
- Accès à la formation professionnelle: il existe une politique nationale à ce sujet mais son application reste à vérifier
- Accès à l'emploi: NUL
- Accès à la détente et au sport: limité
- Accès à la justice: NUL
- Accès aux soins de santé: limité

11.3 Madagascar accorde-t-il des subventions pour handicap ou autre moyen de revenu en vue de soutenir les personnes handicapées?

Aucune subvention ou aide de l'état n'est accordée aux personnes handicapées ou aux OPH à Madagascar.

11.4 Les personnes handicapées ont-elles un droit de participation à la vie politique (représentation politique et leadership, vote indépendant etc.) à Madagascar ?

Oui, mais l'effectivité de ces droits reste problématique à cause du manque de soutien à l'égalisation des chances. Les personnes handicapées ont par exemple du mal à aller voter dès que le bureau de vote ne leur est pas matériellement accessible.

11.5 Catégories spécifiques expérimentant des questions particulières/vulnérabilité:

- Femmes handicapées
- Enfants handicapés
- Autre (exemple: populations indigènes): personnes handicapées vivant dans des zones enclavées

12 Perspective future

12.1 Y'a-t-il des mesures spécifiques débattus ou prises en compte présentement à Madagascar au sujet des personnes handicapées?

Oui, la classification de l'autisme en tant qu'autre type de handicap mais non assimilé au handicap mental.

12.2 Quelles réformes légales sont proposées? Quelle réforme légale aimeriez-vous voir à Madagascar? Pourquoi?

Nous souhaiterions une mise à jour du cadre juridique de la loi n°97-044 et ses textes d'application, pour qu'on soit conformes à la CDPH et que les réformes se concrétisent.

De même, la mise en place d'une « politique spécifique qui serait promulguée en application des différents textes légaux et réglementaires relatifs aux personnes en situation de handicap » est nécessaire. Cela permettrait de mobiliser une partie du budget de l'Etat et de développer des indicateurs destinés à mesurer les progrès en faveur de l'amélioration des conditions de vie des PESH.⁹

9 Rafitoson K. *Etude sur l'intégration professionnelle des personnes en situation de Handicap à Madagascar*, 2016, AFHAM. p73

SECTION C: REGIONAL DEVELOPMENTS

**Disability rights in the African regional human rights system
during 2016**

REGIONAL DEVELOPMENTS

THE RIGHT TO THE HIGHEST ATTAINABLE STANDARD OF MENTAL HEALTH IN SELECTED AFRICAN COUNTRIES: A COMMENTARY ON HOW SELECTED MENTAL HEALTH LAWS FARE AGAINST ARTICLE 25 OF THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

*Elizabeth Kamundia**

1 Introduction

Persons with disabilities have an equal right to access health services, including general health services and disability-related health services. In accessing health care, persons with disabilities encounter many barriers. These include stereotypes about disability on the part of health care providers; a lack of appropriately-trained health care staff; imbalanced power relationships between persons with health needs and medical professionals; inaccessible health care facilities; inaccessible health-related information; and a lack of individualised accommodations.¹ These barriers are heightened in the circumstances of persons with psychosocial disabilities who face additional challenges, including legally-sanctioned involuntary commitment; forced treatment; and the use of restraints and solitary confinement in mental health care institutions. In addition, certain categories of persons with psychosocial disabilities require particular attention in health care settings. In this regard, the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment in his 2013 report notes that 'women living with disabilities, with psychiatric labels in particular, are at risk of multiple forms of discrimination and abuse in health-care settings'.²

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1 Equal Rights Centre *Ill-prepared: Health care's barriers for people with disabilities* (2011) 3.

2 JE Méndez Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment A/HRC/22/53 (2013) para 80.

In recognition of the fact that persons with disabilities continue to experience rights violations, including with regard to the right to the highest attainable standard of health, the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) was adopted on 13 December 2006.³ Forty-seven African states have signed and ratified the CRPD as at 23 April 2017;⁴ 17 states have submitted state reports to the Committee on the Rights of Persons with Disabilities (CRPD Committee) and six states have already received Concluding Observations from the CRPD Committee.⁵

Article 25 of the CRPD provides for the right to the highest attainable standard of health without discrimination on the basis of disability. The right to the highest attainable standard of health falls under the category of economic, social and cultural rights, comprehensively addressed under the International Covenant on Economic, Social and Cultural Rights (ICESCR).⁶ The obligations imposed by economic, social and cultural rights work in a number of different ways, including providing freedoms; imposing obligations on a state regarding third parties; and imposing obligations on the state to adopt measures or to achieve a particular result.⁷

The right to the highest attainable standard of health care is also recognised in African regional human rights instruments, including the African Charter on Human and Peoples' Rights (African Charter),⁸ the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (African Women's Protocol)⁹ and the African Charter on the Rights and Welfare of the Child (African Children's Charter).¹⁰ The African Commission on Human and Peoples' Rights (African Commission) has adopted a Draft Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (African Disability Protocol). Article 13 of the Protocol deals

3 United Nations Division for Social Policy and Development Disability 'Convention on the Rights of Persons with Disabilities' <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> (accessed 26 April 2017).

4 Disabled World 'CRPD List of Countries: Convention, Optional Protocol Signatures, Ratifications' <https://www.disabled-world.com/disability/discrimination/crpd-milestone.php> (accessed 26 April 2017).

5 United Nations Office of the High Commissioner for Human Rights http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5 (accessed 8 May 2017).

6 Art 12 of the ICESCR addresses health.

7 International Commission of Jurists 'Courts and the legal enforcement of economic, social and cultural rights: Comparative experiences of justiciability' http://www.humanrights.ch/upload/pdf/080819_justiziabilit_esc.pdf (accessed 26 April 2017).

8 Art 16 provides for the right to enjoy the best attainable state of physical and mental health. The following articles of the African Charter also have a bearing on the right to the highest attainable standard of health: art 2 (prohibition of discrimination); art 5 (right to dignity, prohibition of torture and slavery); and art 24 (right to a satisfactory environment).

9 Art 14 African Women's Protocol.

10 Art 14 African Children's Charter.

with the rights of persons with disabilities to the highest attainable standard of health.¹¹ In addition, the African Commission has considered a case that touched on mental health care in The Gambia in *Purohit & Another v The Gambia*.¹² In this communication, the Commission, among other issues, addressed the right to health and the treatment of persons with mental illnesses. The communication was brought on behalf of patients detained at the psychiatric unit of the Royal Victoria Hospital in The Gambia. The communication alleged that the Lunatics Detention Act was inadequate in that it did not prescribe requirements to guarantee the safeguarding of rights during diagnosis and detention of patients.

In its decision, the African Commission emphasised that human dignity was an inherent right, which must be respected at all times irrespective of the mental capability of a person. According to the Commission, persons with mental disabilities must not be denied their right to health care, which is necessary for their survival in society, and they should be accorded special treatment to enable them to attain the highest level of health.¹³ The Commission stated that the right to health was vital for the enjoyment of all other rights and included the right to access health care facilities and health services without discrimination. The Commission found that the government was in violation of the African Charter and urged it to repeal the Lunatics Detention Act and to provide adequate medical as well as material care for mental health patients.¹⁴

Despite the widespread ratification of the CRPD and African regional human rights instruments, persons with disabilities in Africa continue to experience violations of their rights to health, pointing to an inadequate implementation of existing human rights treaties. This commentary examines the extent to which domestic mental health legislation in three African countries (South Africa, Ghana and Tanzania) complies with the standards set in article 25 of the CRPD. All three countries have ratified the CRPD,¹⁵ and legislated on mental health after 2000.¹⁶ South Africa follows a dualistic approach to international law other than for international instruments that are 'self-executing'.¹⁷ Hence, any international agreement becomes law in South Africa once it is enacted

11 Draft Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, adopted at the 19th extraordinary session of the African Commission on Human and Peoples' Rights, held 16-25 February 2016 in The Gambia, http://www.achpr.org/files/news/2016/04/d216/disability_protocol.pdf (accessed 26 April 2017).

12 (2003) AHRLR 96 (ACHPR 2003).

13 *Purohit* (n 12 above) para 81.

14 Sec 3 below further discusses the *Purohit* case.

15 United Nations Treaty Collection 'Convention on the Rights of Persons with Disabilities' https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-15&chapter=4&lang=en (accessed 26 April 2017).

16 South Africa's Mental Health Care Act was enacted in 2002; Tanzania's Mental Health Act was enacted in 2008; and Ghana's Mental Health Act was enacted in 2012.

17 I Grobbelaar-Du Plessis 'South Africa' (2013) 1 *African Disability Rights Yearbook* 313.

into law by national legislation.¹⁸ Ghana¹⁹ and Tanzania,²⁰ similarly, follow a dualist approach to international law.

The commentary is divided into five parts including the introduction and conclusion. The second part briefly explores the meaning of the right to the highest attainable standard of health care in the context of persons with disabilities. The third part examines the legislation governing mental health care in South Africa, Ghana and Tanzania, with a view to assessing the extent to which the legislation complies with the standard set in article 25 of the CRPD. The fourth part is a summarised reflection on the three mental health laws using the CRPD as the standard. In scope, the commentary focuses only on the legislative framework and does not address the relevant policy framework in mental health care in the three countries. The commentary also does not address issues of persons with psychosocial disabilities who are in contact with the criminal justice system, such as prisoners.

2 Meaning of the right to the highest attainable standard of health care in the context of persons with disabilities

According to article 1 of the CRPD, persons with disabilities ‘include 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’.²¹ This definition encapsulates the social model of disability according to which disability is not an intrinsic aspect of an individual; rather the emphasis is laid on the various barriers that hinder the full and equal participation of persons with disabilities in society.²²

Since the coming into force of the CRPD, persons with mental disabilities, their allies and, indeed, the CRPD Committee,²³ to a large extent, have adapted the terminology ‘persons with psychosocial

18 Sec 231(4) Constitution of the Republic of South Africa, 1996.

19 Constitution of the Republic of Ghana (1992) sec 75(2): ‘A treaty, agreement or convention executed by or under the authority of the President shall be subject to ratification by an Act of Parliament.’

20 P Josiah Shughuru ‘Tanzania’ (2013) 1 *African Disability Rights Yearbook* 344.

21 Art 1 CRPD.

22 C Ngwena ‘*Western Cape Forum for Intellectual Disability v Government of the Republic of South Africa: A case study of contradictions in inclusive education*’ (2013) 1 *African Disability Rights Yearbook* 145.

23 See, eg, CRPD Committee General Comment 1: Article 12: Equal recognition before the law (2014) CRPD/C/GC/1.

disabilities'.²⁴ Persons with psychosocial disabilities are those 'who experience mental health issues, and/or who identify as "mental health consumers", "psychiatric survivors", or "mad"'.²⁵ In addition, the World Network of Users and Survivors of Psychiatry includes as users of mental health services people who experience mood swings, fear, voices or visions and people experiencing mental health problems or crises as persons with psychosocial disabilities.²⁶ The term 'psychosocial disability' is meant to express 'a social rather than medical model of conditions and experiences labelled as "mental illness"'.²⁷ This commentary uses the terminology 'persons with psychosocial disabilities' or 'mental health care users'.

Article 25 of the CRPD provides for the right to the highest attainable standard of health without discrimination on the basis of disability. Three elements of article 25 that are pertinent to access to health care services by persons with disabilities are equality and non-discrimination; the provision of health services as close as possible to peoples' own communities; and the provision of health care on the basis of free and informed consent.²⁸ The CRPD Committee is yet to develop a General Comment on article 25 of the CRPD. However, the Committee has issued a number of important Concluding Observations on article 25 that touch on mental health. The Committee has also developed a General Comment on article 12 on equal recognition before the law, which has significant implications for mental health care.²⁹ Hence, it is possible to deduce the core of the right to the highest attainable standard of health care in the context of persons with disabilities.

The CRPD Committee has examined the state reports of various countries, including the following African countries: Ethiopia, Gabon, Kenya, Mauritius, Tunisia and Uganda.³⁰ The Committee has issued Concluding Observations on the right to health to five of the six African

24 It is important to note that legislation in the three countries (South Africa, Ghana and Tanzania) uses different terminology. Eg, Tanzania's Mental Health Act uses 'person with mental disorder' and 'patient'. Sec 2 of the Act defines 'mental disorder' to mean 'a significant occurrence of a mental or behavioural disorder classified in the International Classification of Diseases published by the World Health Organisation'. Sec 2 of Tanzania's Mental Health Act defines 'patient' as 'a person suffering or deemed to be suffering from mental disorder'. Sec 1 of the South African Mental Health Care Act defines 'mental health care user' to mean 'a person receiving care, treatment and rehabilitation services or using a health service at a health establishment aimed at enhancing the mental health status of a user'. Ghana's Mental Health Act uses 'patient' and 'person with mental disorder'. According to sec 97, 'patient' means a person with mental disorder receiving mental health care.

25 Mental Disability Advocacy Centre *Guidelines on article 33 of the CRPD* (2011) 55.

26 World Network of Users and Survivors of Psychiatry 'Psychosocial disability' <https://www.google.com/search?q=persons+with+psychosocial+disabilities&ie=utf-8&oe=utf-8&client=firefox-b-ab#> (accessed 7 March 2017).

27 As above.

28 Arts 25(1)(a)(c)(d) & (f) CRPD.

29 General Comment 1 (n 23 above) paras 7, 13, 31, 41 & 42.

30 United Nations Office of the High Commissioner 'State reports' http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=29 (accessed 26 April 2017).

countries whose state reports the Committee has examined so far.³¹ This section summarises the content of Concluding Observations made to African countries on the right to health that relate specifically to mental health.³² Examining these Concluding Observations is important to understand the meaning of the right to the highest attainable standard of mental health.

The CRPD Committee has made several recommendations on article 25 to African states examined so far. These include urging³³

the development of a wide range of community-based services that respond to the needs of persons with disabilities and respect the person's autonomy, choices, dignity and privacy, including peer support and other alternatives to the medical model of mental health.

The Committee also recommended that state parties take the necessary steps to repeal legislation restricting the rights of persons with disabilities to free and informed consent,³⁴ as well as enact laws which explicitly recognise the right of the individual to free and informed consent and prohibits the substitution of consent by a third party.³⁵ The CRPD Committee further recommended the adoption of measures to ensure that all persons with disabilities have access to the highest attainable standard of health on an equal basis with others.³⁶ In addition, the Committee recommended that state parties conduct regular training of hospital and health care personnel on the rights of persons with disabilities, including their right to free and informed consent and reasonable accommodation in all health care settings.³⁷ The Committee also recommended that state parties ensure the availability of essential drugs for persons with mental health conditions in all health centres, especially in rural areas.³⁸

As noted, the General Comment on article 12 on equal recognition before the law has important implications for mental health care. The General Comment states that 'forced treatment by psychiatric and other

31 Concluding Observations on art 25 of the CRPD on the right to health have been issued to Ethiopia, Kenya, Gabon, Uganda and Mauritius. Only Tunisia did not receive Concluding Observations on this article.

32 Kenya, Gabon, Uganda and Ethiopia all received Concluding Observations impacting on mental health care.

33 CRPD 'Concluding Observations on the initial report of Kenya' CRPD/C/KEN/CO/1 para 46(c).

34 CRPD 'Concluding Observations on the initial report of Gabon' CRPD/C/GAB/CO/1 para 57.

35 As above.

36 As above.

37 As above; United Nations Office of the High Commissioner for Human Rights 'Concluding Observations on the initial state report of Uganda' CRPD/C/UGA/CO/1 para 51(a); CRPD 'Concluding Observations on the initial report of Ethiopia' CRPD/C/ETH/CO/1 para 56.

38 Uganda (n 37 above) para 51(c).

health and medical professionals is a violation of the right to equal recognition before the law',³⁹ among other rights.⁴⁰ The General Comment asserts that state parties are obliged to provide access to support for decisions regarding psychiatric treatment, and 'recommends that states parties ensure that decisions relating to a person's mental integrity can only be taken with the free and informed consent of the person concerned'.⁴¹

The General Comment emphasises that 'perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity'.⁴² According to the General Comment, 'persons with cognitive or psychosocial disabilities have been, and still are, disproportionately affected by substitute decision-making regimes and denial of legal capacity'.⁴³ Under a substituted decision-making regime, legal capacity is removed from a person and placed in the hands of another person (a substitute decision maker) by someone other than the person concerned. Substitute decision makers base their decisions on a 'best interests' standard rather than on the will and preferences of the person concerned.⁴⁴

Mental health laws that permit forced treatment are identified as falling under substitute decision-making regimes. As such, the CRPD Committee urges state parties to replace substitute decision-making regimes by supported decision making.⁴⁵ According to the General Comment, a supported decision-making regime 'comprises various support options which give primacy to a person's will and preferences and respect human rights norms'.⁴⁶

3 Evaluation of the mental health laws in selected African countries

In the African context, it is important to acknowledge upfront that poverty impacts the exercise of the right to the highest attainable standard of health by all persons, including persons with disabilities. In *Purohit*,⁴⁷ the African Commission acknowledged that

39 General Comment 1 (n 23 above) para 42.

40 In addition to being a violation of the right to equal recognition before the law, the CRPD Committee identifies that forced treatment by psychiatric and other health and medical professionals is an infringement of the rights to personal integrity (art 7); freedom from torture (art 15); freedom from violence, exploitation and abuse (art 16); and health care based on free and informed consent (art 25).

41 General Comment 1 (n 23 above) para 42.

42 General Comment 1 para 13.

43 General Comment 1 para 9.

44 General Comment 1 para 27.

45 General Comment 1 paras 3 & 28.

46 General Comment 1 para 29.

47 *Purohit* (n 12 above).

millions of people in Africa are not enjoying the right to health maximally because African countries are generally faced with the problem of poverty which renders them incapable to provide the necessary amenities, infrastructure and resources that facilitate the full enjoyment of this right.⁴⁸

However, the African Commission emphasised the need for state parties to the African Charter ‘to take concrete and targeted steps, while taking full advantage of its available resources, to ensure that the right to health is fully realised in all its aspects without discrimination of any kind’.⁴⁹

This section evaluates the extent to which mental health laws in South Africa, Ghana and Tanzania protect and promote the right to the highest attainable standard of mental health for persons with psychosocial disabilities.

3.1 South Africa

Globally, there are many misconceptions on mental health that lead to persons with psychosocial disabilities not being valued as equal members of society. These misconceptions also exist in Africa, and include beliefs that persons with psychosocial disabilities are cursed,⁵⁰ violent, dangerous,⁵¹ and incapable of making their own decisions.⁵² As a result of stigma and discrimination engendered by these misconceptions, persons with psychosocial disabilities all over the world, including in South Africa, find it difficult to enjoy their human rights on an equal basis with others.⁵³

This section examines South African domestic legislation, gauging the extent to which the legislation complies with the key elements of article 25 of the CRPD, namely, equality and non-discrimination; the provision of health services as close as possible to peoples’ own communities; and the provision of health care on the basis of free and informed consent.⁵⁴

48 *Purohit* para 81.

49 *Purohit* para 84.

50 H Combrinck ‘Everybody counts: The right to vote of persons with psychosocial disabilities in South Africa’ (2014) 2 *African Disability Rights Yearbook* 99.

51 M Dako-Gyeke & E Sowah Asumang ‘Stigmatisation and discrimination experiences of persons with mental illness: Insights from a qualitative study in Southern Ghana’ (2013) 11 *Social Work and Society International Online Journal*.

52 Mental Health America ‘Position statement 22: Involuntary mental health treatment’ <http://www.mentalhealthamerica.net/positions/involuntary-treatment> (accessed 7 March 2017); S Kleintjes et al ‘Barriers to the participation of people with psychosocial disability in mental health policy development in South Africa: A qualitative study of perspectives of policy makers, professionals, religious leaders and academics’ (2013) 13 *BioMed Central International Health and Human Rights*.

53 M Swanepoel ‘Human rights that influence the mentally-ill patient in South African medical law: A discussion of sections 9; 27; 30 and 31 of the Constitution’ (2011) 14 *Potchefstroom Electronic Law Journal*; CO Egbe et al ‘Psychiatric stigma and discrimination in South Africa: Perspectives from key stakeholders’ (2014) 14 *Bio Med Central Psychiatry*.

54 Arts 25(1)(a)(c)(d) & (f) CRPD.

3.1.1 *Obligation to prohibit discrimination against persons with disabilities in the provision of health services*

Constitution of South Africa

Section 9 of the Constitution of the Republic of South Africa, 1996 comprises a robust equality and non-discrimination clause that operates both vertically⁵⁵ and horizontally.^{56,57} Disability is one of the prohibited grounds of unfair discrimination. Hence, persons with disabilities are protected from unfair discrimination across all spheres of life, including access to health care. However, as South Africa's state report to the CRPD Committee notes, protection in law does not always translate into protection in practice:

So while persons with disabilities are, in principle, able to harness the law to protect and pursue interests on an equal basis with others, a number of obstacles, including persistent harmful traditional beliefs, ingrained stigmatisation and consequent discrimination on the one hand, and the interrelatedness of disability and poverty on the other ... detract from the equality provided for in law.⁵⁸

Section 27(1)(a) of the South African Constitution provides that everyone has the right to have access to health care services, including reproductive health care. It has been argued that 'the South African Constitution provides for universal access to health care services and not the right to attain the highest standard of physical and mental health'.⁵⁹ However, section 27(1)(a) is phrased broadly enough to be interpreted generously as including 'claims to all services, goods and facilities aimed at securing the greatest attainable standard of physical and mental well-being'.⁶⁰ In addition, the manner in which the right to health is understood in international law must influence the understanding of this right in the context of the South African Constitution. This is particularly pertinent given that South Africa has ratified the ICESCR.

Other sections of the South African Constitution that touch on health care include sections 24 and 184. Section 24 of the Constitution provides

55 Sec 9(3) provides for a vertically-applicable right by prohibiting the state from unfairly discriminating against any person based on any ground.

56 Sec 9(4) provides for a horizontally-applicable right to non-discrimination by prohibiting any person from unfairly discriminating directly or indirectly against any person based on any ground.

57 Grobbelaar-Du Plessis (n 17 above) 314-315.

58 Office of the High Commissioner for Human Rights 'Initial report of South Africa submitted in accordance to Article 35 of the Convention' para 51 http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=29 (accessed 7 March 2017).

59 South African Human Rights Commission *Public inquiry: Access to health care services* (2009) 23.

60 M Pieterse *Can rights cure? The impact of human rights litigation on South Africa's health system* (2014) 20.

that everyone has the right to an environment that is not harmful to their health or wellbeing. According to section 184(3), each year the South African Human Rights Commission must require relevant organs of the state to provide the Commission with information on measures they have taken towards the realisation of the rights in the Bill of Rights concerning a variety of issues, including health care. In practice, the responsiveness of relevant organs of the state to the Commission's request for information varies. For example, in its 2012-2013 report, the Commission states:

All of the departments submitted their responses [to questionnaires sent by the Commission] after the initial deadline and some departments, including Social Development and Agriculture; Forestry and Fisheries had to be threatened with legal action before a response was received. The Commission aims to build stronger relationships with these departments to ensure smoother collaboration and compliance in the future.⁶¹

South Africa does not have a specific Act to address issues of persons with disabilities; rather, disability issues are mainstreamed throughout various Acts as necessary.⁶²

Mental Health Care Act

A key overarching principle under South Africa's Mental Health Care Act 17 of 2002 is the integration of mental health care into the general health services.⁶³ It is important to note, however, that mere integration is not enough; persons with disabilities may require support in exercising their health rights. The Special Rapporteur on the Rights of Persons with Disabilities in her 2016 report notes that support is a human rights obligation arising from various rights, including the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.⁶⁴ In the absence of adequate support, persons with disabilities may not exercise their health rights on an equal basis with others.

With regard to equality and non-discrimination, section 10(1) of the Mental Health Care Act prohibits discrimination against a 'mental health care user' on the grounds of his or her mental health status. Section 1 of the

61 South African Human Rights Commission 'Report on economic and social rights sec 184(3) report' (2012-2013) 10.

62 Acts that mainstream disability issues include the Broad-Based Black Economic Empowerment Act 53 of 2003; the Child Justice Act 75 of 2008; the Children's Act 53 of 2003; the Co-Operatives Act 14 of 2005; the Employment Equity Act 55 of 1998; the National Building Regulations and Building Standards Act 103 of 1977; the National Health Act 61 of 2003; the Sterilisation Act 44 of 1998; the National Land and Transport Act 5 of 2009; the Preferential Procurement Policy Framework Act 5 of 2000; the Social Assistance Act 13 of 2004; and the South African Library for the Blind Act 91 of 1998. See Grobbelaar-Du Plessis (n 17 above) 315.

63 Integrating mental health into general health care services is one of the objects of the Mental Health Care Act under sec 3(a)(iii).

64 C Devandas 'Report of the Special Rapporteur on the Rights of Persons with Disabilities' A/HRC/34/58 (2016) para 31.

Act defines a mental health care user as ‘a person receiving care, treatment and rehabilitation services or using a health service at a health establishment aimed at enhancing the mental health status of a user, state patient and mentally-ill prisoner’.⁶⁵ In cases where the person concerned is below 18 years of age or considered ‘incapable of taking decisions’, the term ‘mental health care user’ may include the person’s next of kin as well as an administrator appointed under the Act.

The Act further states that ‘[e]very mental health care user must receive care, treatment and rehabilitation services according to standards equivalent to those applicable to any other health care user’.⁶⁶

In spite of these provisions on equality between mental health care users and other health care users, the Mental Health Care Act discards the principle of free and informed consent with regard to mental health care users, as is discussed in more detail below. To illustrate, general health users are discharged from hospital unconditionally.⁶⁷ However, often, in mental health care, discharge is conditional, as illustrated by section 34(6) of the Mental Health Care Act:

The head of the health establishment may cancel the discharge and request the user to return to the health establishment on an involuntary inpatient basis, if he or she has reason to believe that the user fails to comply with the terms and conditions of such discharge.

3.1.2 Obligation to provide health services as close as possible to people’s own communities

Article 25(c) of the CRPD places an obligation on state parties to provide ‘health services as close as possible to people’s own communities, including in rural areas’. Article 19 of the CRPD is closely related to article 25(c) and provides for the rights of persons with disabilities to live independently in the community and not to be obliged to live in particular living arrangements, as happens in the case of institutionalisation in mental health facilities. In addition, the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment in his 2013 report recommended that forced treatment and commitment in mental health facilities be replaced by services in the community.⁶⁸ According to the Special Rapporteur:

Such services must meet needs expressed by persons with disabilities and respect the autonomy, choices, dignity and privacy of the person concerned,

65 Sec 1.

66 Sec 10(2).

67 General health users may be given a set of health instructions which they are free to choose either to adhere to or to ignore.

68 JE Méndez (n 2 above) para 89(c).

with an emphasis on alternatives to the medical model of mental health, including peer support, awareness-raising and training of mental health-care and law enforcement personnel and others.⁶⁹

According to the Special Rapporteur on the Rights of Persons with Disabilities, in her 2016 report, '[s]tates must establish an immediate moratorium on new admissions to institutions and set up a policy framework to guide deinstitutionalisation processes'.⁷⁰ The Special Rapporteur clarifies that policy frameworks on deinstitutionalisation should

include the adoption of a plan of action with clear timelines and concrete benchmarks, the redistribution of public funds from institutions to community services and the development of adequate community support for persons with disabilities such as housing assistance, home support, peer support and respite services.

According to the Special Rapporteur, there is evidence to the effect that 'when adequately planned and resourced, community services are much more cost-effective than institutional care'.⁷¹

In its state report to the CRPD Committee, South Africa identifies that its main policy to mental health is community-based care.⁷² Recent reports and academic articles have criticised the South African state for embarking on de-institutionalisation measures without first setting up support services for mental health care in the community.⁷³ The 2017 report by the Office of Health Standards Compliance provides information on deinstitutionalisation in Gauteng Province that went tragically wrong, resulting in the deaths of more than 94 persons with psychosocial disabilities.⁷⁴

69 As above.

70 Devandas (n 64 above) para 86.

71 As above.

72 Office of the High Commissioner for Human Rights 'Initial report of South Africa submitted in accordance to Article 35 of the Convention' para 276(3) http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=29 (accessed 7 March 2017). See also sec 8(2) of the Mental Health Care Act, which states that mental health care services should 'improve the mental capacity of the user to develop to full potential and to facilitate his or her integration into community life'.

73 South African Human Rights Commission *Public inquiry: Access to health care services* (2009) 50; UA Botha et al 'Assessing the efficacy of a modified assertive community-based treatment programme in a developing country' (2010) 10 *BMC Psychiatry* 2; Ubuntu Centre South Africa 'Esidimeni campaign 2016' <https://ubuntucentre.wordpress.com/esidimeni-campaign-2016/> (accessed 27 January 2017); Office of Health Standards Compliance 'Final report into the circumstances surrounding the deaths of mentally-ill patients: Gauteng Province' (2017) <http://www.ohsc.org.za/index.php/news/media-releases/129-report-into-deaths-of-mentally-ill-patients-gauteng-province-3> (accessed 15 February 2017).

74 As above.

South Africa's Mental Health Care Act has a mixed approach on the provision of care in the community: For persons with 'serious' mental health conditions, institutional care is prioritised, whilst community-based care is the main approach for those with 'less serious' mental health conditions. Section 1 of the Mental Health Care Act defines 'health establishment'. From this definition, it is clear that mental health care facilities range from community health and rehabilitation centres and clinics to hospitals and psychiatric hospitals. To further illustrate, section 6(6)(g) provides that psychiatric hospitals may admit, care for, treat and rehabilitate 'persons admitted for a long period as part of their care, treatment and rehabilitation'.⁷⁵ The approach under section 6(6)(g) seems to be that there are certain categories of people whose care can only be provided within an institution – this goes against the spirit of articles 19 and 25(c) of the CRPD, which provide for the right of all persons with disabilities to live in the community.

3.1.3 Obligation to provide health care to persons with disabilities on the basis of free and informed consent

Article 25(d) of the CRPD emphasises that persons with disabilities should receive care of the same quality as those without disabilities 'including on the basis of free and informed consent'. Article 25(d) is closely linked with article 12 of the CRPD on equal recognition before the law. Specifically, article 25(d) is closely related to article 12(2), which states that 'persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life'. Legal capacity 'includes the capacity to be both a holder of rights and an actor under the law'.⁷⁶ As such, legal capacity protects an individual against unwanted interventions such as medical treatment that the person does not wish to receive.⁷⁷

Under the National Health Act 61 of 2003, health services in South Africa are provided on the basis of free and informed consent.⁷⁸ However, South Africa's Mental Health Care Act mandates medical treatment of persons with psychosocial disabilities without their free and informed consent.⁷⁹ In its state report to the CRPD Committee, South Africa

75 See also secs 34(4) and 37. Sec 34(4) mandates transfer for in-patient care in psychiatric hospitals, while sec 37 illustrates that a person can spend more than 12 months as an 'involuntary mental health care user' in a psychiatric hospital.

76 General Comment 1 (n 23 above) para 12.

77 Council of Europe Commissioner for Human Rights *Issue paper: Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities* (2012) 11.

78 Secs 6, 7(3) & 8(2)(b) National Health Act 2003.

79 Sec 32 of the Mental Health Care Act.

identifies laws with a problematic notion of ‘informed consent’ in light of the CRPD.⁸⁰ The Mental Health Care Act is not identified as one of these laws, and this may be read as signalling that the state does not intend changing this aspect of the mental health law.

In its General Comment on article 12 on equal recognition before the law, the CRPD Committee has identified mental health laws that permit forced treatment as being a key area in which persons with disabilities are denied their rights to legal capacity. The General Comment states:

States parties have an obligation to provide access to support for decisions regarding psychiatric and other medical treatment. Forced treatment is a particular problem for persons with psychosocial, intellectual and other cognitive disabilities. States must abolish policies and legislative provisions that allow or perpetrate forced treatment, as it is an ongoing violation of mental health laws across the globe, despite empirical evidence indicating its lack of effectiveness and the views of people using mental health systems who have experienced deep pain and trauma as a result of forced treatment. The Committee recommends that state parties ensure that decisions relating to a person’s physical or mental integrity can only be taken with the free and informed consent of the person concerned.

South Africa’s Mental Health Care Act allows for mental health care, treatment and rehabilitation of persons with psychosocial disabilities without their informed consent.⁸¹ South Africa’s Mental Health Care Act has two categories of care, treatment and rehabilitation without informed consent: ‘assisted care’ and ‘involuntary care’. Assisted care is administered to individuals who are ‘incapable of making informed decisions due to their mental health status and who do not refuse the health interventions’.⁸² Involuntary care is defined as ‘the provision of health interventions to people incapable of making informed decisions due to their mental health status and who refuse health intervention but require such services for their own protection or for the protection of others’.⁸³ Substitute decision makers under the Act include a spouse; next of kin; a partner; an associate; a parent or guardian of the user;⁸⁴ the head of the

80 These include the Choice on Termination of Pregnancy Act, 1996; the Sterilisation Act, 1998; the National Health Act, 2003; and the Children’s Act, 2005. See Office of the High Commissioner for Human Rights ‘Initial report of South Africa submitted in accordance to Article 35 of the Convention’ para 125 http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=29 (accessed 7 March 2017).

81 See secs 6(6)(c), 19(1)(b), 26(b) i & ii, 28(3), 31(3)(b), 31(4), 32, 33(1)(a), 33(5)(b), 34(3), 36, 38(1) & 40(1) & (2).

82 Sec 1.

83 As above.

84 See sec 27(1)(a) on application for assisted care, treatment and rehabilitation services; 29(1)(a) on appeal against decision of head of health establishment to approve application for assisted care, treatment and rehabilitation; 33(1)(a) on application to obtain involuntary care, treatment and rehabilitation; and 35 on appeal against decision of head of health establishment on involuntary care, treatment and rehabilitation.

health establishment,⁸⁵ a health care provider,⁸⁶ the Review Board,⁸⁷ and the High Court.⁸⁸

Section 32 of the Mental Health Care Act involves ‘care, treatment and rehabilitation of mental health care users without consent’. Under this section, several reasons warrant the provision of care, treatment and rehabilitation without the individual’s free and informed consent. The first reason is the existence of a reasonable belief that the mental health care user has a mental illness that may cause him or her to inflict serious harm to himself or herself or others. Second, mental health care, treatment and rehabilitation may be administered without the consent of the individual if such care ‘is necessary for the protection of the financial interests or reputation of the user’.⁸⁹ Third, such care may be given in cases where ‘at the time of the application the mental health care user is incapable of making an informed decision on the need for the care, treatment and rehabilitation services and is unwilling to receive the care, treatment and rehabilitation required’.⁹⁰

Section 26 involves assisted care. Under this provision, assisted care is provided without the individual’s consent to individuals who are ‘suffering from a mental illness or severe or profound mental disability’ in circumstances where the person requires ‘care, treatment and rehabilitation services for his or her health or safety, or for the health and safety of other people’⁹¹ and to individuals who are ‘incapable of making an informed decision on the need for the care, treatment and rehabilitation services’⁹².

Before a person can be treated on an ‘involuntary basis’, two mental health care practitioners must examine the person.⁹³ The mental health care practitioners are required to submit written findings on whether the mental health care user must receive involuntary care, treatment and rehabilitation services.⁹⁴ If after seven days of the assessment the head of the health establishment is still of the opinion that the mental health care user requires further involuntary care, the head of the health establishment must submit a written request to the Review Board to approve further

85 These include sec 14 of the Mental Health Care Act on limitation on intimate adult relationships; sec 26(a) on care, treatment and rehabilitation services for mental health care users incapable of making informed decisions; and 27(5) on application for assisted care, treatment and rehabilitation services.

86 Sec 33(1)(a)(ii).

87 These include sec 9(1)(b) on consent to care, treatment and rehabilitation services and admission to health establishments.

88 As above.

89 Sec 32(b)(ii).

90 Sec 32(c).

91 Sec 26(b)(i).

92 Sec 26(b)(ii).

93 Sec 33(4)(a).

94 Sec 33(5)(b).

involuntary care.⁹⁵ Ultimately, under section 36, the High Court has the ultimate decision on the length of involuntary treatment.

A member of the South African Police Service may also initiate involuntary care, treatment and rehabilitation in circumstances where

from personal observation or from information obtained from a mental health care practitioner, that a person due to his or her mental illness or severe or profound intellectual disability is likely to inflict serious harm to himself or herself or others.⁹⁶

The Act also has provisions on voluntary care, where a person with a psychosocial disability is seen as an adult capable of giving informed consent.⁹⁷

3.2 Ghana

Human rights violations do occur in psychiatric hospitals in Ghana, as in many other parts of the world.⁹⁸ In 2012, Human Rights Watch published a report on abuses against persons with mental disabilities in Ghana.⁹⁹ The Human Rights Watch report documents prevalent human rights violations in psychiatric facilities and prayer camps in Ghana as including

involuntary admission and arbitrary detention, prolonged detention, overcrowding and poor hygiene, chaining, forced seclusion, lack of shelter, denial of food, denial of adequate health care, involuntary treatment, stigma and its consequences, physical and verbal abuse, electro-convulsive therapy, and violations against children with disabilities.¹⁰⁰

In this report, one respondent who had spent time in Accra Psychiatric Hospital revealed that she had 'witnessed people being injected with medications against their will, and nurses beating patients who failed to respond to instructions'.¹⁰¹ The respondent highlighted that what she needed 'was a clinical psychologist to talk to and community-based rehabilitation, but these services are not easy to come by'.¹⁰²

95 Sec 34(3)(c)(i).

96 Sec 40(1).

97 Sec 1(xi) defines voluntary care, treatment and rehabilitation as 'the provision of health interventions to a person who gives consent to such interventions'. Other sections on persons with psychosocial disabilities giving consent include secs 9, 26, 29(3), 30(5)(a)(ii), 34(3)(a), 35(3)(b) and 38(2).

98 M Roberts et al 'An overview of Ghana's mental health system: Results from an assessment using the World Health Organisation's assessment instrument for mental health systems (WHO-AIMS)' (2014) 8 *BioMed Central International Health and Human Rights*; A Ofori-Atta et al 'A situation analysis of mental health services and legislation in Ghana: Challenges for transformation' (2010) 13 *Africa Journal of Psychiatry* 99-108.

99 Human Rights Watch 'Like a death sentence: Abuses against persons with mental disabilities in Ghana' (2012).

100 Human Rights Watch (n 99 above) 11.

101 Human Rights Watch 7.

102 As above.

In addition to psychiatric hospitals, persons with psychosocial disabilities in Ghana are often held in faith-based facilities, partly because mental disability is seen as having been caused by witchcraft or spiritual attacks.¹⁰³ There is a lack of policy and regulation concerning the practice of psychiatry by faith-based practitioners,¹⁰⁴ and there have been complaints of human rights violations in these facilities.¹⁰⁵

This section examines Ghana's domestic legislation, gauging the extent to which the legislation complies with the key elements of article 25 of the CRPD.

3.2.1 Obligation to prohibit discrimination against persons with disabilities in the provision of health services

Constitution of Ghana

The Constitution of the Republic of Ghana, 1992 specifically provides for the rights to equality and non-discrimination of persons with disabilities. According to article 29(4) of the Ghanaian Constitution, persons with disabilities 'shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature'.

Several provisions in the Constitution of Ghana address health. Article 34(2) places an obligation on the President to present an annual report to parliament of all the steps taken to ensure the realisation of basic human rights, including the right to good health care. Article 36(10) mandates the state to safeguard the health, safety and welfare of all persons in employment.

Person with Disabilities Act

The Persons with Disabilities Act 715 of 2006 makes provision for health care for persons with disabilities. Section 31 stipulates that in formulating health policies, the Ministry of Health 'shall provide for free general and specialist medical care, rehabilitative operation treatment and appropriate assistive devices for persons with total disability'. According to section 32, the study of disability-related issues shall be part of the curricula of training institutions for health professionals. Section 33 also requires the Ministry of Health to include education on disability and disability issues in health care programmes. Incorporating specific education on disability issues in health care programmes could potentially ensure better access to good quality mental health care for persons with disabilities, especially if the

103 Republic of Ghana Ministry of Health *The mental health system in Ghana* (2013) 35.

104 Republic of Ghana (n 103 above) 50.

105 UM Read & VCK Doku 'Mental health research in Ghana: A literature review' (2012) 46 *Ghana Medical Journal*.

curriculum approaches disability from a human rights perspective rather than solely from the medical model of disability.

Mental Health Act

The Mental Health Act 846 of 2012 comprises provisions on equality and non-discrimination of mental health care users.¹⁰⁶ Under section 3(j), the Mental Health Authority is obliged to provide psychiatric in-patient care of an equitable standard to physical in-patient care. The Mental Health Act also provides that '[a] person with mental disorder is entitled to the same standard of care as a person with physical health problems and shall be treated on an equitable basis'¹⁰⁷ on all matters, including access to essential medicines. The Act prohibits discrimination and imposes a fine of not more than five hundred penalty units or a term of imprisonment of not more than two years or both the fine and imprisonment to any person who subjects a person with mental disorder to discrimination.¹⁰⁸ According to section 88(1), mental health care is free.

However, similar to the South African Mental Health Care Act, the Ghanaian Mental Health Act makes it clear that, unlike in physical health care, leaving a psychiatric institution – even for a 'voluntary patient' – is at the discretion of the institution. Section 40(5) of the Ghanaian Mental Health Act provides that at the time of admission, a voluntary patient must be alerted that a request for discharge may not be granted if the patient meets the criteria of involuntary admission at the time the request for discharge is made. In the event that a patient leaves the facility without the consent of the psychiatrist or the head of the facility, a report of this fact shall be made to the police, who are mandated to arrest the patient without warrant and return him or her to the hospital.¹⁰⁹

In addition, section 68(1) states that a person with a mental disorder who is unable to manage his or her personal affairs because of the mental disorder shall be protected in a broad range of matters, including the right to treatment of choice. In terms of protection, if a court finds that a person is lacking in mental capacity, and is not competent to make decisions on a broad range of issues, including treatment, 'the court shall appoint a guardian for the personal protection of that person'.¹¹⁰ In taking treatment decisions on behalf of a person with a mental disorder, the guardian is required to 'consult with the incapacitated person where possible' and to make treatment decisions 'on behalf of the incapacitated person using a high standard of substituted judgment'.¹¹¹ This provision runs contrary to

106 See secs 3(g), 54(2) and 94.

107 Sec 57(2).

108 Sec 94.

109 Sec 50(2).

110 Sec 68(4).

111 Sec 68(6).

the General Comment on article 12 on equal recognition before the law, which proposes a complete shift from substitute decision making in the context of adults with disabilities.

3.2.2 *Obligation to provide health services as close as possible to people's own communities*

Section 3.2 highlights that human rights violations often occur in institutional settings,¹¹² and that the human rights of persons with disabilities are best protected when health services are provided as close as possible to people's own communities. This section examines Ghanaian law on the right of persons with disabilities to live in the community as well as provision of community-based health care services.

Constitution of Ghana

The Constitution of Ghana provides for the right of persons with disabilities to live in the community. Article 29(1) provides that '[d]isabled persons have the right to live with their families or with foster parents and to participate in social, creative or recreational activities'. The same article, however, has a claw-back clause on the right of persons with disabilities to live in the community. Article 29(2) provides that a person with a disability shall not be subjected to different treatment in respect of residence other 'than that required by his condition or by the improvement which he may derive from the treatment'.¹¹³ As a safeguard, the article provides that living in 'specialised establishments' for persons with disabilities shall occur in circumstances where such stay is 'indispensable' and the environment and living conditions 'shall be as close as possible to those of the normal life of a person of his age'.¹¹⁴

Mental Health Act

The Ghanaian Mental Health Act espouses the principle of care, treatment and rehabilitation in the least restrictive environment.¹¹⁵ The Act defines 'least restrictive' as 'a regime of treating a person with mental disorder in a situation or environment where the freedom of movement, association and choice of the person is minimally constrained'.¹¹⁶ In addition, the Act requires the Mental Health Authority to 'provide for educational, vocational and leisure opportunities within mental health facilities'.¹¹⁷

112 E Goffman *Asylums: Essays on the social situation of mental patients and other inmates* (1961).

113 Art 29(2).

114 Art 29(3).

115 Sec 2(c).

116 Sec 97.

117 Sec 3(k).

However, the Act mandates in-patient care for persons with psychosocial disabilities.¹¹⁸ In terms of time frames, a person can be institutionalised for a period of up to 12 months under the Ghanaian Mental Health Act once under a ‘prolonged treatment order’.¹¹⁹ Under section 46 of the Act, prolonged treatment in a psychiatric hospital is ordered if the psychiatrist or head of a facility is of the opinion that the severity of the condition warrants this. Section 47 provides that ‘[t]he period of the prolonged treatment order shall not exceed twelve months at a time’.

3.2.3 Obligation to provide health care to persons with disabilities on the basis of free and informed consent

The Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment in his 2013 report details abuses in health care settings that may cross a threshold of mistreatment that is tantamount to torture or cruel, inhuman or degrading treatment or punishment. The report strongly recommends the abolition of legislation ‘authorising institutionalisation of persons with disabilities for their care and treatment without their free and informed consent’.¹²⁰ The Special Rapporteur’s 2013 report further states that ‘informed consent is not mere acceptance of a medical intervention, but a voluntary and sufficiently informed decision’.¹²¹ According to the Special Rapporteur, ‘guaranteeing informed consent is a fundamental feature of respecting an individual’s autonomy, self-determination and human dignity in an appropriate continuum of voluntary health-care services’.¹²²

Mental Health Act

The Ghanaian Mental Health Act defines informed consent as ‘an agreement or consent for a procedure given freely without coercion by a person with capacity when the person has been made fully aware of the nature of the procedure, its implications and available alternative’.¹²³ The Act classifies mental health care users into three main categories, namely, voluntary,¹²⁴ involuntary¹²⁵ and emergency.¹²⁶ The Act requires the consent of a voluntary patient to be obtained before treatment is given, and a voluntary patient has the right to refuse treatment under the Act.¹²⁷ In addition, a voluntary patient can request a discharge from a facility.

118 Secs 42(1), 46(1)& and 48(1).

119 Sec 47.

120 Méndez (n 2 above) para 68.

121 Méndez para 28.

122 As above.

123 Sec 97.

124 Secs 39-41.

125 Secs 42-44.

126 Secs 48-49.

127 Secs 40(2) & (3).

However, such a request can only be honoured if the person does not meet the conditions for involuntary admission.¹²⁸

Section 42 of the Ghanaian Mental Health Act addresses involuntary treatment. According to the Act, involuntary admission and treatment is applicable where a person believed to be suffering from a mental disorder is at personal risk or a risk to other people,¹²⁹ and where 'there is a substantial risk that the mental disorder will deteriorate seriously'.¹³⁰ Once the court is satisfied that a person meets these requirements, the court may place a person in a psychiatric hospital for treatment for a period not exceeding one month.¹³¹ An individual would then require the consent of a psychiatrist or head of a facility in order to leave the psychiatric hospital.¹³² The Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment in his 2013 report recommended the repeal of provisions

authorising the preventive detention of persons with disabilities on grounds such as the likelihood of them posing a danger to themselves or others, in all cases in which such grounds of care, treatment and public security are linked in legislation to an apparent or diagnosed mental illness.¹³³

Emergency treatment is addressed in section 48 of the Act. Under this provision, a police officer, a relative or any other person with or without the assistance of a police officer may take the person to a mental health facility for a certificate of urgency in cases where 'it is expedient either for the welfare of a person suspected to be suffering from mental disorder or for public safety'.¹³⁴

The Ghanaian Mental Health Act mandates several categories of substitute decision makers to make treatment decisions on behalf of a person with a psychosocial disability.¹³⁵ To illustrate, section 29 protects the right to informed consent of the individual seeking mental health care services, in particular with regard to intrusive or irreversible procedures. At the same time, the Act contains a claw-back clause authorising the Mental Health Review Tribunal to approve requests for intrusive or irreversible treatment.¹³⁶ In addition, the Ghanaian Mental Health Act mandates the

128 Sec 41(2).

129 Sec 42(1)(a).

130 Sec 42(1)b.

131 Sec 43(3).

132 Sec 50(1).

133 Méndez (n 2 above). para 68.

134 Sec 48(1).

135 Eg, the court under sec 43(3); the Mental Health Review Tribunal under secs 26(3) & 71(5); the psychiatrist or head of facility under secs 46(1) & 50; a police officer under sec 48(1); a relative under sec 48(1); the personal representative under sec 62(2); and a guardian under sec 68(1).

136 Sec 26(3).

appointment of a guardian to protect a ‘person with mental disorder’ in a range of matters including ‘the right to treatment of choice’.¹³⁷

3.3 Tanzania

Tanzania has been said to have ‘an astonishing shortage in mental health care’.¹³⁸ This section examines mental health care in Tanzania, with a focus on equality and non-discrimination; the provision of health services as close as possible to peoples’ own communities; and the provision of health care on the basis of free and informed consent.¹³⁹

3.3.1 *Obligation to prohibit discrimination against persons with disabilities in the provision of health services*

Constitution of Tanzania

The Constitution of Tanzania does not contain a provision on the right to health. Article 12 of the Tanzanian Constitution addresses the right to equality and provides that ‘all human beings are born free, and are all equal’. Article 13(4) of the Constitution concerns non-discrimination and provides that ‘[n]o person shall be discriminated against by any person or any authority acting under any law’.

Persons with Disabilities Act

Section 26 of the Tanzanian Persons with Disabilities Act 9 of 2010 provides that ‘[e]very person with a disability shall have the right to enjoy the attainable standard of health care services without any discrimination’. The Act also requires health facilities to ‘[p]rovide persons with disabilities with the same level and standard of health and rehabilitation services as provided to other citizens’.¹⁴⁰ Further, the Act requires that health and rehabilitation personnel be equipped with knowledge to respect the ‘rights, dignity and needs of persons with disabilities’.¹⁴¹ In addition, the Minister is mandated to ensure that health services provided to persons with disabilities are provided after the person has given his free and informed consent.¹⁴² In line with article 4(3) of the CRPD, the Act requires that persons with disabilities participate in planning, delivering, monitoring and evaluation of health and rehabilitation services.¹⁴³ It is an offence to

137 Sec 68(1).

138 In2mentalhealth ‘Challenges in mental health care Tanzania: What can eLearning add?’ <https://in2mentalhealth.com/2011/06/07/challenges-in-mental-health-care-tanzania-what-can-elearning-add/> (accessed 9 May 2017).

139 Arts 25(1)(a), (c), (d) & (f) CRPD.

140 Sec 26(3)(a).

141 Sec 26(3)(c).

142 Sec 26(4)b.

143 Sec 26(4)(d).

deny or discriminate against any person with a disability in relation to access to health care and rehabilitation.¹⁴⁴

Mental Health Act 2008

Tanzania's Mental Health Act 21 of 2008 does not expressly provide for equality and non-discrimination of persons with psychosocial disabilities. The Act fails to espouse equality between mental health care users and other health care users. To illustrate, the Mental Health Act discards the principle of free and informed consent with regard to mental health care users. According to section 9, a variety of state officials¹⁴⁵ are mandated to cause a 'mentally disordered person' who is not under 'proper care and control' to be brought to a mental health care facility.

Further, according to section 4(3), a mental health care user may only be discharged 'subject to the procedures available to other patients not suffering from mental disorder' if he or she is assessed and found to be capable of taking care of himself or herself and is no longer dangerous to himself or herself, the community or property.

3.3.2 *Obligation to provide health services as close as possible to people's own communities*

Mental Health Act

The Mental Health Act of Tanzania provides for both institutional care and community-based care. To illustrate, according to Tanzania's Mental Health Act, health care interventions include 'institution-based treatment, community-based treatment and social rehabilitation'.¹⁴⁶ Further, a mental health care facility is defined as including 'a forensic psychiatric hospital, rehabilitation centre, boarding houses or community houses providing care for persons with mental disorders'.¹⁴⁷

The Tanzanian Mental Health Act recognises that persons with psychosocial disabilities may require support in living in the community. According to the Act, the district social welfare officer is required to work with available mental health care facilities to improve social support structures for persons with psychosocial disabilities.¹⁴⁸ Further, mental health care facilities are required to ensure family and community involvement in the care of persons with psychosocial disabilities in the

144 Sec 26(7).

145 These include a police officer; a justice of the peace; a social welfare officer; a religious leader; a ward executive officer; and a village executive officer.

146 Sec 2.

147 As above.

148 Sec 9(3).

mental health care facility, and to be involved in establishing strategies for continuity of care.¹⁴⁹ Finally, one of the functions of the National Council for Mental Health is to encourage and facilitate community involvement in the promotion of mental health.¹⁵⁰

3.3.3 Obligation to provide health care to persons with disabilities on the basis of free and informed consent

Mental Health Act

Tanzania's Mental Health Act provides for three different categories of mental health care users, namely, voluntary, involuntary and temporary. Under the Mental Health Act, care, treatment and rehabilitation can be offered to Tanzanians with psychosocial disabilities without their free and informed consent.

To illustrate, upon the discharge of a voluntary mental health care user, the Act mandates the officer in charge of the mental health care facility to ensure continuity of care on an out-patient basis. The Act gives no consideration to whether or not the individual consents to continuing out-patient care.¹⁵¹ In addition, a person who is received as a voluntary patient in a mental health care institution shall be admitted for treatment and care using involuntary admission procedures if found to be incapable of taking care of himself or herself or a danger to himself or herself, the community or property.¹⁵² Additional criteria for involuntary admission and treatment under the Act are where there is a risk of deterioration¹⁵³ and where the individual is being 'cruelly treated or neglected by the person having the care or charge of him'.¹⁵⁴

Tanzania's Mental Health Act provides a category known as 'temporary patient', a status quite similar to 'assisted' mental health care user under South Africa's Mental Health Care Act. A 'temporary patient' is a 'person who is suffering from mental disorder or mental defect and is likely to benefit by temporary treatment in a mental hospital but is for the time being incapable of expressing himself as willing or unwilling to receive treatment'.¹⁵⁵ Under the Tanzanian Act, where an individual is unable to express himself or herself, the individual is simply deemed as a temporary patient as opposed to being provided with support to make his or her own treatment decisions. Further, Tanzania's Mental Health Act

149 Sec 28(3).

150 Sec 31(1)(c).

151 Sec 4(4).

152 Secs 4(6) & 11(7)(b).

153 Second schedule, Form 2 Medical Certificate.

154 Second Schedule, Form 3 Reception Order.

155 Secs 2 & 6.

provides for a guardian, who is defined as ‘any person having charge of a person with mental disorder’.¹⁵⁶

Section 11 provides for involuntary care ordered by the court ‘for a period not exceeding thirty days, or as may be necessary to enable the mental health practitioner to assess the nature of the mental disorder and provide treatment and care’. The Act also charges ‘any person taking care of a mentally disordered person’ to ‘ensure that the person does not abscond from treatment and care in that mental health care facilities’.¹⁵⁷

4 Assessing the three mental health laws against the CRPD standard

All three mental health laws considered allow for voluntary care, treatment and rehabilitation. However, under all the Acts, voluntary treatment can be converted into involuntary treatment if certain conditions exist. At the same time, all the Acts provide for care, treatment and rehabilitation without the consent of the individual once certain conditions are met. The common condition for involuntary treatment under all the Acts is where the person with a psychosocial disability is a danger to himself or herself or others. Hence, all three Acts limit the exercise of legal capacity by persons with psychosocial disabilities with regard to mental health treatment decision making. In addition, the Acts do not make a distinction between mental capacity and legal capacity. Under all the Acts, once an individual’s mental capacity is questioned, the individual loses the right to exercise legal capacity with regard to health care decision making among other spheres of decision making. It is clear that the Acts operate under a ‘best interests’ model rather than a model premised on the will and preference of the individual with psychosocial disabilities.¹⁵⁸

One of the key guiding principles under the CRPD is that of the full participation of persons with disabilities, often termed ‘nothing about us without us’.¹⁵⁹ The three Acts differ in the extent to which persons with disabilities are involved in mental health care systems, with the Ghanaian Mental Health Act legislating for the fullest involvement comparatively. For example, under the Ghanaian Act, the composition of the Mental Health Review Tribunal includes a service user.¹⁶⁰ Further, under the

¹⁵⁶ Sec 4(7).

¹⁵⁷ Sec 28(1).

¹⁵⁸ Eg, sec 7(2) of the South African Act explicitly states that ‘[i]n exercising the rights and in performing the duties set out in this Chapter, regard must be had for what is in the best interests of the mental health care user’. For more on ‘best interests’ versus ‘will and preference’, see General Comment 1 (n 23 above) para 21; E Flynn & A Arstein-Kerslake ‘Legislating personhood: Realising the right to support when exercising legal capacity’ (2014) 10 *International Journal of Law in Context* 96.

¹⁵⁹ Art 4(3) CRPD.

¹⁶⁰ Sec 25(2)(d).

Ghanaian Act, the Mental Health Authority should ‘consult persons with experience as service users as well as family members for the formulation, development and implementation of mental health policies’.¹⁶¹

The three Acts make mention of human rights, but differ substantially in the extent of rights protected. To illustrate, the South African and Ghanaian Acts propose specifically regulating intrusive and irreversible treatments and seclusion or restraint, while the Tanzanian Act is silent on this issue.¹⁶² South Africa’s Mental Health Care Act and the Ghanaian Mental Health Act make it mandatory for health care providers to inform mental health care users of their rights prior to treatment.¹⁶³ The Tanzanian Act is silent on this issue. The Ghanaian Mental Health Act has specific provisions for especially vulnerable persons, such as female mental health care users.¹⁶⁴ The South African Act also recognises the special vulnerability of children who use mental health services.¹⁶⁵ The Tanzanian Act is silent on this issue. All three Acts impose a penalty for neglecting or abusing a mental health care user.¹⁶⁶ Only the Ghanaian Mental Health Act provides for a treatment plan.¹⁶⁷ Under this Act, the mental health care user and their caregiver are to be involved in the development of a treatment plan.

The Acts contain a variety of safeguards around care, treatment and rehabilitation without informed consent. These include the right of appeal,¹⁶⁸ limiting the amount of time during which one can be held under involuntary care¹⁶⁹ and limiting the use of intrusive and irreversible treatments during emergency care.¹⁷⁰ An additional safeguard found only in the Ghanaian Act allows a person to lay complaints about management.¹⁷¹

Given the prevalence of human rights violations in alternative places of mental health treatment in the African context, it would be essential for mental health care laws to address this issue. Only the Ghanaian Mental

161 Sec 3(a).

162 Secs 26(5) & 66(1)(d) of the Ghana Mental Health Act; secs 66(1)(a) & (d) of the South African Mental Health Care Act.

163 Sec 17 South African Mental Health Care Act; sec 55(5) Ghana Mental Health Act.

164 Sec 64.

165 Sec 66(1)(h).

166 Sec 70(1)(c) South African Mental Health Care Act; sec 37(c) Tanzanian Mental Health Act; sec 94 Ghana Mental Health Act.

167 Sec 45.

168 Eg, sec 44(2) of the Ghana Mental Health Act; secs 35(1)(a) & 19(1)(a) of the South African Mental Health Care Act.

169 Seventy-two hours under sec 49(1) of the Ghana Mental Health Act; 24 hours under sec 9(2)(b) of the South Africa Mental Health Care Act.

170 Secs 26(5) & 57(5) the Ghana Mental Health Act.

171 Sec 59 Ghana Mental Health Act; the Tanzania Mental Health Act has a similar provision, but the provision is not specific about complaints regarding the *management*. Under the Tanzanian Act, one of the functions of the Patient Welfare Board is to receive complaints from individual patients, their relatives or any concerned third party relating to the affairs of patients.

Health Act addresses human rights violations in alternative places of mental health treatment. The Act requires the Minister to 'make regulations to provide for the welfare of patients and minimal conditions of environmental hygiene in mental health facilities including spiritual mental health facilities'.¹⁷²

Persons with psychosocial disabilities can benefit significantly from community support services. Peer support, for example, is an effective tool to support people experiencing severe emotional distress and to prevent coercion in mental health services.¹⁷³ However, none of the Acts entrenches peer support in legislation.

5 Conclusion and recommendations

The mental health laws of South Africa, Ghana and Tanzania all fall below the standard set in articles 12 and 25 of the CRPD. In legalising the non-consensual psychiatric treatment of persons with psychosocial disabilities, the mental health laws of the three countries also violate the rights of persons with disabilities to equality and non-discrimination. Article 4(b) of the CRPD calls upon state parties 'to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities'. Hence, it is clear that the reform of the mental health laws of the three countries is urgently required, given that the three countries have ratified the CRPD.

There are many challenges in Africa in implementing the right to the highest attainable standard of mental health, namely, limited resources;¹⁷⁴ corruption;¹⁷⁵ weak monitoring systems;¹⁷⁶ and limited expertise on providing health care to persons with disabilities.¹⁷⁷ It is conceded that health budgets in Africa have many demands, including HIV/AIDS, malaria and other diseases. However, mental health should also be considered a priority issue, including in resource allocation. Resource allocation should cover all the important elements of mental health care, including support for decision making; the provision of care in the community; monitoring the quality of health care services; and adequate funding for the various bodies set up under the Mental Health Acts.

172 Sec 96(1)(g).

173 Devandas (n 64 above) para 85.

174 O Nnamuchi & S Ortuanya 'The human right to health in Africa and its challenges: A critical analysis of Millennium Development Goal 8' (2012) 12 *African Human Rights Law Journal* 193.

175 Nnamuchi & Ortuanya (n 174 above) 185-189.

176 World Health Organisation Regional Office for Africa, Brazzaville, Congo 'Leveraging eHealth to improve national health systems in the African region' <https://www.who.int/sites/default/files/ahm/reports/47/ahm-issue-14-leveraging-ehealth.pdf> (accessed 9 May 2017).

177 Centre for Human Rights *Changing the landscape: Core curriculum on disability rights for undergraduate law students in Africa* (2015) 79.

In implementing the right to the highest attainable standard of health care, collaboration and partnerships between public authorities and civil society organisations, including representative organisations of persons with disabilities, is important, especially in the area of provision of support.¹⁷⁸

178 Devandas (n 64 above) para 64.

REGIONAL DEVELOPMENTS

DISABILITY RIGHTS DEVELOPMENTS IN THE EAST AFRICAN COMMUNITY POST-2012

*Damalie Naggita-Musoke**

1 Introduction

The development of disability rights saw a spate of growth in the period preceding 2013 both internationally and in the East African region. During this period, most East African Community (EAC) partner states ratified the UN Convention on the Rights of Persons with Disabilities (CRPD)¹ as well as took steps to enact or review domestic legislation in the area of disability. At the East African regional level, several instruments were concluded for the empowerment of persons with disabilities as well as the advancement of their rights. However, there appears to have been a slowing down of this initial momentum, as will be shown below².

As an organising bloc, the EAC has various mandates. Although the Community is premised on the economic co-operation of partner states parties, a number of areas of co-operation are spelt out in both its Establishing Treaty and the Protocol.³ For example, under the Protocol, while partner states have the broad mandate to harmonise social policies, they are specifically obligated to, among others, harmonise their social policies relating to

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1 GA Res A/RES/61/06, adopted on 13 December 2006, entered into force on 3 May 2008.

2 Murungi also reported limited developments in disability rights in the East African sub-region in the period 2013-2014. See LN Murungi 'Disability rights in the sub-regional economic communities during 2013' (2014) 2 *African Disability Rights Yearbook* 323.

3 Treaty for the Establishment of the East African Community 1999 (Treaty), and Protocol on the Establishment of the East African Community Common Market 2009 (Protocol).

good governance, the rule of law and social justice; promotion and protection of human and peoples' rights; promotion of equal opportunities and gender equality; promotion and protection of the rights of marginalised and vulnerable groups.⁴

In addition, partner states must implement programmes which expand and improve social protection; promote the rights of persons with disabilities; and prevent and manage epidemics and other diseases to improve hygiene and health and eliminate ignorance, diseases and poverty.⁵ The implementation of all these aspects is within the spirit and broad mandate of the East African Community Treaty in terms of which partner states must adopt a common approach towards marginalised groups, and ensure equality and equity with the ultimate goal of ensuring empowerment for all.⁶ Thus, while the documents establishing the Community do not specifically spell out disability as a key area for co-operation, the aforesaid provisions as well as the activities of the EAC clearly show that disability has been taken up as a key area for co-operation and intervention.

A potentially significant development during this period has been the judgment of the Appellate Division of the East African Court of Justice in the case of *Democratic Party v The Secretary-General of the EAC*,⁷ which has opened up the possibility of the Court assuming jurisdiction in human rights matters.⁸

In respect of law and policy development, the Community, for example, has developed the EAC Policy on Persons with Disabilities as well as the EAC Persons with Disability Bill. The Community also adopted the Strategic Plan for Gender, Youth, Persons with Disabilities, Social Protection and Community Development 2012-2016. This commentary seeks to analyse these legal developments, and assess how far they have been effective in protecting and promoting the rights of persons with disabilities in the region.

2 EAC Policy on Persons with Disabilities (2012)

This policy was adopted in March 2012 with the broad objective of serving as a mechanism for promoting and ensuring the full and equal enjoyment of human rights and fundamental freedoms by persons with disabilities as well as respect for their inherent dignity.⁹ It was the culmination of a series

4 Protocol (n 3 above) art 39(2).

5 Protocol art 39(3).

6 Treaty (n 3 above) art 120(c).

7 Appeal No 1 of 2014, judgment of Appellate Division delivered on 28 July 2015.

8 See eg A Possi 'It's official: The East African Court of Justice can now adjudicate human rights cases' 1 February 2016 <https://africlaw.com/2016/02/01/its-official-the-east-african-court-of-justice-can-now-adjudicate-human-rights-cases/> (accessed 21 September 2017); see also Murungi (n 2 above) 325.

9 EAC Policy on Persons with Disability (Policy) 28.

of meetings, dialogues and consultations with various stakeholders as well as experts on issues of disability. The first EAC Conference on persons with disabilities also played an important role in the conclusion of this instrument.¹⁰ The policy was seen as a tool for the promotion of equality and equity and would be used as a yardstick to inform other policies, programmes and sectoral plans among EAC partner states.¹¹ It was intended to promote a framework for enhancing the recognition of the roles, contributions and potential of persons with disabilities in the development process; strengthening and developing the informal and formal community-based support systems and actions for persons with disabilities; recognising that disability is not inability; providing special safety nets for persons with disabilities; ensuring and improving access to rehabilitation, education, training and community sports; guiding, co-ordinating and harmonising interventions for persons with disabilities by stakeholders; promoting and protecting disability rights as human rights; promoting research on disability issues; and promoting the self-representation of persons with disabilities in all public decision-making structures.¹²

The policy was developed after a comprehensive analysis of national legislation, policies and reports on the status of implementation of the CRPD. Several gaps and challenges affecting persons with disabilities were identified during the consultations with partner states. This prompted the need for a policy that would provide an enabling environment by partner states for the empowerment of persons with disabilities through facilitating effective participation in development initiatives.¹³ Although the CRPD envisages a limited role for regional integration organisations such as the EAC in its implementation, the EAC Treaty does not bestow on the Community a mandate to ratify treaties.¹⁴ Thus, there is the need for an EAC framework for co-operation in the area of disability rights. Accordingly, the policy has very elaborate provisions on equitable access, social protection and capacity building at all levels.¹⁵

The policy made a number of recommendations for partner states' attention and action, some of which have been implemented. For example, Burundi ratified the CRPD on 22 May 2014 as had been recommended,¹⁶ and there has been increased state spending in Kenya.¹⁷

10 Conference held in February 2010, Kampala, Uganda; see also Murungi (n 2 above) 325.

11 Policy (n 9 above) 28.

12 Policy (n 9 above) 7.

13 <http://www.eac.int/sectors/gender-community-development-and-civil-society/pwds> (accessed 15 May 2017).

14 Murungi (n 2 above) 324.

15 Policy (n 9 above) 28.

16 <http://www.ohchr.org> (accessed 12 May 2017).

17 Government provides sun cream to persons living with albinism. The budget towards the disability fund has increased and grants are offered to organisations to establish peer support groups for persons with disabilities.

Perhaps deserving more detailed mention is South Sudan, the latest entrant to the EAC.¹⁸ One year after joining the Community, it still has not ratified the CRPD or its Optional Protocol¹⁹ as required by the EAC Disability Policy. On a positive note, it has in place the National Disability and Inclusion Policy 2013,²⁰ the purpose of which is to provide a sound direction to all stakeholders on how to overcome multiple barriers at policy, service, community and governance levels towards an inclusive South Sudan where all men and women and boys and girls with different disabilities can contribute to the further development and reconstruction of the country.²¹ The Policy recognises that discrimination against and the exclusion of persons with disabilities are among the major threats to the realisation of the human rights of persons with disabilities, undermining their ability to benefit from the development process.²² The Policy also acknowledges the fact that South Sudan has not ratified a number of International legal instruments, including the CRPD, but asserts that the Policy was developed in conformity with principles enshrined, among others, in the CRPD.²³ The Policy is guided by the principles of non-discrimination and a human rights-based approach, affirmative action, diversity and inclusiveness, participation and disability mainstreaming.²⁴ Finally, one of the priority intervention areas of the Policy is 'support of ratification, awareness and capacity building of the UN Convention on the Rights of Persons with Disabilities and other related international and regional instruments'.²⁵ Apart from this policy, South Sudan has no specific Disability Act, neither does it expressly protect the rights of persons with disabilities in its Constitution, although it refers to (but does not define) 'persons with special needs'.²⁶

It should be noted, however, that five years after the inception of the EAC Policy, there is not much to be written regarding its implementation. State parties continue to adhere to the national implementation of laws and policies as opposed to implementation of the regional policy. The policy provides for review every five years.²⁷ Although the said five years elapsed in March 2017, the policy has not yet been reviewed, neither has there been a comprehensive review of the performance of partner states towards implementing the policy objectives and provisions. It is hoped that

18 South Sudan joined the EAC in April 2016; <http://www.eac.int/republic-south-sudan> (accessed 20 September 2017).

19 <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx> (accessed 20 September 2017).

20 <http://mgcswws.org/wp-content/uploads/South-Sudan-National-Disability-and-Inclusion-Policy.pdf> (accessed 20 September 2017) (South Sudan Policy).

21 South Sudan Policy (n 20 above) 16.

22 South Sudan Policy 6.

23 South Sudan Policy 14.

24 South Sudan Policy 15-16.

25 South Sudan Policy 24.

26 South Sudan *Universal Periodic Review – National Report* UN Doc A/HRC/WG.6/26/SSD/1 3 <https://uprdoc.ohchr.org/uprweb/downloadfile.aspx?> (accessed 20 September 2017).

27 Policy (n 9 above) 41.

this review will still take place and that it will address the issue of ensuring the effective implementation of the policy. This is very important as the implementation framework in the policy provides for the EAC Secretariat as the lead implementation agency, but leaves the responsibility for effective implementation to each partner state. Funding for the policy, meanwhile, is provided for in a vague way that confers the role of resource mobilisation on national disability councils.²⁸ The contradiction here is that these councils depend on national governments for their own funding, and would thus not be in a position to raise adequate funding for the effective implementation of the policy. The additional provision of financing the policy within the existing funding mechanism of the EAC also may not amount to much in the absence of a clear undertaking to commit funds for the implementation of the policy.

3 EAC Persons with Disability Bill (2015)

One of the landmark outcomes of the 2010 EAC Disability Conference was the decision to institutionalise the EAC Disability Conference and to hold it every two years.²⁹ The Conference did not take place in 2012 and no explanation has been put forward for this lapse. The second Conference took place in 2014.³⁰ During the 2014 Conference on disability, a call was made for the development of a regional law on disability. This was viewed as an opportunity to integrate the standards of the CRPD into EAC law and to provide a comprehensive legal framework for the protection of the rights of persons with disabilities in the EAC through the enactment of a 'regional special needs Act'.³¹ The EAC Persons with Disability Bill was subsequently presented to the East African Legislative Assembly (EALA) in July 2015.

The broad objective of this Bill is for partner states *inter alia* to take appropriate and effective measures, including policy, legislative, administrative and budgetary steps, to ensure and protect the rights and dignity of persons with disabilities. In promoting and protecting the rights of persons with disabilities, apart from the general obligations, the Bill is organised around a number of core areas. These are equality and non-discrimination; life and security of persons with disabilities; living in the community; accessibility, mobility and social protection; employment; education; health; and women, children and older persons with disabilities.

28 As above.

29 19-20 February 2010, Kampala, Uganda.

30 19-20 June 2014, Nairobi, Kenya.

31 *Report of the 2nd EAC Conference on Persons with Disabilities* (June 2014) Recommendation (e).

The Bill recognises the fact that persons with disabilities are prone to multiple discrimination on account of various factors, including birth, age, gender, sex, economic and/or social status, and enjoins partner states to ensure their protection through policy, legislative, administrative and other measures.³² It emphasises accessibility to goods, services and information and recognises the right to independent living.³³ The Bill provides for the right to decent and productive work as well as favourable conditions of employment for persons with disabilities, and enjoins partner states to ensure that they are accorded reasonable accommodation at the workplace.³⁴ The rights to education (including inclusive education), health and social protection are guaranteed by the Bill, with partner states under a duty to take effective and appropriate measures to ensure and facilitate the enjoyment of these rights.³⁵ The Bill recognises the multiple vulnerabilities of women, children and older persons with disabilities and makes express provision for their special protection.³⁶ In particular, the Bill recognises and obliges partner states to take into account age-related aspects of disability in their programming and resourcing, and devotes a whole article to areas of intervention partner states must include in addressing disability and ageing.³⁷ The recognition of the link between ageing and disability is a welcome development that should help to address a section of the population which is at increasing risk due to urbanisation and the breakdown of traditional ways of life, where social support is no longer guaranteed in the family setting as was the case in the past. In addition to the above, the Bill provides for political participation of persons with disabilities.³⁸

Part XIII of the Bill is devoted to institutional arrangements, with the establishment of the EAC Commission for Persons with Disabilities as the monitoring and implementing agency for the law, with powers to establish technical committees for the better execution of its functions.³⁹ The Bill also provides for the establishment of the East African Community Persons with Disability Fund for purposes of providing support to persons with disabilities. This funding, among others, is to be contributed by partner states.⁴⁰

Another provision worth noting in this Bill, for example, is the recognition that persons with disabilities are not only rights holders but also duty bearers.⁴¹ In this respect, persons with disabilities have the duty to respect and give consideration to others without discrimination on any

32 EAC Persons with Disability Bill (2015) (EAC Bill) arts 5 & 6.

33 EAC Bill (n 32 above) arts 13 & 16.

34 EAC Bill Part V.

35 EAC Bill Parts VII, VIII & X.

36 EAC Bill Part XI.

37 EAC Bill art 24.

38 EAC Bill Part IX.

39 EAC Bill arts 26 & 31.

40 EAC Bill arts 35 & 36(a).

41 EAC Bill Part XV.

ground and to promote and reinforce mutual respect and tolerance. Persons with disabilities must also fully participate in all spheres of life within their families, communities and states, and raise awareness and educate others on issues of disability. Finally, these persons have the duty to preserve and strengthen positive African cultural values in society and contribute to its moral well-being. In this respect, it is in consonance with the draft African Disability Rights Protocol⁴² adopted in 2016 by the African Commission on Human and Peoples' Rights. Guided by the African Charter on Human and Peoples' Rights (African Charter),⁴³ this Protocol recognises persons with disabilities as duty bearers by providing:

- 1 State parties shall recognise that persons with disabilities have duties on an equal basis with others as elaborated by the African Charter.
- 2 State parties shall ensure that persons with disabilities are rendered the forms of assistance and support, including reasonable accommodations, which they may require in performance of such duties.⁴⁴

In addition to the above, there is the provision that the EAC Persons with Disability Act shall take precedence over other laws in partner states to which its provisions relate.⁴⁵ This provision makes good sense when viewed from the perspective of the EAC Treaty, and especially the Protocol to the Treaty, which provides for harmonisation of social policies. By expressly making national legislation subject to this law, it avoids situations of partner states invoking supremacy of their domestic laws, including their constitutions in case of a conflict of provisions. However, as novel as this provision may be, perhaps it has created the very situation where the Bill has failed to move to the status of an Act which would bind all partner states since it would have had the effect of imposing on the sovereignty of partner states. While the Bill does not impose sanctions on states for infringing its provisions, no state would like to be found wanting since in many respects the proposed Bill imposes mandatory obligations. Some of these obligations would require states to commit huge sums of money from their budgets towards their implementation.⁴⁶ This could be one of the reasons why, after exhaustive debate and after seemingly having been well received, there is no instrument formally pronouncing this Bill as law, despite media reports to this effect.⁴⁷

42 Draft Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (Draft Protocol).

43 African Charter on Human and Peoples' Rights OAU Doc CAB/LEG/67/3 rev. 5, entered into force on 21 October 1986.

44 Draft Protocol (n 42 above) art 26.

45 EAC Bill (n 32 above) art 40.

46 See eg provisions that guarantee education, health and social security as rights.

47 See 'EALA passes Bill on PWDs, wants dignified, humane treatment for all' <http://www.eac.int/news-and-media/press-releases/20160601/eala-passes-bill-pwds-wants-dignified-humane-treatment-all> (accessed 28 July 2017); 'East Africa: EALA passes Bill on Persons with Disability' <http://allafrica.com/stories/201606070902.html> (accessed 28 July 2017).

The status and progress of this proposed legislation thus remains unclear with some claims that it has already been passed into law by the EALA.⁴⁸ Since 1 June 2016, the date of the latest recorded activity by the EALA concerning this Bill, there appears to have been no progress in either formalising the legislative process for the Bill to pass into law, or taking up the implementation of its provisions, assuming it has been enacted into law. From the EAC Secretariat, there appears to be no evidence of further discussions, dialogues or debates that have taken place regarding this Bill. There is also no evidence that the biennial third EAC Conference on Disability took place in 2016. What should be noted, though, is that according to the EAC Treaty, the heads of state may assent to or withhold assent to a Bill of the Assembly, but if a Bill does not receive assent within three months from the date on which it was passed by the Assembly, it shall be referred back to the Assembly, giving reasons, and with a request that the Bill or a particular provision thereof be reconsidered by the Assembly.⁴⁹ If the Assembly discusses and approves the Bill, the Bill shall be resubmitted to the heads of state for assent, but if a head of state withholds assent to a resubmitted Bill, the Bill shall lapse.⁵⁰ At the time of writing, it has been more than three months since the Bill was passed by the EALA and, for now, it is more likely than not that for it to pass into law, it will have to go through the above procedure as provided for in article 63. What is of great concern, though, is the possibility of one or more of the EAC heads of state refusing to assent to it after resubmission. This would be a huge blow to development and the harmonisation of laws, policies and practice in the area of disability in the region since, according to the EAC Treaty, in such a case the proposed law lapses.⁵¹

It should be pointed out that in the meantime, some partner states have embarked on processes to amend their national disability legislation.⁵² While noting that the content of these Bills may change along the way, it is still pertinent to point out some areas of importance. For example, Uganda's Bill in its current form tends to make government shirk its responsibilities of providing for persons with disabilities.⁵³ While according to the current Act government is under an obligation to promote the educational development of persons with disabilities,⁵⁴ according to the 2014 Bill there is no similar obligation on government but, instead,

48 As above.

49 Treaty (n 3 above) art 63.

50 As above.

51 As above.

52 Uganda has drafted and presented for input and debate the Persons with Disabilities Bill 2014; Kenya is also in the process of amending its current law on disability (Persons with Disabilities Act 14 of 2003).

53 V Kange 'The Persons With Disabilities Bill 2014: A poor attempt at reinventing the wheel' <https://www.scribd.com/document/288873582/PWD-BILL-2014-A-Poor-Attempt-at-Re-inventing-the-Wheel-Final> (accessed 22 August 2017).

54 Persons with Disabilities Act 2006 (Uganda) sec 5.

only a prohibition of discrimination by schools or institutions of higher learning.⁵⁵ Likewise, in the area of health services, the current law enjoins government to promote special health services required by persons with disabilities, including by

- (a) providing access to reproductive health services which are relevant to women with disabilities;
- (b) enforcing user-friendly hospital materials, for use by persons with disabilities visiting hospitals; and
- (c) encouraging population-based public health programmes relevant to persons with disabilities.⁵⁶

However, there is no similar provision in the proposed 2014 Bill, which instead is totally silent about this area of the lives of persons with disabilities. The same applies to employment, with the Bill narrowing down or completely removing the express obligation of government to act, promote, protect and ensure the equal enjoyment of all rights by persons with disabilities. Ultimately, the Bill adopts mostly passive language in place of the mandatory obligations that the current Act places on government as a key actor in the implementation and realisation of the provisions of the proposed law.

As far as Kenya is concerned, on the whole, Kenya's Bill contains a tightening of the obligations and duties of the Kenyan government towards empowerment and the realisation of the rights of persons with disabilities. For example, in the area of education, government has the duty to facilitate participation of persons with disabilities in accessible and adaptable continuing adult education programmes on an equal basis, as well as to ensure that persons with disabilities have access to inclusive education, without discrimination and on an equal basis at all levels.⁵⁷ This imposes an obligation on government to act, as opposed to the corresponding provision of the Act⁵⁸ which prohibits discrimination in education and imposes duties to act on 'learning institutions' without any direction obligation on government.⁵⁹ The Bill also guarantees education, health and employment as rights, which is not the case with the Act.⁶⁰ However, it remains for the courts to determine how justiciable these will be if or when the Kenyan Bill is passed into law.

It is not yet clear what the import of these developments is, especially as far as co-operation in the area of disability rights is concerned, and if such ongoing legislative processes may not undermine achievements so far

55 Persons with Disabilities Bill 2014 (Uganda) sec 6.

56 As above.

57 Persons with Disabilities Bill 2016 (Kenya) secs 18(3) & (4).

58 Persons with Disabilities Act 14 of 2003 (Kenya) sec 18(1).

59 Persons with Disabilities Act 14 of 2003 (Kenya) sec 18(3).

60 Persons with Disabilities Bill (n 58 above). See secs 18, 19 & 22.

made. It is also not clear whether these law reform processes may not be precipitated by the lack of progress and/or inability to enact a uniform legal instrument for disability rights and concerns for the region. In the case of Uganda, it is not certain why it would opt for a watered-down version of the current law in light of its obligations under the CRPD as well as the provisions of the East African Community Disability Bill. Owing to criticism of the 2014 proposed Bill, Uganda is in the process of redrafting an improved version intended to address the concerns raised by disabled people's organisations (DPOs) as well as other activists in the area.⁶¹ However, this 2016 version is yet to be presented to parliament for debate.

4 EAC Strategic Plan for Gender, Youth, Persons with Disabilities, Social Protection and Community Development (2012-2016)

This Plan was intended to promote the inclusion of diversity of the people in the region in development, and seeks to eliminate disparities in service provision. It is also intended to ensure that services are available to all citizens with disabilities, older persons and those disadvantaged and vulnerable due to a lack of social security for everyday socio-economic needs.⁶² The Strategic Plan recognised disability as a development issue, noting that disability may increase the risk of poverty and *vice versa*, with adverse impacts on education, employment and earning ability and increased expenditure related to disability. The Plan also makes the fundamental link between disability and ageing.⁶³ According to the Strategic Plan,

[s]ocial protection has multiple beneficial impacts and is essential to build human capital, break the intergenerational poverty cycle and reduce the growing inequalities that constrain ... economic and social development.⁶⁴

The Plan thus came up with various objectives for the thematic area of persons with disabilities, the main objective being promoting and ensuring the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities for improved livelihoods.⁶⁵ It is worth noting that most of the activities envisaged for the realisation of the main goal, as well as the immediate objectives of the Plan for the thematic

61 Persons with Disabilities Bill 2016 (Uganda) taking into account concerns of DPOs to include affirmative action which was omitted in the 2014 version (see Part II); and provides for health and education as rights of persons with disabilities which is not in the 2014 version. At the time of writing, the 2016 version is yet to be tabled before cabinet.

62 EAC Strategic Plan for Gender, Youth, Persons with Disabilities, Social Protection and Community Development 2012-2016 (EAC Strategic Plan) 32.

63 EAC Strategic Plan (n 61 above) 31-34.

64 EAC Strategic Plan 34.

65 EAC Strategic Plan 53.

area, mainly hinge around the development of a harmonised regional policy and legal framework on disability issues.⁶⁶ As already noted, the relevant policy is in place but with some shortcomings, as observed above. At the same time, the relevant law has not yet been enacted although it had been envisaged to be in place by 2014.⁶⁷ At the time of writing, about a year after the life span of the Plan, the EAC has not carried out any review process to assess the implementation and performance of this Plan by partner states. There is also no follow-up Strategic Plan for the post-2016 period in place.

5 Conclusion

It is evident that the EAC has taken some steps towards adopting and harmonising regional law and policy for promoting and ensuring the protection of the rights of persons with disabilities.⁶⁸ The Community must thus be commended for the steps so far taken, since the creation and harmonisation of standards would go a long way towards ameliorating the plight of persons with disabilities in the region. Co-operation in this area is thus a positive step which can provide a platform for partner states to plan and share information and to learn from and assist each other in matters concerning disability. However, it should be remembered that the key issue is the need for effective implementation of laws, policies, programmes and plans as agreed upon. Law reform and legislation may not in themselves be solutions if these are not backed by clear implementation programmes as well as budgeting for intended activities and interventions. Partner states thus need to fully commit, not only by signing legal and policy instruments but, in addition, by taking active steps to ensure the implementation of these instruments. A key aspect of this, apart from political will, is the need to identify and allocate adequate funding for essential activities, especially since many of the necessary practical interventions in the area of disability require substantial funding. This is what will indicate the level of seriousness of the EAC as opposed to paying lip service to disability rights. To a great extent, this is what will determine the success or failure of the EAC in its endeavours to secure the protection and enjoyment of human rights and fundamental freedoms to persons with disabilities. In this respect, the EAC has slowed down, gravely impacting its initial momentum in the protection of the rights of persons with disabilities.

66 EAC Strategic Plan 37 53-56 74.

67 EAC Strategic Plan 54.

68 As part of its efforts towards the harmonisation of laws and policies, the EAC has also adopted the EAC Child Policy with the purpose, among others, of providing a framework for harmonisation, prioritisation and implementation of children's rights at the national level, as well as promoting joint planning, monitoring and evaluation of emerging children's rights concerns. On the whole, the policy provides for children generally with no specific emphasis on children with disabilities, except in a few areas such as the promotion of child participation in line with age, disability and maturity of the child; <http://ovcsupport.org/wp-content/uploads/2017/04/FinalEACChildRightsPolicy2016.pdf> (accessed 19 September 2017).

BOOK REVIEW

ELIZABETH BARNES: *THE MINORITY BODY: A THEORY OF DISABILITY* (2016)

Charles Ngwena*

Oxford: Oxford University Press 1-197; i-xii. ISBN 978-0-19-873258-7

1 Introduction

Regardless of the cultural setting, it is hard to find consensus on how we understand or, much less, ought to understand disability. Within as well as across cultures, there are different epistemologies of disability, each with its own cultural history and normative implications. Some epistemologies are built on culturally-embedded assumptions of disability as something explicable primarily in terms of bodily and mental impairment which is intrinsically bad. Others seek to counter this deficit approach in a variety of ways. Furthermore, disability epistemologies forever are in flux rather than fixed. Indeed, part of the explanation behind the absence of a definition of 'disability' in the first disability rights-specific human rights treaty, adopted in 2006 – the Convention on the Rights of Persons with Disabilities (CRPD)¹ – is precisely because its architects wished to avoid dogmatism in favour of an understanding of disability which is cognisant of the contested and ever-evolving nature of disability.²

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1 GA Res 61/611, adopted on 13 December 2006, entered into force on 3 May 2008.

2 A Lawson 'The United Nations Convention on the Rights of Persons with Disabilities: New era of false dawn' (2007) 34 *Syracuse Journal of International Law and Commerce* 563 593-594.

The subject of this review – *The minority body: A theory of disability* – is a book written by Elizabeth Barnes, an American philosopher. *The minority body* belongs to the domain of discourses that seek to vigorously counter a deficit epistemology of disability built around disability primarily as a biological disorder and its medicalised imprimatur. Barnes's book is an important addition to contemporary debates on disability. Its importance does not lie in saying something entirely new about disability to contest a deficit approach to disability. Rather, it lies in giving theoretical voice to a marginalised view in disability discourses. It is a voice which is open-minded about whether disability is good or bad and, thus, leaves sufficient discursive space for conceiving disability as plenitude rather than always sub-optimal. This is an approach Barnes describes as a 'value-neutral model' of disability in which disability is 'mere-difference' but not automatically 'bad-difference'.

Barnes's central thesis or her overriding motif is neatly summarised in the following proposition which she makes in chapter 3 of the book:³

Having a disability is something that makes you different but not something that makes you worse off because of that difference. Being disabled is something that makes you a minority – it is a way of having a *minority* body.

This proposition, which speaks to the title of book, encapsulates the main claim the author attempts to theorise and substantiate through argumentation. Barnes's basic argument is that to be disabled is not to have a 'broken or defective body'; it is not something intrinsically bad or sub-optimal but rather is analogous to other minority status such as being gay in respect to sexuality.⁴

To appreciate the arguments in *The minority body* it is essential to begin with an understanding of what the book is *not* about, partly because 'disability' is often used as an umbrella term to encompass a multitude of disability conditions. Barnes begins by entering a caveat to limit the disability scope of her discourse. *The minority body* is primarily about 'physical disability'.⁵ The author highlights that she does not wish to be understood as seeking to develop a discourse that addresses all types of disabilities. Behind this caveat is the author's acknowledgment of the heterogeneous nature of disability and the difficulties of developing arguments that speak for all disabilities. Thus, whilst Barnes's arguments may have relevance for other types of disabilities, such as psychosocial and intellectual disabilities, the focus of her book squarely is on physical disabilities. She underscores the fact that there is no single notion of disability regardless of the fact that people who experience disability may organise on the basis of a common experience and solidarity.

3 78 (emphasis in original).

4 5.

5 2.

Another reason for limiting the scope of the book to physical disabilities is a method or theoretical approach emanating from what feminist discourses describe as 'standpoint epistemology'.⁶ For her argumentation, Barnes mainly relies on testimonies of disabled people who claim to value having a physical disability. The author uses first-hand testimonies from individuals who have experienced physical disabilities or from disability pride movements that speak on their behalf as an essential method for persuading readers about the authenticity and cogency of her claim that having a physical disability is something that makes you different but not worse off.

2 Overview of the book

The introduction aside, the book comprises six chapters. In the introduction, which is substantive, Barnes explains the goal of her book, its scope, method of argumentation and theoretical leanings. Describing her theoretical approach as 'social philosophy that is heavily influenced by feminist philosophy',⁷ the author explains her main goal as 'defending' (as opposed to advocating for the first time) a view that is already shared among disability rights movements which is that a 'physically-disabled' body is not a 'defective' body but simply a 'minority body'. She seeks to counter a culturally-dominant view of disability as a biological disorder and its deficit implications. In order to achieve her objective, the author regards it as crucial to reflect philosophically on the following questions: (1) What is disability? (2) What is the connection between disability and well-being? (3) What would it mean to say that disability is not something inherently bad or sub-optimal?⁸ Barnes regards these issues as foundational for any disability discourse.

The introduction is also important for an attempt to clear a terminological underbrush or, at least, to explain how the terminology to describe disability is used in this book. Barnes does not attempt to find universal terminology for describing disability since it would be a futile effort as disability is contested, thus, defying universalism. She 'uses' disability in a contingent manner that is synergic with her overall 'minority body' thesis. This thesis acknowledges disability as implicating the physical body and, more specifically, bodily difference. At the same time, Barnes's thesis is neutral to disability and does not read difference as implying something inherently sub-optimal.

6 In this context, 'standpoint epistemology' means not merely the desirability but, more significantly, the necessity of building knowledge and understanding about equality norms through integrating the lived experience of those that have been at the receiving end of exclusionary social practices: A Brooks 'Feminist standpoint epistemology: Building knowledge and empowerment through women's lived experience' in SN Hesse-Biber & P Leavy (eds) *An invitation to feminist method* (2007) 53-82.

7 2.

8 As above.

For Barnes, ‘disability’ means ‘particular bodily features or conditions’,⁹ and ‘disabled people’ are individuals who have such bodily features or conditions.¹⁰ Her use of ‘disability’ deliberately parts company with deficit approaches to disability. Equally significant, Barnes’s use of ‘disability’ is different from how the concept is used in popularised ‘people first language’ such as ‘people’ or ‘persons with disabilities’ which finds its formal human rights global adoption in the CRPD.¹¹ Barnes makes it abundantly clear that she is using ‘disability’ in a sense which approximates ‘impairment’ under naturalistic accounts of disability but without importing their underpinning deficit assumptions about corporeal difference. She says:¹²

I use the word ‘disability’ to refer to particular bodily features or conditions ... ‘disability’ refers to the physical states of bodies-to particular bodily features – my usage of ‘disability’ is closer to what is often meant by ‘impairment’ in the literature on disability ... I use ‘disabled people’ to refer to people who have the sorts of bodily features or conditions picked out by the term ‘disability’. I use ‘disabled people’ rather than ‘people with disabilities’ because ‘disabled people’ mirrors our usage of other terms which pick out minority groups – for example, we say ‘gay people’, not ‘people with gayness’.

In subsequent chapters, beginning with chapter 1, Barnes develops arguments to clarify and, more importantly, substantiate her premise of disability as bodily difference which is not intrinsically bad and is ‘neutral’ with respect to well-being.

In chapter 1 titled ‘Constructing disability’, Barnes clarifies her own social construction of disability. In addition to providing an alternative reading of disability to contest deficit approaches built around naturalistic assumptions about bodily capacity and functioning, she unpacks what is often painted with a broad brush or deliberately not given attention in the more popularised ‘social model’ discourses of disability, especially the version pioneered by British sociologists.¹³ She argues that it is better to treat the ‘social model’ of disability not as a single epistemology but, instead, as social constructionism of disability that encompasses a ‘family’ of approaches that may even contest one another.¹⁴ Her main contention is that the version of a social model approach which claims that disability is entirely constituted by prejudice against or lack of accommodation of persons with disabilities is inadequate, if not flawed and implausible. It is not true, Barnes argues, that all the bad effects of disability are socially mediated. Even if society were completely accepting, disability would still have dramatic effects on the lives and health of the affected individuals. To

9 5.

10 As above.

11 IK Zola ‘Self, identity, and the naming question: Reflections on the language of disability’ (1993) 36 *Social Science and Medicine* 167-173.

12 5.

13 M Oliver & C Barnes *The new politics of disablement* (2012).

14 25.

make her point, Barnes gives as examples disabilities that cause chronic pain; that require continued medical interventions or are progressive; and for which societal discrimination and social injustice do not hold any explanatory power.¹⁵

Barnes's criticism of the more popularised genus of the social model is not novel. Rather, it reiterates criticisms that, over the years, have come from within disability movements as well as from disability scholars, more generally. At the heart of the criticism is discontent with social constructionism which attributes disability entirely to discrimination and social injustice, but without taking full stock of the existential experience of impairment.¹⁶ Critics are not dismissive of the value this type of social constructionism has bestowed on disability rights struggles, but they say it is an inadequate epistemology. They do not deny that framing disability as the effect of an ableist society has been transformative in providing the impetus for the development of a jurisprudence of substantive equality and unfair discrimination for affirming the inherent dignity and equal citizenship of disabled people. Such framing has raised political consciousness about the marginalisation and exclusion of disabled people as social oppression and disadvantage which is structural in nature and ought to place an onus on society to dismantle disabling barriers. What critics contest is the effacement of embodiment in a social model of disability which attributes *all* the disadvantages experienced by disabled people to the social environment, but without saying a word about the experience of bodily impairment. Critics, including Barnes, say this type of social model is too reductionist; it over-dichotomises impairment and disability.¹⁷ By focusing on the social environment as the cause, the personal experiences (both positive and negative) of those who live with impairments are effectively silenced.

Partly against the backdrop of discontent with the adequacy of a social model which focuses only on the disabling effects of the social environment, Barnes argues for an epistemology of disability that takes impairments into account. She does not abandon social constructionism but decentres it. She describes her approach as 'moderate social constructionism'.¹⁸ It is an approach to disability which is socially constructed but places a *greater* emphasis on the actual features of the body.¹⁹ Barnes brings to social constructionism the visibility of the existential reality of impairments. The author puts a gloss on her approach

15 26.

16 T Shakespeare & N Watson 'The social model of disability: An outdated ideology' (2002) 2 *Research in Social Science and Disability* 9; D Anastasiou & JM Kauffman 'The social model of disability: Dichotomy between impairment and disability' (2013) 38 *Journal of Medicine and Philosophy* 441; B Hughes & K Patterson 'The social model and the disappearing body: Toward a sociology of impairment' (1997) 12 *Disability and Society* 325.

17 26-27.

18 38.

19 As above.

when she says ‘though disability doesn’t seem to be entirely explained by what disabled bodies are like, it’s also not entirely separate from what disabled bodies are like’.²⁰

The rest of the book (that is, chapters 2 to 6) is taken up by explicating and defending a ‘value-neutral model’ of disability which is a way of seeing physical disability as not defective or inherently bad. Above all, a value-neutral model is an approach to disability which asks us to view disability without any prior assumptions. In articulating this model of disability, it is important to Barnes to draw a distinction between ‘bad-difference’ and ‘mere-difference’ and their intersection with the concept of well-being.²¹ At the same time, the author is careful not to draw a rigid dichotomy between ‘bad-difference’ and ‘mere-difference’ as within each difference there is more than one view of what constitutes well-being. The point Barnes ultimately underscores is that ‘bad-difference’ is our ‘common sense’ epistemology of disability. It is not an objective truth but, instead, a product of socially-embedded views emanating from normative values about human flourishing which distinguish between what is normal and what is not.²² According to these values, impairment which reduces ability invariably is a detraction. Thus, even if ableism were eradicated, a disabled person would still be seen by the general society as someone who is likely to have unfulfilled desires than their counterpart without a disability. Even if a disabled person were to assert the contrary and claim to value disability as an experience of plenitude, this claim is likely to be dismissed not as an objective truth but as a mere ‘adaptive preference’.²³

To counter ‘bad-difference’, Barnes explains that the ‘mere-difference’ approach, which is an essential component of how the author constructs her value-neutral model, does not require us to see disability as something that is positively valued by everyone.²⁴ Equally, it does not require us to discount that some bad effects of disability are caused by societal prejudice and a lack of accommodation.²⁵ Barnes is not saying that ability is not valuable, but rather that it can be valuable without those who lack it being universally worse off and their experience of valuing disability being dismissed.²⁶ She is saying that there are some who value disability. Drawing on the work of Miranda Fricker, Barnes argues that to dismiss the experience of those who value disability amounts to both epistemic and

20 36.

21 Ch 2 especially focuses on articulating the concepts of ‘bad-difference’ and ‘mere-difference’.

22 61-63.

23 123-133. Barnes is critical of discourses of ‘adaptive preference’ she regards as speaking for disabled people from unarticulated assumptions rather than hearing their own voices, including the work of Harman: E Harman ‘I’ll be glad I did it reasoning and the significance of future desires’ (2009) 23 *Philosophical Perspectives* 177.

24 77-78.

25 As above.

26 95.

hermeneutic injustice.²⁷ It is injustice which is socially produced by a dominant epistemology of disability as a lack.

3 Significance

Barnes's book is a reminder that our disability debate did not end with the adoption of the CRPD in 2006. Contestation, contingency and conceptual metamorphosis are here to stay, and will continue to shape our disability discourses. As long as we are open to critical thinking and to interrogating not just prejudiced and stigmatising assumptions about disability but even progressive views about disability, including the hugely-popularised version of the 'social model' of disability, epistemologies of disability will forever be on the march.

For several reasons *The minority body* is an important book. It revitalises a marginalised epistemology of disability. It reminds us that, as we focus on implementing the CRPD to consolidate the gains made by the 'social model' largely pioneered by British sociologists,²⁸ the body still matters and should not be 'disappeared'. Whilst it is strategic to construct disability as the effect of a disabling environment, we need not efface embodiment. Impairments are real and, yet, they are not coterminous with intrinsic badness.

The emphasis of Barnes's discursive inquiry ultimately is on countering epistemic and hermeneutic justice, taking into account positionality so that we affirm the experience of each person, including those that experience impairment. The book affirms and celebrates human difference. Barnes explores the connection between disability and well-being in a manner designed to hearing all the voices, especially the voices of those who experience impairment and yet value their disability.

It is customary in a book review to attempt to find shortcomings in the subject of the review. Often the opportunity for criticism is presented when an author makes broad and sweeping claims. My sense is that Barnes meticulously avoids these common pitfalls. Therefore, Barnes's book does not easily provide one with a vantage point for criticism unless we are asking her to write a book she did not intend to write. From the very outset, Barnes is careful about making broad claims, including limiting her inquiry to physical disabilities rather than attempting to speak for all disabilities. The book is a work of admirable scholarship.

27 69-171; M Fricker *Epistemic injustice* (2007).

28 n 13 above.