

African Disability Rights Yearbook

Volume 7 2019

Pretoria University Law Press
PULP

2019

African Disability Rights Yearbook

Published by:

Pretoria University Law Press (PULP)

The Pretoria University Law Press (PULP) is a publisher at the Faculty of Law, University of Pretoria, South Africa. PULP endeavours to publish and make available innovative, high-quality scholarly texts on law in Africa. PULP also publishes a series of collections of legal documents related to public law in Africa, as well as text books from African countries other than South Africa. This book was peer reviewed prior to publication.

For more information on PULP, see www.pulp.up.ac.za

Printed and bound by:

Pinetown Printers, Durban, South Africa

To order, contact:

PULP
Faculty of Law
University of Pretoria
South Africa
0002
Tel: +27 12 420 4948
pulp@up.ac.za
www.pulp.up.ac.za

Cover:

Yolanda Boozyen, Centre for Human Rights

ISSN: 2311-8970
EISSN: 2413-7138
Open access online: <http://www.adry.up.ac.za>

© 2019

The financial assistance of the Open Society Foundations is gratefully acknowledged



OPEN SOCIETY
FOUNDATIONS

TABLE OF CONTENTS

EDITORIAL v

SECTION A: ARTICLES

- 1 The implications of Article 12 of the Convention on the Rights of Persons with Disabilities for the legal capacity of persons with psychosocial and intellectual disabilities in Ethiopia 3
Merga Yadesa Dibaba
- 2 Human rights and access to health care for persons with albinism in Africa 35
Ebenezer Durojaye and Satang Nabaneh
- 3 Conflicting discourses on conceptualising children with disabilities in Africa 59
Shimelis Tsegaye Tesemma and Susanna Abigaël Coetzee
- 4 Right to self-representation for people with mental disabilities in Kenya's courts 81
Paul Juma
- 5 The place of sign language in the inclusive education of deaf learners in Zimbabwe amid CRPD (mis)interpretation 96
Martin Musengi
- 6 Left in the periphery: An appraisal of voting rights for persons with disabilities in Zimbabwe 112
Nkosana Maphosa, CG Moyo and B Moyo

SECTION B: COUNTRY REPORTS

- Tchad 143
Serge Marcellin Tengho
- Mali 164
Marianne Séverin
- Burundi 186
Gerard Emmanuel Kamdem Kamga
- Republic of Congo 206
Marianne Séverin and Chretien Fontcha
- South Sudan 229
Innocentia Mgijima-Konopi, Theophilus M Odaudu and Reshoketswe Mapokgole

SECTION C: REGIONAL DEVELOPMENTS

Leveraging the international human rights system to
advance local change for South African women with
disabilities 247

Anastasia Holoboff & Suzannah Phillips

The right to an adequate standard of living in the Protocol
to the African Charter on Human and Peoples' Rights on
the Rights of Persons with Disabilities Africa 258

Yvette Basson

BOOK REVIEW

Simon Foley: *Intellectual disability and the right to a
sexual life* (2019) 268

Charles Ngwena

EDITORIAL

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

Section A of this volume features six articles by: Merga Yadesa Dibaba on the implications of article 12 of the CRPD for the legal capacity of persons with psychosocial and intellectual disabilities in Ethiopia; Ebenezer Durojaye and Satang Nabaneh on human rights and access to health care for persons with albinism; Shimelis Tsegaye Tesemma and Susanna Abigaël Coetzee on conceptualising child youth with disabilities and the dehumanising disability discourse; Paul Juma on the right to self-representation for people with mental disabilities in Kenya's courts; Martin Musengi on the place of sign language in the inclusive education of deaf learners in Zimbabwe; and Nkosana Maphosa, CG Moyo and B Moyo on the voting rights for people with disabilities in Zimbabwe.

Section B contains country reports on: Chad by Serge Marcellin Tengho; Mali by Marianne Séverin; Burundi by Gerard Emmanuel Kamga; and the Republic of Congo, Brazaville by Marianne Séverin, Chretien Fontcha; and South Sudan by Innocentia Mgiijima Konopi, Theophilus M Odaudu and Reshoketswe Mapokgole.

Section C on regional developments contains two commentaries by: Anastasia Holoboff & Suzannah Phillips on leveraging the international human-rights system to advance local change for South African women with disabilities; and Yvette Basson on Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa and the right to an adequate standard of living.

The 2019 volume ends with a book review of *Intellectual disability and the right to a sexual life* (2019) authored by Simon Foley. The book is reviewed by Charles Ngwena.

The financial assistance of the Open Society Institute Budapest Foundation (OSI) a Hungarian charitable foundation within the Open Society Foundations (OSF), in particular the Higher Education Support Project (HESP) is gratefully acknowledged.

Editors

Charles Ngwena (convening editor)

Ilze Grobbelaar-du Plessis

Heléne Combrinck

Serges Djoyou Kamga

Nkatha Murungi

SECTION A: ARTICLES

THE IMPLICATIONS OF ARTICLE 12 OF THE CONVENTION ON THE RIGHT OF PERSONS WITH DISABILITIES FOR THE LEGAL CAPACITY OF PERSONS WITH PSYCHOSOCIAL AND INTELLECTUAL DISABILITIES IN ETHIOPIA

Merga Yadesa Dibaba*

Summary

Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD) requires state parties to recognise the right to legal capacity of persons with disabilities in its fullest sense. Historically, persons with disabilities have been denied their right to legal capacity. Various states at different times declared persons with psychosocial disabilities, intellectual disabilities, communicative barriers, and in some cases, physical disabilities as legally incapable.¹ As a result, the fate of persons with disabilities has been decided either by their relatives or formally appointed guardians. This is the lived reality of persons with intellectual and psychosocial disabilities in many countries including Ethiopia even after the CRPD came into force. This article scrutinises the implications of article 12 of the CRPD for the right to legal capacity of persons with intellectual and psychosocial disabilities in Ethiopia.

1 Introduction

Making decisions about one's own affairs is central to a person's autonomy and is at the core of personhood.² It is a vital component that enables an individual to have a say over his/her life and take part in society.³ Legal

* LLB (Addis Ababa University), LLM (University of Pretoria), Legal researcher, Secretariat of the African Committee of Experts on the Right and Welfare of the Child. The author would like to thank editors of the African Disability Rights Yearbook for their constructive comments. The article is based on a dissertation I completed for the LLM in Human Rights and Democratisation in Africa (HRDA), Centre for Human Rights, Faculty of Law, University of Pretoria.

1 W Holness 'Equal recognition and legal capacity for persons with disabilities: Incorporating the principle of proportionality' (2014) 30 *South African Journal on Human Rights: Disability* 313 314.

2 S Pathare & LS Shields 'Supported decision-making for persons with mental illness: A review' (2012) 34 *Public Health Reviews* 1.

3 Pathare & Shields (n 2 above).

MY Dibaba 'The implications of article 12 of the Convention on the Right of Persons with Disabilities for the legal capacity of persons with psychosocial and intellectual disabilities in Ethiopia' (2019) 7 *African Disability Rights Yearbook* 3-34 <http://doi.org/10.29053/2413-7138/2019/v7a1>

capacity is the concept that refers to power of persons to make legally recognised decisions. Without legal capacity, an individual is not considered as a person in the eyes of the law.⁴ Hence his/her decisions have no legal effect. Consequently, a person who is stripped of legal capacity cannot perform day to day activities like opening and maintaining a bank account, buying or selling property, renting accommodation, and so forth.

In many states, persons with disabilities particularly persons with psychosocial and intellectual disabilities have been denied legal capacity.⁵ Recently, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) has introduced a new paradigm by fully recognising the right to legal capacity of persons with disabilities. The CRPD requires states parties to recognise persons with disabilities' right to enjoy legal capacity on an equal basis with others in all aspects of life.⁶

Although Ethiopia signed the CRPD on 30 March 2007 and ratified it on 7 July 2010,⁷ it did not adopt legal reforms to recognise the right to legal capacity of persons with disabilities. As a result, persons with disabilities (particularly persons with intellectual and psychosocial disabilities) are denied their right to legal capacity. This article examines how the right to legal capacity of persons with intellectual and psychosocial disabilities is addressed under the Ethiopian legal system. It discusses the implications of article 12 of the CRPD for the right to legal capacity of persons with psychosocial disabilities⁸ and persons with intellectual disabilities⁹ in Ethiopia. It commences by shedding light on how legal capacity is understood in the context of human rights. It then discusses the right to legal capacity of persons with disabilities, in particular persons with intellectual and psychosocial disabilities as envisaged by the CRPD. After discussing the right to legal capacity of persons with intellectual and

4 European Commissioner for Human Rights 'Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities' (2012) https://www.coe.int/t/commissioner/source/.../IP_LegalCapacity_GBR.pdf (accessed 21 March 2015).

5 CRPD Committee General Comment 1: Article 12: Equal recognition before the law (2014) UN Doc CRPD/C/GC/1 dated 19 May 2014 paras 7 and 9.

6 Art 12(2) of the CRPD.

7 See art 3 of the CRPD Ratification Proclamation, Proclamation No 676/2010.

8 Persons with psychosocial disabilities are: Persons who define themselves as: users or consumers of mental health services; survivors of psychiatry; people who experience mood swings, fear, voices or visions; mad; people experiencing mental health problems, issues or crises. See World Network of Users and Survivors of Psychiatry 'Psychosocial disability' (2012) http://www.wnusp.net/documents/2012/Psychosocial_disability.docx (accessed 20 August 2015).

9 Intellectual disability, also known as developmental delay or mental retardation, can be understood as a disability characterised by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills and originates at birth or before the age of 18. See M Bach & L Kerzner 'A new paradigm for protecting autonomy and the right to legal capacity' (2010) 15-16 <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf> (accessed 5 June 2015).

psychosocial disabilities under the Ethiopian legal system, the article ends with a conclusion and recommendations.

2 Understanding legal capacity in the context of human rights

Legal capacity is the concept that refers to a person's power to act within the framework of a legal system.¹⁰ According to the UN Office of High Commissioner for Human Rights (OHCHR), 'legal capacity' is defined as:¹¹ 'The capacity and power to exercise rights and undertake obligations by way of one's own conduct, ie without assistance of representation by a third party.'

According to the Committee on the Rights of Persons with Disabilities (CRPD Committee), 'legal capacity' is 'the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency)'.¹² In the words of the Centre for Disability Law and Policy (CDLP), 'legal capacity' is an 'individuals' right to make decisions – big and small – for him/her self and have those decisions respected'.¹³ As it can be deduced from the above definitions, 'legal capacity' is the legally recognised power of individuals to make decisions about their own affairs and engage in day-to-day activities.

Legal capacity facilitates personal freedom by allowing persons to manage their own property, family, and other individual affairs. According to Quinn, the exercise of legal capacity serves as both a sword and a shield. Used as a sword, it reflects an individual's right to make decisions for himself/herself and to have those decisions respected by others.¹⁴ Used as a shield, legal capacity is the power of the individual to protect himself/herself from other persons' unnecessary intervention.¹⁵

10 See European Commissioner for Human Rights (n 4 above).

11 See OHCHR *Background conference document on legal capacity* para 24 <http://www.un.org/esa/socdev/enable/rights/.../ahc6ohchrlegalcap.doc> (accessed 22 March 2015).

12 CRPD Committee (n 5 above) para 13.

13 Centre for Disability Law & Policy (CDLP), NIU Galway *Submission on legal capacity to the Oireachtas Committee on Justice, Defence & Equality* 9 http://www.nuigalway.ie/cdlp/documents/cdlp-submissionon-legalcapacitythe-oireachtascommitteeonjustice-defenceandequality_.pdf (accessed 20 August 2015).

14 G Quinn 'Rethinking personhood: New directions in legal capacity law & policy' (2011) 7-10 http://www.cic.arts.ubc.ca/files/.../Gerard_Quinn_s_Keynote_-_April_29_2011.pdf (accessed 30 June 2015).

15 Quinn (n 14 above).

History reveals that denying persons with disabilities legal capacity is a phenomenon that has been around for a long time. For instance, under the law of ancient Rome, both mental and physical impairments such as blindness and muteness resulted in denial of active legal capacity.¹⁶ The trend of depriving persons with disabilities of legal capacity has also continued under modern law, especially for persons with psychosocial and intellectual disabilities.¹⁷ Various approaches have been adopted to assess capacity of persons with disabilities to confer legal capacity. The widely recognised approaches to legal capacity are highlighted below as follows.

2.1 The status approach

The 'status approach' assesses a person's capacity based on disability instead of person's capacity in relation to a particular decision taken at a particular time.¹⁸ It assumes that a person lacks legal capacity if he/she has a disability.¹⁹

This approach is flawed since it determines an individual's capacity to make decisions simply on the basis of a medical diagnosis. It has also faced serious criticism and has been rejected in many jurisdictions on the ground that it perpetuates the existing stereotyping against persons with intellectual and psychosocial disabilities.²⁰

2.2 The outcome approach

The 'outcome approach' assesses the consequences of the individual's decision to confer legal capacity.²¹ It is based on the belief that individuals should lose legal capacity if they make unreasonable decisions.²² In other words, a person who makes a decision that reflects values which are not acceptable in society or which rejects accepted values is likely to be denied legal capacity.²³

16 I Hoffman & G Könczei 'Legal regulations relating to the passive and active legal capacity of persons with intellectual and psychosocial disabilities in light of the Convention on the Rights of Persons with Disabilities and the impending reform of the Hungarian Civil Code' (2010) 33 *Journal of Loyola of Los Angeles International and Comparative Law Review* 153.

17 CRPD Committee (n 5 above) paras 7 and 9.

18 *Accessed on April 29, 2011.pdf* (CRPD Committee (n 5 above) para 15; Ireland: The Law Reform Commission 'Consultation paper on vulnerable adults and the law: Capacity' (2005) 45 www.lawreform.ie/_.../Consultation%20Paper%20on%20Capacity.pdf (accessed 27 August 2015).

19 CDLP (n 13 above) 10; A Dhanda 'Legal capacity in the disability rights convention: Stranglehold of the past or lodestar for the future?' (2007) 34 *Syracuse Journal of International Law & Commerce Syracuse University* 429-431.

20 Ireland: The Law Reform Commission (n 18 above).

21 CRPD Committee (n 5 above) para 15; Ireland the Law Reform Commission (n 18 above) 48.

22 CDLP (n 13 above) 10.

23 Ireland: The Law Reform Commission (n 18 above).

The fallacious nature of this approach lies in the fact that the concept of ‘reasonableness’ is vague and subjective. Even if the individual may benefit from what he/she decided, the individual loses his/her legal capacity according to this approach for the mere fact that the decision of the individual is not accepted by other persons or the society.²⁴

2.3 The functional approach

The ‘functional approach’ also known as the ‘continuum’ approach looks at both mental impairment and a test whether the individual can understand the nature and consequences of his/her decision to confer legal capacity.²⁵ Unlike the status approach and the outcome approach, the functional approach presumes that a person has capacity unless proven otherwise.²⁶ This approach recognises that if a person lacks legal capacity in relation to one decision, it does not necessarily mean that he/she lacks legal capacity in relation to all decisions.²⁷ Consequently, under this approach individuals’ capacity is assessed on a case-by-case basis.

The discriminatory nature of this approach lies in the fact that it takes the presence of impairment or disability as a threshold condition and only persons with such conditions run the risk of losing their legal capacity.²⁸ This approach also has the potential of denying persons with disabilities legal capacity based on equivocal assessment of mental capacity.²⁹

2.4 The universal approach

The ‘universal approach’ is a very recent approach hailed by disability-right activists. It views legal capacity as a universal human attribute, which is possessed by all persons.³⁰ Unlike the above three approaches, this approach separates legal capacity from mental capacity. It regards legal capacity as a social and legal status that stands irrespective of an individual’s particular mental capacity and that does not reflect an individual’s ability to make decisions.³¹

24 Mental Disability Advocacy Center (MDAC) ‘Legal capacity in Europe: A call to action to governments and the EU’ (2013) 19 http://www.mdac.info/sites/mdac.info/files/legal_capacity_in_europe.pdf (accessed 17 March 2015).

25 MDAC (n 24 above); CRPD Committee (n 5 above) para 15; European Commissioner for Human Rights (n 4 above) 15; Dhanda (n 19 above).

26 CDLP (n 22 above).

27 Ireland: The Law Reform Commission (n 18 above) 49.

28 CRPD Committee (n 5 above) para 14.

29 As above.

30 M Browning et al ‘Supported decision making: Understanding how its conceptual link to legal capacity is influencing the development of practice’ (2014) 1 *Journal of Research and Practice in Intellectual and Developmental Disabilities* 34 38-39 http://www.supporteddecisionmaking.org/sites/default/.../browning_et_al_2014.pdf (accessed 30 August 2015).

31 Browning et al (n 30 above).

According to the universal approach, legal capacity is understood as a tool that reflects an individual's right to make decisions and have those decisions respected.³² Viewing legal capacity from the human-rights perspective, the universal approach would hope to counter the prevalent underestimation of abilities of persons with psychosocial, intellectual and other cognitive disabilities.³³

3 The right to legal capacity of persons with intellectual and psychosocial disabilities as envisaged by the CRPD

Although the right to recognition as a person before the law is guaranteed by the Universal Declaration of Human Rights (Universal Declaration) and the International Covenant on Civil and Political Rights (ICCPR) to all persons,³⁴ these human-right instruments did not explicitly recognise the right to legal capacity. The CRPD is the first of its kind to recognise the right to legal capacity of persons with disabilities. Article 12 of the CRPD is perhaps the most revolutionary provision of the CRPD. It has introduced a paradigm shift by recognising the right to legal capacity of persons with disabilities in the fullest sense.

Article 12(1) of the CRPD provides that: 'States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.' Article 12(2) of the CRPD provides that: 'States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.'³⁵ Although the CRPD does not define the concept of legal capacity, the CRPD Committee in its general comment 1 focussing on article 12 has given a detailed explanation in this regard.

As per the interpretation of the Committee, legal capacity as enshrined in the CRPD encompasses two strands of capacities.³⁶ The first capacity is a person's capacity to be a holder of rights. This component of legal capacity entitles a person to full protection of his or her rights by the legal

32 L Kerzner 'Paving the way to full realization of the CRPD's rights to legal capacity and supported decision-making: A Canadian perspective' (2011) 8-9 http://www.supporteddecisionmaking.org/.../paving_the_way_for_crpd_canada.pdf (accessed 4 October 2015).

33 Browning et al (n 30 above).

34 See art 6 of the Universal Declaration and art 16 of the ICCPR.

35 Similarly, art 8 of the Protocol to the African Charter on Human and Peoples' Right on the Rights of Persons with Disabilities fully recognises the right to legal capacity of persons with disabilities and equal recognition before the law. Article 8(1) of this Protocol reads: 'Every person with a disability has the right to legal capacity.' Article 8(2) also provides: 'States Parties shall recognise that persons with disabilities are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.'

36 CRPD Committee (n 5 above) paras 12 and 14.

system.³⁷ Accordingly, having a birth certificate, seeking medical assistance, registering to be on the electoral roll or applying for a passport are some of the rights that flow from this strand of legal capacity. The second component of legal capacity is the capacity to act under the law. This aspect of legal capacity recognises a person as an agent with the power to enter into, modify or end juridical acts such as contracts and marriage among others.³⁸ It deals with exercising rights or entitlements. In many states, persons with intellectual and psychosocial disabilities are denied this component of legal capacity.³⁹ For operative legal capacity to exist, both components of legal capacity should be respected for individuals.⁴⁰ The CRPD Committee accentuated that legal capacity is an inherent right of persons. It vividly underscored that all people, including persons with disabilities, have legal standing and legal agency simply by virtue of being human.⁴¹

Traditionally, legal capacity is linked with mental capacity. In many jurisdictions including Ethiopia, individuals enjoy legal capacity as long as they are deemed to be mentally capable. The CRPD is a ground-breaking Convention in that it dissects the concept of legal capacity from mental capacity. As the CRPD Committee noted, legal capacity is all about ability to hold rights and duties as well as to exercise those rights and duties,⁴² whereas mental capacity refers to decision-making skills of a person.⁴³ Having noted that mental capacity naturally differs from one person to another and may even be different for a given individual depending on environmental, social and other factors, the Committee underscored that perceived or actual deficits in mental capacity should not be used as justification for denying legal capacity.⁴⁴ By adopting this approach, the Committee endorsed the universal approach to legal capacity which values notions of dignity and equality on which the CRPD is founded. This necessitates that state parties to the CRPD replace traditional approaches to legal capacity with the universal approach to legal capacity.

4 Right to access support to exercise legal capacity

One of the main criteria used to deprive persons with intellectual and psychosocial disabilities of the right to legal capacity is that a person should understand the nature and consequences of his/her decisions, understand all available options in any particular situation, and voluntarily

37 As above.

38 As above.

39 CRPD Committee (n 5 above) para 14.

40 CRPD Committee (n 5 above) paras 12 and 14.

41 As above.

42 CRPD Committee (n 5 above) para 13.

43 CRPD Committee (n 5 above) para 14.

44 As above.

make and communicate a clear choice.⁴⁵ This criterion is shaped by the medical model of disability.

The medical model of disability considers disability as a health problem. It perceives disability as an illness which is intrinsic to the individual.⁴⁶ Consequently, it assumes that both problems and solutions of disability lie within people with disabilities themselves rather than within society.⁴⁷ This model of disability has faced serious criticism on the ground that it results in a disabling culture that perpetuates negative attitudes and discriminatory practices which eventually result in exclusion of persons with disabilities.⁴⁸

Conversely, the social model of disability attributes the cause of disability in the social environment and views disability as a social construct.⁴⁹ Proponents of this model consider disability as a form of oppression, whereby social structures and practices are viewed as disabling, rather than the individual being seen as disabled.⁵⁰ This model radically shifts the focus from cure, treatment, care and protection to acceptance of impairment as a positive aspect of human diversity as well as to the problematisation and rejection of a social norm that results in exclusion.⁵¹

On the other hand, the human-rights model of disability approaches disability from the point of view of human rights. It focuses on the inherent dignity of the human being and considers the person's medical characteristics only if necessary.⁵² It puts the person at the centre in all decisions affecting him/her.⁵³ According to this model, the problem of disability stems from a lack of responsiveness by the state to the difference

45 M Bach 'The right to legal capacity under the UN Convention on the Rights of Persons with Disabilities: Key concepts and directions from law reform' (2009) <https://irisinstitute.files.wordpress.com/.../the-right-to-legal-capacity-unde...> (accessed 20 August 2015).

46 G Quinn et al *The current use and future potential of United Nations human rights instruments in the context of disability* (2002) 14-15; M Kemple et al 'Shaping disability rights through shaping the disability movement' (2011) 3 *Journal of Human Right Practice* 356-358; M Retief & R Letšosa 'Models of disability: A brief overview' (2018) 74 *HTS Teologiese Studies/Theological Studies* <https://www.ajol.info/index.php/hts/article/view/177914/167285> (accessed 15 September 2019). See also Disabled World 'Definitions of the models of disability' <https://www.disabled-world.com/definitions/disability-models.php> (accessed 16 September 2019).

47 Kemple et al (n 46 above); Disabled World (n 46 above); Quinn et al (n 46 above); Retief and Letšosa (n 46 above).

48 T Degener 'A human rights model of disability' (2014) 3-5 https://www.researchgate.net/publication/283713863_A_human_rights_model_of_disability/link/5644463208aef646e6ca7886/download (accessed 15 September 2019).

49 Disabled World (n 46 above); Quinn et al (n 46 above); Retief and Letšosa (n 46 above); Kemple et al (n 46 above).

50 Kemple et al (n 46 above); Retief and Letšosa (n 46 above); Quinn et al (n 46 above); Disabled World (n 46 above).

51 T Degener 'Disability in a human rights context' (2016) *Laws* 5 <https://www.mdpi.com/2075-471X/5/3/35/htm> (accessed 8 October 2019).

52 Degener (n 48 above) 6- 7; Quinn et al (n 46 above).

53 Degener (n 52 above); Quinn et al (n 46 above).

that disability represents.⁵⁴ Consequently, proponents of this model insist that the state has the responsibility to tackle social barriers to ensure full respect for the dignity and equal rights of all persons.⁵⁵

Unlike the medical model of disability, the human-rights and social models of disability played a significant role in shaping the CRPD.⁵⁶ Each provision of the CRPD reflects either of the two or both models. This is especially the case for article 12 of the CRPD. Article 12 on the one hand recognises the right to legal capacity of persons with disabilities from a human-rights point of view. On the other hand, considering environmental and social barriers persons with disabilities, in particular persons with intellectual and psychosocial disabilities may face, it obliges state parties to provide persons with disabilities with support they need to exercise legal capacity.⁵⁷ Consequently, states can no more deny persons with disabilities legal capacity on the ground that they cannot understand the consequence of their decisions or cannot communicate their decisions. Rather, they should provide support to enable them to exercise their legal capacity. This implies that Ethiopia, as a state party to the CRPD, has to remove substitute decision-making and put in place mechanisms to provide persons with intellectual and psychosocial disabilities with support that enables them to exercise their legal capacity.

The CRPD does not provide the form and type of support needed for persons with disabilities to exercise their legal capacity. However, the CRPD Committee elucidated that ‘support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making’.⁵⁸

Supported decision-making is a process of decision-making that is directed by an individual and also involves persons who can assist him/her with full respect of the individual’s autonomy.⁵⁹ Under the system of supported decision-making, a person who cannot make decisions under normal circumstances may be able to make his/her own decisions with the help of other persons and exercise legal capacity.⁶⁰

The support envisaged by the CRPD refers to the provision of any type of assistance to persons with disabilities that helps them make decisions, express their will, or communicate their personal identity to potential

54 As above.

55 Degener (n 52 above).

56 As above.

57 Art 12(3) of the CRPD.

58 CRPD Committee (n 5 above) para 17.

59 Kerzner (n 32 above).

60 United Nations *From exclusion to equality – Realizing the rights of persons with disabilities* (2007) <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex> (accessed 22 June 2015); R Dinerstein ‘Supported decision making for people with intellectual disability: An alternative to guardianship’ (2014) 2 [http://: www.rwjms.rutgers.edu/boggscenter/dd.../DinersteinAMpacket4-4-14.pdf](http://www.rwjms.rutgers.edu/boggscenter/dd.../DinersteinAMpacket4-4-14.pdf) (accessed 1 October 2015).

parties to a legal arrangement.⁶¹ It encompasses informal and formal support arrangements of different types and intensity.⁶² Informal assistance of family and friends in making daily decisions, individualised plain language assistance, assisted/adaptive communication and visual aids are some forms of support that can enhance exercise of legal capacity.⁶³

To date, there is no a single model of supported decision-making system in the world. Different models of supported decision-making are practiced in various states. In this regard, the Swedish practice is one of the notable supported decision-making models.

The Swedish supported decision-making is known as the ‘personligt ombud’ (personal ombudsman) support model. It is a system by which an individual who seeks support to exercise legal capacity is assisted by a personal ombudsman (PO/ombudsman).⁶⁴ A personal ombudsman is a professional (most of the time a person who has a social work or legal background) who works for the individual taking into consideration the will and preferences of the individual as opposed to perceived best interests.⁶⁵ The personal ombudsman in no case has a link with entities like psychiatrist, social services, any other authority, with the client’s relatives or any other person in his/her surroundings.⁶⁶ All municipalities run their own personal ombudsman system which is also linked to the national programme.⁶⁷ While POs are funded by municipalities, they are usually hired through NGOs in order to minimise potential conflicts of interest which may arise especially when individuals want to make a complaint against the municipality.⁶⁸ In this system clients control all the information provided to the personal ombudsman, and confidentiality is of a paramount importance.⁶⁹ The ombudsman is required to return all personal documents to the client or destroy it in the client’s presence when the relationship between a client and personal ombudsman comes to an end.⁷⁰ Building a relationship of trust with the client and identifying the client’s needs may be time-taking, but the ombudsman should be patient,

61 Bach (n 45 above) 12.

62 CRPD Committee (n 5 above) para 17.

63 Bach (n 45 above) 12.

64 CDLP (n 13 above) appendix 3.

65 CDLP (n 13 above) appendix 3; M Jespersen ‘A service which offers supported self-decision making for persons with severe psychosocial disability’ <https://europe.ohchr.org/EN/Stories/Documents/MathsJespersen.pdf> (accessed 10 September 2019).

66 CDLP (n 13 above) appendix 3; Jespersen (n 65 above)

67 As above.

68 As above.

69 CDLP (n 13 above) appendix 3; Jespersen (n 65 above); L Salzman ‘Guardianship for persons with mental illness – A legal and appropriate alternative?’ (2011) 4 *Saint Louis University Journal of Health Law and Policy* 306-310 http://supporteddecisionmaking.org/sites/default/files/guardianship_for_persons_with_mi.pdf (accessed 14 October 2015).

70 CDLP (n 13 above) appendix 3; Jespersen (n 65 above); Salzman (n 69 above).

even in the situation his/her client's life is chaotic.⁷¹ This type of support has been successful in helping even persons with severe mental/intellectual impairment. Absence of bureaucratic procedure to get a personal ombudsman, flexibility of an ombudsman's working hours, the readiness of an ombudsman to support the client in a number of matters are some of the characteristics that contributed to the success of the personal ombudsman model of supported decision-making system.⁷²

This is a typical model of supported decision-making that empowers persons with intellectual and psychosocial disabilities by respecting their will and preferences and providing the support needed irrespective of their mental capacity. The Swedish experience is an indication of the possibility of realising the right to legal capacity of persons with intellectual and psychosocial disabilities using the system of supported decision-making. This model of supported decision-making not only enhances the decision-making capacity of persons with intellectual and psychosocial disabilities, but also reduces the numbers of inpatient hospital stays, which in turn reduces state expenditure in mental health.⁷³

Article 12(4) of the CRPD requires state parties to ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse. As the CRPD Committee noted, the primary purpose of the safeguards should be to ensure the respect of the person's rights, will and preferences.⁷⁴ If it is not possible to determine the will and preferences of an individual despite a significant attempt, the Committee stipulated that the principle of 'best interpretation of will and preferences' should be applied instead of the principle of 'best interests'.⁷⁵ The Committee rejected the principle of 'best interests' on the ground that this principle is not a safeguard which complies with article 12 in relation to adults.⁷⁶ However, in real life it may not always be possible to determine the will and preferences of persons. Even in the presence of support, persons with severe impairment in some circumstances may not be able to express their will and preferences. It may also not be possible to infer their will and preferences from their previous actions or by asking their affiliates. The Committee did not explain what should be done in such circumstances. The question that begs to be answered in relation to the Committee's interpretation of article 12 is whether support envisaged by article 12 of the CRPD is the perfect solution to enable persons with disabilities, particularly persons with severe impairment, to exercise their legal capacity in all circumstances. Studies show that decision-making capacity differs among persons with disabilities

71 CDLP (n 13 above) appendix 3; Jespersen (n 65 above); Salzman (n 69 above).

72 As above.

73 CDLP (n 13 above) appendix 3.

74 CRPD Committee (n 5 above) para 20.

75 CRPD Committee (n 5 above) para 21.

76 As above.

depending on severity of impairment.⁷⁷ However, it seems clear that there are some situations such as a state of coma or case of a non-verbal profound intellectual disability where individuals cannot make decisions or communicate their decisions even in the presence of support.⁷⁸ If this is the case, at least some persons with disabilities may run the risk of abuse in situations when their will and preferences cannot be determined. Another concern is that the Committee's General Comment is silent on safeguards that should be taken during the transition from a system of substitute decision-making to a supported decision-making system. As per interpretation of the Committee, regimes permitting substitute decision-making cannot continue in parallel with the gradual implementation of new supported decision-making models even if these systems have not been fully developed. However, a newly adopted supported decision-making system may not adequately address the needs of persons with intellectual and psychosocial disabilities and may have adverse effects for the rights of these persons especially if it fails to work effectively as intended. In the absence of a gap-filling tool in these circumstances, persons with intellectual and psychosocial disabilities may run the risk of a violation of their rights.

Although Article 12(4) seems to allow room for substituted decision-making, at least where it is necessary to prevent 'abuse' and where it is 'proportional and tailored to the person's circumstances', the CRPD Committee underlined that article 12 of the CRPD does not leave any room for substitute decision-making. Given the abovementioned potential problems that may arise in exercising legal capacity in the framework of supported decision-making, absolute rejection of the principle of 'best interests' may hinder protection of rights of persons with disabilities. As state parties have an obligation to respect the right to legal capacity, they also have an obligation to protect other rights of persons with disabilities. Arguably, considering respect for legal capacity as being absolute and not considering the best interests of the person in some cases leads to inconsistency with other provisions of the CRPD. A good example is a situation where a person with severe impairment in need of serious medical treatment could not decide on medical treatment even in the presence of support as a result of diminished mental capacity. Obviously, states' failure to provide treatment in such serious conditions would be in conflict with article 25 of the CRPD which requires states parties to recognise persons with disabilities' right to the enjoyment of the highest attainable standard of health without discrimination on the basis of

77 K Villar 'Should supported decision-making replace substituted decision-making? The Convention on the Rights of Persons with Disabilities and coercive treatment under Queensland's Mental Health Act 2000' (2015) 4 *Journal of Laws MDPI* 193 <http://www.mdpi.com/2075-471X/4/2/173/notes> (accessed 20 October 2015).

78 G Szmukler et al 'Mental health law and the UN Convention on the rights of persons with disabilities' (2014) 37 *International Journal of Law and Psychiatry* 245 252 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4024199/> (accessed 13 September 2019); Villar (n 77 above).

disability and article 10 of the CRPD which requires state parties to take all necessary measures to ensure effective enjoyment of the right to life by persons with disabilities, especially if life of such persons is jeopardised owing to lack of medical treatment.⁷⁹ Similarly, the states' failure to take necessary measures to ensure the protection and safety of persons with severe impairment in situations of risk, when such person could not give his/her consent to emergency measures even in the presence of support would be in conflict with the states' obligation to take measures to ensure the protection and safety of persons with disabilities in situations of risk.⁸⁰ Given the fact that addressing the abovementioned and other similar cases requires considering the best interests of the person, it would be difficult for state parties to harmonise the Committee's interpretation with their obligations arising from other provisions of the CRPD.

Moreover, since article 12 does not leave any room for substitute decision-making it is not clear from a reading of the provision whether this interpretation may be welcomed by the state parties. Even before the Committee's controversial interpretation of article 12, a number of state parties including Australia,⁸¹ Canada,⁸² Estonia, Ireland and Egypt have

79 In this regard, Dawson noted that: Involuntary psychiatric treatment, for instance, could both limit a person's autonomy and promote their social inclusion, health and standard of living. Would it therefore violate or promote the person's rights under the Convention as a whole? In many legal systems, a key concept in settling the balance between these competing imperatives or rights is that of capacity (or competence) on the part of the person to take the necessary action or make the relevant decision. If they have the capacity to decide on their own need for treatment, for example, it would usually violate their right to autonomy and integrity to impose treatment without their consent, even if the treatment proposed would assist their health or promote their social inclusion. The balance between those different interests would be for them to decide. If they lacked the capacity to make the relevant decision, on the other hand, the state would have the power (and often the duty) to intervene, to promote their positive entitlements, even if that might require their involuntary treatment. See J Dawson 'A realistic approach to assessing mental health laws' compliance with the UNCRPD' (2015) 40 *International Journal of Law and Psychiatry* 70 <http://dx.doi.org/10.1016/j.ijlp.2015.04.003> (accessed 14 September 2019).

80 Art 11 of the CRPD.

81 Australia also noted in its Initial Report to the CRPD Committee that: 'Australia strongly supports the right of persons with disabilities to legal capacity. In some cases, persons with cognitive or decision-making disabilities may require support in exercising that capacity. In Australia, substituted decision-making will only be used as a measure of last resort where such arrangements are considered necessary, and are subject to safeguards in accordance with article 12(4).' See Australia's Initial Report under the Convention on the Rights of Persons with Disabilities (3 December 2010) para 55 <https://www2.ohchr.org › CRPD › futuresession › CRPD.C.AUS.1-ENG.doc> (accessed 11 November 2019).

82 Canada also noted in its report that: 'Canada strongly supports the equal recognition of persons with disabilities as persons before the law. As with other members of society, a determination of incapacity should only be based on evidence of the individual's actual decision-making ability, rather than on the existence of a disability. Anyone who requires support in exercising their legal capacity should have access to the support required to do so, subject to appropriate regulation and safeguards. Canada's interpretative declaration and reservations in relation to Article 12 set out Canada's understanding of its obligations under the article. All P/Ts have in place laws related to substitute and/or supported decision-making with safeguards to protect against abuse.' See Canada's Initial Report to the CRPD Committee CRPD/C/CAN/1 (7 July 2015) paras 33 and 34.

already entered declarations and reservations in relation to article 12 of the CRPD, foreseeing the potential difficulties that may arise from interpretation of this article.⁸³ Reports of many state parties on the same subject also imply that the state parties' understanding of article 12(4) is not consistent with interpretation of the CRPD Committee.⁸⁴

In a nutshell, although the interpretation by the Committee can play a great role in abolishing entrenched substitute decision-making systems, it may also have unintended adverse effects for persons with disabilities in some circumstances.

5 The right to legal capacity of persons with psychosocial and intellectual disabilities under the Ethiopian legal system

5.1 The right to legal capacity of persons with intellectual and psychosocial disabilities under the Constitution

The Constitution of the Federal Democratic Republic of Ethiopia (hereinafter the FDRE Constitution) allocated one-third of its provisions to a bill of rights. The FDRE Constitution under its third chapter has enshrined many of the rights recognised under the Universal Declaration; ICCPR; International Covenant on Economic, Social and Cultural Rights; and other human-rights treaties. Yet, it did not explicitly incorporate the right to legal capacity. However, some provisions of the Constitution can be interpreted to include this right. Article 24(3) of the FDRE Constitution stipulates that: 'Everyone has the right to recognition everywhere as a person'. Article 25 of the FDRE Constitution also provides that:⁸⁵

All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall guarantee to all persons equal and effective protection without discrimination on grounds of race, nation, nationality, or other social origin, colour, sex, language, religion, political or other opinion, property, birth or other status.

From the above provision, it can be deduced that the right to equality before the law and equal protection before the law have been incorporated in the Constitution. Furthermore, the Constitution prohibits discrimination based on the abovementioned and other unstated grounds.

83 All reservations and declarations to the CRPD are available at https://treaties.un.org/pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4#EndDec (accessed 11 September 2019).

84 See for instance State party reports of Sweden, CRPD/C/SWE/1 (18 September 2012) paras 137, 140; Denmark: CRPD/C/DNK/1 (7 May 2013) paras 129-132; New Zealand: CRPD/C/ NZL/1 (1 October 2013) paras 67-69, 83-89.

85 Art 25 of the 1995 FDRE Constitution.

Nonetheless, the Constitution does not provide disability as one of prohibited grounds of discrimination.

For various reasons, persons with disabilities face discrimination for the mere fact that they have a disability.⁸⁶ Explicitly identifying disability as one of prohibited grounds of discrimination is one way of ensuring visibility of persons with disabilities. Failure to provide disability as one of the prohibited grounds of discrimination in the Constitution has negative implications for subsidiary legislation and policies adopted by the state. Consequently, the fact that the FDRE Constitution did not recognise disability as one of prohibited grounds of discrimination has adverse implications for the protection and promotion of the rights of persons with disabilities in Ethiopia. In this regard, disability-right activists and advocates in Ethiopia have to put pressure on the Government of Ethiopia so that the Constitution is amended in a way that explicitly recognises disability as a prohibited ground of discrimination as this has direct relevance for the realisation of rights of persons with disabilities in Ethiopia.

Notwithstanding this, the above provisions of the FDRE Constitution can be interpreted to protect the right to legal capacity of persons with disabilities, particularly persons with intellectual and psychosocial disabilities. The phrase 'other status' which concludes the list of prohibited grounds of discrimination provided under article 25 indicates that the list is not exhaustive. As the purpose of this provision of the Constitution is to ensure equal protection of individuals rights and prohibition of discrimination, other grounds on which persons face discrimination like disability can be covered by the phrase 'other status'.⁸⁷ In the case *Wesen v Amhara National Regional State Justice Professional Training and Legal Research Institute*, the House of the Federation⁸⁸ implied disability as one of prohibited grounds of discrimination recognised by article 25 of the FDRE Constitution. The House of the Federation held that the practice prohibiting visually impaired persons from being recruited to serve as a judge amounts to discrimination on the ground of disability and contravenes inter alia, article 25 of the Constitution.⁸⁹

86 A Lawson 'The United Nations Convention on the Rights of Persons with Disabilities: New era or false dawn?' (2007) 34 *Syracuse Journal of International Law & Commerce* 563-565; UN (n 73? above) 1.

87 In one of its notable decisions, the African Commission on Human and Peoples' Rights (the African Commission) interpreted the phrase 'other status' to cover disability and held that the practice of detaining persons regarded as mentally ill indefinitely and without due process constitutes discrimination on the ground of disability and is in violation of article 2 of the African Charter on Human and Peoples' Rights which prohibits discrimination on different grounds. See *Purohit v The Gambia* (2003) AHRLR 96 (ACHPR 2003) paras 54 and 85.

88 The House of the Federation is the only organ with a mandate of interpreting the Constitution in Ethiopia. See art 62(1) of the FDRE Constitution.

89 See decision of the House of the Federation (2 September 2016) on Application No 019/08 paras 20-23.

Pursuant to article 13(2) of the FDRE Constitution, the fundamental rights and freedoms guaranteed by the Constitution should be interpreted in a manner conforming to the principles of the UDHR and other international instruments adopted by Ethiopia. Among international instruments ratified by Ethiopia, the Convention on the Rights of the Child (CRC)⁹⁰ and CRPD explicitly prohibit discrimination on the ground of disability. Therefore, article 25 should be construed to prohibit discrimination on the ground of disability so that it conforms to the above international conventions. As it will be discussed in the following sections, under the Ethiopian legal system, persons with intellectual and psychosocial disabilities are denied legal capacity on the basis of assessment of mental capacity. Seen in the light of the CRPD, this amounts to discrimination against persons with intellectual and psychosocial disabilities on the ground of disability.

Moreover, as noted by the CRPD Committee, the right to equal recognition before the law implies existence of the right to legal capacity.⁹¹ Law that does not guarantee legal capacity for everyone cannot ensure equal recognition of persons. Hence the right to be recognised as a person enshrined under article 24 of the FDRE Constitution should be construed to imply the right to legal capacity. Based on the above premises, it can be concluded that the right to legal capacity of persons with intellectual and psychosocial disabilities is implicitly guaranteed by the FDRE Constitution.

In addition to the above points, the FDRE Constitution also has a unique feature that enhances protection and promotion of individuals' rights. According to article 9(4) of the FDRE Constitution, international treaties ratified by Ethiopia are an integral part of the law of Ethiopia. In other words, human-right instruments like the CRPD that Ethiopia ratified are considered as one of the laws enacted by Ethiopia.⁹² This approach in the Constitution is helpful to ensure the right to legal capacity of persons with intellectual and psychosocial disabilities.⁹³

In general, the FDRE Constitution does not explicitly address the issue of legal capacity of all persons directly. Had this right been explicitly incorporated in the Constitution, persons at risk of losing this right such as persons with intellectual and psychosocial disabilities could have a better chance to have their rights protected. However, if the Bill of Rights in the Constitution is interpreted in line with international human-rights

90 See Art 2(1) of CRC.

91 CRPD Committee (n 5 above) para 8.

92 S Yeshanew 'The justiciability of human rights in the Federal Democratic Republic of Ethiopia' (2008) 8 *African Journal of Human Right Law* 285.

93 Although the author does not delve into discussion of The monist-dualist divide as it is beyond the scope of this article, he believes that the fact that international treaties ratified by Ethiopia are an integral part of the law of Ethiopia is clearly discerned from the wording of article 9(4) of the Constitution and is beyond controversy.

instruments to which Ethiopia is a party as envisaged by the FDRE Constitution, the Constitution can effectively be used to protect the right to legal capacity of persons with intellectual and psychosocial disabilities.

5.2 The right to legal capacity of persons with intellectual and psychosocial disabilities under the 1960 Ethiopian Civil Code

The Ethiopian Civil Code has been at the very core of the Ethiopian civil law for more than half a century. It incorporates many legal concepts and institutions of continental European law, amongst others, legal person, family, succession, goods, property, literary and artistic ownership, tort, agency, contract and arbitration.⁹⁴ It is the only Code in Ethiopia that regulates legal personality. The first book of the Civil Code contains the law of persons. The first article of the Code stipulates how legal personality is gained under the Ethiopian legal system. It provides: ‘The human person is the subject of rights from its birth to its death.’⁹⁵ From this provision, it can be inferred that everyone is recognised as a person under the Ethiopian legal system as soon as he/she is born. As noted by Vanderlinden, under the Ethiopian legal system birth is sufficient to confer legal personality.⁹⁶ Consequently, irrespective of disability, persons with disabilities including persons with intellectual and psychosocial disabilities are recognised as persons before Ethiopian law.

With regard to legal capacity, the Ethiopian Civil Code uses the term ‘capacity’ instead of ‘legal capacity’. Although the term ‘capacity’ may refer to either mental capacity or legal capacity depending on the context used,⁹⁷ in the Ethiopian legal system it refers to legal capacity rather than mental capacity. This can be inferred from a reading of article 192 of the Civil Code that provides the rule of legal capacity. This article reads: ‘Every physical person is capable of performing all the acts of civil life unless he is declared incapable by the law.’⁹⁸ According to this provision, every person has capacity to perform any civil act unless he/she is declared incapable by the law. Capacity in this sense is different from mental capacity in that it can be conferred or taken away by the law depending on circumstances. In this respect, the Code provides that incapacity may result from factors like age or mental condition of persons or sentences

94 L Haile ‘A critical analysis of Ethiopian Civil Code: In the light of the core features of Continental European Codification’ unpublished LLM thesis, University of London, 2012 5 http://sas-space.sas.ac.uk/.../1/Liku_Worku_Haile_LLM_ALS_Dissertation.pdf (accessed 30 August 2015).

95 Art 1 of the 1960 Ethiopian Civil Code.

96 J Vanderlinden *Commentaries upon the Ethiopian Civil Code the Law of Physical Persons (Art 1-393)* (1969) 9.

97 For instance, in Canadian legal system, the term ‘capacity’ is generally used to refer the cognitive requisites considered necessary for individuals to be recognised as able to exercise legal capacity. See Back & Kerzner (n 9 above) 16.

98 Art 192 of the Ethiopian Civil Code.

passed on them.⁹⁹ Consequently, under the Ethiopian legal system, regardless of mental capacity one can be incapacitated. Although the Civil Code uses the term ‘capacity’, for the sake of consistency and to avoid confusion, the term ‘legal capacity’ will be used throughout this article.

As it can be discerned from a reading of article 192 of the Civil Code, legal capacity is a rule under the Ethiopian legal system. In other words, everyone is presumed to have legal capacity save in the exceptions. As persons are entitled to their rights the moment they come into existence, they are also capable of exercising their rights.¹⁰⁰ Hence legal capacity is gained at birth unless it is lost in accordance with the law. From the approach taken by the Civil Code, it can be discerned that the Ethiopian Civil Code does not recognise a universal legal capacity as it leaves room where legal capacity of individuals can be stripped by law. This approach of the Ethiopian Civil Code is in stark contradiction with the article 12 of the CRPD which calls for a universal approach to legal capacity. As mentioned elsewhere in this article, the CRPD Committee has plainly underscored the fact that the CRPD leaves no room where legal capacity is lost as a matter of law.

As provided under article 193 of the Civil Code, mental condition is one of the exceptional grounds on which a person can be declared legally incapable. Persons with intellectual and psychosocial disabilities are directly affected by this exception. In the eyes of the Civil Code, persons with intellectual and psychosocial disabilities are regarded as insane. The consequence of insanity is either limited or loss of legal capacity. Article 339 of the Civil Code defines insane person as follows:¹⁰¹

[An] [i]nsane person is one who, as a consequence of his being insufficiently developed or as a consequence of a mental disease or of his senility, is not capable to understand the importance of his actions.

Pursuant to the above article, two cumulative conditions should be present for a person to be considered as insane. First, there should be either insufficient development of the individual¹⁰² or mental disease. While insufficient development is an indication of intellectual impairment,¹⁰³ long lasting mental disease is an indication of mental impairment. Second, the person should be in a condition that he/she cannot understand the consequence/importance of his/her decision due to insufficient development or mental disease. Therefore, the law assesses ability to

99 Art 193 of the Ethiopian Civil Code.

100 Vanderlinden (n 96 above) 59-60.

101 Art 339(1) of the Ethiopian Civil Code.

102 As Vanderlinden noted, insufficient development in context of art 339(1) refers to mental development than physical development. See Vanderlinden (n 96 above) 64-65.

103 Intellectual disability is characterised by diminished cognitive and adaptive development. See Disabled World ‘Cognitive disability: Information on intellectual disabilities’ <http://www.disabled-world.com/disability/types/cognitive/> (accessed 11 October 2015).

understand the importance of one's action by taking impairment as a threshold. Considering the fact that mental/intellectual impairment and a person's inability to understand the importance of his/her actions are elements of the definition of insanity, it can be said on the face value that the Ethiopian legal system follows the functional approach to legal capacity to deny or limit the legal capacity of persons with intellectual and psychosocial disabilities. However, strictly speaking, this is not the case for the reason elaborated below.

Under the Civil Code, there are three different statuses of insanity. The Code adopts different approaches to legal capacity depending on the status of insanity. The first status of insanity is known as notorious insanity. As per the Civil Code, a person is considered to be notoriously insane if he becomes an inmate of a hospital or an institution for insane persons or of a nursing home by reason of his mental condition.¹⁰⁴ Besides, pursuant to article 341(2) of the Civil Code, in a town or rural community of less than 2000 inhabitants, the person is considered to be notoriously insane if the family of that person keep a watch on him and his liberty of moving is restricted by the society as a result of his mental condition.

Persons vilified as notoriously insane have limited legal capacity. The law presumes that the consent of such person is affected by defect which brings about its nullity unless proven otherwise.¹⁰⁵ As a result, juridical acts performed by such persons are subject to invalidation if requested by themselves, their heirs and their representatives.¹⁰⁶ Here it should be emphasised that once individuals are labelled as notoriously insane, they are considered as not understanding the importance of their actions. Although the law refers to elements of a functional approach to legal capacity such as understanding the importance of one's actions, unlike legal systems that follow the functional approach to legal capacity, the Ethiopian Civil Code does not provide grounds on which actual ability of individuals is assessed on a case-by-case basis. Instead, it presumes that notoriously insane persons do not understand the importance of their actions. Consequently, the law assesses capacity based on disability instead of a person's capacity in relation to a particular decision taken at a particular time. Therefore, the Civil Code in actual sense follows the status approach to legal capacity as opposed to the functional approach in this regard.

The second status of insanity is referred by the Code as persons whose insanity is not notorious.¹⁰⁷ In principle, persons who are not notoriously insane are legally capable.¹⁰⁸ Thus juridical acts performed by persons

104 Art 341 of the Ethiopian Civil Code.

105 Art 344 of the Ethiopian Civil Code.

106 Art 343 and 344 of the Ethiopian Civil Code.

107 Art 347 of the Ethiopian Civil Code.

108 See arts 347-349 of the Ethiopian Civil Code.

who are not notoriously insane are not invalidated on the grounds of insanity unless they requested invalidation by proving that at the time of performance of such acts they were not in a condition to give consent free from defects.¹⁰⁹ In this respect, the law provides a possibility by which capacity of individuals can be assessed on a case-by-case basis at the request of the person. The legal capacity of an individual can be restricted only if it can be proved that his/her decision is affected by his/her disability. Hence, the Code employs the functional approach to legal capacity with regard to persons whose insanity is not notorious.

The third status of insanity is judicial interdiction. Under the Civil Code, persons with severe intellectual/mental impairment are declared as judicially interdicted persons.¹¹⁰ Once they are declared as a judicially interdicted person, they will be legally incapable. As a result, the law that applies to minors is applicable to judicially interdicted persons with respect to their person and property.¹¹¹ Consequently, the court appoints a guardian and tutor for judicially interdicted persons.¹¹² A very disappointing side of this law is the fact that persons with intellectual and psychosocial disabilities can be declared as judicially interdicted persons as a result of the application of third persons like heirs, relatives and the public prosecutor.¹¹³ Like notoriously insane persons, persons with intellectual and psychosocial disabilities declared as judicially interdicted are presumed to be incapable of understanding the importance of their actions. The law does not provide a mechanism by which their capacity is assessed in relation to particular action at a particular time. Therefore, strictly speaking, the Code follows the status approach to legal capacity in relation to persons declared as judicially interdicted.

In the Initial state party Report Ethiopia submitted to the CRPD Committee on the implementation of CRPD, the Government of Ethiopia noted:

Legal capacity has nothing to do with disability except in the case of mental disabilities. The restriction of legal capacity on the ground of mental disability is to protect the interest of such a person.¹¹⁴

The Government of Ethiopia is of the view that in order to protect the interest of persons with intellectual and psychosocial disabilities, the right to legal capacity of these persons should be restricted. The CRPD Committee stood against Ethiopia's stand by expressing its concern about situation of persons with intellectual and psychosocial disabilities in

109 Art 347 of the Ethiopian Civil Code.

110 Art 351 of the Ethiopian Civil Code.

111 Art 358 of the Ethiopian Civil Code.

112 Art 359 of the Ethiopian Civil Code.

113 Art 353 of the Ethiopian Civil Code.

114 See Ethiopia's Initial State party Report to CRPD Committee para 58 <https://www.refworld.org/publisher,CRPD,,ETH,57aae13b4,0.html> (accessed 6 October 2019).

Ethiopia in its Concluding Observations on the Initial Report of Ethiopia as follows:¹¹⁵

The Committee is concerned that the legislative provisions of the Civil Code contradict article 12 of the Convention, in particular articles 339-388 and 1728 in chapter 3 ('Insane persons and infirm persons') and chapter 4 (Judicial interdiction), and article 740 of the Commercial Code. Those provisions restrict the right of persons with psychosocial disabilities and intellectual disabilities to the full enjoyment and exercise of their rights, including the right to marry, to act as witness and to vote, and parental rights and, for blind, deaf and deaf-blind persons, the right to carry out banking transactions.

Accordingly, the Committee's recommendation to Ethiopia reads:¹¹⁶

The Committee recommends that the state party repeal the legislative provisions that are non-compliant with article 12 of the Convention, in particular those provisions of the Civil Code (chaps. 3 and 4, arts. 339-388 and 1728) and Commercial Code (art. 740) and all forms of substituted decision-making. It also recommends that the state party explicitly recognize in law the full legal capacity of persons with disabilities with respect to all rights, including the right to marry, to enter into a contract, to vote, to own property, to a family, to carry out banking transactions and to have access to justice, in line with the Committee's general comment No. 1 (2014) on equal recognition before the law.

Although the CRPD Committee properly addressed the right to legal capacity of persons with intellectual and psychosocial disabilities in its Concluding Observations, it failed to directly comment on the erroneous submission of the Ethiopian Government that claims restriction of legal capacity on the ground of mental disability is necessary to protect the interests of persons with mental disabilities. The Committee should have in plain language communicated to the Ethiopian Government that restricting legal capacity of persons on the basis of mental disability is no longer considered as protecting the interests of these persons.

In a nutshell, although the Ethiopian Civil Code recognises the right to legal personality of persons with intellectual and psychosocial disabilities, it restricts the right to legal capacity of persons with intellectual and psychosocial disabilities on the basis of disability. The Ethiopian Civil Code follows traditional approaches to legal capacity that have been rejected by the CRPD. Moreover, it conceptualises disability as a factor embedded in the personality of an individual. Only individual's

115 See Concluding Observation on the Ethiopia's Initial State Party Report on the Implementation of CRPD, CRPD Committee (4 November 2016) UN Doc CRPD/C/ETH/CO/1 (2016) para 25 <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhsp2gZdYXWBKA18z%2FSv%2F6lkjiDqI9zs5hd5%2BUAXK5vbPAJ7j6jyrAv5vGf3%2BKDAISC4bHZ89os5fSRy3geaPEuCRLunudv%2BuislMknxs7omG> (accessed 1 September 2019).

116 CRPD Committee (n 115 above) para 26.

impairments such as insufficient development (intellectual impairment, mental disease (mental condition)) are considered by the Civil Code as causes of disability. The Code disregards physical/environmental barriers like societal bias, oppression and discrimination that place persons with intellectual and psychosocial disabilities in a situation in which they cannot understand the importance of their actions. This indicates that the Code follows the medical model of disability which has been rejected by the CRPD.

5.3 The right to legal capacity of persons with intellectual and psychosocial disabilities under the Ethiopian family law

Since Ethiopia has a federal state structure, there is no single family law that applies throughout the country. The Federal Government has a Federal Family Code. Regional states also have their own respective family codes that apply in their jurisdictions. In the interest of time and space, in this discussion a reference will be made only to the Ethiopian Federal Family Code with a focus on the right to establish a family as well as other related issues as all family codes are on the same page on the subject under discussion.

5.3.1 *The right to establish a family*

Persons with disabilities' right to establish a family has been recognised by the CRPD. The CRPD requires states parties to take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships.¹¹⁷ To the contrary, the Ethiopian Revised Federal Family Code (RFFC) has a provision that undermines the right to marriage of persons with intellectual and psychosocial disabilities. This code provides that 'any person who is judicially interdicted shall not conclude marriage unless authorized, for that purpose, by the court.'¹¹⁸ The above provision of the Family Code leaves the right to marriage of judicially interdicted persons at the discretion of court. As per article 34(1) of the same Code, if a judicially interdicted person concludes a marriage without the prior authorisation of the court, the dissolution of such marriage may be requested from the court by either the judicially interdicted person himself or his guardian. The fact that the guardian is allowed to request dissolution of the marriage of a judicially interdicted person is a typical case of encroaching on a person's private life.

Moreover, the contract of marriage entered into by a judicially interdicted person does not have effect unless it is approved by the

117 Art 23(1) of the CRPD.

118 Art 15(1) of the 2002 Ethiopian Revised Federal Family Code (RFC).

court.¹¹⁹ Under the Ethiopian legal system, a contract of marriage is a very personal contract that is concluded by spouses following the conclusion of marriage to determine the pecuniary effect of a marriage and other related issues like consequences of dissolution of marriage. In this regard, persons with intellectual and psychosocial disabilities who are declared as judicially interdicted person have partial legal capacity. Aside from judicially interdicted persons, the law allows everyone to enter into such contracts without court intervention. Therefore, the law discriminates against persons with intellectual and psychosocial disabilities in this regard.

Another area where the legal capacity of persons with intellectual and psychosocial disabilities is restricted is in relation to parenthood. Persons with disabilities have the right to have children and to act as guardians for their children.¹²⁰ The CRPD obliges states parties to ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, adoption of children or similar institutions.¹²¹ However, the Ethiopian family law highly restricts legal capacity of persons with intellectual and psychosocial disabilities who are declared as judicially interdicted persons. Article 175(1) of the RFFC provides that a judicially interdicted person may institute an action to disown¹²² a child with the permission of the court. As it can be grasped from the above provision, unlike other persons, judicially interdicted persons cannot institute action to disown without permission of the court. If the court refused to permit this, the person retains paternity of the child even if he is not the real father of the child. When the law gives discretion to the court on these issues, it does not lay down grounds of giving permission or denying permission. At the end of the day, this is decided by the judge. In addition, the law allows a guardian of a judicially interdicted person to institute action of disowning in the name of such person.¹²³ This provision also has negative implications for persons with psychosocial and intellectual disabilities especially if the guardian institutes an action of disowning without taking in to account the will of the person.

The worst scenario that needs discussion in relation to legal capacity of persons with intellectual and psychosocial disabilities is the issue of guardianship and parenting. Under the Ethiopian family law, the father and the mother are jointly guardians and tutors of their minor children as long as their marriage subsists.¹²⁴ However, this is not the case for persons

119 Art 43(1) of the RFC.

120 Art 23(1) of the CRPD.

121 Art 23(2) of the CRPD.

122 Disowning under the Ethiopian legal system refers to an action by which the paternal filiation of a child is contested by the person to whom the law attributes the paternity of a child and is totally different from other civil actions like adoption. See arts167-179 of the RFFC.

123 Art 175(2) of the RFC.

124 Art 219 of the RFC.

with intellectual and psychosocial disabilities. The law prohibits judicially interdicted persons from serving as a guardian or tutor of their children.¹²⁵ In this respect, the family law discriminates against persons with intellectual and psychosocial disabilities.

In general, under the Ethiopian family law the legal capacity of persons with intellectual and psychosocial disabilities is not recognised as envisaged by the CRPD. The family law either restricts or denies legal capacity of persons with intellectual and psychosocial disabilities (particularly those labelled as judicially interdicted persons) as the case may be.

5.4 The right to legal capacity of persons with intellectual and psychosocial disabilities under Ethiopian electoral law

Not only civil rights, but also political rights of persons with intellectual and psychosocial disabilities are restricted if their right to legal capacity is not respected. One of the distinguishing features of democracy is the presence of universal adult suffrage without discrimination.¹²⁶ However, in Ethiopia persons whose legal capacity is restricted on the basis of mental capacity are deprived of the right to vote. Under the Ethiopian electoral law, a person should be eligible in order to vote. One of criteria of eligibility is having required mental capacity to understand the electoral process. Pursuant to article 18 of the recently adopted Ethiopian Electoral and Political Parties Proclamation, 'a person who is proved to be incapable of making decision due to mental disorder as confirmed by the relevant authority or sufficient evidence' cannot be registered to vote.¹²⁷ Accordingly, the Ethiopian electoral law denies persons with intellectual and psychosocial disabilities labelled as judicially interdicted persons and notoriously insane persons the right to vote.¹²⁸ Although the main legislation governing election in Ethiopia has recently been amended, a directive for its implementation is yet to be adopted. However, even if the new directive is adopted, the stand of the new directive will not be different from the above mentioned directive since the newly adopted Ethiopian electoral law followed the same approach with its predecessor regarding voting rights of persons with intellectual and psychosocial disabilities.

In a similar vein, persons with intellectual and psychosocial disabilities are deprived of the right to be elected under Ethiopian electoral law. In this regard, the Ethiopian Electoral and Political Parties Proclamation

125 Art 243(1) of the RFC.

126 The FDRE Constitution also recognises this under its art 38(1)(B).

127 See art 18(3)(A) of The Ethiopian Electoral and Political Parties Proclamation, Proclamation No 1162/2019.

128 Art 20(3) of the Directive for Registration of Voters prohibits notoriously insane persons from voting. See the National Electoral Board of Ethiopia, Directive for the Registration of Electors No 2/2009 (as amended).

stipulates that a person who is declared by an authorised body to be incapable of making effective decisions due to insanity is not eligible for candidature.¹²⁹ As aforementioned, in the eyes of the Civil Code, persons with intellectual and psychosocial disabilities are regarded as insane. Therefore, in the actual sense, it is persons with intellectual and psychosocial disabilities who are declared to be incapable of making effective decisions and run the risk of losing the right to stand as a candidate for election.

Accordingly, under the Ethiopian electoral law, the right to legal capacity of persons with intellectual and psychosocial disabilities has not been recognised. Persons with intellectual and psychosocial disabilities should not be denied any of their rights categorically for the mere fact they are declared judicially interdicted or considered to be notoriously insane. While interpreting the right to political participation enshrined under article 13(1) of the African Charter on Human and Peoples' Rights, the African Commission on Human and Peoples' Rights accentuated that this right can only be denied based on objective and reasonable criteria established by law and questioning the mental ability of mentally disabled patients to make informed choices in relation to their civic duties and obligations cannot be regarded as objective bases to exclude mentally disabled persons from political participation.¹³⁰

Ethiopia's Initial state party Report to the CRPD Committee is silent on the right to political participation of persons with intellectual and psychosocial disabilities. However, in its Concluding Observations on the Initial Report of Ethiopia, the CRPD Committee has expressed its concern on this issue as follows:¹³¹

The Committee is concerned that restriction to the right to vote of 'notoriously insane persons' is possible under law. It is further concerned that support to exercise the right to vote by persons with disabilities is not guaranteed in law and in practice.

On this note, the Committee recommended that Ethiopia should:¹³²

Take all legislative and other measures to guarantee political rights of persons with disabilities, in particular persons with psychosocial or intellectual disabilities, including by removing any restrictions on the exercise of political rights, in law or in practice.

As aforementioned, under Ethiopian electoral law, persons with intellectual and psychosocial disabilities labelled as judicially interdicted

129 See Art 31(1)(e) of the Ethiopian Electoral and Political Parties Proclamation, Proclamation No 1162/2019.

130 See *Purohit* (n 87 above) paras 75 and 76.

131 CRPD Committee (n 115 above).

132 CRPD Committee (n 115 above) para 64.

and notoriously insane persons are denied the right to vote. The fact that there is actual restriction of voting rights of persons with intellectual and psychosocial disabilities in Ethiopia is clearly discerned from a reading of the provisions of the Ethiopian Electoral Law. Given this fact, the CRPD Committee does not seem to fully appreciate the lived reality of persons with intellectual and psychosocial disabilities in Ethiopia when it views restriction of voting rights of these groups of persons as a possibility as opposed to a lived reality. Furthermore, the CRPD Committee failed to recognise the fact that persons with intellectual and psychosocial disabilities in Ethiopia are denied not only voting rights, but also the right to stand for election which is an indispensable strand of the right to political participation. The fact that the Committee noted that the support to exercise the right to vote by persons with disabilities is not guaranteed in law and in practice in Ethiopia is notable, as lack of support to exercise legal capacity is one of the main factors contributing to a violation of the rights of persons with intellectual and psychosocial disabilities in Ethiopia. The newly adopted Ethiopian electoral law could have changed the status quo by recognising the right of persons with intellectual and psychosocial disabilities to vote and stand for election had it considered the recommendations of the CRPD Committee. It is very regrettable that Ethiopia turned a deaf ear to the recommendations forwarded by the CRPD Committee. From the foregoing, it can be safely concluded that the Ethiopian electoral law is in stark contradiction with article 12 of the CRPD.

5.5 The need to recognise the right to legal capacity of persons with intellectual and psychosocial disabilities in Ethiopia

Ethiopia has to recognise the right to legal capacity of persons with intellectual and psychosocial disabilities at least for the following two principal reasons:

5.5.1 Inadequacy of the guardianship system to address the needs of persons with intellectual and psychosocial disabilities

The substitute decision making retained under the Ethiopian legal system does not cater for the rights of persons with intellectual and psychosocial disabilities. Although the primary aim of guardianship laws is protection of property interests of persons with impaired capacity such as persons with intellectual and psychosocial disabilities,¹³³ these laws have the effect of undermining the rights of persons with intellectual and psychosocial disabilities. Stripping persons of legal capacity on the ground of mental

133 S Burningham 'Developments in Canadian adult guardianship and co-decision-making law' (2009) 119 <https://ojs.library.dal.ca/djls/article/view/4173> (accessed 11 September 2015).

capacity and placing them under control of other persons is a violation that brings social and legal harm to individuals.

When individuals lack the legal capacity to act, they are not only robbed of their right to equal recognition before the law, they are also robbed of their ability to defend and enjoy other human rights.¹³⁴

Furthermore, a person who is stripped of legal capacity is no longer addressed as a person in his/her own right.¹³⁵ As a result, their moral and legal status is more likely to be diminished in the eyes of those in close personal relationships, caregivers, community members, as well as public institutions.¹³⁶ This in turn perpetuates stereotyping, objectification, negative attitudes and other forms of exclusion which people with disabilities disproportionately face and increases powerlessness and vulnerability to abuse, neglect and exploitation.¹³⁷ By limiting an individual's right to make decisions, guardianship takes away an individual's ability to make vital personal decisions.¹³⁸ It also removes individuals from a multitude of interactions involved in decision making and eventually segregates them from a number of significant aspects of social, economic, as well as political life.¹³⁹ In addition, the guardianship system also has the effect of isolating individuals by explicitly depriving them of their right to make certain social decisions like establishing family.¹⁴⁰ By excluding persons with intellectual and psychosocial disabilities from the decision-making process, guardianship exacerbates their marginalisation and isolation from mainstream society.¹⁴¹ It also curtails individuals' opportunities to test their abilities by taking away their power to manage their own affairs.¹⁴² Lack of decision-making power may lead to a further decline in the individual's capabilities and competence to act in the world.¹⁴³ Allowing persons with intellectual and psychosocial disabilities to retain legal capacity and providing them with support to help them exercise their right if necessary does not only respect their dignity and autonomy, but also enables them to remain actively engaged in the full range of life activities and maximise their decision-making capacity.

As aforementioned, the CRPD Committee has recommended that Ethiopia repeal all forms of substituted decision-making and explicitly recognise in law the full legal capacity of persons with disabilities with

134 UN (n 60 above) 89-90.

135 Bach & Kerzner (n 9 above) 8-11.

136 As above.

137 As above (n 135 above).

138 Salzman (n 69 above) 289-291.

139 As above.

140 Salzman (n 69 above) 289-291; MDAC (n 24 above) 10-16.

141 S Then 'Evolution and innovation in guardianship laws: Assisted decision-making' (2013) 35 *Sydney Law Review* 139-140 http://sydney.edu.au/law/slr/slr_35/slr35_1/06_Then.pdf (accessed 28 August 2015).

142 Then (n 141 above).

143 As above.

respect to all rights.¹⁴⁴ In another note, recognising that the provision of support is not effectively available in Ethiopia to ensure the exercise of legal capacity of persons with disabilities on an equal basis with others, the Committee recommended that Ethiopia should ensure the provision of support in order for persons with disabilities to be able to exercise their legal capacity.¹⁴⁵ The Committee further recommended that Ethiopia develop and implement supported decision-making models that respect the autonomy, will and preferences of the person.¹⁴⁶

Therefore, Ethiopia should recognise the right to legal capacity of persons with intellectual and psychosocial disabilities and replace the system of substitute decision-making with the supported decision-making system in order to ensure full enjoyment of rights of persons with intellectual and psychosocial disabilities.

5.5.2 *Obligations under international law*

As a state party to the CRPD, Ethiopia has the obligation to implement rights of persons with intellectual and psychosocial disabilities guaranteed by the CRPD. One of the underlying principles of the CRPD is the respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.¹⁴⁷ The CRPD further prohibits all forms of discrimination on the basis of disability. According to the CRPD, discrimination on the basis of disability means:¹⁴⁸

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 in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.

Accordingly, state parties should eliminate any action that discriminates against persons with disabilities in effect. The Convention prohibits both *de jure* and *de facto* discrimination.¹⁴⁹ Denying persons with intellectual and psychosocial disabilities their right to legal capacity based on their degree of impairment by virtue of law is a typical example of *de jure* discrimination on the basis of disability.¹⁵⁰ The CRPD also requires state parties to adopt appropriate legislative, administrative and other measures that enhance

144 CRPD Committee (n 115 above) para 26.

145 CRPD Committee (n 115 above) paras 27 and 28.

146 CRPD Committee (n 115 above) para 28.

147 See para (N) of the Preamble and art 3(A) of the CRPD.

148 See art 2 of the CRPD.

149 UN *The Convention on the Rights of Persons with Disabilities training guide* Professional Training Series No 19, 81 https://www.ohchr.org/Documents/Publications/CRPD_TrainingGuide_PTS19_EN%20Accessible.pdf (accessed 17 October 2015).

150 UN (n 149 above).

implementation of the rights guaranteed by the Convention.¹⁵¹ State parties should further take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that directly or indirectly discriminate against persons with disabilities.¹⁵² As discussed in previous sections, article 12 of the CRPD requires state parties to recognise the right to legal capacity of persons with disabilities in its fullest sense. To comply with this provision of the Convention, Ethiopia should recognise the right to legal capacity of persons with intellectual and psychosocial disabilities under her legal system.

With regard to obligations emanating from international treaties, the principle of *pacta sunt servanda* dictates that treaties wilfully entered into should be implemented in good faith.¹⁵³ As Mr Briggs, delegate of USA, during the UN Conference on the Law of Treaty underscored:¹⁵⁴

The *pacta sunt servanda* rule had come down through the ages as a self-evident truth. Both comparative law and the history of legal systems showed that it had gained universal acceptance; it had been found to be a legal necessity. The principle had been a basic rule of international law from its earliest origins, and was the foundation-stone of further progress and development.

Obviously, the principle of *pacta sunt servanda* in the law of treaties has been part of customary-international law since time immemorial. Thus, the fact that Ethiopia denies the right to legal capacity of persons with intellectual and psychosocial disabilities that has been recognised under the CRPD is against customary-international law since she ratified the Convention with full understanding of the rights enshrined therein.

6 Conclusion and recommendations

With the introduction of the CRPD, the right to legal capacity of persons with disabilities, including persons with intellectual and psychosocial disabilities has been recognised under international human-rights law. Ethiopia as a state party to the CRPD has to respect the right to legal capacity of persons with intellectual and psychosocial disabilities. Article 12 of the CRPD guarantees both capacity to be a holder of rights and capacity to exercise those rights for persons with disabilities. It also guarantees the right to access support needed to exercise legal capacity.

151 Art 4(A) of the CRPD.

152 Art 4(B) of the CRPD.

153 T Bulto 'The monist-dualist divide and the supremacy clause: Revisiting the status of human rights treaties in Ethiopia' (2009) 23 *Journal of Ethiopian Law* 135. Art 26 of the Vienna Convention on the Law of Treaties also reads: '[E]very treaty in force is binding upon the parties to it and must be performed by them in good faith.'

154 The extract from the Official Records of the United Nations Conference on the Law of Treaties para 65 http://www.legal.un.org/diplomaticconferences/...1969/.../a_conf_39_c1_sr29.pdf (accessed 20 October 2015).

This implies that the system of substitute decision-making should be replaced by the supported decision-making system.

It has been nine years since Ethiopia ratified the CRPD. However, the right to legal capacity of persons with disabilities has not been recognised under the Ethiopian legal system in its fullest sense. Capacity to act on one's rights, the key element of legal capacity is restricted or denied in the case of persons with intellectual and psychosocial disabilities depending on the degree of impairment. In this respect, there is stark incompatibility between Ethiopian laws like the Civil Code, the Family law, and the Electoral law on one hand and the CRPD on the other hand. As a result, the system of substitute decision-making is retained under the Ethiopian legal system. Despite the fact that the CRPD is part of Ethiopian laws pursuant to the FDRE Constitution, the right to legal capacity of persons with intellectual and psychosocial disabilities is far from realisation in Ethiopia owing to the absence of legislative, judicial, as well as administrative framework that gives effect to the rights guaranteed by the CRPD.

Be that as it may, Ethiopia has to recognise the right to legal capacity of persons with intellectual and psychosocial disabilities since it has an international obligation to do so. Furthermore, the system of substitute decision-making retained under the Ethiopian legal system no longer serves the interests of persons with intellectual and psychosocial disabilities. Instead, it perpetuates existing stereotyping and invisibility of persons with intellectual and psychosocial disabilities. The Ethiopian legal system should discard the medical model of disability and conceptualise disability from the perspective of human-rights and social models of disability. The term 'insane', which the law uses to refer to persons with intellectual and psychosocial disabilities, is a derogatory term that perpetuates discrimination and stereotyping against persons with intellectual and psychosocial disabilities. In addition, it is an outdated term that does not go in line with the modern understanding of disability. The law formalises existing discrimination and marginalisation when it employs this terminology to refer to persons with intellectual and psychosocial disabilities.

Ethiopia should additionally introduce the system of supported decision-making to enable persons with intellectual and psychosocial disabilities to exercise their legal capacity. The author is of the view that the Swedish supported decision-making model is worth considering to realise the right to legal capacity of persons with intellectual and psychosocial disabilities in Ethiopia. This model of supported decision-making can easily make the support needed to exercise legal capacity accessible freely or at affordable price. Lack of resources and expertise can be a potential challenge to introduce this model of supported decision-making.

Strengthening international cooperation to mobilise the required resource, empowering disabled peoples' organisations and encouraging participation of domestic as well as international civil societies can help to tackle challenges of resources that may arise in this respect. It should also be noted that an effective supported decision-making system cannot fully develop overnight. Although the CRPD Committee emphasised that the safeguard envisaged by the CRPD should not in any case amount to substitute decision-making, considering unintended consequences that this interpretation may have, the author believes that the legal system that employs a system of supported decision-making as a rule and a system of substitute decision-making in very exceptional circumstances can better advance the rights of persons with intellectual and psychosocial disabilities. However, this can be the case only if there is a stringent safeguarding mechanism that prevents unwarranted use of exceptional grounds leading to retaining the substitute decision-making system.

Based on the above premises, the author recommends the following to implement the right to legal capacity of persons with intellectual and psychosocial disabilities in Ethiopia:

- a) The right to legal capacity of persons with intellectual and psychosocial disabilities should be recognised unequivocally under the Ethiopian legal system. In this regard, the Ethiopian Civil Code should be amended in a way that reflects the social and human-right models of disability. Derogatory terms like 'insane' should not have a place in the Ethiopian legal system. The family law and the electoral law should also be amended to recognise the legal capacity of persons with intellectual and psychosocial disabilities.
- b) For persons in need of support to exercise their legal capacity, the support needed should be available. The substitute decision-making should be abolished and replaced with the supported decision-making system. For this to happen, Ethiopia has to enact legislation establishing the supported decision-making system as the current substitute decision-making regime does not have room for this system.
- c) In the situation persons with intellectual and psychosocial disabilities could not make decisions even with the presence of support, priority should be given to their will and preferences.
- d) In exceptional circumstances where identifying their will and preferences is not possible after employing the principle of the best interpretation of will and preferences, as a matter of necessity substituted decision-making should come in to play as a last resort. The substituted decision-making should not, however, take the form of guardianship. Rather, there should be the system of prior representation that allows persons with intellectual and psychosocial disabilities to represent a person who makes decisions on their behalf in situations in which they could not make decisions even with the presence of support. The representation agreement should be deposited in the public registry.

- e) There should be robust safeguarding mechanisms that protect persons with intellectual and psychosocial disabilities from abuse especially in exceptional situations where substitute decision-making applies. This can for instance be placing activities of the support provider under the supervision of courts. The law should also provide mechanisms by which persons with intellectual and psychosocial disabilities can make complaints against support providers in cases of abuse and disagreement.
- f) If substitute decision-making is a must, the functional approach to legal capacity should be employed to assess capacity. This approach is preferable since it has an element of periodic review of assessment of capacity and individual capacity is assessed on case-by-case basis.

CHAPTER 2

HUMAN RIGHTS AND ACCESS TO HEALTHCARE FOR PERSONS WITH ALBINISM IN AFRICA

Ebenezer Durojaye & Satang Nabaneh***

Summary

Discrimination and stigma relating to persons with albinism remain the norm in many African countries. There are documented reports of how persons with albinism have been subjected to gross human-rights violations owing to their colour. While attention has been given to the killings of persons with albinism worldwide, little attention has been given to other human-rights violations they encounter while seeking social services, particularly healthcare services. Discrimination against persons with albinism can lead to deleterious health consequences and at the same time hinder access to care for them. Women are generally historically disadvantaged and continue to encounter challenges with regard to their sexual and reproductive health. Being a woman with albinism can aggravate the situation as these women may encounter multiple forms of discrimination in healthcare settings. Thus, this paper examines the human-rights challenges relating to the health of persons with albinism with a focus on women with albinism in Africa. It draws on the intersectionality approach to argue that women with albinism suffer from multiple forms of discrimination, which further compound access to healthcare services for them. It discusses the relevance of regional human-rights instruments in addressing the right to healthcare of women with albinism. In particular, the paper discusses the potential of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa and the norms developed by the African Commission on Human and Peoples' Rights as well as its counterparts at the international level

* LLM, LLD (Free State); Dullah Omar Institute, University of the Western Cape; ebenezerdurojaye19@gmail.com.

** LLB (Gambia), LLM (Pretoria); LLD Candidate (Centre for Human Rights, Faculty of Law, University of Pretoria); satang.nabaneh@gmail.com. The authors are deeply grateful to the anonymous reviewers and editors of the *Yearbook*, whose valuable and insightful comments on earlier drafts of this article greatly enhanced the quality of this work. All errors and omissions in the article, of course, remain solely ours.

in advancing the right to health of women with albinism in the region. Furthermore, the paper recommends to the African Commission and African governments measures and steps to adopt in order to safeguard the right to health of women with albinism in the region.

1 Introduction

Albinism is a rare, non-contagious, genetically inherited difference present at birth. It results in a lack of pigmentation (melanin) in the hair, skin and eyes, causing vulnerability to the sun and bright light for persons with albinism.¹ The condition is found in both genders, regardless of ethnicity and in all countries of the world.²

There are various types of albinism with diverse implications for persons with this condition. The most common form is known as oculocutaneous albinism (OCA) and this affects the skin, hair and the eyes.³ There are different types and subtypes of OCA with varying degrees of melanin deficiency. The main ones are tyrosinase negative (OCA1) where there is little or no melanin production; and OCA2 type, wherein some melanin is produced, giving rise to white or cream-coloured skin, sandy-coloured hair and light blue, grey or brown irises in those affected. These are the most prevalent in African countries.⁴

Due to ignorance and myths, persons with albinism face severe discrimination and violence. Hundreds of attacks against persons with albinism have been reported in 25 countries.⁵ These acts of violence and abuses against persons with albinism demonstrate how their fundamental human rights are constantly violated or disregarded. Superstitious beliefs about persons with albinism in many African countries are rife and include the belief that they are ghosts, that they never die, that sexual intercourse with a woman or a girl with albinism can cure HIV/AIDs and most grotesque of all, that their body parts can bring about wealth and good luck when consumed in potions and worn as amulets.⁶ In response to human-rights abuses against persons with albinism, the Former UN Secretary-General Ban Ki-moon on 13 June 2016, called on all countries to end all

1 This paper uses the term 'persons with albinism' rather than the term 'albino(s)', which has been labelled as demeaning and offensive by various quarters of the community of persons with albinism for failing to appreciate their humanity first before the condition.

2 Report of the Office of the United Nations High Commissioner for Human Rights on Persons with albinism, HRC (12 September 2013) UN Doc A/HRC/24/57 (2013) paras 10 & 11.

3 ES Hong et al 'Albinism in Africa as a public health issue' (2006) 2 *BMC Public Health* 212.

4 As above.

5 Report of the Independent Expert on the enjoyment of human rights by persons with albinism, HRC (18 January 2016) UN Doc A/HRC/31/63 (2016) para 20. See also Preliminary study on the situation of human rights of persons living with albinism (30 July 2014) UN Doc A/HRC/AC/13/CRP.1 (2014) para 10.

6 See HRC (n 2 above) para 17.

forms of discriminatory practices that threaten the well-being, health and even the lives of people with albinism, and to adopt programmes that would enable them to play a full part in society.⁷

2 Albinism as a form of disability

According to the World Report on Disability, disability is a 'complex, dynamic, multidimensional and contested' concept.⁸ At first, disability was viewed exclusively as a medical condition, but subsequently construed as a social construct, which takes into account social and environmental circumstances. These two views are regarded as the medical and social models respectively.⁹ On the one hand, the medical model 'locates the disability within the person and views persons with disabilities as objects for clinical intervention'.¹⁰ Persons with disabilities are thus primarily seen as 'passive patients' and are not empowered to make decisions concerning their lives.¹¹

On the other hand, the social model of disability makes the distinction between impairment and lost or limited functioning experienced by individuals. The social model further notes that people with disabilities or impairments encounter various barriers simply because of the social structure;¹² thus, such barriers may be as a result of social, cultural, physical, material or attitudinal factors, but they tend to exclude people with impairment from mainstream life. This conceptualisation applies to persons with albinism who daily encounter various forms of barriers to living a life of dignity. The social model is complementary to the rights-based approach to disability, which is applied throughout this paper. Indeed, Thomas has advanced the social-model approach through the 'social relational understanding of disability'.¹³ By this, he identifies the 'significance of impairments effects', that is, the daily impact of living with particular impairments. He further emphasises the implications of understanding the psychosocial effects of disability.¹⁴ With regard to women with albinism, the impairment effects include poor vision, power

7 'On Albinism Awareness Day, Ban urges all countries to break cycle of attacks and discrimination' *UN News* 13 June 2016 <http://www.un.org/apps/news/story.asp?NewsID=54206#.V7DZo7grLIV> (accessed 10 February 2019).

8 World Health Organisation (WHO) 'World report on disability' (2011) xxi.

9 C Ngwena 'Deconstructing the definition of "disability" under the Employment Equity Act: Social deconstruction' (2006) 22 *South African Journal of Human Rights* 619.

10 G Quinn & T Degener *Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability* (2002) 11.

11 See C Ngwena 'Interpreting aspects of the intersection between disability, discrimination and equality: Lessons for the Employment Equity Act: Part 1 (Defining disability)' (2005) 2 *Stellenbosch Law Report* 221.

12 Union of the Physically Impaired against Segregation *Fundamental principles of disability* (1976).

13 C Thomas 'How is disability understood? An examination of sociological approaches' (2004) 16 *Disability and Society* 569.

14 As above.

imbalance, social prejudice and potential skin damage due to sun. Buttressing this point, a study carried out among 15 adults with albinism in South Africa has shown the negative effects the disablist external environment can have on self-image and on their sense of belonging at home and within the wider community.¹⁵

In addition to these two approaches to disability, the third model – the human-rights model – has emerged. The human-rights model to disability does not define disability, but recognises it as an ‘evolving concept’.¹⁶ It sees persons with disabilities not as objects of charity, but as subjects of rights.¹⁷ The adoption of the Convention on the Rights of Persons with Disabilities (CRPD)¹⁸ in 2006 and its entry into force in 2008 was a historic shift in protecting the rights of persons with disabilities. The CRPD aims to promote and ensure inclusion of persons with disabilities in all aspects of society. According to Viljoen, the CRPD ensures ‘accountability and legal obligations on states’.¹⁹

As of March 2019, there are currently 161 signatories and 177 ratifications of the CRPD.²⁰ At the core of CRPD are the values and principles of non-discrimination and equality of opportunity. There are eight guiding principles to the CRPD namely: respect for inherent dignity and individual autonomy; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance as part of human diversity and humanity; equality of opportunity; accessibility; equality between men and women; and respect for the evolving capacities of children with disabilities.²¹ The CRPD targets not only the law, but also prejudicial societal attitudes, which undermine equality. It recognises the personhood of every persons with disabilities and requires states to provide support in exercising that capacity.

15 MBJ Pooe-Moneymore et al ‘The experience of people with oculocutaneous albinism’ (2012) 17 *Health SA Gesondheid* 592.

16 Preamble, para e CRPD.

17 The CRPD adopts this approach and gives a more effective normative legal framework for the protection of the rights.

18 Adopted by the UN General Assembly on 13 December 2006 and came into force on 3 May 2008.

19 F Viljoen *International human rights law in Africa* (2012) 140.

20 See <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> (accessed 4 March 2019).

21 Art 3 CRPD. For an in depth analysis of the CRPD with a special focus on Africa, see TP Van Reenen & H Combrinck ‘The UN Convention on the Rights of Persons with Disabilities in Africa: Progress after 5 years’ (2011) 18 *SUR International Journal of Human Rights* 133; J Biegon ‘The promotion and protection of disability rights in the African human rights system’ in IGD Plessis & TV Reenen *Aspects of disability law in Africa* (2011) 53-83.

In some of its recent decisions, the Committee on the CRPD has affirmed the rights of persons with albinism. For instance, in *Y v Republic of Tanzania*,²² the Committee found that the government of Tanzania was in violation of article 5 when it failed to protect the applicant from violence as a result of albinism. According to the Committee, since these attacks were a form of violence exclusively directed at persons with albinism, failure to investigate constituted a form of discrimination against persons with albinism. The Committee expressed the view that despite discrimination and acts of violence against persons with albinism, the state has failed to take appropriate measures to create awareness and to redress the violations.

An important point to note from this decision is that the Committee found that acts of violence against persons with disabilities were in violation of article 5 on non-discrimination. This is an implicit recognition of albinism as constituting disability. In addition to violation of article 5, the Committee found that the government of Tanzania was equally in violation of articles 7, 8 and 16 of the Convention. This decision by the Committee sends a strong signal that acts of discrimination and violence against persons with disabilities, especially persons with albinism, will not be condoned.

The Human Rights Council appointed an Independent Expert on the enjoyment of human rights of people with albinism for three years in 2015. The mandate includes the promotion and protection of the rights of persons with albinism at the UN and the regional human-rights mechanisms.²³ The mandate of the Independent Expert was extended by Human Rights Council on 22 March 2018.²⁴

At the regional level, there are various human-rights instruments that have a number of provisions that seek to promote and protect the rights of persons with disabilities. The instruments include the African Charter on Human and Peoples' Rights (African Charter),²⁵ the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women (African Women's Protocol),²⁶ the African Charter on the Rights and

22 *Y v Republic United of Tanzania* Communication 023/2014 (Views adopted on 31 August 2018).

23 Resolution 28/6: Independent Expert on the enjoyment of human rights by persons with albinism, HRC (10 April 2015) UN Doc A/HRC/RES/28/6 (2015).

24 Resolution 37/5: Mandate of the Independent Expert on the enjoyment of human rights by persons with albinism, HRC (9 April 2018) UN Doc A/HRC/RES/37/5 (2018). On her various reports, see <https://www.ohchr.org/EN/Issues/Albinism/Pages/Reports.aspx> (accessed 21 October 2019).

25 The African Charter on Human and Peoples' Rights adopted in 1981 and came into force in 1986, art 2.

26 Protocol to the African Charter on Human and Peoples' Rights and on the Rights of Women in Africa, adopted 11 July 2003, 2nd Ordinary Session of the Assembly of the African Union, AHG/Res. 240 (XXX) (entered into force 25 Nov 2005) art 23.

Welfare of the Child (African Child Charter),²⁷ and the African Youth Charter.²⁸ The African Union (AU) adopted 1999 to 2009 as the African Decade of Disabilities.²⁹

The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities (African Disability Rights Protocol) was adopted on 30 January 2018.³⁰ The African Disability Rights Protocol is a binding legal document protecting the human rights of persons with disabilities taking into account their lived realities in the continent while maintaining the core values and principles as set out in the CRPD. The Protocol has not come into force as it has yet to be ratified by at least 15 member states.³¹ Article 1 of the Protocol notes that:

[T]he purpose of this Protocol is to promote, protect and ensure the full and equal enjoyment of all human and people's rights by all persons with disabilities, and to ensure respect for their inherent dignity.

The African Disability Rights Protocol complements the CRPD by highlighting the continued exclusion, harmful practices, and discrimination affecting those with disabilities, especially women, children and the elderly. The Protocol in the Preamble recognises the risk of violence and abuse, particularly for those with albinism. It equally refers to maiming and killings of persons with albinism. The Protocol, therefore, makes it abundantly clear that persons with albinism are within the treaty's conceptualisation of persons with disabilities. However, the Protocol fails to address in detail some of the challenges facing persons with albinism in Africa.

The adoption of the African Disability Rights Protocol builds on existing work of the African human-rights system. For instance, on 5 November 2013, the African Commission adopted Resolution 263 on the prevention of attacks and discrimination against persons with albinism.³² Among other things, this resolution requires member states to include in their reports to the African Commission, information on the situation of persons with albinism, including good practices in protecting and

27 African Charter on the Rights and Welfare of the Child, OAU Doc CAB LEG/24.9/49, adopted on 11 July 1990, entered into force on 29 November 1999, art 13.

28 The African Youth Charter, adopted in 2006 and came into force in 2009, art 2.

29 http://sa.au.int/en/sites/default/files/Disability_Decade%20Plan%20of%20Action%20-Final.pdf (accessed 2 March 2019).

30 Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities https://au.int/sites/default/files/treaties/35475-treaty-protocol_to_the_achpr_on_the_rights_of_persons_with_disabilities_in_africa_e.pdf (accessed 4 March 2019).

31 The Protocol has so far registered only one signature from the Central African Republic. The Protocol can only come into force when it is ratified by 15 of the 54 AU member states that have accepted to be bound by the African Charter.

32 ACHPR 'Resolution 263 on the prevention of attacks and discrimination against persons with albinism' (5 November 2013) <http://www.achpr.org/sessions/54th/resolutions/263/> (accessed 3 August 2016).

promoting their rights.³³ In addition, on the same day, the African Committee on the Rights and Welfare of the Child (ACRWC) adopted a Declaration to End Discrimination and Violence against Girls in Africa in which the situation of children with albinism is addressed.³⁴ While these developments are significant, they will only result in positive outcomes in addressing discrimination and violence against persons with albinism if African countries exhibit the desired political will to implement them at the national level. This will require creating an enabling legal environment where rights of persons with disabilities are respected and protected.

3 Intersectionality, discrimination and human rights abuses against persons with albinism in Africa

Until recently, international and regional human-rights mechanisms had only fragmentally addressed the needs of persons with albinism.³⁵ For instance, the UN Special Procedures Mandate Holders noted that persons with albinism are seen as ‘ghosts and not human beings who can be wiped off the global map’ and are the ‘target of many false and harmful myths in several countries, especially in the African region’.³⁶

Persons with albinism have continued to live in perpetual fear for their lives and physical integrity. The Human Rights Council adopted a resolution in which it expressed grave concern about the ‘attacks against persons with albinism, including women and children, which are often committed with impunity’.³⁷ There are records of routine infanticide committed on children with albinism among some ethnicities in the region.³⁸ The Special Representative on Violence against Children stated that:

33 ACHPR (n 32 above) para 4.

34 ACERWC ‘The Addis Ababa Declaration on ending discrimination and violence against girls in Africa’ (5 November 2013) <http://sa.au.int/en/sites/default/files/ACERWC%20-%20Addis%20Ababa%20Declaration%20Discrimination%20and%20Violence%20Girls-%20Eng.pdf> (accessed 3 February 2019).

35 Moreover, in response to the call from civil-society organisations advocating to consider persons with albinism as a specific group with particular needs that require special attention, on 26 March 2015 the United Nations Human Rights Council adopted resolution 28/L.10 on creating the mandate of the Independent Expert on the enjoyment of human rights of persons with albinism, HRC (25 March 2015) UN Doc A/HRC/28/L.10 (2015) http://www.un.org/ga/search/view_doc.asp?symbol=A/HRC/28/L.10 (accessed 4 February 2019).

36 ‘African Children’s Charter (art. Not ghosts, but human beings ... persons with albinism)’ *OHCHR* 4 May 2013 <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=13294&LangID=E> (accessed 5 March 2019).

37 Res 24/33: Technical cooperation for the prevention of attacks against persons with albinism, HRC (8 October 2013) UN Doc A/HRC/RES/24/33 (2013) http://www.ohchr.org/Documents/HRBodies/HRCouncil/AdvisoryCom/A_HRC_RES_24_33_ENG.pdf (accessed 10 February 2019) Preamble.

38 HRC (n 2 above) para 44.

Children with albinism are at high risk of abandonment, discrimination and exclusion as a result of the appearance of their skin, and due to disability factors, such as impaired eyesight and high susceptibility to skin cancer and other health risks associated with albinism.³⁹

According to Franklin et al:

Myths and superstitions, fuelled by a lack of understanding surrounding albinism and the visible difference in the appearance of persons with albinism can lead to stigmatization, rejection, a lack of acceptance, violence, perceptions of difference and limited social integration.⁴⁰

The corollary is discriminatory practices in virtually every area of human endeavour, including the health-care setting. Some of the health challenges facing persons with albinism include the fact that they are viewed as a 'curse' or 'omens of disaster'.⁴¹ This tends to fuel stigma and discrimination against persons with albinism and further creates barriers to social services, including health.

Non-discrimination is a core human-rights principle that is enshrined in different human-rights treaties,⁴² and regional human-rights instruments.⁴³ Article 1 of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW),⁴⁴ adopts a comprehensive and nuanced definition of discrimination against women. It defines discrimination as:

[A]ny distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.

This definition by CEDAW is aimed at achieving substantive equality and not merely formal equality. This is commendable since it is aimed at addressing the historical differences and injustices meted out to women. Other provisions on non-discrimination are found in the Universal

39 Special Representative's submission as highlighted in the OHCHR Report, para 43.

40 A Franklin et al 'Children with albinism in Africa: Heir rights to "being" and "doing"' (2018) 18 *BMC International Human Rights and Health* 5.

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

42 Art 2 International Covenant on Civil and Political Rights; art 2 International Covenant on Economic, Social and Cultural Rights; art 2 Convention on the Rights of the Child; art 7 International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families; art5 5 Convention on the Rights of Persons with Disabilities. The Convention on the Elimination of All Forms of Racial Discrimination prohibits discrimination on the ground of race and the Convention on the Elimination of All Forms of Discrimination against Women on the ground of gender.

43 Art 2 ACHPR; art 2 African Women's Protocol; art 3 African Children's Charter.

44 Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) GA Res 54/180 UN GAOR 34th session Supp 46 UN Doc A/34/46 1980.

Declaration on Human Rights (UDHR),⁴⁵ the International Covenant on Civil and Political Rights (ICCPR)⁴⁶ and the International Covenant on Economic, Social and Cultural Rights (ICESCR).⁴⁷ All these instruments prohibit discrimination on various grounds including 'colour' and the open-ended category 'other status'. This can be purposively interpreted to cover vulnerable groups such as persons with albinism. With specific regard to persons with disabilities, article 2 of the CRPD defines discrimination broadly to include:

[A]ny distinction, exclusion or restriction based on 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. It includes all forms of disability discrimination, including denial of reasonable accommodation.

It should be noted that article 2 of the CRPD is reinforced by article 5 on equality. It can be argued that the non-discrimination provision of the CRPD is modelled on the CEDAW in that they both aim at achieving substantive equality. In other words, articles 2 and 5 of the CRPD are not only aimed at correcting the past injustices experienced by persons with disabilities, but also aim at ensuring that they live a dignified life. In this regard, the Committee on CRPD has affirmed a new model of inclusive equality to include the following:

(a) [A] fair redistributive dimension to address socioeconomic disadvantages; (b) a recognition dimension to combat stigma, stereotyping, prejudice and violence and to recognize the dignity of human beings and their intersectionality; (c) a participative dimension to reaffirm the social nature of people as members of social groups and the full recognition of humanity through inclusion in society; and (d) an accommodating dimension to make space for difference as a matter of human dignity.⁴⁸

On the CRPD's disability concept, Ngwena notes that:

It implicitly envisages transcending not just a medicalised notion of disability but also formal equality in order to achieve substantive equality. The CRPD's approach anticipates the imposition of a societal duty to dismantle barriers or

45 Universal Declaration of Human Rights (Universal Declaration) adopted 10 December 1948, UNGA 217 A (III).

46 International Covenant on Civil and Political Rights (ICCPR) adopted 16 December 1966, GA Res 2200A (XXI), UN Doc A/6316 (1966) 993 UNTS 3 (entered into force 23 March 1976).

47 International Covenant on Economic, Social and Cultural Rights (ICESCR) adopted and opened for signature, ratification and accession by General Assembly resolution 2200A (XXI) of 16 December 1966 (entered into force 3 January 1976) in accordance with art 27.

48 CRPD Committee, General Comment 6: Equality and non-discrimination (2018) UN Doc CRPD/C/GC/5 dated 9 March 2018 para 18.

to restructure the socio-economic environment in order to enable disabled people to participate equally.⁴⁹

This concept of disability recognises multiple forms of discrimination. In this line, the Committee on CRPD has further noted that:

The concept of intersectional discrimination recognizes that individuals do not experience discrimination as members of a homogenous group but, rather, as individuals with multidimensional layers of identities, statuses and life circumstances. It acknowledges the lived realities and experiences of heightened disadvantage of individuals caused by multiple and intersecting forms of discrimination, which requires targeted measures to be taken with respect to disaggregated data collection, consultation, policymaking, the enforceability of non-discrimination policies and the provision of effective remedies.⁵⁰

The Committee's recognition of intersectionality as crucial to addressing discrimination against persons with disabilities is useful in the context of persons with albinism. For persons with albinism, life can be unbearable due to the level of stigma and violence they experience on a daily basis. The situation is even compounded for women with albinism as they are exposed to discrimination on account of colour or skin, gender and disability. These different levels or forms of discrimination are often referred to as intersectionality. In her seminal work on intersectionality, Crenshaw in capturing the plight of black American women has noted that 'boundaries of sex and race discrimination doctrine are defined respectively by white women's and Black men's experiences'.⁵¹ In order to highlight the diverse nature of discriminatory practices black women encounter, she metaphorically explains as follows:

Consider an analogy to traffic in an intersection, coming and going in all four directions. Discrimination, like traffic through an intersection, may flow in one direction, and it may flow in another. If an accident happens in an intersection, it can be caused by cars travelling from any number of directions and, sometimes, from all of them. Similarly, if a Black woman is harmed because she is in an intersection, her injury could result from sex discrimination or race discrimination ... But it is not always easy to reconstruct an accident: Sometimes the skid marks and the injuries simply indicate that they occurred simultaneously, frustrating efforts to determine which driver caused the harm.⁵²

49 C Ngwenya 'Developing juridical method for overcoming status subordination in disability: The place of transformative epistemologies' (2014) 30 *South African Journal on Human Rights* 287.

50 CRPD General Comment 3: Art 6: Women and girls with disabilities (2016) UN Doc CRPD/C/GC/3 dated 2 September 2016 <https://www.refworld.org/docid/57c977344.html> (accessed 10 January 2019).

51 K Crenshaw 'Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics' (1989) 1 *University of Chicago Legal Forum* 143.

52 Crenshaw (n 51 above) 149.

In essence, Crenshaw calls for a rethinking of the definitions of discrimination, which perceive sex and race as mutually exclusive, thereby rendering the simultaneous experience of gendered racism almost non-existent. Rather she argues for a more nuanced and realistic definition taking cognisance of historical and structural oppression of black women. Echoing Crenshaw, Carastathis notes that:

[I]ntersectionality has become the predominant way of conceptualising the relation between systems of oppression which construct our multiple identities and our social locations in hierarchies of power and privilege.⁵³

Some of the benefits of applying intersectionality include simultaneity, complexity, irreducibility and inclusivity.⁵⁴ Intersectionality responds to lived experiences and helps to capture how oppressions are experienced simultaneously. In a true-life scenario a person is not a woman on Monday, a woman with albinism on Tuesday and a woman from a disadvantaged background on Wednesday. These diverse experiences are captured simultaneously and not treated exclusive of each other. This is consistent with Crenshaw's notion of structural intersectionality, which seeks to 'render visible phenomenological experiences of people who face multiple forms of oppression without fragmenting those experiences through categorical exclusion'.⁵⁵ Crenshaw's theory resonates perfectly with the lived experiences of persons with albinism in general and women with albinism in particular.

4 The right to health of persons with albinism under international law

The right to health is well recognised in numerous international and regional human-rights instruments. The starting point for the recognition of the right to health is the UN Charter of 1945.⁵⁶ The Charter urges states parties to it to respect rights to a higher standard of living and solutions to international health problems. This is buttressed by the Preamble to the World Health Organization (WHO) where it is provided that:

Health is a state of complete physical, mental and social well-being, not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of all human beings without distinction as to race, colour, and religion.⁵⁷

53 A Carastathis 'The concept of intersectionality in feminist theory' (2014) 9 *Philosophy Compass* 304.

54 As above.

55 Carastathis (n 53 above) 307.

56 Art 55 of the Charter of the United Nations, 26 June 1945 (entered into force 24 October 1945) TS 67 (1946).

57 The Constitution of the WHO was adopted by the International Health Conference, New York, 1922 June 1945; opened for signature on 22 July 1946 by the representatives of 61 states; 14 UNTS 185.

Article 25(1) of the UDHR provides that ‘everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services’.⁵⁸ Although the Universal Declaration is not a treaty, it has been widely accepted as an authoritative document on human rights by states worldwide. In short it is established that some of the norms set out in the UDHR constitute part of customary international law.⁵⁹ By far, however, the most authoritative provision on the right to health can be found in article 12 of the ICESCR.⁶⁰ Article 12 of the ICESCR provides that ‘states parties to the present Covenant recognize the right to every one of the highest attainable standard of physical and mental health’. In article 12(2) states are urged to take necessary measures, including taking into consideration underlying determinants of health to realise the right to health.

The Committee on the Covenant on Economic, Social and Cultural Rights (CESCR) in General Comment 14 has elaborated on the meaning of the right to health.⁶¹ According to the Committee, the right to health entails both ‘freedoms’ and ‘entitlements’—the former relates to the right to non-consensual medical treatment while the latter relates to access to healthcare services.⁶² The Committee emphasises that the right to health does not mean that states must guarantee good health as this is impossible given individuals’ idiosyncrasies. The Committee notes that the right to health contains four essential elements namely: availability; accessibility; acceptability; and quality (AAAQ).⁶³ The Committee explains that availability means that healthcare services must be of sufficient quantity, accessibility implies that healthcare services must be physically and economically accessible, particularly to vulnerable and marginalised groups.⁶⁴ It further explains that acceptability requires states to ensure healthcare services that are culturally and ethically acceptable. The Committee remarks that quality healthcare services require states to invest in the healthcare sector through training of health providers, payment of competitive wages and provision of facilities.⁶⁵

While the Committee recognises that the right to health may be realised progressively, it however, notes that the minimum core contents

58 Universal Declaration of Human Rights, GA Res 217 A (III), UN Doc A/810 (10 December 1948).

59 JP Humphrey ‘The Universal Declaration of Human Rights: Its history, impact and juridical character’ in BG Ramcharam (ed) *Human rights: Thirty years after the Universal Declaration* (1979) 21, 28

60 International Covenant on Economic, Social and Cultural Rights adopted 16 December 1966; GA Res 2200 (XXI) UN Doc A/6316 (1966) 993 UNTS 3 (entered into force 3 January 1976).

61 CESCR General Comment 14: The right to the highest attainable standard of health (2000) UN Doc E/C/12/2000/4 dated 11 August 2000.

62 General Comment 14 (n 61 above) para 33.

63 General Comment 14 (n 61 above) para 34.

64 As above.

65 As above.

of the right are not subject to progressive realisation.⁶⁶ The Committee identifies the principle of non-discrimination as one of the core contents of the right to health, which must be realised immediately. In the Committee's view, states are obligated to ensure the provision of healthcare services to all on a non-discriminatory basis paying attention to the needs of vulnerable and marginalised groups in society.⁶⁷ The Committee identifies children, persons with disabilities, people living with HIV and immigrants as vulnerable and marginalised groups that deserve special attention in health-care services. This clarification of the Committee is important in assessing steps and measures taken by states to realise the right to health of everyone, including persons with albinism.

In addition to the provision of the ICESCR, all other human-rights instruments relevant to the discussion in this paper include article 12 of the CEDAW⁶⁸ and article 25 of the CRPD. Article 25 of the CRPD provides that 'persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability'. It further enjoins states parties to ensure access to healthcare services that are gender-sensitive. The provision also covers access to sexual and reproductive health services and requires states to eliminate discriminatory practices in the healthcare setting against persons with disabilities.

The Committee on the CRPD has noted in General Comment 3 on women and girls with disabilities that states should adopt measures that give priority to healthcare services for persons with disabilities.⁶⁹ The Committee further notes that women and girls with disabilities particularly encounter challenges with regard to access to sexual and reproductive health services, and to family-planning information, services and methods as well as access to HIV/AIDS services.⁷⁰ It laments the various challenges facing women and girls with disabilities in the context of healthcare services, which may include discrimination, lack of respect for confidentiality and autonomy, lack of access to information and health facilities, forced or coercive treatment and negative attitudes of healthcare providers.

Furthermore, the Committee affirms that 'article 6 is a binding non-discrimination and equality provision that unequivocally outlaws discrimination against women with disabilities and promotes equality of opportunity and equality of outcomes'.⁷¹ In the Committee's view, girls with disabilities face multiple and intersectional discrimination on account of their age, gender, sex and disability. This may further predispose them

66 General Comment 14 (n 61 above) para 46.

67 As above.

68 n 44 above.

69 General Comment 3 (n 50 above) CRPD.

70 General Comment 3 (n 50 above) para 7.

71 General Comment 3 (n 50 above) para 9.

to human-rights abuses including acts of violence, violation of the right to dignity and denial of access to healthcare services.

Thus, the Committee notes that ‘States parties must guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds’.⁷² In *Munir al Adam v Saudi Arabia*,⁷³ the Committee found that failure by the government of Saudi Arabia to provide urgent surgery to save the applicant’s ear impairment from becoming permanently worse was a violation of the right to health guaranteed in article 25 of the Convention. It further notes that ‘States Parties to the Convention are under an immediate legal obligation to respect, to protect and to fulfil the rights of women and girls with disabilities under article 6’ in order to guarantee them the enjoyment and exercise of all human rights and fundamental freedoms.⁷⁴ While the Committee does not specifically refer to persons with albinism, it is argued that the clarification provided in General Comment 3 on women and girls with disabilities will apply to them. This is further supported by the Committee’s decision in *Y v Republic of Tanzania* discussed earlier in this paper.⁷⁵ The Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health noted that ‘people living with albinism often do not receive the necessary special attention, health care or treatment that corresponds to their health needs’.⁷⁶

At the regional level, articles 16 of the African Charter, 24 of the African Children’s Charter and 14 of the African Women’s Protocol all guarantee the right to health. In interpreting the right to health in the African Charter, the African Commission on Human and Peoples’ Rights (African Commission) has adopted a purposive approach linking the enjoyment of this right with other rights, including life, dignity and non-discrimination.⁷⁷ For instance in *International Pen (on behalf of Ken Saro Wiwa) v Nigeria*,⁷⁸ the African Commission affirmed that a denial of access to treatment to a prisoner would result in violation of the rights to life and dignity.

72 General Comment 3 (n 50 above) para 15.

73 Communication 038/2016 (Views adopted 20 September 2018).

74 Communication 038/2016 (n 73 above).

75 (n 23 above).

76 See UN News ‘Persons with albinism must not be treated as ‘ghosts’, UN experts stress’ available at www.new.un.org (accessed on 25 November 2019)

77 For more on the approaches of the African Commission to the enjoyment of the right to health in Africa, see E Durojaye ‘The approaches of the African Commission to the right to health under the African Charter’ (2013) 17 *Law Development and Democracy* 393.

78 AHRLR 212 (ACHPR 1998).

The African Commission in *Purohit v The Gambia*,⁷⁹ a case involving the maltreatment of persons with mental disabilities, noted that articles 2 and 3 of the Charter relating to non-discrimination and equal protection of the law are crucial to the enjoyment of all other rights guaranteed in the Charter. Article 2 of the African Charter provides that states must prohibit discrimination on various grounds including 'other status', a phrase that can be interpreted to cover persons with disabilities, including persons with albinism.

The Commission further noted that non-discrimination is a fundamental principle of the Charter that is not subject to derogation. The Commission had reasoned in that case, among other things, that failure to provide proper medical attention to patients with mental disabilities is a violation of the right to health guaranteed in article 16 of the African Charter. This case provides an illustration of how a state may be held accountable for failure to meet the health needs of persons with disabilities, including persons with albinism.

The African Commission in recent times has begun to develop important norms to clarify state obligations with regard to provisions of the African Women's Protocol. For instance, the Commission has issued two important general comments to clarify the content of article 14 of the Protocol.⁸⁰ Although these clarifications relate to women in general, they remain very useful in advancing the sexual and reproductive health and rights of women with albinism in Africa. Both General Comments 1 and 2 emphasise the need for African governments to ensure access to sexual and reproductive healthcare services to all women on a non-discriminatory basis. Furthermore, they reinforce the importance of paying more attention to the health needs of vulnerable and marginalised groups in society such as refugee women, women with disabilities and women living with HIV. Undoubtedly, this reasoning of the Commission would seem to apply to persons with albinism in general and women with albinism in particular. In other words, African governments are obligated to eliminate discriminatory practices in access to healthcare services for persons with albinism, especially women with albinism.

As noted earlier, Africa remains the region with the highest number of persons with albinism and experience has shown that they are subjected to discriminatory practices daily. This can undermine their right to dignity and other related rights. In *Hoffman v SAA*,⁸¹ the South African

79 Communication 241/2001 decided at the 33rd Ordinary Session of the African Commission held from 15th–29th in Niamey, Niger May 2003.

80 See ACHPR General Comments: Article 14(1)(d) and (e) of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (2012); ACHPR General Comment 2: Article 14(1)(a),(b),(c) and (f) and Article 14(2)(a) and (c) of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (2014).

81 2001 1 SA 1 (CC).

Constitutional Court explains that the denial of employment opportunity to an individual solely based on his HIV status not only violates the right to equality in section 9 of the Constitution, but also impairs the dignity of the individual.⁸² In explaining the connection between the right to equality and dignity the court reasons as follows:

At the heart of the prohibition of unfair discrimination is the recognition that under our Constitution all human beings, regardless of their position in society, must be accorded equal dignity. That dignity is impaired when a person is unfairly discriminated against. The determining factor regarding the unfairness of the discrimination is its impact on the person discriminated against.⁸³

While the *Hoffman* case deals specifically with discrimination in the context of HIV, the principle of law established by the court is relevant in addressing discriminatory practices against persons with albinism, including women with albinism. Thus, failure by African governments to ensure access to healthcare services to women with albinism will amount to a violation of the right to dignity. Dignity requires that all human beings be treated with decency and respect. The notion of dignity is an intrinsic part of every human being, which is not subject to variation or modification. It is how people feel, think and behave in relation to the worth or value of themselves or others. Hence, the right to dignity is universal and unfringeable by the state or private parties. It should be noted that a violation of the right to dignity not only affects the victim, but the society as a whole, in that it questions how we choose to live or relate to others.⁸⁴

5 Barriers to access to healthcare for persons with albinism

The various forms of discrimination highlighted above are interrelated. The CESCR in General Comment 14 has emphasised that the right to health is closely related to and dependent upon the realisation of other human rights, including the rights to food, work, education, human dignity, life, non-discrimination and the prohibition against torture.⁸⁵

This is particularly important as women and children with albinism are vulnerable and exposed to multiple forms of discrimination and violations of their rights such as infanticide, physical attacks, lack of access to education, unemployment, sexual violence and lack of access to

82 As above.

83 *Hoffman* (n 81 above) para 27

84 C Dupre 'What does dignity mean in a legal context?' <http://www.guardian.co.uk/commentsfree/libertycentral/2011/mar/24/dignity-uk-europe-human-rights> (accessed 23 February 2019).

85 General Comment 14 (n 61 above) para 3.

healthcare. As earlier indicated, violence against persons with albinism is fuelled by cultural practices and misconceptions. This is often extended to the healthcare setting where discriminatory practices manifest against persons with albinism, since healthcare providers are products of the society.

Unlike a monistic approach to oppression, which tends to reduce complex experiences of simultaneous oppressions to simplistic categories, intersectionality uses the intra-categorical lens, to reveal various forms of oppressions and lived experiences of certain groups.⁸⁶ According to King, 'a hallmark of intersectionality is the necessity of addressing all oppressions'.⁸⁷ Proponents of intersectionality argue that it offers the promise of addressing

white solipsism, heteronormativity, elitism, and ableism of dominant power and hegemonic feminist theory by making social locations and experiences visible that are occluded in essentialist and exclusionary constructions of the category 'women'.⁸⁸

This approach is no doubt applicable to women with albinism, who daily encounter discrimination based on their skin and gender. This in turn has led to other forms of discrimination, especially with regard to healthcare services. These multiple forms of discrimination cannot be treated in isolation but must be seen as intersecting. Echoing the social-model approach, the multiple forms of discrimination persons with albinism encountered are often rooted in cultural superstition that tends to disable them from living a dignified life. Consequently, based on prejudices and unfounded societal myths, persons with albinism are deprived of social services, including healthcare services.

The CEDAW Committee has referred to women with albinism as a group of women in a vulnerable situation.⁸⁹ Also, the Special Rapporteur on violence against women, its causes and consequences has noted:⁹⁰

[V]iolence against women is deeply rooted in multiple layers of discrimination and inequality. As these layers of discrimination intersect,

86 As above.

87 D King 'Multiple jeopardy, multiple consciousness: The context of a black feminist ideology' (1988) 14 *Signs: Journal of Women in Culture and Society* 42.

88 Carastathis (n 53 above); see also E Spelman *Inessential woman: Problems of exclusion in feminist thought* (1988).

89 In its Concluding Observations on the United Republic of Tanzania, the Committee expressed concern at reports that women and girls with albinism had been targeted in ritual killings, recommending that the state party protect them. See Report of the CEDAWFortieth session (14 January-1 February 2008) Forty-first session (30 June-18 July 2008) UN Doc A/63/38 (2008) [https://undocs.org/pdf?symbol=en/A/63/38\(SUPP\)](https://undocs.org/pdf?symbol=en/A/63/38(SUPP)) (accessed 19 November 2019) paras 142 & 143

90 See HRC Report of the Special Rapporteur on violence against women, its causes and consequences UN Doc A/HRC/17/26 dated 2 May 2011 <http://www2.ohchr.org/english/bodies/hrcouncil/docs/17session/A-HRC-17-26.pdf> (accessed 5 March 2019).

violence against women intensifies. Addressing systematic discrimination and marginalization is crucial to ending violence against women.

Additionally, the General Assembly's Resolution on 'Realizing the millennium development goals for persons with disabilities' called for states to pay special attention to the gender specific needs of persons with disabilities, including by taking measures to ensure their full and effective enjoyment of all human rights and fundamental freedoms.⁹¹

Several other studies and reports have documented discriminatory practices and human-rights violations persons with albinism experience in Africa.⁹² Hong et al have captured the different health challenges of persons with albinism in some African countries.⁹³ In their very comprehensive article they identified some of the public-health issues relating to persons with albinism in the continent. It was noted that persons with albinism would seem to have shorter life expectancy compared to others in society. For instance, they noted that in the East Central state of Nigeria, 89 per cent of identified people with albinism were in the age range of 0–30 years⁹⁴ while another study reported that 77 per cent were under the age of 20 in the same Nigerian state.⁹⁵ A mean age of 17.8 years was reported in Soweto, South Africa.⁹⁶ The study further notes that a lack of proper medical attention for persons with albinism often compromises their health needs. It explains that in many African countries due to stigma and discrimination against persons with albinism and lack of trained personnel, persons with albinism encounter difficulty in accessing healthcare services.

The Cancer Association of South Africa (CANSA) has acknowledged that persons with albinism face the highest risk of developing skin cancer. CANSA found that albinism increases skin cancer risk in South Africa. The risk is especially higher for people who rely on state hospitals for the provision of their sunscreen.⁹⁷ A researcher at the University of South Africa (UNISA) has noted that:

91 GA Resolution 63/150: Realizing the millennium development goals for persons with disabilities dated 18 December 2008 para 8.

92 See for instance, Human Right Council Advisory Committee 'Study on the situations of the human rights of persons living with albinism' submitted to the twenty-eighth session of the Human Rights Council (2015) UN Doc A/HRC/28/75 dated March 2015; International Federation of the Red Cross and Red Crescent Societies *Through albino eyes: The plight of albino people in Africa's Great Lakes region and a Red Cross response* (2009); S Fellows *Trafficking body parts in Mozambique and South Africa* (2010).

93 Hong (n 3 above) 212.

94 AN Okoro 'Albinism in Nigeria' (1975) 92 *British Journal of Dermatology* 485.

95 RA King et al 'Albinism in Nigeria with delineation of new recessive oculocutaneous type' (1980) 17 *Clinical Genetics* 259.

96 JGR Kromberg et al 'Albinism and skin cancer in Southern Africa' (1989) *Clinical Genetics* 43.

97 CANSA 'Research findings: Albinism increases skin cancer risk in South Africa' (12 March 2015) <http://www.cansa.org.za/albinism-increases-skin-cancer-risk-in-south-africa/> (accessed 30 January 2019).

[D]iscrimination against persons living with albinism impedes their right of access to healthcare services, and the government should adopt a comprehensive approach to ensuring that healthcare services specifically cater for the unique needs of this group of people.⁹⁸

A study to ascertain the barriers to accessing safe motherhood and reproductive health services in Lusaka for women with disabilities identified the deep traditional beliefs about the cause and transmission of disability which prevents women with albinism from integrating at antenatal clinics.⁹⁹ An interviewee stated:

[W]hat you must realise is that for the fellow pregnant women, the able bodied, pregnancy is a very difficult time for most of the mothers and it's got a lot of superstitions about it. So, one, there's a common belief that the child you are carrying, for example, you want to avoid people like albinos ...¹⁰⁰

In some situations, healthcare providers exhibit prejudices and hostile attitudes towards persons with albinism. While this situation limits access to healthcare to persons with albinism in general it can lead to more devastating effects for women with albinism seeking sexual and reproductive health services. In communities where persons with albinism are isolated, women and girls with albinism may find it difficult to seek information and services relating to contraception, unwanted pregnancies or maternal care. In essence, multiple forms of discriminatory practices against persons with albinism may aggravate their health condition and well-being and at the same time may predispose them to sexual and reproductive ill health. Moreover, the study documents failure by states to adopt appropriate laws, policies and programmes relating to the health needs of persons with albinism.

This would seem inconsistent with the AAAQ approach of the CESCR in its General Comment 14 discussed above. According to the Committee, accessibility has four dimensions, including physical accessibility, information accessibility, economic accessibility and non-discrimination. In essence, states would need to ensure that persons with albinism enjoy unhindered access to healthcare services. More importantly, states must ensure that services to persons with albinism are ethically and medically acceptable and do not undermine their dignity.

Failure to meet the health needs of persons with albinism clearly shows lack of political will on the part of African governments in meeting the health needs, including sexual and reproductive health of persons with

98 'People with albinism need urgent protection' *UNISA* 10 August 2016 <http://www.unisa.ac.za/sites/corporate/default/News-&-Media/Articles/People-with-albinism-need-urgent-protection> (accessed 27 February 2019).

99 E Smith et al 'Barriers to accessing safe motherhood and reproductive health services: The situation of women with disabilities in Lusaka, Zambia' (2004) 26 *Disability and Rehabilitation* 125.

100 As above.

albinism. In its Concluding Observations to the government of Ethiopia, the Committee on CRPD has recommended that the government:

[E]nsure that hospital and health-care centre staff are given regular and compulsory training on the rights of persons with disabilities, including on the individual right to free and informed consent, sexual and reproductive health, HIV and sexually transmitted infections.¹⁰¹

At the International Conference on Population and Development (ICPD) in Cairo, the international community affirmed the rights of women and girls to reproductive healthcare including the right to determine the timing and number of their children.¹⁰² It was further affirmed that all individuals shall have the right:

[T]o be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice of regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant.¹⁰³

This was reaffirmed in Beijing during the Fourth World Conference on Women. This landmark declaration has now been codified in article 14 of the African Women's Protocol. This provision can be interpreted broadly to protect the sexual and reproductive health of persons with albinism, especially women with albinism.

In clarifying the provision of article 14 of the Maputo Protocol the African Commission has urged states to take appropriate measures towards eliminating stigmatisation and discrimination in relation to sexual and reproductive health.¹⁰⁴ This broadly covers HIV-related stigma and discrimination which often hinder women and girls from seeking information and services in healthcare institutions. More importantly, the Commission enjoins states to adopt legislative measures, administrative policies and procedures to ensure that 'no woman is forced because of her HIV status, disability, ethnicity or any other situation, to use specific contraceptive methods or undergo sterilization or abortion'.¹⁰⁵ This position of the Commission provides a bulwark for persons with albinism who often encounter discrimination in healthcare services. It requires states to take a substantive-equality approach to addressing the multiple forms of discriminatory practices against persons with albinism in society.

101 See Concluding Observations on the initial report of Ethiopia, CRPD Committee (3 November 2016) UN Doc CRPD/C/ETH/CO/1 (2016) para 56.

102 UN 'Report of the International Conference on Population and Development (ICPD): 5-13 September 1994' UN Doc A/CONF.171/13 (18 October 1994) <https://www.un.org/popin/icpd/conference/offeng/poa.html> (accessed 4 March 2019).

103 UN (n 102 above) para 7.2.

104 UN (n 102 above) para 44

105 UN (n 102 above) para 47

More importantly, it requires states to adopt positive measures including the provision of sunglasses, training of healthcare providers and allocation of resources to meet the needs of persons with albinism. In addition, persons with albinism must be involved in any measures aimed at addressing stigma and discrimination against them. This would be consistent with the common principle ‘nothing for us without us’.

6 Way forward

From the foregoing, it has become more urgent than ever, that African governments exhibit political will to address the different challenges facing persons with albinism in the region. In the face of persistent acts of prejudice and violence against persons with albinism which may lead to dire health consequences for them, it has become crucially urgent that African governments embark on massive awareness and education programmes to address prejudices and myths relating to persons with albinism. This will go a long way in correcting misconceptions and superstitious beliefs about persons with albinism. It should be noted that articles 2 and 5 of the African Women’s Protocol urge African governments to embark on education and awareness programmes with a view to addressing cultural practices that may impair women from enjoying their rights. These provisions can broadly be interpreted to include prejudices and misconception, which impair women with albinism from enjoying their rights.

As noted above, it will also be important that governments and policy makers include persons with albinism in the development of policies and programmes affecting their health and well-being. A report has noted that any effort to address inequities in health of people must address power imbalance and empower disadvantaged people to participate in decision-making that affects their well-being.¹⁰⁶ The right to participation is recognised in articles 29 of the CRPD and 21 of the Protocol to the African Charter on the Rights of Persons with Disabilities. Participation is generally believed to constitute an element of a rights-based approach. Indeed, Mary Robinson, former UN High Commissioner for Human Rights, opines that ‘[p]articipation and active involvement in the determination of one’s own destiny is the essence of human dignity’.¹⁰⁷ With regard to the right to health, participation requires that every individual, including vulnerable and marginalised groups should be involved in the decision-making process relating to the adoption of policies and programmes about their health.

106 WHO Commission on Social determinant of health ‘Closing the gap in a generation: Health equity through action on the social determinant of health’ (2008) <http://repository.essex.ac.uk/9714/1/participation-right-highest-attainable-standard-health.pdf> (accessed 5 March 2019).

107 Cited in H Potts *Participation and the right to the highest attainable standard of health* (2008) 8.

The CESCR has noted that ensuring participation of all individuals in the development of laws and policies on health constitutes part of the right to health.¹⁰⁸ Participation is a powerful means of ensuring the autonomy of people to make decisions concerning their lives. It allows vulnerable and marginalised groups to air their views on issues that affect their lives. Yamin has argued that effective participation enables disadvantaged groups to challenge political and other forms of exclusion that prevent them from exercising agency over decisions and processes that may affect their lives and health.¹⁰⁹ In Potts's view, people who are likely to be affected by a health policy or programme should have equal opportunity to be part of the decision-making process.¹¹⁰

The former Special Rapporteur on extreme poverty and human rights has noted that participation empowers marginalised and disadvantaged groups to have a say in matters affecting their lives.¹¹¹ It ensures that the views of disadvantaged and marginalised groups are adequately taken into consideration before decisions are made. This is very important in the context of meeting the health needs of persons with albinism in general and in particular. Exclusion of persons with albinism from participating in decision-making about their health is not only a violation of their right to health, but may also impair the rights to dignity and non-discrimination. Yamin has noted that:

If health is a matter of rights, it cannot be considered a handout, and the people who receive services are not objects of charity from their own governments...; they are agents who have a role to play in the definition of programs and policies that structure the possibilities for their own well-being.¹¹²

In addition, African governments need to commit adequate resources to the health sector to meet the specific needs of persons with albinism. In this regard, Cruz-Inigo et al have suggested that:

In the clinical setting, individuals with albinism should be provided with dermatologic examinations, guidelines on how to shield themselves from the sun, and sun protection products such as sunscreen, sunglasses, opaque clothing that covers most of the skin, scarves, high socks, and wide-brimmed hats. Given that most albinos are unemployed, they cannot afford sun-protective gear, which is expensive in Africa, thus it should be encouraged that society establish measures to support albinos and their families. Governmental endeavors may include assistance with indoor job placement,

108 General Comment 14 (n 61 above).

109 A Yamin 'Suffering and powerlessness: The significance of promoting participation in rights-based approaches to health' (2009) 11 *Health and Human Rights* 6.

110 Potts (n 107 above) 15-25.

111 See Report of the Special Rapporteur on extreme poverty and human rights: Participation of people living in poverty in decisions affecting their lives (11 March 2013).

112 Yamin (n 109 above) 4.

supplying adequate amounts of sun-protective products and funding for organizations involved in albinism awareness and support.¹¹³

Given the constant acts of prejudice and discriminatory practices against persons with albinism, it will be necessary that African governments enact appropriate laws and policies to eliminate discriminatory practices against them. Where similar legislation already exists, it should be broadly interpreted to cover specific discriminatory practices against persons with albinism. On the other hand, any legislation or policy that may potentially fuel discriminatory practices against persons with albinism generally and in relation to healthcare should be repealed immediately.

Recently, the UN Independent Expert on the rights of person with albinism, Ikpowonsa Ero, has proposed a continental framework to address human-rights violations experienced by persons with albinism.¹¹⁴ The Plan of Action is broadly divided into four sections namely: preventive measures; protective measures; accountability measures; and equality and non-discrimination. In essence, the Plan of Action urges African governments to take proactive measures in order to nip in bud any form of human-rights violations against persons with albinism. The protection measures require African governments to adopt appropriate laws and policies to protect persons with albinism and further ensure their effective implementation. They also require training of healthcare providers on issues relating to the rights of persons with albinism in healthcare settings. The accountability measures require African governments to ensure that perpetrators of human-rights violations against persons with albinism are brought to book.

More importantly, African governments are enjoined to provide support services such as psychosocial, medical, legal and socioeconomic support to persons with albinism that have experienced violations of their rights. Equality and non-discrimination measures require more involvement of persons with albinism in decision-making in society. They also require the creation of a post for persons with albinism with appropriate ministries such as disability, gender or social development. Furthermore, states are required to implement and adhere to the principle of reasonable accommodation in all facets of life for persons with albinism. The Regional Action Plan has now been adopted as a resolution by the African Commission.¹¹⁵ Undoubtedly, these are very practical and

113 AE Cruz-Inigo 'Albinism in Africa: Stigma, slaughter and awareness Campaigns' (2011) 29 *Dermatologic Clinics* 82.

114 Regional Action Plan on Albinism in Africa 2017-2021: Five-year plan to address attacks and related violations against persons with albinism in Sub-Saharan Africa presented at the 60th Ordinary Session of the ACHPR held in Niamey, Niger from 8-22 May 2017. See Report of the Independent Expert on the enjoyment of human rights by persons with albinism on the Regional Action Plan on Albinism in Africa (2017–2021), HRC (19 December 2017) UN Doc A/HRC/37/57/Add.3 (2017).

115 See Resolution 373 on the Regional Action Plan on Albinism in Africa (2017-2021), ACHPR (22 May 2017) ACHPR/Res. 373 (LX) (2017).

important measures that are capable of addressing human-rights violations experienced by persons with albinism in the region. It will also go a long way in addressing barriers to the enjoyment of the right to health of persons with albinism. The ball is now in African governments' court to ensure the full and effective implementation of this Action Plan.

7 Conclusion

This paper has shown that persons with albinism encounter stigma and discrimination in virtually every aspect of their lives. More importantly, persons with albinism face challenges in accessing healthcare services. While no human-rights instrument specifically addresses the human rights of persons with albinism, the existing provisions in international and regional human-rights instruments are applicable to them. In particular, the provisions on non-discrimination, dignity and health recognised by the CRPD, African Charter and African Women's Protocol are relevant in advancing the sexual and reproductive health and rights of women living with albinism. In line with their obligations under international law, African governments are required to take appropriate measures to address discriminatory practices against persons with albinism in general and women with albinism in particular. This requires committing more resources to address the health needs of persons with albinism. In addition, African governments must commit to training healthcare providers in order to meet the specific needs of persons with albinism.

CHAPTER 3

CONFLICTING DISCOURSES ON CONCEPTUALISING CHILDREN WITH DISABILITIES IN AFRICA

Shimelis Tsegaye Tesemma & Susanna Abigaël Coetzee***

Summary

Despite the wide ratification of the United Nations Convention on the Rights of Persons with Disabilities, children with disabilities are still marginalised and their status as rights holders not fully acknowledged in many parts of Africa. In response to the call for research to focus on a distinct African conceptualisation of disability, an exploratory desk study was conducted on the disability discourse on children with disabilities in Africa. Though the authors uncovered positive African cultural and legislative narratives of disability, the dehumanising discourse identified, was more pronounced. The authors suggest that any strategy to improve the plight of children with disabilities in Africa will have to take into account and not underestimate the dehumanising discourse. The power of discourse should be used to emphasise the positive African cultural and legislative narratives of disability to counter the dehumanising discourse.

1 Introduction

The Kigali Declaration, adopted in 2003 during the first African Union Ministerial Conference on Human Rights in Africa, laments the absence of sufficient protection of children's rights and the plight of vulnerable groups

* BSc (Addis Ababa University), MA (Addis Ababa University), DEd (Unisa); stsegaye@africanchildforum.org.

** BA Ed (RAU), BEd (Potchefstroom) MEd (Potchefstroom), DEd (Unisa) Certificate Programme in Law (Unisa) LLB (Unisa); Coetzsa1@unisa.ac.za.

including persons with disabilities in Africa.¹ Almost a decade later, the situation has not improved. Koszela records his personal experiences during 2011 of the severe stigmatisation and exclusion that people with disabilities and in particular children, experienced in Patriensa, Ghana.² Plan International Norway et al conducted a study in Uganda (Kamuli district) and Malawi (Mulanje and Kasungu districts) in 2015 and concluded that the fact that children with disabilities are regarded as easy targets of violence can be attributed to how they are perceived and in particular to the perception that they are useless.³ The African Committee of Experts on the Rights and Welfare of the Child issued a press release to commemorate Children's Day 2016 and identified violence against children with disabilities as one of the continued challenges Africa faces.⁴ In 2018, Njelesani et al conducted a study on violence against children with disabilities in four West-African countries, namely Guinea, Niger, Sierra Leone and Togo. They positively linked stigma, traditional beliefs and the perception that children with disabilities are worthless to the violence perpetrated against these children.⁵

It is evident that the contention of the National Disability Authority that the social construct of disability is a barrier to social inclusion because it supports the denial of human rights and resistance to change is correct.⁶ There is a need to reconceptualise people with disabilities in Africa. This need was indeed identified in a study conducted in nine Southern African countries under the auspices of the Open Society Initiative for Southern Africa, the Open Society Foundations' Disability Rights Initiative, and the Open Society Foundation for South Africa.⁷

Concepts or ideas are formed and reinforced by means of discourse⁸ with the result that the disability discourse will empower or disempower, include or exclude.⁹ One can therefore agree with the Foucauldian notion

1 African Commission on Human and Peoples' Rights *Kigali Declaration* adopted at Kigali, Rwanda on 8 May 2003, 19 <https://www.achpr.org/legalinstruments/detail?id=39> (accessed 24 October 2019).

2 K Koszela 'The stigmatization of disabilities in Africa and the developmental effects' (2013) 10-11 http://digitalcollections.sit.edu/isp_collection/1639 (accessed 24 October 2019).

3 Plan International Norway et al *Protect us! Inclusion of children with disabilities in child protection* (2016) 51 <https://plan-international.org/protect-us> (accessed 24 October 2019).

4 African Committee of Experts on the Rights and Welfare of the Child 'Conflict and crisis in Africa: Protecting all children's rights' Press Release 16 June 2016 https://au.int/sites/default/files/pressreleases/30785-pr-dac_2016_acerwc_press_statement_.pdf (accessed 24 October 2019).

5 J Njelesani et al 'From the day they are born: A qualitative study exploring violence against children with disabilities in West Africa' (2018) 18 *BMC Public Health* 156.

6 National Disability Authority *Literature review on attitudes towards disability* (2006) 27 https://www.ucd.ie/t4cms/0048-01%20NDA_public_attitudes_disability_2006_literature_review.pdf (accessed 24 October 2019).

7 H Kotzé *Status of disability rights in Southern Africa* (2012) 22 <http://www.safod.net/library/files/m26904.pdf> (accessed 24 October 2019).

8 EJ Allan *Policy discourses, gender, and education: Constructing women's status* (2008) 6.

9 G Deleuze *Foucault* (1988) 47.

of discourse which stresses the role of discourse in the establishment, maintenance, extension and resistance or mobilisation of power relations.¹⁰ Discourse can legitimise a dominant social ideology and support unfair discriminatory practices against children with disabilities. Or it can play an important role in resisting disempowering discourses, such as the dehumanising-disability discourse, and replace them with empowering and equalising discourses.¹¹ Cobbinah argues that language, names, tags and labels carry meaning that reinforces behaviour.¹² The nature of the response that a name triggers relates to the stereotypical meaning attached to such a name.

The authors conducted an exploratory desk study on the disability discourse on children with disabilities in Africa to determine how these children are conceptualised. They worked deductively by basing explanations and conclusions on a few examples.¹³ They identified a pronounced dehumanising discourse, but also initiatives to promote positive African cultural and legislative narratives of disability.

One initiative to change peoples' conceptualisation of people with disabilities is the adoption of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa of 2018 (African Disability Protocol).¹⁴ The fact that the African Disability Protocol is adopted as an African initiative indicates the presence of a regional awareness of the need to reconceptualise disability in Africa and that there is a need for discourse that will counter discourse that supports the stigmatisation and exclusion of people with disabilities and in particular children with disabilities. The African Disability Protocol was approved for adoption by Heads of State of the African Union on 31 January 2018, but is subject to the ratification by 15 countries to come into force and that has not been the case yet. In the light of the power that discourse holds, the authors hope this article will contribute to the reconceptualisation of children with disabilities in Africa in line with the positive discourse supported in the African Disability Protocol.

The authors organised the article in four sections. In the first, before reporting on the exploratory desk study that they conducted on the discourse on children with disabilities in Africa, they explain when a

10 F Armstrong *Spaced out: Policy, difference and the challenge of inclusive education* (2003) 4; R Doherty 'Critically framing education policy: Foucault, discourse and governmentality' in MA Peters & T Besley (eds) *Why Foucault? New directions in educational research* (2007) 195.

11 EH Tenorio 'Critical discourse analysis: An overview' (2011) 10 *Nordic Journal of English Studies* 183 184.

12 ST Cobbinah 'Labelling and framing disability: A content analysis of newspapers in Uganda' unpublished LLM dissertation, University of Pretoria, 2013 19.

13 Tenorio (n 11 above) 189.

14 See <http://blindsa.org.za/2018/02/13/protocol-african-charter-human-peoples-rights-rights-persons-disabilities-africa/> (accessed 24 October 2019). The Protocol has thus far been signed by five countries. No country has ratified the Protocol.

discourse will be regarded as dehumanising. Thereafter, they present the dehumanising discourse in terms of three main strands that emerged, namely: the discourse portraying children with disabilities as non-humans; as unworthy of social interactions; and as having ‘compromised’ humanness. In the second section, they briefly consider the positive African cultural narratives of disability. In the third section, the authors reflect on legislative narratives countering the dehumanising discourse before drawing conclusions and making recommendations to conclude the article.

2 Dehumanising disability discourse

In the medical models, the emphasis is on protection and welfare and people with disabilities are depicted as sick and in need of being cured. According to this model, a disability is something that is wrong with the child and the identity of a person with disabilities is described primarily through his or her condition.¹⁵ In the social models, on the other hand, the emphasis is on the barriers that prevent the child with disabilities from being included in society. The AbleChild Africa identifies three possible barriers, namely, environmental, institutional and attitudinal which ‘can interact in any combination, with an individual’s impairment to prevent them from participating equally in everyday activities’.¹⁶ According to Stone-MacDonald and Butera¹⁷ in terms of the social model of disability, disability is but one characteristic of an individual that – depending on the individual’s social interactions – becomes either more salient or more pronounced.

The human-rights variant of the social model considers disability as the consequence of social organisation and the relationship of the individual to society and aims at the provision of political and social entitlements through reformulation of economic, social and political policy.¹⁸ Reformulation of political policy was, inter alia, done through the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).¹⁹ The UNCRPD²⁰ defines ‘a person with disabilities’ in terms of the social model to include people:

15 E Barton ‘Discourses of disability in the *Digest*’ (2001) 21 *JAC* 555; EM Sammon & G Burchell *Family care for children with disabilities: Practical guidance for Frontline Workers in low- and middle-income countries* (2018) 11.

16 AbleChildAfrica 2013 *AbleChildAfrica Strategic Plan 2013-2016* 9 <http://ablechildafrica.org/wp-content/uploads/2010/02/AbleChildAfrica-Strategy-2013-2016-FINAL.pdf> (accessed 24 October 2019).

17 A Stone-MacDonald & GD Butera ‘Cultural beliefs and attitudes about disability in East Africa’ (2014) 8 *Review of Disability Studies: An International Journal* 63-64.

18 Sammon & Burchell (n 15 above) 11.

19 Preamble of the Convention on the Rights of Persons with Disabilities (UNCRPD).

20 Art 1.

[W]ho 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.

The major difference between the dehumanising discourse and the human-rights disability discourse is the legal status afforded to people with disabilities. The human-rights discourse is based on the recognition of people with disabilities' individual autonomy, their independence, and ability and freedom to make their own choices (UN 2006, Preamble). Although the human-rights discourse, as a variant of the social model, is making progress in Africa, the disempowering, dehumanising discourse is still deafening. There is still a strong tendency to portray 'the person with rights ... to be fully rational, able-bodied, able-minded, and psychologically an adult',²¹ thereby implying that people (and especially children) with disabilities cannot be rights holders. Children in general are marginalised because, despite the growing emphasis on children's rights, they are still regarded as less human, less equal and less deserving of having their rights recognised. Children with disabilities are thus doubly marginalised: first, as children and, second, as persons with disabilities who are defined by what they lack rather than by what they have.²²

A dehumanising discourse is a discourse that fails to acknowledge a person's humanness, that stigmatises, excludes or dissociates, immobilises and silences, devaluates and invalidates by stripping a person of any self-worth.²³ Discourse has the power to perpetuate the plight of persons with disabilities.²⁴ As far back as 1963, Goffman observed that: 'By definition, of course, we believe the person with a stigma is not quite human.'²⁵ A person who is perceived as not quite human will not be regarded as someone with human dignity and, consequently, he/she will be treated in a manner that is inconsistent with his/her intrinsic worth.²⁶ If a person is dehumanised, he or she is viewed as someone who falls outside the scope of morality and justice, which makes it easy for others to regard any harm done to such a person as morally justified and warranted.²⁷

21 MM O Donovan 'Feminism, disability, and evolutionary psychology: What is missing?' (2013) 33 *Disabilities Studies Quarterly* <http://dsq-sds.org/article/view/3872/3403> (accessed 24 October 2019).

22 UNICEF *The state of the world's children: Children with disabilities* (2013) 2.

23 M Baffoe 'Stigma, discrimination and marginalization: Gateways to oppression of persons with disabilities in Ghana, West Africa' (2013) 3 *Journal of Educational and Social Research* 187 193-194; Barton (n 15 above) 558; B Hughes 'Civilising modernity and the ontological invalidation of disabled people' in D Goodley B Hughes & L Davis (eds) *Disability and social theory: New developments and directions* (2012) 17-32.

24 R Slee 'Education and the politics of recognition: Inclusive education – An Australian snapshot' in D Mitchell (ed) *Contextualizing inclusive education: Evaluating old and new international perspectives* (2005) 158.

25 E Goffman *Stigma: Notes on the management of spoiled identity* (1963).

26 C Sanger 'Decisional dignity: Teenage abortion, bypass hearings, and the misuse of law' (2009) 18 *Columbia Journal of Gender and Law* 415.

27 M Maiese *Dehumanization* (2003) <http://www.beyondintractability.org/essay/dehumanization> (accessed 24 October 2019).

Three main strands emerged in the dehumanising-disability discourse, namely discourse portraying children with disabilities as non-humans; as unworthy of social interactions; and as having ‘compromised’ humanness which makes them worthless.

2.1 Children with disabilities portrayed as non-humans

According to Stone-MacDonald and Butera, it is common in East Africa to use terms from the *ki-vi* noun class, which is reserved for inanimate, non-human objects, to denominate people with disabilities.²⁸ In some Namibian villages, children with disabilities are ‘made into objects of superstitious fear’ in that children are warned that if they misbehave, a person with a disability will come and get them. Children are, in other words, taught from a very early age that it is morally acceptable – and even preferable – to distance themselves from and not to have any compassion for persons with disabilities.²⁹

Children with disabilities are either elevated to a superhuman standing or relegated to a sub-human status. A very prominent dehumanising discourse is found in the perception that people with disabilities are possessed by evil spirits or have inherited demonic powers.³⁰ According to Njelesani et al children who are blind or suffer from polio are branded as ‘devils’ in certain communities in Sierra Leone.³¹ UNICEF Sierra Leone mentions the case of Alpha, a street child with a disability from Kambia in Sierra Leone, whose mother abandoned him because herbalists couldn’t cure him of the ‘debul’ (devil).³² There are accounts from West African communities of children with autism who were thrown into a bush because they were considered ‘possessed’ and their behaviour was deemed ‘demonic’.³³ A community member, in the Sierra Leone-part of the study conducted by Njelesani et al, admitted that, in his community it is custom to, when the community has identified a child with disabilities as a witch, take the child into the bush in the middle of the night, kill her and leave her there. The community is then told: ‘The witch has returned where it came from.’³⁴

28 Stone-MacDonald & Butera (n 17 above) 70.

29 Kotzé (n 7 above) 22.

30 D Kaplan *The definition of disability* (2005) 1-2 <http://www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm> (accessed 24 October 2019).

31 Njelesani et al (n 5 above) 153.

32 UNICEF Sierra Leone *The out-of-school children of Sierra Leone* (2008) 42 http://www.unicef.org/wcaro/wcaro_SL_Out_of_school_aug_09.pdf (accessed 10 August 2018).

33 World Health Organisation & Mental Health and Poverty Project *Mental health and development: Targeting people with mental health conditions as a vulnerable group* (2010) 9 https://www.who.int/mental_health/policy/mhtargeting/en/ (accessed 24 October 2019).

34 Njelesani et al (n 5 above) 156.

Stobart documented cases of children who were accused of witchcraft and subjected to ‘exorcism’ or ‘deliverance’ rituals which involved beatings, holding a red hot blade, forced ingestion of potentially fatal substances and incisions to release ‘evil forces’.³⁵ In Sierra Leone, for example, persons with disabilities are forced to drink kerosene.³⁶ In 2013 Cobbinah found the belief that disability is a curse was still quite widespread in Uganda.³⁷ The practice to consult traditional spiritual mediums who are believed to have supernatural powers to keep demons at bay and to bring about healing from ‘disability’ is common in rural Ethiopia.³⁸ In some parts of Ghana, children with psychosocial disabilities are subject to abuse in prayer camps where they are chained to trees for hours, denied food, and exposed to the sun as part of their ‘healing’ process.³⁹ Odoom and Van Weelden reveal that in Northern Ghana two reasons are proffered why children with intellectual disabilities are referred to as *kinkirigo* (spirit children). These children are either seen as ‘not meant for this world’ or as being sent by the spirits to bring harm to a family.⁴⁰

Accusations of witchcraft are used to explain the perceived abnormality and unnaturalness of disability.⁴¹ In the Central African Republic and neighbouring countries, children (mostly boys) with physical deformities or conditions such as autism, are accused of witchcraft, subjected to abuse and driven out of their homes and communities. Molina reports the case of a ten-year-old girl with a hunchback living in the Democratic Republic of Congo who was abandoned by her mother in the marketplace after her father died. Her witchcraft was regarded as the cause of her father’s death and her ‘hump’ was taken as proof of her witchcraft.⁴² In the Central African Republic, a disabled child accused of witchcraft can be executed because ‘witchcraft’ is a criminal offence under the Penal Code punishable by execution in cases where the ‘witch’ is accused of

- 35 E Stobart ‘Child abuse linked to accusations of “possession” and “witchcraft”’ in JS La Fontaine *The devil’s children: From spirit possession to witchcraft; new allegations that affect children* (2009) 21.
- 36 United Nations Department of Economic and Social Affairs (DESA) *Toolkit on disability for Africa: Culture, beliefs and disability* (2016) 11 <https://www.un.org/development/desa/dspd/2016/11/toolkit-on-disability-for-africa-2/#English> (accessed 24 October 2019).
- 37 Cobbinah (n 12 above) 37.
- 38 T Tirusew *Disability in Ethiopia: Issues, insights and implications* (2005) 37.
- 39 Human Rights Watch ‘“Like a death sentence”: Abuses against persons with mental disabilities in Ghana’ (2012) 59 <http://www.hrw.org/sites/default/files/reports/ghana1012webwcover.pdf> (accessed 24 October 2019).
- 40 AJ Odoom & K van Weelden (ed) *Report on the level of stigmatization, discrimination and exclusion of persons with intellectual disability and their families in Ghana* (2011) 1.
- 41 A Cimpric *Children accused of witchcraft: An anthropological study of contemporary practices in Africa* (2010) 2, 17 http://www.unicef.org/wcaro/wcaro_children-accused-of-witchcraft-in-Africa.pdf (accessed 8 October 2019); Njelesani et al (n 5 above) 156.
- 42 JA Molina *The invention of child witches in the Democratic Republic of Congo: Social cleansing, religious commerce and the difficulties of being a parent in an urban culture. Summary of the research and experiences of Save the Children’s 2003-2005 programme* (2005) 20.

homicide.⁴³ In its 2010 Concluding Observations to Nigeria, the CRC Committee expressed its 'utmost concern at reports of arbitrary killings of children during the course of activities designed to extract a confession of witchcraft or resulting from exorcism ceremonies'.⁴⁴

Several child participants in Baffoe's study on the stigmatisation of people with disabilities in Ghana referred to the fact that their humanness is vilified: 'People don't regard us as human beings', 'They say all kinds of dirty things about me as if I am not a human being' and 'Why can people not accept us for who we are as human beings?'.⁴⁵ A 12-year-old boy from Guinea with a physical impairment explained that his father took him out of school because the other children called him 'half a person' and 'incomplete'.⁴⁶

Discourse that demotes children with disabilities to the status of animals is common. Kumar describes the plight of a Nigerian girl with a clubfoot who is called 'a goat' by village children.⁴⁷ In some places in South Africa, children with albinism are referred to by members of some communities as 'nkau', which means 'apes', 'monkeys' or 'baboons'.⁴⁸ This is also the case in certain communities in Swaziland where children with albinism are referred to as *izinkawu* (monkeys).⁴⁹

In parts of Togo, children with cerebral palsy or children who cannot stand are called 'snakes' and are drowned during a ritual where the children are believed to be sent back to where they came from.⁵⁰ A participant in the study conducted by Njelesani et al referred to above confirmed that in some communities in Togo children with cerebral palsy who cannot stand are called 'snakes' and are drowned during a ritual to 'prevent the return of the snake in [sic] the family'.⁵¹ A study conducted by Bayat in the Ivory Coast (mostly in Abidjan) on children with intellectual

43 Art 51-58 Loi N 10.001 Du 06 Janvier 2010 Portant Code Penal Centrafricain Journal Officiel De La Republique Centrafricaine Edition Speciale; R Bannor-Addae *Central African Republic: Children, not witches* (2009) 2 https://www.unicef.org/infobycountry/car_49658.html (accessed 25 October 2019).

44 Concluding Observations— on the consideration of reports submitted by states parties under article 44 of the Convention: Nigeria, CRC (21 June 2010) UN Doc CRC/C/NGA/CO/3-4 (2010) para 67.

45 Baffoe (n 23 above) 193-194.

46 Plan International Norway et al (n 3 above) 7.

47 D Kumar 'Africa's disabled cursed by apathy and abuse' (2013) 23 September *Al Jazeera* <http://www.aljazeera.com/indepth/features/2013/09/2013922121017135639.html> (accessed 24 October 2019).

48 African Child Policy Forum *The African report on violence against children* (2014) 52 <https://app.box.com/s/iclv9c70sigmceyl30ym> (accessed 24 October 2019); 'Albinos' lonely call for recognition' *Mail & Guardian* 17 May 2012 <http://mg.co.za/article/2012-05-17-albinos-lonely-call-for-recognition> (accessed 24 October 2019).

49 HL Ndlovu 'African beliefs concerning people with disabilities: Implications for theological education' (2016) 20 *Journal of Disability & Religion* 33.

50 Plan International *Outside the circle: A research initiative by Plan International into the rights of children with disabilities to education and protection in West Africa* (2013) 25-26 <https://www.planusa.org/docs/education-outside-circle.pdf> (accessed 24 October 2019).

51 Njelesani et al (n 5 above) 156.

and developmental disabilities found that these children are commonly called 'snake children'. The term seems to have originated from a folktale of a pregnant woman who, although forbidden to do so, ate some food in the woods and dropped a few bread crumbs. A snake that ate them became so obsessed with human food that he exchanged places with the unborn child in the women's womb and was born into the human world.⁵² Bayat concluded that these children are regarded as 'animals with no moral status'.⁵³ To get rid of them, they are either killed or taken back into the woods and left there to turn back into snakes or allowed to live in the community as an 'other', in other words, a 'non-human'.⁵⁴ Julieth, a woman with albinism, recalls how her uncle once told her father to get rid of her because she looks like a fish.⁵⁵

The plight of children with albinism is at the centre of the demonising discourse. Traditional societies are torn between the contradictory discourses that portray persons with albinism as divine beings on the one hand and sacred monsters on the other.⁵⁶ They are believed to be in possession of *evu* – the witch substance – which they can use either in a positive way as a healer, seer, musician, dancer, orator or hunter, or in a harmful way as a witch.⁵⁷ In Kenya, Swaziland and Tanzania, children with albinism are referred to as *zeru-zeru* (the Swahili word for 'ghostlike creature'). The first person with albinism who became a Member of Parliament in Tanzania, Ms Kway-Geer recalls how, when she was a child, other children ran after her shouting '*zeru-zeru*'.⁵⁸ In the Central African Republic, a child with albinism is believed to be the offspring of a woman who had sexual intercourse with a water spirit.⁵⁹ In Malawi, people living with albinism are sometimes referred to as *napwere* which equates them to a tomato with leaf-spots.⁶⁰ Amnesty International mentions that women with albinism in Malawi are called *machilitso*, meaning 'cure', because of the belief that sex with them can cure men of HIV.⁶¹

52 M Bayat 'The stories of "snake children": Killing and abuse of children with developmental disabilities in West Africa' (2015) 59 *Journal of Intellectual Disability Research* 7.

53 Bayat (n 52 above) 9.

54 Bayat (n 52 above) 7-8.

55 G Brocco 'Albinism, stigma, subjectivity and global-local discourses in Tanzania' (2016) 23 *Anthropology & Medicine* 234.

56 Cimpric (n 41 above) 29.

57 Cimpric (n 41 above) 11.

58 UN Office of the High Commissioner for Human Rights 'The human rights of people with albinism in Kenya' (2014) para 24; DH Salewi 'The killing of persons with albinism in Tanzania: A social-legal inquiry' unpublished LLM thesis, University of Pretoria, 2011 10; 'Surprise of Tanzania's albino MP' *BBC News* 2008 <http://news.bbc.co.uk/2/hi/africa/7348528.stm> (accessed 24 October 2019).

59 Cimpric (n 41 above) 29.

60 As above.

61 Amnesty International "'We are not animals to be hunted or sold": Violence and discrimination against people with albinism in Malawi' (2016) 18 https://www.amnesty.org.uk/files/we_are_not_animals_-_malawi_report_-_final_formatted.pdf (accessed 24 October 2019).

Hosea, himself a person living with albinism, divulges that people living with albinism are confronted with myths such as they are 'not human', 'never die', are cursed by the gods and anyone who touches them will become cursed too. Another myth is that anyone possessing charms and potions containing hair, body parts and organs of persons living with albinism will be rich and prosperous.⁶² Hosea conveys how they had to flee Mwanza in Tanzania after being warned that there were people planning to murder him and his brother (also living with albinism) to harvest their body parts.⁶³ Amnesty International reports children living with albinism in Malawi are hunted like animals because it is believed that their bones contain gold and having their bones in your possession will bring wealth, happiness and good luck.⁶⁴

Because children with albinism are defined as something less than human, it is considered acceptable to discriminate against them or mistreat them.⁶⁵ Mostert attests to the death ritual customary to north-eastern Tanzania where babies with albinism are dropped into a lake and if they drown, it is taken as proof that they were not truly human.⁶⁶

2.2 The invisibility and exclusion discourse

Another discourse that came to the fore was the one that children with disabilities are unworthy of social (human) interaction. Partly because they are concealed, the majority of children with disabilities in African countries are not registered at birth or their birth is not recorded in public documents. For instance, about 80 per cent of children with visual impairments surveyed in Ethiopia and about 70 per cent of children with multiple disabilities surveyed in Uganda were not registered at birth.⁶⁷

These children are hidden or abandoned because they are regarded as a sign of impurity, a curse and a shame on their families.⁶⁸ Members of the community tend to disassociate themselves from members of that family

62 M Hosea 'Living with albinism, discrimination and superstition' in UNICEF *The state of the world's children: Children with disabilities* (2013) 6.

63 M Hosea (n 62 above) 7.

64 Amnesty International (n 61 above) 9.

65 K Allen 'The human rights case of persons with albinism in Uganda' (2011) 1 *Undergraduate journal of global citizenship* 9 http://digitalcommons.fairfield.edu/jogc/vol1/iss1/1?utm_source=digitalcommons.fairfield.edu%2Fjogc%2Fvol1%2Fiss1%2F1&utm_medium=PDF&utm_campaign=PDFCoverPages (accessed 24 October 2019).

66 MP Mostert 'Stigma as [a] barrier to the implementation of the Convention on the Rights of Persons with Disabilities in Africa' (2016) 4 *African Disability Rights Yearbook* 3 12.

67 African Child Policy Forum *Educating children with disabilities in Africa: Towards a policy of inclusion* (2011) 35.

68 African Child Policy Forum *The lives of children with disabilities in Africa: A glimpse into a hidden world* (2011) 42, 52; Baffoe (n 23 above) 195; Kumar (n 47 above); Plan International (n 50 above) 8, 25; UNICEF Promoting the rights of children with disabilities (2007) 4, 14 *Innocenti Digest* http://www.un.org/esa/socdev/unyin/documents/children_disability_rights.pdf (accessed 8 October 2019).

and effectively isolate the child and his/her family from community participation. This can be attributed to the fact that the stigma tends to spread from the stigmatised – the child with the disability – to his or her close relatives. More often than not, those closest to the stigmatised person tend to deny, hide or sever relations with the stigmatised person.⁶⁹ Ghoneim relates the story of a 13-year-old boy who suffers from cerebral palsy and spina bifida who whenever he and his family visit relatives, is kept in a bedroom away from others because they find his presence embarrassing.⁷⁰ The common belief that disability is punishment from God results in the practice of hiding children with disabilities in the house so that their supposed sins do not become known.⁷¹ Her research team found children with disabilities who were kept hidden away for their whole lives. A woman living with albinism in Malawi mentioned, in an interview with Amnesty International, that she and her sister – who also lives with albinism – were given food separately from the other children.⁷²

Brocco mentions that because mothers who give birth to a child with albinism are believed to be the primary cause of the ‘abnormality’ they are marginalised and the choice whether or not to reject a child with albinism lies mostly with fathers.⁷³ The UN Office of the High Commissioner for Human Rights⁷⁴ reported the case of a mother who received a one-year prison sentence for killing her 4-month-old baby daughter because she was born with albinism. The father threatened to divorce the mother because having a child with albinism was a bad omen and a disgrace to the family.

Some customs prohibit a person with a disability from attending national or cultural events where royalty will be present (such as the reed dance in Swaziland) because it is believed that ‘a disabled person making contact or coming close to royalty will actually bring bad luck to either the king or the queen mother’.⁷⁵ Eide and Jele inferred from their national representative study in Swaziland, that there is a belief that people with disabilities are bewitched or possessed by bad spirits. As a result, people with disabilities are not allowed to be part of society.⁷⁶ Even after death, persons with disabilities are excluded from customary practices as they may not be buried according to traditional funeral rites.⁷⁷

69 Goffman (n 25 above) 30; DESA (n 36 above) 6; Njelesani et al (n 5 above) 156.

70 ‘Breaking “the curse” of disabled children in South Africa’ *Al Jazeera News South Africa* 21 April 2017 <https://www.aljazeera.com/blogs/africa/2017/04/breaking-curse-disabled-children-south-africa-170421190937536.html> (accessed 24 October 2019).

71 Cobbinah (n 12 above) 36-37; KA Erikson et al ‘Recognition as a valued human being: Perspectives of mental health service users’ (2012) 19 *Nursing ethics* 358.

72 Amnesty International (n 61 above) 17.

73 Brocco (n 55 above) 234.

74 UN Office of the High Commissioner for Human Rights (n 58 above) para 37.

75 Kotzé (n 7 above) 52.

76 AH Eide & B Jele *Living conditions among people with disabilities in Swaziland: A national representative study* (2011) 11.

77 DESA (n 36 above) 7.

It seems to be quite common to deny children with disabilities any participation or voice.⁷⁸ Non-participation by people with disabilities is not due to inability, but to discriminatory attitudes and practices.⁷⁹ Their right to develop towards self-determination is denied. Parents do not allow children with disabilities to attend school either because they want to protect them or because they are ashamed of them. Human Rights Watch quotes a person with a mental disability who claimed: 'People look down upon you; those who know you will not want you to speak in society.'⁸⁰

The ultimate form of denying somebody self-determination is institutionalisation without consent. Slee correctly describes institutionalisation as 'social severance'.⁸¹ Institutionalisation worsens stigmatisation and stereotyping, and isolates children with disabilities from their communities.⁸² In the case of *Purohit v The Gambia*, the African Commission on Human and People's Rights deals with the forced and indefinite institutionalisation of mentally disabled persons under the Gambian Lunatics Detention Act. The Commission confirmed the following:

The Commission maintains that mentally disabled persons would like to share the same hopes, dreams and goals and have the same rights to pursue those hopes, dreams and goals just like any other human being. Like any other human being, mentally disabled persons or persons suffering from mental illnesses have a right to enjoy *a decent life, as normal and full as possible*, [our emphasis] a right which lies at the heart of the right to human dignity.⁸³

2.3 The discourse of denunciation

People with disabilities – and children in particular – are regarded as worthless and without any future.⁸⁴ In the Luganda language spoken in Uganda, people with disabilities are called *kikulekule*, which means 'something strange'. They are also referred to as *kateyamba*, which means 'helplessness' or 'someone who cannot help him or herself'.⁸⁵ They grow up with a profound sense of their own incapacity and being defined by what they are not and what they cannot do.⁸⁶ Having a child with disabilities is regarded as a setback or a punishment sent by the gods.

78 B Ransom *Missing voices: Children with disabilities in Africa* (2009) 4.

79 Ransom (n 78 above) 5.

80 Human Rights Watch (n 39 above) 59.

81 Slee (n 24 above) 102.

82 Inclusion International *Hear our voices: A global report – People with an intellectual disability and their families speak out on poverty and exclusion* (2006) 44 <http://inclusion-international.org/wp-content/uploads/2013/07/Hear-Our-Voices-with-Covers.pdf> (accessed 24 October 2019).

83 (2003) AHRLR 96 (ACHPR 2003) para 61.

84 African Child Policy Forum (n 68 above) 50-51.

85 Cobbinah (n 12 above) 27.

86 G Lansdown *Disabled children in Nepal: Progress in implementing the Convention on the Rights of the Child* (2003).

Children are, it is believed, given to parents to assist them in old age and a child with a disability is incapable of that.⁸⁷

Plan International tells the story of a ten-year-old girl who is paralysed from the waist down. She is regarded as a liability by her parents who see no use in sending her to school. After all, she has no prospects and will never be able to marry.⁸⁸ This belief was also evident in a study conducted by the Kenyan Red Cross Society et al on children with disabilities in the Turkana County in Kenya.⁸⁹ Kavesu conducted a study for Save the Children Sweden in 3 districts, Jonglei, Lakes and Northern Bahr el Ghazal in Southern Sudan and it is evident that girl participants accept that they are regarded as liabilities without any future prospects. The girls commented inter alia: 'Girls with disabilities are not taken to school because they may not get married and thus bring wealth to the family' and 'Parents feel like they are wasting resources sending a girl with disability to school'.⁹⁰ Sadly, these comments also speak to the marginalisation of girls in general and the fact that their 'value' lies in being a commodity. Girls with disabilities do not even have the value of being a commodity. A parent with a child with disabilities who participated in the study conducted under the auspices of Inclusion Ghana in the Greater Accra, Volta, Upper East and Brong Ahafo regions in Ghana commented on her attempts to take her child to school: 'The teacher in the regular school called to tell me it was useless bringing my child to school. He would never learn anything'.⁹¹

A mother with a daughter with epilepsy who participated in a qualitative study conducted in December 2015 in the Kamuli District in Uganda's Eastern Region by Plan International Norway et al explains that children with disabilities are vulnerable to violence because they are perceived as having no value, 'are good as nothing', 'very useless' and have 'nothing good in them'.⁹²

Plan International links the conceptualisation of and the attitudes towards children with disabilities to infanticide and the trade in body parts of children with disabilities in West Africa.⁹³ Infanticide and the trade in body parts illustrate how children with disabilities are objectified and not regarded as human beings with self-worth. In fact, the study conducted in Turkana referred to above found these children are described as 'not alive'

87 JK Gona et al 'Caring for children with disabilities in Kilifi, Kenya: What is the carer's experience?' (2010) 37 *Child care, health and development* 179.

88 Plan International (n 50 above) 25-29.

89 Kenyan Red Cross Society et al *Childhood disability and malnutrition in Turkana Kenya: A summary report for stakeholders and policy* (2014) 9 <https://www.lshtm.ac.uk/sites/default/files/2019-06/Malnutrition-and-Disability-Report-Full-Report.pdf> (accessed 24 October 2019).

90 B Kavesu *Children discriminated against in Southern Sudan* (2007) 10.

91 Odoom & Van Weelden (n 40 above) 14.

92 Plan International Norway et al (n 3 above) 30.

93 Plan International (n 50 above) 8, 36.

and ‘dead useless person(s)’.⁹⁴ Brocco refers to the fact that, in Tanzania, people with albinism are referred to as *dili* – which means ‘to deal’ – and signifies the fact that their body parts are traded as commodities.⁹⁵ A participant in a study conducted by Bucaro recalls the common practise in the city of Mwanza in Tanzania where a crowd would run after a person with albinism harassing him or her yelling *dili-dili*.⁹⁶ The same beliefs and practices were identified in Malawi and Burundi.⁹⁷

During a workshop organised by the Southern African Federation of the Disabled held in Kempton Park in October 2007, people with disabilities described how they were branded by people in their communities. A discourse of invalidation is evident from descriptions such as: ‘morons’, ‘idiots’, ‘stupid’, ‘non-achievers’, ‘not worthy of wasting money on’, ‘useless to society’, ‘remains a child – not expected to ever behave like an adult’, ‘a burden’, ‘a liability’, ‘unproductive’, and ‘cannot be educated’.⁹⁸

According to Plan International, children with disabilities are regarded as only good for becoming beggars.⁹⁹ Kamaleri and Eide concluded after a national household survey in Lesotho during 2009 and 2010 that people with disabilities are perceived as ‘objects of charity and passive recipients of rehabilitation’ and excluded from society.¹⁰⁰ Wa-Mungai¹⁰¹ argues that beggary is seen as an activity reserved for people with disabilities. In support of his argument, he refers to the Gikũyũ phrase *Urahooya nĩ kwonja wonjete?*, meaning: ‘Why beg as if you are crippled?’ It appears in a song by Daniel Kamau Mwai and also to the Kiswahili phrase, with the same meaning, *mbona unaomba kama wewe ni kilema?*

There is a general belief that children with disabilities cannot be educated because they are stupid.¹⁰² The Akan-speaking people in Ghana, call a person with intellectual disabilities *jimijimi* or *nea wanyinagya n’adwene ho* (a person who has outgrown his brains).¹⁰³ Odoom and van Weelden mention that the Ewe-speaking people in Ghana refer to a person with intellectual disabilities as *asotowo* (idiot or fool). They also quote an

94 Kenyan Red Cross Society et al (n 88 above) 9.

95 Brocco (n 55 above) 230. Also see UN Office of the High Commissioner for Human Rights (n 58 above) para 24.

96 S Bucaro ‘A black market for magical bones: The current plight of East African albinos’ (2010) 15 *Loyola Public Interest Law Reporter* 131 134.

97 DESA (n 36 above) 7.

98 R Rieser *Developing disability equality: Implementing inclusive education in South Africa Part 1* (2008) 7, 8.

99 Plan International (n 49 above) 37.

100 Y Kamaleri & AH Eide *Living conditions among people with disabilities in Lesotho* (2011) 16.

101 M Wa-Mungai ‘“For I name thee ...”: Disability onomastics in Kenyan folklore and popular music’ (2009) 29 *Disability Studies Quarterly* <http://dsq-sds.org/article/view/984/1172> (accessed 7 October 2019).

102 Ransom (n 78 above) 5.

103 Odoom & Van Weelden (n 40 above) 7, 16, 43.

educator in the Navrongo in the Upper East Region who said he is called 'the teacher of fools' or the 'fools' teacher'.¹⁰⁴ In Uganda persons with intellectual disabilities who are also hard of hearing are called *kasiru* which means 'a stupid person'.¹⁰⁵ The World Health Organisation contends that even teachers who support inclusive education do not have high expectations of learners with disabilities.¹⁰⁶

The African disability landscape is, as seen in the foregoing sections, littered with dehumanising and belittling discourses. But, countering those narratives, the Continent also offers us examples of inclusive and disability-friendly discourses, to which we now turn.

3 Positive African cultural narratives of disability

As revealed in the foregoing sections, the predominant lay narratives about disability in Africa are dehumanising. But there are societies where discourses are respectful and inclusive with clear indications of the person-first discourse.¹⁰⁷ 'People-first' language prefers the postmodified noun to the premodified noun.¹⁰⁸ 'Children with disabilities' instead of 'disabled children' and 'people who are hearing impaired' instead of 'deaf and dumb' or 'the deaf'.¹⁰⁹ For instance, among the Dinka in Sudan, the phrase *raan chie ming* is used, which translates to 'one who speaks using gestures', to describe people with hearing impairments. It is worth noting that the focus on the mode of communication rather than on the impairment itself is perfectly in line with the social model of disability.¹¹⁰ In the DRC, among the Lingala, the term *ebosono* is used to describe a person with physical disabilities. The term literally means 'someone who cannot walk or perform physical tasks'.¹¹¹ Among the Acholi of Northern Uganda, the term *latowa* (pl *Lutuwa*) which means 'a person with visual impairments' is used to describe a blind person. Similarly, the term *lading yit* which is translated as 'a person who cannot hear' is used to describe a deaf person.¹¹²

In Botswana, the concept *kagisano* imposes the responsibility for caring for the disabled on societies and communities; denoting that disability is seen as socially constructed.¹¹³ This is related to the *botho* concept in

104 Odoom & Van Weelden (n 40 above) 1, 23.

105 Cobbinah (n 12 above) 7, 16, 43.

106 World Health Organisation & Mental Health and Poverty Project (n 33 above) 216.

107 Wa-Mungai (n 101 above).

108 H Halmari 'Political correctness, euphemism, and language change: The case of "people first"' (2011) 43 *Journal of Pragmatics* 828 829.

109 Halmari (n 108 above) 832.

110 Wa-Mungai (n 101 above).

111 As above.

112 As above.

113 AG Hopkin 'Special education in Botswana: Social inclusion or exclusion?' (2004) 18 *Pula: Botswana Journal of African Studies* 88 90.

Tswana, which means respect for the humanity in all human beings. A related notion, called ubuntu (in full it reads *Umntu ngumuntu ngabantu*), is found among the Zulu. Eze¹¹⁴ argues that the worldview of many other ethnic groups in sub-Saharan Africa is the principle of ubuntu. This concept embodies the fact that 'a person is a person through other people'.¹¹⁵ The African view of what it means to be human based on Ubuntu, regards disability as a common humanity and any threat to a child with disability is a threat to humanity.¹¹⁶ Berghs¹¹⁷ explains that:

Disablement happens when that otherness or diversity becomes a difference predicated as inhuman, for example, in that a person is viewed as threatening the social order, kinship relations or is viewed as morally outside the realm of what it socially means to be human.

The theory of Goodley and Runswick-Cole¹¹⁸ that intellectual disabilities challenge people to reconsider 'normative, taken-for-granted, deeply societally ingrained assumptions about what it means to be human' also rings true with regard to children with disabilities. Because people do not want their idea of what it means to be human disrupted they tend to *dis* (African-American slang term meaning to 'put down, fail to show respect, abuse, and disparage') the person with disabilities and not accept him or her into the human registry. This theory may explain why the ubuntu worldview is *dissed* in favour of harmful customary beliefs about children with disabilities.

The authors contend that ubuntu, because it is a worldview of humanity as determined by the interrelatedness of people,¹¹⁹ can be utilised to counter the dehumanising discourse. For example, sayings that support the ubuntu worldview such as *Motho gase mphshe ga a tshewe sesotlho* (no single human can be thoroughly and completely useless),¹²⁰ could be employed to contradict dehumanising discourse on the worthlessness of children with disabilities.

114 MO Eze 'What is African communitarianism? Against consensus 'as a regulative ideal' (2008) 27 *South African Journal of Philosophy* 386-387.

115 Desmond Tutu quoted in DR Jolley *U B U N T U: A person is a person through other persons* (2011) 6.

116 M Berghs 'Practices and discourses of ubuntu: Implications for an African model of disability?' (2017) 6 *African Journal of Disability* 2.

117 Berghs (n 116 above) 6.

118 D Goodley & K Runswick-Cole 'Becoming dishuman: Thinking about the human through dis/ability' (2016) 37 *Discourse: Studies in the Cultural Politics of Education* 6.

119 G Mji et al 'An African way of networking around disability' (2011) 26 *Disability & Society* 365.

120 Eze (n 114 above) 388.

4 Legislative narratives countering the dehumanising discourse

Human rights instruments counter the dehumanising discourse through the principle of human dignity – dubbed as ‘the normative fountainhead of human rights’.¹²¹ A number of countries in Africa have ratified major international human rights treaties which – directly or indirectly – promote a discourse focusing on the dignity of children with disabilities. Human-rights instruments that apply to all people (children included) that are notable in this regard include the Convention on the Rights of Persons with Disabilities (UNCRPD)¹²² and the African Disability Protocol.¹²³

Under article 8(2)(a), the UNCRPD calls upon states parties to take measures, to ‘promote positive perceptions and greater social awareness towards persons with disabilities’. The Convention itself contributes towards promoting such positive perceptions and it contains ample evidence of discourse that focuses on people-first language, countering dehumanising discourse. Under its underlying principles, the UNCRPD promotes discourse emphasising people of disability as part of humanity. It calls for the ‘respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons with disabilities’. It also calls for ‘respect for difference and acceptance of persons with disabilities as part of *human diversity and humanity*’ [our emphasis].¹²⁴ The UNCRPD counters exclusion and invisibility discourses by urging states parties to take measures to put children with disabilities on an equal footing with other children, to ‘ensure that children with disabilities have equal rights with respect to family life’ and ‘to prevent concealment, abandonment, neglect and segregation of children with disabilities’.¹²⁵ The UNCRPD contains provisions which are a direct contrast to dehumanising cultural discourses and practices. Under article 8(1)(a), the Convention urges states parties: ‘To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life.’

The African Disability Protocol¹²⁶ contains a similar provision imploring states parties to reconceptualise people with disabilities:

States Parties shall take measures to discourage stereotyped views on the capabilities, appearance or behaviour of persons with disabilities, and they shall prohibit the use of derogatory language against persons with disabilities.

121 A Dimopoulos *Issues in human rights protection of intellectually disabled persons* (2010) 4.

122 Preamble, arts 1, 3(a), 8(1)(a) and 25(d) UNCRPD.

123 Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Persons with Disabilities in Africa of 2018 (African Disability Protocol).

124 Art 3 UNCRPD.

125 Art 7 & 23(3) UNCRPD.

126 Art 2 African Disability Protocol.

The African Disability Protocol acknowledges persons with disabilities' inherent dignity, individual autonomy and freedom to make their own choices.¹²⁷ It further appreciates the 'value of persons with disabilities including those with high support needs, as full members of society' (our emphasis).¹²⁸ The African Disability Protocol defines harmful practices to include 'behaviours, attitudes and practices based on tradition, culture, religion, superstition, which negatively affect the human rights and fundamental freedoms of persons with disabilities or perpetuate discrimination'.¹²⁹ Similar to the UNCRPD, the African Disability Protocol urges states to take measures 'to eliminate harmful practices on persons with disabilities, including witchcraft, *abandonment, concealment, ritual killings* or the association of disability with *omen*' (our emphasis).¹³⁰

Except for the above instruments, specific instruments were adopted to provide extra protection for children in particular. These include, inter alia, the Convention on the Rights of the Child (CRC)¹³¹ and the African Charter on the Rights and Welfare of the Child (ACRWC).¹³²

The UNCRC General Comment 9 recognises the invisibility of children with disabilities:

Children with disabilities are disproportionately vulnerable to non-registration at birth. Without birth registration they are not recognized by law and *become invisible* in government statistics ... Children with disabilities who are not registered at birth are at greater risk of neglect, institutionalization, and even death [our emphasis].¹³³

Though people-first language is not used in the ACRWC as it is in the UNCRC, it still supports equalising and empowering discourse. Equalising and empowering discourse is especially evident in article 13:

- a) Value: 'active participation in the community';
- b) Humanness: 'the right to special measures of protection in keeping with his physical and moral needs and under conditions which ensure his dignity';
- c) Social inclusion: 'fullest possible social integration'; and

127 Preamble African Disability Protocol.

128 Preamble African Disability Protocol.

129 Art 1 African Disability Protocol.

130 Art 9(1) African Disability Protocol.

131 Preamble and art 23(1) United Nations Convention on the Rights of the Child (UNCRC).

132 Preamble, art 13(1) & 21(1) African Charter on the Rights and Welfare of the Child (ACRWC).

133 UNCRC Committee General Comment 9: The rights of children with disabilities (2006) UN Doc CRC/C/GC/9 dated 27 February 2007 para 35.

- d) The social model of disability: 'special measures of protection', 'conditions which ensure ...', 'assistance', 'achieving progressively the full convenience ... to movement and access to public highway buildings and other places'.¹³⁴

Depending on the country's legal tradition, treaties can either automatically become part of domestic law or be domesticated through parliamentary enactment of related laws. Many countries have not only domesticated these international human rights instruments but have also incorporated the spirit of human dignity that lies at the heart of these instruments within their domestic laws. This spirit is especially evident in constitutional discourse. For example, the Constitution of the Republic of Uganda, 1995 (as amended) requires society and the state to 'recognise the right of persons with disabilities to respect and *human dignity*' (our emphasis).¹³⁵ The Constitution of the Democratic Republic of the Congo, 2005 provides '[t]he abandonment and maltreatment of children, in particular paedophilia, sexual abuse and the charge of engaging in witchcraft, are prohibited and punishable by law'.¹³⁶ The Constitution of the Arab Republic of Egypt, 2014 explicitly guarantees the rights of children with disabilities and ensures them of the government's commitment to their rehabilitation and incorporation into society.¹³⁷ Constitution of Kenya, 2010 article 54(1)(a) provides that '[a] person with any disability is entitled to be treated with dignity and respect'. It further acknowledges that the manner in which persons with disabilities are addressed and referred to can marginalise them. It thus prescribes that people with disabilities should not be addressed or referred to in a manner that demeans them.¹³⁸

There are examples of national legislation that criminalise the exclusion of persons with disabilities through upholding the right to non-discrimination or through criminalising concealment. '[U]sing words, gestures or caricatures that demean, scandalize or embarrass a person with disability' constitutes discrimination in terms of the Sierra Leone Persons with Disability Act 3 of 2011.¹³⁹

Several countries have laws criminalising the concealment of persons with disabilities. For instance, the Zambian Persons with Disabilities Act 6 of 2012;¹⁴⁰ the Sierra Leone Persons with Disability Act 3 of 2011;¹⁴¹ and Persons with Disability Act 14 of 2003 of Kenya.¹⁴² The Persons with Disabilities Act 33 of 1996 of Zambia contains anti-discrimination

134 Art 13 ACRWC.

135 Sec 35(1) Constitution of the Republic of Uganda, 1995 (as amended).

136 Sec 41 Constitution of the Democratic Republic of the Congo, 2005.

137 Art 80 Constitution of the Arab Republic of Egypt, 2014.

138 Art 54(1)(a) Constitution of Kenya, 2010.

139 Sec 1 Sierra Leone Persons with Disability Act 3 of 2011.

140 Sec 61 Zambian Persons with Disabilities Act 6 of 2012.

141 Sec 35 Sierra Leone Persons with Disability Act 3 of 2011.

142 Sec 45 Persons with Disability Act 14 of 2003 of Kenya.

provisions including those practices that discriminate among persons with disabilities, such as:

Treating a person with a disability less favourably from a person without a disability; treating a person with a disability less favourably from another person with a disability; requiring a person with a disability to comply with a requirement or condition which persons without a disability may have an advantage over; or not providing different services or conditions required for that disability.

According to section 35 of the Sierra Leone Persons with Disability Act 3 of 2011, a parent, guardian or next-of kin or carer who:

- a) Conceals a person with disability, or
- b) fails to register a person with disability,

commits an offence and shall on conviction be liable to a fine not exceeding two million leones or to imprisonment for a term not exceeding one year or to both such fine and imprisonment.

A similar provision is contained in section 45 of the Persons with Disabilities Act 14 of 2003 of Kenya:

- (1) No parent, guardian or next of kin shall conceal any person with a disability in such a manner as to deny such a person the opportunities and services available under this Act.
- (2) A person who contravenes subsection (1) is guilty of an offence and is liable on conviction to a fine not exceeding twenty thousand shillings.

The Kenyan Children Act 8 of 2001 as amended by CAP 141 of 2012 prohibits discrimination against children with disabilities.¹⁴³ It further requires that a child with a disability accused of an offence be treated with the same dignity as a child with no disability.¹⁴⁴ The Egyptian Childhood Law 12 of 1996 (as amended by Law 126 of 2008) provides that children with disabilities have the right to '[e]njoy special social, physical, and mental care promoting self-reliance, and facilitating the child's integration and participation in the community'.¹⁴⁵ The Act also guarantees the right to rehabilitation of children with disabilities. In terms of this right, children with disabilities have a right to social, mental, medical, educational and professional services that they or their families may require to overcome the barriers created as a result of their disabilities.¹⁴⁶ Under the Mauritius Child Protection Act 30 of 1994 sexual offences on children with disability, ill treatment, exposure or abandonment or forcing a child with a disability

143 Sec 5 Kenyan Children Act 8 of 2001.

144 Sec 186(h) Kenyan Children Act 8 of 2001.

145 Art 76 Egyptian Childhood Law 12 of 1996.

146 Art 77 Egyptian Childhood Law 12 of 1996.

to beg are criminal offences.¹⁴⁷ Though the Act does not specifically mention children with disabilities, it is clear that they are covered under the protection that this Act offers since 'child' is defined as '... any unmarried person under the age of 18'.¹⁴⁸

Great strides were made towards positive disability discourse in Nigeria on 23 January 2019, when the Nigerian President Muhammadu Buhari signed the Discrimination against Persons with Disabilities (Prohibition) Act 2018 into law. The main aim of the Act is the full integration into society of people with disabilities. In terms of section 1(2) it is an offence to discriminate against a person on ground of his or her disability.¹⁴⁹ It can be taken that since discrimination is broadly defined as 'differential treatment'¹⁵⁰ it covers discrimination through discourse. Other offences provided for in the Act include to abuse a person with a disability by employing, using or involving him or her in begging, to parade a person with a disability in public for the purpose of soliciting handouts and to use having a disability as a guise for begging in public.¹⁵¹

The above discourses foster inclusion rather than exclusion, acceptance rather than rejection. They promote humanity's oneness and, consequently, protect persons with disabilities.¹⁵² These discourses can be used as a stepping stone in reconceptualising children with disabilities in Africa. The focus should be to build upon the existing positive discursive practices and create more inclusive, humane and respectful discourses.

6 Concluding words

Two general observations can be made from the preceding discussions. First, the continent abounds with examples of progressive legislative narratives, where the principles of human rights, human dignity and equality of children with disabilities are promoted. The fact that the UNCRPD is one of the instruments which enjoyed a rapid rate of ratification in the continent is testimony to growing awareness about the issue. Africa's adoption of the African Disability Protocol, which takes into account existing negative cultural narratives, is yet another commitment to the realisation of the rights of persons (children) with disabilities. The African Disability Protocol, in its Preamble, rightly expresses the prevailing concern that 'persons with disabilities continue to

147 Secs 13, 13B, 13C, 14 and 18 Mauritius Child Protection Act 30 of 1994.

148 Sec 1 Mauritius Child Protection Act 30 of 1994.

149 Sec 1(2) Nigerian Discrimination against Persons with Disabilities (Prohibition) Act, 2018.

150 Sec 57 Nigerian Discrimination against Persons with Disabilities (Prohibition) Act.

151 Sec 16 Nigerian Discrimination against Persons with Disabilities (Prohibition) Act.

152 DJ Louw (2004) 'Ubuntu: An African assessment of the religious other' (1998) August 10-15 Twentieth World Congress of Philosophy, in Boston, Massachusetts <https://www.bu.edu/wcp/Papers/Afri/AfriLouw.htm> (accessed 24 October 2019).

experience human rights violations, systemic discrimination, social exclusion and prejudice within political, social and economic spheres'.¹⁵³ Furthermore, in line with these and other relevant instruments, many countries have put in place legislative frameworks that counter dehumanising, denouncing and exclusionary discourses.

Secondly, there is a mixed and contradictory cultural discourse of disability, whereby both the dehumanising, denouncing and discriminatory discourses live side by side with inclusive, human-rights based narratives. Such discourses vary from one community to another and even from one family to another, hence rendering any generalisations about these discourses practically impossible.

Based on these observations, it is important to deconstruct the negative discourses and reconstruct them to reinforce the existing positive, inclusive discourses such as the ubuntu worldview so that the humanising, inclusive and empowering discourse becomes the dominant discourse. That is the first important step towards creating a continent where children with disabilities enjoy their full range of rights, as humans, as rights holders and as equal citizens.

153 Preamble African Disability Protocol.

*Paul Juma**

Summary

In Kenya, persons with mental disabilities have a different experience from able-bodied people in the criminal justice system. Regrettably, the rules are applied differently when persons with mental disabilities are the accused. In most cases, they are unable to afford lawyers and are forced to represent themselves. That is when their position becomes more challenging and their vulnerability more pronounced. Their right to give evidence will depend on the individual's form of disability. Article 13 of the Convention on the Rights of Persons with Disabilities provides for the right to legal capacity including the right to file complaints and to represent oneself in court. The aim of this paper is to look at the extent of Kenya's implementation record of the right to self-representation and make recommendations on the best possible ways of ensuring that persons with mental disabilities are able to represent themselves and fully participate in court proceedings.

1 Introduction

Kenya's criminal justice system is adversarial in nature. Parties involved in a dispute present their case before an impartial tribunal for determination and judgement.¹ The system demands that testimony should be given through oral or documentary evidence. In order for witnesses to be believed, judicial practice requires that their evidence must be declared credible by the judicial officer. That fact is usually determined by the observation of their demeanour.² Witnesses are expected to have good memory coupled with quick responses if they want their testimony to be

* LLM student on the Masters Degree in Disability Rights in Africa Programme, Centre for Human Rights, Faculty of Law,, University of Pretoria; LLB (Kenya); advocate of the High Court of Kenya.

1 *Kenya Airports Authority v Mitu-Bell Welfare Society* [2016] eKLR.

2 Criminal Procedure Code Chapter 75 of 1930 (Laws of Kenya) sec 199.

believed by the trier of facts. This applies to everyone except people with cognitive or mental disabilities.

There is no single definition of mental disability.³ It varies depending on jurisdictions and professions.⁴ There are clinical definitions, legal definitions and sociological definitions among others. According to the American Association of Intellectual and Development Disabilities, mental disability occurs when a person has limited adaptive behaviour and understanding ability.⁵ For the purposes of this paper, a person has a mental disability when he or she has a limited decision making capacity depending on several factors including environmental and social.⁶ This should be contrasted with legal capacity which is the 'ability to hold rights and duties and to exercise those rights and duties.'⁷ Therefore, the difference between mental capacity and legal capacity is that the latter is an absolute right and is not dependent on the former.⁸

Regrettably, persons with mental disabilities will be readily denied their right to legal capacity on an equal basis with others where it 'becomes apparent to the court' that they are 'not able to understand court proceedings or make' their defence.⁹ Surprisingly, this denial may be determined merely by considering the circumstances surrounding the accused person such as their 'immediate preceding or immediate succeeding or even the contemporaneous conduct'.¹⁰ Once that finding is reached, the court will halt the hearing and the affected party will not participate in any further proceedings unless they are declared to be of sound mind. According to the law, one is presumed to be of sound mind when he or she is declared 'to be capable of making his defence'.¹¹ In case they achieve that fit, then they will have to prove that they are telling the truth and to do this they must strive to overcome the institutionalised hurdles of the adversarial system such as cross-examination. The objective of this article is to look at the extent to which Kenya has implemented the right to self-representation for persons with mental disabilities and suggest reforms geared towards ensuring the adequate participation of persons with mental disabilities in court trials. In order to do this, the article will

3 M Karras et al *On the edge of justice: The legal needs of people with a mental illness* (2006) 2.

4 Karras et al (n 3 above) 2.

5 American Association of Intellectual and Development Disabilities 'Definition of intellectual disability' (2018) <http://aaid.org/intellectual-disability/definition> (accessed 6 November 2019).

6 CRPD Committee General Comment 1: Article 12: Equal recognition before the law (2014) UN Doc CRPD/C/GC/1 dated 19 May 2014 para 13.

7 Protocol to the African Charter on Human and People's Rights on the Rights of Persons with Disabilities (African Disability Protocol) Adopted 29 January 2018, art 1.

8 M Scholten & J Gather 'Adverse consequences of article 12 of the UN Convention on the Rights of Persons with Disabilities for persons with mental disabilities and an alternative way forward' (2018) 44 *Journal of Medicine and Ethics* 228.

9 *Leonard Mwangemi Munyasia v Republic* [2015] eKLR.

10 As above.

11 Criminal Procedure Code (n 2 above) secs 163(1).

mainly rely on the Convention on the Rights of Persons with Disabilities¹² (CRPD) which is the primary international treaty that deals with the rights of persons with disabilities and which guarantees their rights to legal capacity on an equal basis with others.¹³

2 Background

An arbiter of the facts is not expected 'to descend into the arena and give the impression of acting as advocate'¹⁴ on behalf of any of the parties involved. However, in instances where the accused is 'unrepresented and seems not to understand the court procedures', the 'presiding judicial officer' will be allowed to assist.¹⁵ Be that as it may, it is also noteworthy to point out that 'the court cannot act as an advisor to the accused as to various tactical possibilities open to him as the trial unfolds'.¹⁶ But the court has the discretion, upon the application of either party, to allow the use of intermediaries or relevant assistive devices in court in order to facilitate the testimony of witnesses. Despite the Constitution of the Republic of Kenya, 2010 (the Constitution) making provision for the use of intermediaries, parliament is yet to pass any detailed legislation to give effect to that provision. That does not mean that judicial officers cannot assist persons with disabilities to communicate effectively and understand proceedings in court. On the contrary, they have a wide discretion when it comes to the interpretation of laws. Therefore, 'a judge or magistrate must not preside on a trial like a football match referee'.¹⁷ Instead, they 'must ensure that an unrepresented party', and especially, a party with a mental disability, is assisted in order 'to present his case as fully as possible, without the court appearing to lose its impartiality'.¹⁸

From the above paragraph, it is not in dispute that persons with mental disabilities have legal rights. However, in order to bring meaning to these rights it is imperative for them to be adequately represented in court. The right to self-representation for persons with mental disabilities in court has elicited fierce debates from around the globe. In *Faretta v California*¹⁹ the United States Supreme Court fundamentally acknowledged accused persons' rights to self-representation. That right requires the state to grant an accused adequate time and facilities to prepare a defence and to accord them an opportunity to adduce and challenge all the evidence which the prosecution intends to rely on.²⁰ It is aligned with article 12(3) of the

12 Convention on the Rights of Persons with Disabilities (CRPD), adopted on 13 December 2006 UN Doc A/61/611 (entered into force on 3 May 2008).

13 Art 12(2) CRPD.

14 *R v Hamilton* unrep 9 June 1969.

15 *Rabonko v the State* [2006] 2 BLR 166 168C-D.

16 *Sunasse v State* [1998] MLR 84.

17 *Moses Muhagama Laurence v the Government of Zanzibar* Criminal Appeal 17 of 2002.

18 As above.

19 422 US 806 (1975).

20 Art 50(2)(c) & (k) Constitution of the Republic of Kenya, 2010.

CRPD which obliges states to grant persons with mental disabilities with the relevant accommodations in order for them to understand and effectively participate in the criminal process. The concept of reasonable accommodation has been defined by the CRPD to mean:

[N]ecessary and appropriate modification and adjustments 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.²¹

In Kenya, the issue of legal capacity has remained a pipe dream. The current evidential procedures were formulated for those without disabilities, mental or otherwise. The CRPD's aim is to radically change this position by ensuring that the fair trial rights of people with mental disabilities are respected and protected.

3 Right to self-representation for persons with mental disabilities under international law

The right to self-representation has been conceptualised under various international instruments. Article 14(3)(d) of the International Covenant on Civil and Political Rights (ICCPR)²² stipulates that:

In the determination of any criminal charge against him, everyone shall be entitled to the following minimum guarantees, in full equality ... (d) To be tried in his presence, and to defend himself in person or through legal assistance of his own choosing; to be informed, if he does not have legal assistance, of this right; and to have legal assistance assigned to him, in any case where the interests of justice so require, and without payment by him in any such case if he does not have sufficient means to pay for it.²³

It is clear from the above provision that every accused person has a right to self-representation. Regionally, article 8(2)(d) of the African Charter on Human and Peoples' Rights (African Charter)²⁴ and article 7 of the Protocol to the African Charter on Human and People's Rights on the Rights of Persons with Disabilities (African Disability Protocol)²⁵ ensures the rights of every accused person 'to defend himself personally'²⁶ and to 'equal recognition before the law' respectively.²⁷ In Europe, the right is

21 Art 2 CRPD.

22 International Covenant on Civil and Political Rights, adopted 16/12/1966; GA Res 2200 (XXI), UN Doc A/6316 (1966) 999 UNTS 171 (entered into force on 23 March 1976).

23 Art 14(3)(d) ICCPR.

24 The African Charter on Human and Peoples' Rights, 27 June 1981, OAU Doc CAB/LEG/67/3/Rev.5 (1981) (entered into force on 21 October 1986).

25 Protocol to the African Charter on Human and People's Rights on the Rights of Persons with Disabilities (African Disability Protocol) adopted 29 January 2018.

26 Art 8(2)(d) African Charter.

27 Art 7 African Disability Protocol.

contained in article 6(3)(c) of the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR)²⁸ where all criminal defendants are guaranteed the right to defend oneself.²⁹ Finally, apart from the African Charter and the African Disability Protocol all the other international instruments have limited this right where 'the interest of justice so requires'.³⁰ Also, all of the instruments are not specific to persons with disabilities.

The main aim of the CRPD is to 'promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all person with disabilities and to promote respect for their inherent dignity'.³¹ Kenya ratified the CRPD in 2008. By virtue of article 2(6) of the Constitution, the same now forms part of the laws in Kenya. That article stipulates that all the treaties and conventions which have been ratified by the Government of Kenya automatically form part of the country's laws even without enabling legislation. Persons with mental disabilities have a right of access to justice on an equal basis with the non-disabled. Moreover, the state has an obligation to ensure that persons with mental disabilities enjoy equal rights to legal capacity with others in all aspects of life. Article 12 of the CRPD provides at that:

- 1) States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
- 2) States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
- 3) States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
- 4) States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
- 5) Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons

28 European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) 213 UNTS (entered into force 3/09/1953).

29 Art 6(3)(c) ECHR.

30 I Zavoli 'The right to self-representation in international criminal justice: Between legal fairness and judicial effectiveness' (2016) *diritto penale contemporaneo* 3.

31 Art 1 CRPD.

with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

In its 11th session, the Committee on the Rights of Persons with Disabilities (the Committee) which is the treaty-monitoring body of the CRPD, in its General Comment on Article 12 on Equal recognition before the Law defined legal capacity in the following terms;

Legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (legal standing) and to exercise these rights and duties (legal agency). It is the key to accessing meaningful participation in society. Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors. Under article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.³²

Simply put, 'legal capacity is the law's recognition of a person's decisions'.³³ By 'persons' it means both those with 'mental disabilities' which includes 'mental disorders' and those without.³⁴ The dominating attitude of judges and magistrates in the Kenyan judicial structure is fuelled by the medical model of disability which views disability as a defect which must be cured through medical intervention.³⁵ For example, in *Republic v CMW*³⁶ the court after finding the accused guilty, but insane, recommended that the country should build 'a Mental Asylum where persons with mental disabilities facing trial for various offences may be held, and consequently properly medically treated'.³⁷ Also, in *Leonard Mwangemi Munyasia v Republic*³⁸ the Court of Appeal held that 'insane' accused persons who are found guilty should 'be detained in a mental hospital, prison or other suitable place of safe custody'.³⁹ This reasoning is based on the medical model of disability. The CRPD eschews the medical model of disability and in its stead adopts the human-rights model which focuses on the diversity of PWDs and their interaction with 'attitudinal and environmental barriers'.⁴⁰

32 General Comment 1 (n 6 above) par 13.

33 Mental Disability Advocacy Centre 'The right to legal capacity in Kenya' (2014) 18.

34 J Craigie 'Against a singular understanding of legal capacity: Criminal responsibility and the Convention on the Rights of Persons with Disabilities' (2015) 40 *International Journal of Law and Psychiatry* 6.

35 A Dube 'Protection of the rights of persons living with disabilities under the African human rights system' LLM Dissertation, University of Pretoria, 2007 7.

36 *Republic v CMW* [2018] eKLR.

37 *Republic v CMW* (n 36 above) para 48.

38 *Leonard Mwangemi Munyasia v Republic* (n 9 above).

39 As above.

40 Communication 22/2014, *X v United Republic of Tanzania*, CRPD Committee (31 August 2017) UN Doc CRPD/C/18/D/22/2014 para 7.6.

Regionally, one of the aims of the African Union (AU) towards the implementation of article 12 has been to encourage state parties to accord persons with disabilities their right to 'full recognition before the law' and 'effective access to justice on an equal basis with others'.⁴¹ The main goal of the AU under this heading is to get member states to repeal or amend 'any guardianship and inheritance laws' which have in the past taken away the freedom to make choices for those with mental disabilities. In its place, states are urged to grant those with disabilities the requisite capacity to enter into 'legal contracts or take legal action' on their 'own behalf'.⁴²

As seen above, the removal of barriers with regard to legal capacity enhances the right to self-representation for persons with mental disabilities. Therefore, the CRPD presupposes that by virtue of being human beings, persons with disabilities must be allowed to 'enjoy the right to access the civil and judicial system and the independence to speak on one's own behalf'.⁴³ The concept of 'universal capacity' has caused a lot of controversy within the academic community. For example, Christopher Slobogin and Tina Minkowitz support the interpretation that allows for capacity in all aspects of life while others like Michael Bach and Lana Kerzner argue for a narrow approach which should be limited to one's 'ability to express an intention'.⁴⁴ When it comes to the issue of self-representation in court for persons with mental disabilities, the same fierce debates have been advanced.⁴⁵ In most jurisdictions like the United States, defendants with 'severe mental illness' will be denied the right to self-representation since they are considered incompetent to advance any meaningful defence while in that condition.⁴⁶ In such a situation, the CRPD makes provision for the use of 'supported decision-making' models.

The CRPD recognises that every person is an autonomous being with the ability to choose the course of their own lives.⁴⁷ However, in certain instances, an individual may require some support in order to fully exercise their legal capacity. That means that they need a certain degree of assistance in order to realise their rights.⁴⁸ This kind of assistance is usually

41 The Kenya National Commission on Human Rights (KNCHR) 'A briefing paper on implementing article 12 of the Convention on the Rights of Persons with Disabilities regarding legal capacity in Kenya' (2016) 16.

42 As above.

43 KNCHR (n 41 above) 18.

44 C Slobogin 'Eliminating mental disability as a legal criterion in deprivation of liberty cases: The impact of the Convention on the Rights of Persons with Disabilities on the insanity defence, civil commitment, and competency law' (2016) 40 *Law and Psychology Review* 319; T Minkowitz 'Rethinking criminal responsibility from a critical disability perspective: The abolition of insanity/incapacity acquittals and unfitness to plead, and beyond' (2014) 23 *Griffith Law Review* 443; Craigie (n 34 above).

45 EL Johnston 'Communication and competence for self-representation' (2016) 84 *Fordham Law Review* 2121-2126.

46 Johnston (n 45 above) 2126.

47 N Devi et al 'Moving towards substituted or supported decision-making? Article 12 of the Convention on the Rights of Persons with Disabilities' (2011) 5 *European Journal of Disability Research* 254.

48 Craigie (n 34 above).

offered by a support person depending on the circumstances of the individual. In a court setting, this person will assist those with mental disability to participate fully during the proceedings. Around the globe, most countries have made an effort towards implementing and incorporating the use of support persons in their domestic laws.⁴⁹ Kenya is yet to do so. Some of the reasons why this is so includes the lack of political goodwill, limited understanding of the CRPD's provisions, corruption and inadequate resources.

4 Implementing the right to self-representation for persons with mental disabilities in Kenya

The laws of Kenya are structured to take away the decision-making capacity of persons with mental disabilities.⁵⁰ Those laws are still grounded on a 'system of substitute decision-making' where decisions are made on behalf of persons with mental disabilities.⁵¹ An example of this scheme is the guardianship system which is contained in laws such as the Mental Health Act, Children's Act and the Civil Procedure Act and Rules⁵² of 1924 (Civil Procedure Act).

The Civil Procedure Act⁵³ and the Civil Procedure Rules of 2010 (Civil Procedure Rules) provide for the procedure of filing and instituting civil proceedings in Kenya. Section 93 of the Civil Procedure Act provides that all consents and agreements made by a person with a disability should not be done without the permission of the court. An application for permission can only be made by the next-friend or guardian of the suit. With regard to the Civil Procedure Rules, Order 4 rule 1(e) requires plaintiffs and defendants of 'unsound mind' to make a written declaration to that effect. In Order 10 rule 1 the plaintiff may make an application for the appointment of a guardian where a defendant of unsound mind has failed to enter an appearance.⁵⁴ Lastly, order 32 rule 15 provides for the procedure of appointing a guardian or next friend on behalf of a person of unsound mind.⁵⁵ The position is the stark opposite of what is required under the CRPD. It requires state parties to abolish all forms of substituted decision-making regimes and ensure the restoration of legal capacity to persons with mental disabilities.⁵⁶

49 Devi et al (n 47 above) 254.

50 KNCHR (n 41 above).

51 As above.

52 Chap 21.

53 As above.

54 Order 10 rule 1 Civil Procedure Rules 2010.

55 Order 32 rule 15 Civil Procedure Rules 2010.

56 General Comment 1 (n 6 above) par 7.

In criminal proceedings the situation is equally appalling. Sections 162-164 and 280 of the Criminal Procedure Code⁵⁷ of 1930 detail the procedure for determining whether an individual is of 'unsound mind'. Under these provisions, any person who is declared to be of unsound mind is not allowed to represent himself or herself or be represented by an advocate unless he or she is declared fit to stand trial. Instead, they will be indefinitely remanded in safe custody in serious non-bailable cases or released on bail on the condition that they will be adequately taken care of until such a time when they will be pronounced fit to stand trial. The Committee in the case of *Noble vs Australia*⁵⁸ (*Noble's Case*) considered a related provisions in Australia's Mentally Impaired Defendants Act of 1996 which required the detention of persons with mental disabilities who are unable to understand the proceedings indefinitely until such a time when they will be declared fit to plead.⁵⁹ The Committee found the provisions to be discriminatory and a violation of rights under articles 12(3) (legal capacity), 13(1) (access to justice), 14(1) (liberty), and 15 (freedom from torture) of the CRPD.⁶⁰

Lastly, the Kenyan Evidence Act⁶¹ of 1963 (Evidence Act) is the main legislation that regulates the procedure of giving and receiving evidence in court. Section 2(1) of the Evidence Act provides that it applies to 'all judicial proceedings in or before any court'. It is also the law that is concerned with a witnesses' competence to testify in court. With regard to those with mental disabilities, the law provides that they are 'not incompetent to testify'.⁶² However, where the disability prevents them 'from understanding the questions put to' them 'and giving rational answers' then they will not be allowed to give evidence in court.⁶³ In short, their right to enjoy legal capacity is pegged on their ability to understand questions and give rational answers. Those provisions are in contrast to article 12 of the CRPD which requires states to recognise that persons with mental disabilities have 'the right to enjoy legal capacity on an equal basis with others in all aspects of life'. Moreover, the Constitution of Kenya mandates the state and its people to treat all persons with disabilities with 'dignity and respect'.⁶⁴ Therefore, in order to effectively implement the provisions of article 12 of the CRPD, Kenya should endeavour to adopt one or more types of supported decision-making methods such as the

57 Chap 75.

58 Communication No 7/2012, views adopted at its sixteenth session (2 September 2016) UN Doc CRPD/C/16/D/7/2012 (10th October 2016).

59 Concluding observations on the initial report of Kenya, CRPD Committee (30 September 2015) UN Doc CRPD/C/KEN/CO/1 (2015) para 30(b).

60 *Noble v Australia* (n 58 above) paras 8.6, 8.7, 8.8 and 8.9.

61 Chap 60.

62 Sec 125(2) of the Evidence Act Chapter 60 Laws of Kenya.

63 As above.

64 Art 54(1)(a) Constitution of the Republic of Kenya.

formal or intermediary or communication-assistant schemes⁶⁵ and the use of communication aids.

4.1 The intermediary or communication assistants' schemes

The Constitution makes provision for the appointment of intermediaries for purposes of assisting 'a complainant or an accused person to communicate with the court'.⁶⁶ Unfortunately, the government is yet to formulate any guidelines relating to the appointment and qualifications of such intermediaries. Also, according to the Constitution the appointment of these intermediaries is limited to criminal proceedings. The Sexual Offences Act 3 of 2006 (Sexual Offences Act) also makes provision for the appointment of intermediaries who include any:⁶⁷

[P]erson authorized by a court, on account of his or her expertise or experience, to give evidence on behalf of a vulnerable witness and may include a parent, relative, psychologist, counsellor, guardian, children's officer or social worker.

The scheme under the Sexual Offences Act is only limited to witnesses and not accused persons. Section 31 has granted to the court the power to declare a witness 'vulnerable' where that witness is among others a 'person with mental disabilities'. Further, the court is allowed to call any intermediary who will advise it on the vulnerability of such witnesses. However, the court will not convict an accused person solely on the uncorroborated evidence of an intermediary.

The other challenge with the application of this scheme in Kenya relates to the interpretation of the role of intermediaries among different judicial officers. The judicial hierarchy in Kenya consists of superior courts and subordinate courts. The former is made up of the Supreme Court, Court of Appeal, and the High Court in the order of seniority, while the latter is made up of the Magistrates' Courts and Kadhis Courts. The decisions of the Court of Appeal are binding on the High Court. Some judges have stated that the testimony of the intermediary should be substituted with that of the witness.⁶⁸ According to them, intermediaries are witnesses who speak on behalf of vulnerable witnesses and not through them. For example in *Kennedy Chimwani Mulokoto v Republic*⁶⁹ the court held that;

When the mother of the little girl gave her evidence, she was deemed to be giving evidence on behalf of that little girl. Section 31(7) recognizes the fact

65 Melbourne Social Equity Institute 'Addressing the indefinite detention of people with cognitive and psychiatric impairment due to unfitnes to plead laws' (2016) 9.

66 Sec 50(7) Constitution of the Republic of Kenya.

67 Sec 2 of the Sexual Offences Act 3 of 2006.

68 *Kennedy Chimwani Mulokoto v Republic* Eldoret High Court Criminal Appeal 51 of 2011.

69 As above.

that a vulnerable witness can be allowed to give evidence through an intermediary. Therefore, for all intents and purposes, when the mother of the little girl gave evidence, she did so as a legally recognized intermediary, for and on behalf of the little girl. Such evidence was admissible.

Similarly in *Francis Ogoti Otundo v Republic*⁷⁰ the court held on the role of an intermediary that:

Article 50(7) of the Constitution provides that in the interest of justice, a court may allow an intermediary to assist a complainant or an accused person to communicate with the court. I believe that if the complainant or accused person is unable to articulate or explain herself well, then an intermediary can be allowed to do so.

Is an intermediary simply a mouth piece of the vulnerable witness or is he or she the witness?⁷¹ That question was answered by the Kenyan Court of Appeal in the case of *MM v Republic*.⁷² The Appeals' Court faulted the positions in *Kennedy Chimwani Mulokoto v Republic* and *Francis Ogoti Otundo v Republic*. In its place the Court of Appeal responded by holding that an intermediary testifies through the witnesses and not on their behalf. That means that:

[A]n intermediary is a medium through which the accused person or complainant communicates with the court. In our understanding, the evidence to be presented is not that of the intermediary himself or herself but that of the witness relayed to court through the intermediary. The intermediary's role is to communicate to the witness the questions put to the witness and to communicate to the court the answers from the victim to the person asking the questions, and to explain such questions or answers, so far as necessary for them to be understood by the witness or person asking questions in a manner understandable to the victim, while at the same time according the victim protection from an unfamiliar environment and hostile cross-examination; to monitor the witness' emotional and psychological state and concentration, and to alert the trial court of any difficulties.

The word through is used also in subsection 4 (b) in describing the protection of the witness by providing an intermediary through whom his evidence is relayed. It is the witness who gives the evidence which is explained and communicated to the court and the reverse through an intermediary in the manner and style developed between the two.

Similarly, in the case of *Republic v Elijah Weru Mathenge*,⁷³ the accused who had been charged with the offence of murder contrary to section 203 as read with section 204 of the Kenyan Penal Code was diagnosed with psychogenic conversion disorder with aphonia which resulted in him

70 Criminal Revision 397 of 2012.

71 As above.

72 Criminal Appeal 41 of 2013.

73 [2017] eKLR.

losing his voice while in custody. The court, in an attempt to safeguard the accused person's right to participation in his trial ruled in favour of the appointment of an intermediary. Moreover, the court affirmed the position in *MM v Republic*.⁷⁴ How does this position stand in comparison to the intermediary schemes in England, South Australia, and New Zealand?

According to the English model, intermediaries are registered and are tasked with the function of facilitating communication between witnesses and the court.⁷⁵ They are used in assisting the following three categories of persons: children, adults with mental disabilities who may experience difficulties when testifying in court, and adults with other forms of physical disabilities.⁷⁶ Registered intermediaries may include: speech and language therapists, teachers, psychologists, occupational therapists, nurses, and social workers.⁷⁷ They may take part in the relevant proceedings and translate information or 'indicate to the court any questions that require rephrasing'.⁷⁸ Most importantly, an intermediary in this model is not a witness, supporter, or an interpreter.⁷⁹ Those functions are provided for in section 29(2) of the Youth Justice and Criminal Evidence Act of 1999. That legislative scheme was available only to witnesses. However, in *C v Sevenoaks Youth Court*⁸⁰ the High Court of England extended its applicability to defendants in order to ensure their right to a fair trial.⁸¹

In South Australia, the use of intermediaries was introduced through the enactment of the Statute Amendment (Vulnerable Witnesses) Act of 2015 (Vulnerable Witnesses Act). That scheme allowed for the assistance of those with communication disabilities in court.⁸² In fact according to section 14A(3) of the Evidence Act of 1929, communication aids of this nature are available to all people with 'communication needs'. In this system a communication assistant is usually employed and assistance may be accorded to a witness, defendant or victims.⁸³ Communication assistants are to be appointed by the minister in charge of implementing the Vulnerable Witnesses Act.⁸⁴ Certain devices like the speak and spell communication gadgets may also be used to assist.⁸⁵ The main role of the

74 n 72 above.

75 P Bowden et al 'Balancing fairness to victims, society and defendants in the cross-examination of vulnerable witnesses: An impossible triangulation?' (2014) 37 *Melbourne University Law Review* 539 572.

76 Tasmania Law Reform Institute 'An intermediary/communication assistant scheme for Tasmania?' (2018) 52.

77 As above, 53.

78 Bowden (n 75 above) 572.

79 As above.

80 [2010] 1 All ER 735 742.

81 Melbourne Social Equity Institute (n 65 above) 11.

82 Tasmania Law Reform Institute (n 76 above).

83 As above.

84 As above.

85 As above.

communication assistants is to act a 'quasi-interpreters' for the witnesses and defendants.⁸⁶

In New-Zealand, section 80 of the Evidence Act 2006 makes provision for the use of intermediaries for both witnesses and defendants with mental disabilities. The form of assistance can take various forms which may either be oral, written or technological depending on the circumstances.⁸⁷ In *R v Hetherington*⁸⁸ the Court of Appeal in New-Zealand affirmed the use of an intermediary for a witness with Down syndrome. While doing so the court stated that;

The accused's right to a fair trial is a keystone of our criminal justice system. It is not the only keystone. People with intellectual difficulties and challenges should be able to come to our Courts and present their evidence in a way that is tailored to their needs to ensure that the trier of fact ... can be as confident as possible that the answers are true answers, that is as to what occurred, rather than the witness being confused and challenged by the questions being asked.

Therefore, the function of the interpreters is mainly to ensure that those with communication difficulties understand the proceedings and respond effectively and efficiently.

From the above brief analysis of the three jurisdictions, it is clear that intermediaries/ communication assistants only play assistive roles. What happens when an intermediary acts beyond what is lawfully accepted? In *R v Christian*⁸⁹ the court had an opportunity to determine this issue. There, the intermediary noticed that the witness was distressed during cross-examination. She decided to put her arm around the witness and asked counsel to lower the tone of her voice. That was done in the presence of the jury. Those comments and her actions aggrieved the accused who later argued that the intermediary had violated his right to a fair trial. However, his assertions were rejected and the court held that the actions of the intermediary were not serious enough to prejudice the rights of the accused. Every case will depend on its own peculiar circumstances. Intermediaries are not witnesses. Their work is only to explain questions to the witnesses or defendants and then state their answers back to the trier of facts. Therefore, they do not testify on behalf of the witnesses as suggested in the cases of *Kennedy Chimwani Mulokoto v Republic* and *Francis Ogoti Otundo v Republic* as seen earlier. The intermediary scheme in Kenya is still not in tandem with the requirements of article 12 of the CRPD mainly because the scope of the scheme is only limited criminal proceedings and not to civil proceedings. The position is exacerbated by a

86 As above.

87 Tasmania Law Reform Institute (n 76 above) 64.

88 [2015] NZCA 258.

89 [2015] EWCA Crim 1582.

lack of guidelines which provides for the procedure for appointment, qualifications, and functions of intermediaries.

4.2 Aids to communication

Aids to communication may mean the use of augmentative and alternative communication (AAC) methods such as using 'picture exchange communication systems (PECS), Makaton signing, or speech-generating devices (SGDs)'.⁹⁰ These methods are usually used to complement the natural speech of an individual. In Kenya, section 26 of the Evidence Act Chapter 60 (Evidence Act) stipulates that:

A witness who is unable to speak may give his evidence in any other manner in which he can make it intelligible, as, for example, by writing or by signs; but such writing must be written, and the signs made, in open court.

Therefore, the court has been granted the discretion to adopt any special measures geared towards improving the quality of testimony for those witnesses who are unable to speak. However, that provision is limited only to those without functional speech. There is no correspondent provision for those with mental disabilities. Similarly, the country lacks an express provision for the use of alternative communication methods in order to assist those with mental disabilities. That does not mean that our courts should just lie in wait for parliament to enact one as those with disabilities continue to be marginalised and denied their rights. This is in tandem with the finding in the 1988 United States case of *People vs Miller*⁹¹ where the court urged that;⁹²

Just because a procedure is unusual does not mean that it should not take place in a courtroom. The courts today should make every effort to open their door to all who seek to come through them. We can no longer take the attitude that if it has not been done in the past, it should not be done in the future. The age-old stereotyping of people with physical or mental disabilities or a combination of both should be dispensed with as soon as possible. The courts have come out of the dark ages with respect to the treatment of the deaf and hearing impaired, and we should likewise do so with respect to other physical and mental disabilities. If the power to appoint an interpreter in cases of an unusual disability does not exist directly by statute, then it does by statutory interpretation.

Therefore, courts have a wide discretion when it comes to the interpretation of the law. They should endeavour to ensure that persons with mental disabilities receive a fair hearing as their non-disabled

90 J Doak & L Doak 'Non-verbal victims in the adversarial criminal process: Communication, competency, and credibility' (2017) 4 *Northern Ireland Legal Quarterly* 453.

91 530 N.Y.S.2d 490 (City Ct Rochester Cty 1988).

92 As above.

counterparts. Their evidence should not be disregarded or excluded merely because they are unable to understand questions or give rational answers to them. The state should employ mechanisms which will facilitate their communication in court. In the United States such technologies have been employed successfully without infringing on the rights of any other parties involved. For example in *Commonwealth v Tavares*⁹³ a witness with cerebral palsy was allowed to testify through 'a speak-and-spell communication device'.⁹⁴ Kenya should employ and adapt some of these procedures in its own systems. 'A fair trial cannot be realised where an accused person does not understand the import of the criminal proceedings'.⁹⁵ Therefore, courts must ensure that those with cognitive or mental disabilities are able to understand judicial proceedings and participate affectively.

5 Conclusion and recommendations

Kenya is lagging behind when it comes to ensuring the right to self-representation for those with mental disabilities. Our judicial system is ridden with some of the most egregious abuses against people with mental disabilities. Our laws are outdated and most of them are still based on the supposition that disability and lack of capacity are intertwined. The lack of guidelines and rules to protect and ensure that those with mental disabilities are adequately assisted when testifying in court has compounded the matter further. Fortunately, not everything is lost. The country has tremendous opportunity to change the present situation by giving effect to article 12 of the CRPD. The revolutionary concept of supported decision-making envisages a situation where everyone has the capacity to make decisions and participate fully in all aspect of their lives including judicial proceedings. It is the only way through which persons with disabilities will live and exercise their rights on an equal basis with the rest of the society.

Therefore, it is important for the state to repeal all substituted decision making laws and replace them with supported decision-making provisions whose aim is to enhance the legal capacity of accused persons with mental disabilities so that they are able to effectively represent themselves. In order to do this, practical measures such as the use of communication assistants, intermediaries, and assistive devices such as the speak and spell communication gadgets may be employed. The state should also promote more awareness on the provisions of the CRPD by training policymakers, judicial officers, prosecutors and police officers.

93 555 A.2d 199 (Pa. Super. Ct. 1989).

94 DN Bryen & C Wickman 'Ending the silence of people with little or no functional speech: Testifying in court' (2011) 31 *Disability Studies Quarterly*.

95 *Rabonko v The State* [2006] 2 BLR 166 168C-D.

CHAPTER 5

THE PLACE OF SIGN LANGUAGE IN THE INCLUSIVE EDUCATION OF DEAF LEARNERS IN ZIMBABWE AMID CRPD (MIS)INTERPRETATION

Martin Musengi*

Summary

This paper sets to explore how Zimbabwean law and policy relate to the CRPD in informing educational practice for learners who are deaf. The paper is an analytical discussion of the educational policy and practice issues related to the recent recognition of Zimbabwean Sign Language (ZSL) in a multicultural context where mother-tongue-based teaching is a right for meeting the inclusive education needs of all learners, including those who are deaf. It argues that one-size-fits-all, deficit interpretations of Zimbabwean inclusive education policies and law are in violation of the 'sensory exception' enshrined in the Salamanca Statement (UNESCO, 1994). These interpretations occur in the midst of major misinterpretations of the CRPD evident in General Comment 4. Misinterpretations of the CRPD affirm instances of local policy contradictions, inconsistencies and co-articulation as some policies are imbued with perceptions of deafness as a disability at the same time also having aspects that recognise deaf people as a linguistic minority. The deficit interpretations and inconsistencies in local policies occur despite constitutional provisions that recognise deaf learners' right to a preferred sign language. Based on this case example of deaf learners, a general re-interpretation of the CRPD and a re-conceptualisation of inclusive education are recommended.

1 Introduction

Persons with disabilities were historically viewed as welfare recipients. They are now generally recognised as having the right to education without discrimination and on the basis of equal opportunities. Various

* Jairos Jiri Centre for Special Needs Education, Robert Mugabe School of Education, Great Zimbabwe University, Masvingo, Zimbabwe.

M Musengi 'The place of sign language in the inclusive education of deaf learners in Zimbabwe amid CRPD (mis)interpretation' (2019) 7 *African Disability Rights Yearbook* 96-111
<http://doi.org/10.29053/2413-7138/2019/v7a5>

disability protocols such as the United Nations Convention on the Rights of Persons with Disabilities (CRPD) all reflect awareness of the right of persons with disabilities to education.¹ It is, however, paradoxical that the growing awareness of this right appears to result in interpretations through policies and practices that discriminate against learners who are deaf and hard of hearing (hereafter 'deaf learners'). Historically deaf learners were viewed as disabled, welfare recipients who were taught in separate special schools. Natural law interpretations of the right of persons with disabilities to education have perceived separate education as inherently discriminatory and have therefore advocated education in mainstream, ordinary schools alongside hearing peers. Education in mainstream, ordinary schools has been called 'inclusive'. This article, however, argues that being deaf is morally a cultural difference requiring separate, special school provision in order to ensure access to a critical mass of sign language users and therefore to inclusive education. The article therefore proposes a separation thesis in which having a legal right to send learners who are deaf to a mainstream, ordinary school does not entail a moral right to do so.² To advance this thesis, the article establishes the extent to which the CRPD, which is touted as the implementation vehicle for various disability protocols, can be interpreted to enable local legislation and policies for the inclusive education of deaf learners.³ This is done by analysing whether Zimbabwe's legal and policy interpretations embrace the moral responsibility to ensure access to sign language and therefore to inclusive education by referencing the CRPD at a broader level. To provide context to this analysis, the article initially explores the condition of being deaf and the evolution of the education of deaf learners. It then discusses the development of these learners' rights to communication in education in light of the CRPD before reviewing how legislation and policy documents regulating education and disability in Zimbabwe relate to the flawed interpretation in General Comment 4 (hereafter GC 4).

2 Being deaf or hard of hearing: From a medical to a social, rights-based perspective

The condition of not hearing spoken language has traditionally been referred to as deafness. This condition is measured as hearing loss greater than 25 decibels.⁴ Every year more than 10 000 infants are born with such hearing loss in the United States.⁵ According to the Zimbabwean Ministry of Health, the prevalence of disabilities such as deafness is on the increase

1 See CRPD Committee General Comment 4: Article 24: Right to inclusive education (2016) UN Doc CRPD/C/GC/4 dated 2 September 2016 (hereafter GC 4).

2 HLA Hart 'Positivism and the separation of law and morals' (1958) 71 *Harvard Law Review* 593.

3 WFD Global Survey Report for Southern and Eastern Africa (2010).

4 FN Martin & JG Clark *Hearing care for children* (2009).

5 NK Mellon et al 'Should all deaf children learn sign language?' (2015) 136 *Pediatrics* 170.

globally because of the rise in chronic health conditions.⁶ Incidence of disabilities such as deafness is reported to be higher in lower income than higher income countries, for example 90 per cent of children born with deafness are said to be from lower income countries.⁷ Zimbabwe is a low income country.⁸ In Zimbabwe, the government carried out a national disability survey which identified 22 500 people as having deafness and of these 7 500 were children of a school-going age.⁹ The prevalence of hearing loss in Zimbabwe is significant at 2,4 per cent of the population.¹⁰ There are no accurate figures on the prevalence of children who are deaf in Zimbabwe. The most recent Zimbabwe Persons with Disabilities Survey¹¹ does not provide figures specific to deafness and organisations of people who are deaf provide widely varying estimates ranging from 80 000 to 1.5 million people with deafness in Zimbabwe.¹² In light of the Ministry of Health's reported global increase in the prevalence of disabilities, there is no reason to assume that the incidence of deafness is declining in Zimbabwe.

The descriptions in the preceding paragraphs are normative in that they are quite clear that hearing is the norm and deafness is a disability. This normative, pathological discourse is part of the medical perspective in which deafness is viewed as a condition that, like an illness, needs treatment either medically or through remedial education. In the medical perspective the characteristics of hearing groups are considered as mainstream and are given high-status. Remedial education therefore usually focuses on listening skills and articulation training in a curriculum that is delivered through a spoken language. This is done to deliberately assimilate deaf learners into a hearing norm as far as possible. In this discourse deaf learners do not receive an education that includes their own culture and history because their condition is devalued as a disability.

A growing body of literature in the social perspective counter-argues that being deaf is a condition that has for long been erroneously viewed as a deficiency or disability. The perspective argues that it is hearing society which disables those who are deaf by insisting on the superiority of sound-based, spoken languages at the expense of visual-gestural, signed languages. Belief in the supremacy of spoken languages results in discrimination which is referred to as 'audism'. Proponents of the social perspective argue that it is progressive and more productive to view people

6 Zimbabwe Ministry of Health 'Living conditions among persons with disabilities survey report' (2013).

7 C Storbeck 'Childhood hearing loss in the developing world' (2012) 1 *International Journal of Child Health and Nutrition* 59.

8 WFD (n 3 above).

9 Zimbabwe Ministry of Labour and Manpower Planning 'National Disability Survey' (1981).

10 BD Westerberg et al 'Prevalence of hearing loss in primary schoolchildren in Zimbabwe' (2005) 69 *International Journal of Pediatric Otorhinolaryngology* 517.

11 Zimbabwe Ministry of Health (n 6 above).

12 WFD (n 3 above).

who are deaf in terms of what they can do rather than what they cannot do. Deaf people can use sign languages for communication and therefore have a right to this language in education. They are only different from hearing people in that they use sign languages whereas hearing people use spoken languages. In that light, the perspective argues that the appropriate comparison group for people who are deaf are other linguistic minority groups rather than groups of people with disabilities. In Zimbabwe, the sign language of the deaf community is called Zimbabwean Sign Language (ZSL) and it is a language that is recognised in the 2013 Constitution as one of the 16 languages that should be used in education.

3 Evolution of the education of deaf learners

Three boarding institutions were established specifically for deaf children before independence in Zimbabwe. These are Emerald Hill School which was established in 1927, Henry Murray School which was established in 1947 and Jairos Jiri Naran School which was established in 1969. In these institutions, children underwent elementary education after which most of them were then taught practical skills such as basketry, woodwork, leatherwork, sewing and cookery.¹³ Historically in Zimbabwe, teaching such children was considered more of a charitable and religious obligation than a legal right, as churches and humanitarian organisations educated deaf children without national coordination and direction.¹⁴

After the attainment of independence in 1980, the government began to exert greater control over the education of deaf children and insisted on following the mainstream curriculum¹⁵ often in mainstream schools.¹⁶ Special units for deaf learners were opened at various mainstream schools. Despite government coordination and direction, deaf learners in Zimbabwe still typically do not go beyond primary school education. Their primary school education is usually longer than hearing peers and this longer stay in school is attributed to various factors. One of the prime factors is that in addition to learning the mainstream curriculum also followed by hearing pupils, the deaf pupils have other areas of need dictated by their deafness.¹⁷ These areas are specialist and technical-vocational skills aimed at preparing deaf pupils to earn a living and fit into

13 M Chitiyo & J Wheeler 'The development of special education services in Zimbabwe' (2004) 19 *International Journal of Special Education* 46.

14 M Peresuh & L Barcham 'Special education provision in Zimbabwe' (1998) 25 *British Journal of Special Education* 75.

15 M Musengi & C Storbeck 'Teaching in residential schools for the deaf in Zimbabwe: Professional and vocational perspectives' (2015) 16 *Journal of the International Association of Special Education* 14.

16 R Chimedza 'Disability and inclusive education in Zimbabwe' in L Barton & F Armstrong (eds) *Policy, experience and change: Cross cultural reflections on inclusive education* (2008).

17 M Musengi 'The experience of teaching in residential schools for the deaf in Zimbabwe' unpublished PhD thesis, University of the Witwatersrand, 2014 369.

society. The specialist areas in the curriculum have traditionally included articulation or speech training, lip or speech-reading and auditory training. This focus on deficiencies is not surprising since the development of communication rights which recognises the social perspective's focus on ZSL is a relatively recent development.

The reality for deaf learners is that decisions regarding their education rest with specialists in the medical and educational fields. The focus is on specialists identifying individual weaknesses and trying to treat them and 'normalise' the deficient learner to facilitate entry into an ordinary school or classroom. This medical focus on remediating the individual initially resulted in the creation of separate special schools for the deaf. Globally, these special schools fell out of favour with some because their results were not good. It was suggested that since such separate education in special schools resulted in inferior education, it would be better to integrate the learners. The practice of integration of deaf learners became popular in the 1980s because it was argued that since the learners now had greater access to hearing models in mainstream schools, they could be remediated in special classes and integrated in mainstream classes for part of the day as appropriate. However, integrated education did not appear to be producing the desired result. There was therefore a paradigm shift from a medical perspective focus on trying to remediate individual learners within mainstream schools to a more social focus on dealing with barriers that all learners face in mainstream schools in order to improve educational outcomes. The social perspective birthed inclusive education as focus was now on making the environment accessible for all. From this social perspective, it was easy to make the jump to a rights-based model in which deaf learners were viewed as having rights to access the environment. It is therefore on the basis of social and rights models that inclusive education is properly grounded.

4 Development of rights to communication systems in education of deaf learners

Sign language was added to the traditional curriculum through a government directive that it should be one of the languages to be taught in schools.¹⁸ Government followed this up with another directive *Special examination arrangements for learners with disabilities* which allowed the signed interpretations of examinations.¹⁹ In addition, to give legal force to the status of sign language, the current Constitution of Zimbabwe lists ZSL as one of the official languages in the country. Section 4 of Chapter 6 of the Constitution states that: 'The State must promote and advance the use of

18 Secretary for Education *Secretary's Circular 3 of 2002: Curriculum policy in primary and secondary schools* (2002).

19 Secretary for Education *Special examination arrangements for learners with disabilities and other special needs* (2007).

all languages used in Zimbabwe, including Sign Language, and must create conditions for the development of those languages.’

These legal and policy instruments serve to recognise a language that emerged from bringing together deaf children in boarding special schools in the pre-independence era as the need for communicative interaction resulted in this visual-gestural language.²⁰ It is a natural, manual language using hand-shapes, facial expressions and movement to convey messages as it is visually accessible to people who are deaf. It, however, has no orthography. In pre-independence times the language was not recognised as real and was therefore prohibited from use in schools as it was generally perceived as interfering with the acquisition of spoken languages which can be written. Internationally, deaf children are renowned for having displayed resilience over the years by using sign language underground, away from hearing teachers who prohibited it.²¹ It is this situation that the Zimbabwean government, informed by its egalitarian values of equal opportunity, sought to rectify by developing appropriate legal and policy instruments after independence in 1980.²² These legal and policy instruments were developed in the broader context of the CRPD.

4.1 The CRPD and the communication rights of deaf learners

The normative content of article 24 of the CRPD states that state parties must ensure the right of persons with disabilities to education through an inclusive-education system without discrimination and on equal terms with others at all levels. GC 4 appropriately explains this as meaning that inclusion is a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education. In tandem with rights-based theory and practice of inclusive education, GC 4 aptly explains that these systemic reforms are meant to overcome barriers in order to provide all students of the relevant age range an equitable and participatory learning experience and environment that best corresponds to their requirements and preferences. Surprisingly, GC 4 abandons this social, rights-based focus on systemic reform and learner preferences in subsequent definitions and explanations of inclusive education.

Contrary to inclusion theory and practice which focuses on the learner’s experience,²³ GC 4 misdirects itself by focusing on placement in

20 M Kadenge & M Musengi ‘Zimbabwean Sign Language’ in T Kamusella & F Ndlovu (eds) *A handbook of the social and political history of the languages of Southern Africa* (2016).

21 HG Morgans ‘Where did South African sign language originate?’ (1999) 30 *Language Matters: Studies in the Languages of Africa* 53.

22 E Mpofu et al ‘Inclusive education in Zimbabwe’ in P Engelbrecht & L Green (eds) *Responding to challenges of inclusive education in southern Africa* (2007).

23 M Jones ‘Inclusion, social inclusion and participation’ in *Critical perspectives on human rights and disability law* edited by MH Rioux et al 57-82 (2011).

mainstream schools as the default setting for inclusive education. The GC 4's misdirected focus on placement is evident in their definition of segregation. It says segregation occurs when the education of students with disabilities is provided in separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities (paragraph 11). Segregation is a concept that does not appear in the CRPD itself and is introduced by GC 4 to mean discrimination.²⁴ This one-size-fits-all explanation is problematic as it assumes that whenever deaf learners are educated separately from hearing learners, they are being discriminated against. The explanation negates the normative content of article 24 of the CRPD which focuses on school culture, policy and practice to accommodate the differing requirements and identities of individual students. The requirements and identities of individual deaf learners may very well be accommodated in separate rather than mainstream schools. An earlier protocol, the Salamanca Declaration, had been wary of such negation when it made this 'sensory exception' owing to the particular communication needs of learners who are deaf: their needs may best be accommodated in special schools for the deaf.²⁵ This is because deaf learners would then be at schools where sign language is already a part of the implicit curriculum as there is a critical mass of users of the language.²⁶ It is these other users of sign language who are appropriate peers for many deaf learners.

The GC 4 emphasises placement in mainstream schools because it misdirected itself through a medical perspective understanding of appropriate 'peers' for deaf learners as typically developing, non-deaf and non-sign language using. The GC 4's implied definition of peers in paragraph 3 is clear that hearing students are the norm or privileged centre thereby 'othering' deaf learners. Deaf learners are therefore expected to aspire to join the privileged centre. This normative discourse is based on the medical model which informed the practice of 'integration' in an earlier era. It is a discourse which is contrary to the latter-day social and human-rights models on which inclusive education is grounded.

GC 4 views of mainstreaming as the default position to enable inclusive education of all learners results in a one-size-fits-all position which is the antithesis of inclusion. Using placement to define inclusion contradicts the GC 4's initial use of participatory learning experience as the essence of inclusion. If communication rights and participatory learning experiences are paramount, then inclusion cannot be about places where education occurs, but is about reasonable accommodations for learners to

24 JJ Murray et al 'Intersectional inclusion for deaf learners: Moving beyond General Comment no. 4 on Article 24 of the United Nations Convention on the Rights of Persons with Disabilities' (2018) *Journal of Inclusive Education* 1.

25 UNESCO 'The Salamanca declaration and framework for action' (1994).

26 See C Reilly & N Reilly *The rising of the lotus flower: Self-education by deaf children in Thai boarding schools* (2005).

equitably and successfully participate in learning. Places where these accommodations occur are not the issue, reasonable accommodations are the issue.

The first implication here is that places where learners are taught cannot be a defining characteristic of inclusive education as the key issue is about the learners' rights and ability to access knowledge in whatever setting. The second related implication is that inclusive education for many deaf learners is only possible when they have access to a preferred language such as a sign language that they can visualise. Therefore, assimilation into hearing culture and its spoken languages should never be allowed to override the communication rights of deaf learners. In light of the GC 4's perceived misinterpretation discussed here, Zimbabwean inclusive education policies are analysed to see how they fare in interpreting the CRPD and placing ZSL in the school curriculum.

4.2 Zimbabwean inclusive-education policies in the context of the CRPD

Zimbabwean policy documents reviewed in this case example are national laws and lower level interpretations of the laws through policy guidelines on special education in general or where available, the education of deaf learners in particular. Document review was vertical, that is starting with national laws and moving to lower level policies. Documents were sourced by searching relevant government agency websites and consulting policy experts in the Ministry of Education. Analysis revealed four themes: prohibition of discrimination, safeguarding the right to access, expected role of ZSL in the curriculum and comparison of ZSL with other languages in the curriculum.

4.2.1 Prohibition of discrimination

Two pieces of Zimbabwean legislation assert the right of people with disabilities to access public services such as education and training. The Zimbabwean Education Act of 1996 asserts the right of every child in Zimbabwe to attend school. Section 4, subsection 2 states:

No child in Zimbabwe shall be refused admission to any school on the grounds of race, tribe, colour, religion, creed, place of origin, political opinion or the social status of his parents.²⁷

One view contests whether this facilitates the right of children with disabilities since they are not specifically identified here.²⁸ It can, however, be argued that children with disabilities are first and foremost children so

27 Zimbabwe Education Act 1996.

28 As above.

their right to school education is also entrenched in the Act. Therefore even though the Act does not specify disability, let alone deafness, it implies prohibition of discrimination in education on any grounds.²⁹ It argues that such an interpretation is in accordance with the CRPD. Article 24(1) of the CRPD stipulates that the 'State Parties recognise the right of persons with disabilities to education ... without discrimination and on the basis of equal opportunity, States shall ensure an inclusive education system at all levels.'³⁰

Denying deaf children education would be contrary to the education-for-all spirit and moral on which the law is grounded. This spirit is more explicitly captured in another piece of Zimbabwean legislation.³¹ The Disabled Persons Act expressly outlawed the denial of people with disabilities access to public premises, services and amenities in clear accordance with the CRPD. Section 8 of the Act states: 'No disabled person shall on the ground of his disability alone be denied the provision of any service or amenity ordinarily provided to members of the public... ' If it is agreed that education is a service, then this section of the Act would appear to be complementing the Education Act in ensuring that children with disabilities have a right to school education. The Disabled Persons Act states in section 7:

Where premises, services or amenities (are considered) inaccessible to disabled persons by reason of any structural, physical, administrative or other impediment to such access the provider of the service may be required to undertake such action as may be specified in order to secure reasonable access by disabled persons ...

4.2.2 *Safeguarding the right to access*

What the foregoing prohibition of discrimination implies is that this law safeguards the right of people with disabilities to access public buildings, services and amenities and where these are considered inaccessible, service providers must rectify this. For example people with physical disabilities who cannot access public buildings which only have stairs, can take the owners of such buildings to court using this Act in order to get the buildings altered so that they can access them. Reference to 'other impediments to access' appears to be an open, catch-all phrase which can also be used to the advantage of people who are deaf. This phrase appears to allow wide interpretation which recognises not only physical and structural impediments to physical access, but also various other impediments to accessing services. Access in education can be

29 See FN Muchemwa 'Presidential Advisor's report on national disability issues: Visits to special schools' (2009).

30 GA Res A/61//06, adopted on 13 December 2006, entered into force on 3 May 2008.

31 See Zimbabwe Disabled Persons Act 1996

conceptualised as formal, physical or epistemological.³² The legislation is not restricted to ensuring the right to formal, physical access, but can also be interpreted as facilitating epistemological access as suggested by the phrase 'other impediments to access' in section 7 of the Act.³³ Interpretation that focuses on epistemological access would be consistent with the CRPD's focus on learner experiences while focus on physical access would be consistent with the GC 4 focus on specific places.

This moral interpretation of the law which embraces epistemological access is supported by the Zimbabwean policy document *Guidelines on equal access to education for learners with disabilities*.³⁴ The policy stipulates that children with disabilities be provided with disability-friendly facilities so that they are able to access instruction. It is implied that once they have physical access to schools, learners with disabilities need only to indicate how they are impeded from accessing knowledge in the schools in order to get redress from the law. For example deaf learners could employ this provision of the Act to observe that no one will be helped by any one-size-fits-all approach to deaf education.³⁵ The legislation could be used to argue that employing a one-size-fits-all approach to teach deaf learners impedes epistemological access. It could be argued that access would only be possible if schools made reasonable accommodations by using ZSL in education. Adjustments could also involve streaming the deaf learners so that those who understand ZSL better could be taught using ZSL in a bilingual approach, while those who would benefit from spoken language could be taught verbally. Inappropriate teaching approaches could therefore be cited under the Act as 'other impediments' to epistemological access while appropriate adjustments could be cited as disability-friendly under the policy. The Disabled Persons Act and the Education Act complement each other in safeguarding the right of formal and physical access to such services as education and also epistemological access through linguistic access to the curriculum.³⁶ The latter is a reasonable interpretation in light of the Constitution of Zimbabwe's official recognition of ZSL as one of the 16 languages in Zimbabwe. Legislation has therefore attempted to improve formal, physical access and could facilitate epistemological access through appropriate use of language.

The focus on prohibiting discrimination and safeguarding access through use of appropriate language of teaching is in tandem with the

32 See H Lotz-Sisitka 'Epistemological access as an open question in education' 46 *Journal of Education* 58; WE Morrow *Learning to teach in South Africa* (2007).

33 See Disabled Persons Act.

34 See Director *Guidelines on providing equal access to education for learners with disabilities: Ministry of Education, Sports and Culture policy* (2006).

35 See M Marschark 'What we know and what we need to know: Where do we go from here?' Paper presented at the *1st International Conference on Teaching Deaf Learners* (2014).

36 See R Johnson 'Unlocking the curriculum: Principles for achieving access in deaf education' (1989).

CRPD's conception of 'reasonable accommodation'. The CRPD defines reasonable accommodation as:

[N]ecessary 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.

Even though the CRPD and Zimbabwean legislation mandate it, epistemological access through ZSL in schools still requires a properly aligned lower level policy framework. The following section discusses the alignment of Zimbabwe's education policy framework to the ideals of its legislation and the CRPD.

4.2.3 Comparison of ZSL to other languages on the curriculum

The policy document *Curriculum to be followed in Special Education Institutions* advocates bilingual or multilingual mainstream education in which English is taught alongside Shona, Ndebele or other local languages. If Shona, Ndebele or another local language is the dominant home language in an area, the language becomes the language of instruction for the first three years of primary school while English is taught as a second language. From the fourth year onwards, English becomes the language of instruction, and the other language is only taught as a subject. This kind of bilingual-education policy is based on a developmental maintenance model as it aims at developing a student's local, home language skills to full proficiency, and full bi-literacy in English.³⁷ For hearing students the choice of local language to use in mainstream education is usually a straightforward matter because this is the language used in the home. On the other hand, deciding which language is the first, home or local language for deaf learners is complicated by the diversity of deaf learners, and the need to make decisions within the optimal period of language acquisition yet their predisposition to language is not yet certain. Deaf learners' individual needs, strengths and experiences are so varied that deaf learners could become bilingual in various ways.³⁸ Some learn to sign first, and then learn an oral form of a hearing language, while others learn to speak from hearing parents followed by learning to sign. The deaf child should be the guide regarding his or her disposition toward a more oral or more visual (sign) language.³⁹ Decisions about degree of exposure to signed and spoken language to be used as the deaf child's first language have to be made very early, at a time when there is rarely enough information to

37 See C Baker *Foundations of bilingual education and bilingualism* (2008).

38 As above.

39 SN Mahshie 'A first language: Whose choice is it? Sharing ideas' (1997).

determine the child's predisposition. Many deaf children in Zimbabwe are identified rather late⁴⁰ and arrive at school without any language at all, spoken or signed.⁴¹ This situation further complicates decisions about predisposition towards a first language. All three schools for the deaf interpret the bilingual policy to mean the teaching of English and Shona or Ndebele, in the same way that mainstream schools teach hearing learners. ZSL is not taught as a subject in any of the schools despite the policy *Curriculum policy: Primary and secondary schools* which says that it is a subject for the hearing impaired. The teaching of Shona or Ndebele, rather than ZSL indicates that the schools have decided that Shona or Ndebele is the first language of deaf learners.⁴² This audist position is indicative of the medical model in which deaf learners are expected to join the privileged centre in tandem with GC 4 misinterpretation. There are several reasons why schools do not comply with the policy on teaching ZSL, but one reason appears to be inherent in the policy document and relates to the expected role of the language. This is discussed in the next section.

4.2.4 Expected role of ZSL in education

One reason for non-compliance with the policy on teaching ZSL emanates from an internal inconsistency of the policy. In its explanation of how bilingual or multilingual education is to include previously marginalised languages in Zimbabwe, the policy provides a clear time-frame for the gradual and systematic introduction of all locally spoken minority languages starting from 2002 up to 2005. The introduction of the spoken minority languages in phases, such as up to grade four in 2002 and then up to grade five in 2003 and so on, indicates that human and material resources were incrementally availed to ensure success at the various levels. An inconsistency in this otherwise well planned introduction of previously marginalised languages, is that there is nothing written about when and how ZSL is to be introduced. This silence might suggest that the policy-makers assumed that human and material resources were already in place in the schools for the deaf and so the language would be introduced with effect from the date of the policy document in 2002. This suggests that ZSL was 'othered' as focus was on the special schools rather than availability of adjustments within them. Adjustment would have included teacher education in sign language to appropriate levels. Whatever the actual reason, the net effect is that the language has not been adopted as a subject in any of the three special schools for the deaf.

40 Director *Guidelines on over-aged learners in special education: Ministry of Education, Sports and Culture policy* (2006).

41 M Musengi et al 'Rethinking education of deaf children in Zimbabwe: Challenges and opportunities for teacher education' (2013) 18 *Journal of Deaf Studies and Deaf Education* 62.

42 M Musengi 'Teachers' sign language beliefs and their influence on Zimbabwean curriculum-in-practice for deaf learners' (2016) 1 *Dzimbabwe Journal of Multidisciplinary Research* 51.

The policy might also be incomplete as it lists ZSL as a subject to be taught, but does not show who is to teach it or what skills, fluency and qualifications they should have. The manner that the learning of ZSL is supposed to be organised has not been made clear by policy, and therefore the formal teaching and learning of the language as a subject had not even begun, nearly 20 years after the policy was issued. This is despite the *Curriculum policy: Primary and secondary schools* indicating that all languages have equal time allocations of four and half hours per week. ZSL is referred to as a subject 'for the hearing impaired' and this indicates that it is to be offered on condition that there are deaf and hard of hearing learners who need it in the school. ZSL is considered as among 'other local languages' which include previously marginalised languages spoken in Zimbabwe other than English, Shona and Ndebele. In addition, policy stipulates that all learners will sit the public examinations,⁴³ but this gives rise to uncertainty on the role that ZSL should play in these examinations.

Government policies mandate various accommodations to enable deaf candidates to access examinations through the provision of extra time, sign interpretations of examinations, speech-reading and finger-spelling in examinations as well as modification of syntax and vocabulary among others.⁴⁴ In order to enable access to examination questions, the policy stipulates:

Modifications can be made to general vocabulary and syntax by approved teachers of the deaf well in advance of the examination date. Such modifications may not be done to vocabulary specific to the subject.

The policy also allows the principal to ask for the signing of questions to candidates who were normally taught through signing if access to questions was not possible through other means. The deaf candidates are not allowed to sign their responses to the examination items which perpetuates misperception of sign languages as inadequate access tools instead of natural languages, quite in tandem with GC 4 misinterpretation in paragraph 34(d). This reflects a deviation from the social, linguistic model in the text of the CRPD. Modifications mandated by the same policy circular for signed examinations were that the principal should provide for sign language interpreters to sign examination instructions or questions to deaf learners in each paper. These interpreters are specialist teachers with experience in teaching deaf learners and they become special invigilators who carry out signed examinations and also become markers for the candidates' scripts. These modifications are in the spirit of removing linguistic impediments to accessing public examinations in line with the CRPD.

43 *Secretary's Circular P36: Special education placement procedures* Zimbabwe Ministry of Education, Sport and Culture (1990).

44 *Secretary for Education Special examination arrangements for learners with disabilities and other special needs* Zimbabwe Ministry of Education Permanent Secretary (2007b).

The policy specifies that the signing of examinations is meant for candidates who are normally taught through signing. This policy ideal might not be matched by the reality on the ground. The reality is that there is restricted input of sign language in formal learning situations where children are taught by teachers who are not fluent signers.⁴⁵ In schools where spoken language is mostly used, the teachers are unlikely to have the fluent signing skills that come with regular use. Interpretation requires native-like competency.⁴⁶ Therefore there appears to be a mismatch between the policy's idealistic notion of signing for the deaf candidates and reality. The reality is that there are no learners who are formally taught through fluent sign language. A related reality emanating from the lack of regular, consistent use of signing is that the schools might not have teachers with sufficient competence to interpret examinations into sign language. It can, however, be argued that as the policy advocated the signing of general words and phrases while maintaining the key words of the written language, this is compatible with what some of the teachers do, and so they can be expected to have the competence. The efficacy of signing general words and phrases while retaining key words of the written language has, however, been strongly contested.⁴⁷

The policy position advocating the signing of general words and phrases while maintaining the key words of the written language also appeared to contradict in principle another provision in the same policy which allowed the modification of syntax. Modification of syntax shows acceptance of the principle that the examination is being interpreted into another language: A sign language. This principle was contradicted by the policy's stipulation that subject-specific vocabulary from the written language must be maintained and not modified. As changes in general and subject-specific vocabulary are a necessary part of any real interpretation from one language to another, the policy's outlawing of modifications to subject-specific vocabulary is inconsistent with the basic principles of interpretation. The policy therefore has internal inconsistency as it is based on two incompatible philosophies. On one hand, it allowed signing and changes to syntax, both of which are concessions based on a philosophy of the acceptance of human diversity hence interpretation into a more accessible language. On the other hand, the policy outlawed changes to subject-specific vocabulary and candidates' signed responses to examination questions, which are stipulations that could be viewed as

45 B Schick 'The development of American sign language and manually coded English systems' in M Marschark & P Spencer (eds) *The Oxford handbook of deaf studies, language and education* (2011).

46 J Napier et al *Sign language interpreting* (2010).

47 See R Johnson et al (n 36 above); D Power et al 'Learning English from signed English: An impossible task?' (2008) 153 *American Annals of the Deaf* 37.

based on an audist philosophy that places a higher value on sound-based, written languages over signed ones.⁴⁸ This may be based on fears of diluting the essence of the subject under examination because policy-makers may not believe that sign language is a real language capable of being used to examine academic subjects. It could also be based on the observation that ZSL is not sufficiently developed for academic purposes. In any case, the prohibition of changes to subject-specific vocabulary results in internal contradictions to the policy. This might defeat the purpose of enabling access to the examination. It is understandable that the policy does not want the examination content to be changed. What the policy-makers may be unaware of is the possibility that teachers who are able to interpret correctly can still maintain the subject-specific content intact even if the language and the form presenting the material changes. The policy's choice of the word 'modifications' instead of 'interpretation' or 'translation' in reference to the written language is a telling example of the hidden bias towards sound-based language. In an explicit show of audism the policy went on to state:

For aural tests, special amplification may be used or tests may be read to enable candidates to lip-read. In addition to speech-reading the content of the tape in an aural test, the presenter may finger-spell the initial letter of words which are easily confused.

In this excerpt the earlier preference for sound-based languages over sign language becomes quite clear.

5 Conclusions and recommendations

In light of the above results, it can be concluded that the role that ZSL is expected to play in teaching and learning in special schools is ambiguous. The study found contradictions where, on one hand, legal and some policy positions took a diversity perspective viewing ZSL as a real language for inclusive education while on the other hand there were policy positions which took a deficit perspective viewing ZSL as a crutch to augment broken communication. Lower level policies tended to downplay the role of ZSL for teaching and examination and this contrasts government's legal position to utilise this language for these purposes. Such contradictions lead to uncertainty about whether it is a real language that can be used as a language of teaching and learning. Even though the constitution and some policy documents refer to ZSL as a language, it does not get the same equitable treatment that other previously marginalised spoken languages are getting in policy and practice. ZSL was not understood to be an independent visual-gestural language of equal standing to any spoken

48 HDL Baumann, HDL & JJ Murray 'Deaf studies in the 21st Century: Deaf gain and the future of human diversity' in M Marschark & P Spencer (eds) *The Oxford handbook of deaf studies, language and education* (2010).

language. These contradictions can be traced back to one-size-fits-all, deficit interpretations of Zimbabwean inclusive education policies and the CRPD. There were also instances of inconsistencies which resulted from policy co-articulation as some policies were imbued with perceptions of deafness as a disability at the same time also having aspects that recognised deaf people as a linguistic minority. The deficit interpretations and inconsistencies are despite provisions that recognise deaf learners' right to a preferred language of instruction such as sign language. The demeaning of ZSL could reflect a hangover of patronising, colonial attitudes towards this language which was marginalised in colonial times. This paper argues that the contradictions follow Hart's Separation Thesis in which those taking the diversity perspective opined the law as it ought to be while those who took a deficit perspective championed the law as it is.

It is therefore recommended that in order for ZSL to take its proper place in schools, policy-makers should leverage progressive legislation and align policies to a diversity perspective that recognises ZSL as a real language. This would allow the language to have comparable status to other languages that are being used in the school system. ZSL could then be taken as the first language of pupils who prefer it so that it can be used for inclusive education in a multilingual curriculum in mainstream and special schools.

More generally, it is recommended that interpretations of international disability protocols such as the CRPD should be open-minded to avoid unwittingly reverting to one-size-fits-all scenarios that inclusive education is intended to remedy. If the case example of deaf learners is taken into account it may be prudent to avoid defining inclusive education in terms of places where education takes place, in other words mainstream versus special schools. The overriding defining characteristic of inclusive education would appear to be access to knowledge rather than specific geographical settings. On this basis, a more appropriate reconceptualisation and redefinition of inclusive education in the GC 4 is recommended.

CHAPTER 6

LEFT IN THE PERIPHERY: AN ANALYSIS OF VOTING RIGHTS FOR PERSONS WITH DISABILITIES IN ZIMBABWE

Nkosana Maphosa, * CG Moyo** & B Moyo***

Summary

In Zimbabwe, the right to vote is a constitutionally guaranteed right which can only be exercised by citizens who meet prescribed minimum requirements. Notwithstanding, the modalities meant to ensure that persons with disabilities participate in decision-making processes, usually through elections, are arguably inadequate. In the Zimbabwean context (and indeed in most African countries) the right to vote is underlined by a history of blatant racial exclusion and discrimination where the right was exclusively enjoyed by the white minority. Despite this regressive phenomenon; the 2013 constitutional dispensation makes a progressive clarion call for the inclusion of every citizen in the right to vote or to stand for public office, a move which underscores how a democratic society should function. Being a part of the international community, the country is also a signatory to international conventions such as the Convention on the Rights of Persons with Disabilities (CRPD), the International Covenant on Civil and Political Rights (ICCPR) and the Universal Declaration of Human Rights; all of which deeply entrench the right to universal and equal suffrage. Consequently, this article examines the right to vote of persons with disabilities from a human rights perspective converse to an arguably untenable welfare model. Therefore, the overarching intent of the article is to succinctly analyse laws and where relevant, policies which seek to promote the participation of persons with disabilities in elections; identify practical barriers and enablers that can engender the participation of persons with disabilities; assess approaches and interventions that have been employed in Zimbabwe to increase the participation of persons with disabilities in elections and interrogate the possible impact of the said interventions.

* LLB (University of the Witwatersrand); LLM (Loyola University Chicago). Lecturer of Law, Great Zimbabwe University.

** LLB; LLM (University of KwaZulu Natal). Lecturer of Law, Great Zimbabwe University.

*** LLB (University of Fort Hare); LLM (University of Pretoria); LLD Candidate (University of Johannesburg). Lecturer of Law, Great Zimbabwe University.

1 Introduction

The World Health Organisation (WHO) and the World Bank opine that approximately 15 per cent of the global population lives with some form of disability.¹ Historically, persons with disabilities have contended with challenges which have left them in the peripheries of society, removed from equal participation in more aspects than one.² Atikson et al³ observed that women with disabilities constitute 60 per cent of persons with disabilities and their plight is even worse because of additional barriers resultant from their gender and disability.⁴ Therefore, for countries to truly display their democratic processes, all citizens including those living with disabilities must have equal access to the vote, stand for public office and participate in electoral processes as election officials or observers.⁵ The right to vote is an indispensable civil and political guarantee. It underlies an open, democratic and transformative society endeavoured in several legal and policy instruments. Practically speaking, this right is foundational in nature meaning its realisation is intrinsically linked to the enjoyment and attainment of other enshrined fundamental rights. Importantly, it creates a platform for persons to exercise free will, stand for political office and choose their political representatives. Moreover, it essentially allows people to determine the course of life they desire. In the Zimbabwean context (and indeed in most African countries) the right to vote is underlined by a history of blatant racial exclusion and discrimination where the right was exclusively enjoyed by the white minority. Consequently, most modern democracies have taken strides to ensure that people enjoy this crucial right, but challenges are still abound in so far as persons with disabilities are concerned.

Although the international legal framework seeks to ensure that persons with disabilities enjoy the same rights that able-bodied people enjoy, the reality is that they usually face social, legal and most importantly, practical barriers in claiming and fully enjoying their voting rights.⁶ Persons with disabilities more often than others encounter enormous discrimination and marginalisation. They have limited access to education, healthcare, and their participation in the economic and political

- 1 World Health Organisation and World Bank 'World report on disability' (2011) http://who.int/disabilities/world_report/2011/en/ (accessed 15 November 2019).
- 2 Global Initiative to Enfranchise People with Disabilities 'The Bill of Electoral Rights for citizens with disabilities' http://www.electionaccess.org/rs/Bill_English.htm (accessed 28 March 2019); International Foundation for Electoral Systems (IFES) 'Accessible elections for persons with disabilities in five Southeast Asian countries' (2013); 'Equal opportunities for persons with disabilities' <http://www.electionaccess.org> (accessed 28 March 2019).
- 3 V Atkinson et al 'Equal access: How to include persons with disabilities in elections and political processes' (2014) 375.
- 4 Atkinson et al (n 3 above) 375.
- 5 Atkinson (n 3 above) 375.
- 6 Disability Right Advocates (2013) 'Blind and visually impaired face barriers in voting' www.draregal.org (accessed 15 November 2019).

dimension is minimal if not non-existent thereby making them vulnerable to poverty more than the able-bodied.⁷ Thus, to resolve this disparity the formulation of domestic legal and policy framework must comply with international standards, promote and protect the rights of persons with disabilities, and play a complementary role to societal behaviour change programmes which seek to alter perceptions of and/or about persons with disabilities.⁸

Additional barriers that hinder the equal participation of persons with disabilities in society include communication barriers, for deaf or dumb people and this significantly limits access to information. Physical barriers may limit access to buildings and in some cases, access to buildings where voting is taking place thereby depriving them of their right to cast votes for their preferred candidates for public office.⁹ Furthermore, attitudinal barriers which include stereotypes and stigma of persons with disabilities limit access to public life and may affect the confidence of those intending to stand for public office.¹⁰ In some African countries,¹¹ communities believe that persons with physical or psychological disabilities are possessed by evil spirits or victims of witchcraft due to their 'evil' actions.¹² As a result of this families of such persons may not register them as citizens or may limit their participation in social, economic and political processes thereby depriving them of the rights that able-bodied members of the society enjoy.¹³

Against this background, this article considers the right to vote of persons with disabilities. As such, the overarching intent of the paper is to examine laws and policies which seek to promote the participation of persons with disabilities in elections; identify barriers and enablers of participation of persons with disabilities; assess approaches and interventions that have been employed in Zimbabwe to increase the participation of persons with disabilities in elections; and interrogate the possible impact of implemented interventions. Although several approaches will be discussed, a human-rights approach will be the premise for analysis of the domestic regulatory framework in assessing whether it complies with international standards for the treatment of persons with disabilities and ensuring that they are not excluded from political

7 Disability Right Advocates (n 6 above).

8 Zimbabwe Human Rights Forum 'Rights of persons with disabilities' (2015) 1.

9 Inclusion International 'Inclusive civic engagement: An information toolkit for families and persons with intellectual disabilities' (2015) <http://electionaccess.org/en/media/news/39/> (accessed 15 November 2019).

10 Election Access (October 2016) 'Political Participation of Persons with Disabilities in Remote and Rural Areas' <http://electionaccess.org/en/media/news/40/> (accessed 26 November 2019).

11 Inclusion International (n 9 above).

12 V Atkinson et al (n 3 above).

13 DL Cogburn 'The grand challenge of disability and development in ASEAN' in DL Cogburn & T Kempin Reuter (eds) *Making disability rights real in Southeast Asia: Implementing the UN Convention on the Rights of Persons with Disabilities in ASEAN* (2017).

participation. The aftermath of the harmonised elections held in 2018 may set in motion electoral reforms as the country prepares for the 2023 elections. As such, the article illuminates gaps in legal and policy framework which significantly limits the equal participation of persons with disabilities in political life so that these can be remedied before the next election to achieve a truly democratic, just and egalitarian society.

2 The right to vote for people with disabilities: The Zimbabwean context

Since Zimbabwe gained its independence from the clutches of its colonial masters in 1980, it has had four censuses. However, it is observed that from all four censuses, there are no official, reliable statistics on the prevalence of disability or the kinds of disability in the country.¹⁴ A study conducted in 2007 estimated that there are about 1.4 million people with at least one form of disability in Zimbabwe.¹⁵ In 2012, the Housing and Population Report recorded that the national disability prevalence stood at 2,9 per cent of which 55 per cent were women and 45 per cent were men.¹⁶ According to the recent Inter-censal Survey, disability prevalence stands at 9 per cent, with 10 per cent of persons with disabilities being women while their male counterparts constitute 8 per cent respectively.¹⁷ However, the credibility of these statistics is often questioned leading to assumptions that there might not be any reliable statistics on the prevalence of disability in Zimbabwe.¹⁸

The contentious nature of the estimates on the prevalence of disability in Zimbabwe is partly attributable to the fact that there is no universally agreed upon definition of what constitutes a disability.¹⁹ This is demonstrated by the varieties of estimates that have been presented above. Nonetheless, the lack of a universally accepted definition of disability makes it difficult not to question the accuracy of the estimates on persons with disabilities. Peta and Moyo concur with our reasoning and importantly submit that 'the conceptualization and definition of disability has been a complex, controversial, multidimensional and evolving issue dating back to the 17th century'.²⁰ For example, one study could limit its scope to rural Zimbabwe and focus on physical disabilities only while another could focus on urban Zimbabwe and limit the scope to physical

14 E Mandipa & G Manyatera 'Zimbabwe' (2014) 2 *African Disability Rights Yearbook* 287.

15 T Choruma 'The forgotten tribe: Persons with disabilities in Zimbabwe' (2007) <http://www.progressio.org.uk/sites/default/files/Forgotten-tribe.pdf> (accessed 15 November 2019).

16 Mandipa & Manyatera (n 14 above).

17 Zimbabwe National Statistics Agency 'Inter-censal demographic survey' (2017) 7.

18 Choruma (n 15).

19 As above.

20 C Peta & A Moyo 'The rights of persons with disabilities in Zimbabwe' in A Moyo *Selected aspects of the 2013 Zimbabwean Constitution and the Declaration of Rights* (2019) 86.

and mental disability. Both studies would present findings and statistics, but those would not provide a complete picture on the prevalence of disability. However, common forms of disability in Zimbabwe include physical impairments, mental impairments, hearing impairments, speech and functional disabilities, intellectual and sensory impairments.²¹ We subscribe to the definition of disability contained in the Convention on the Rights of Persons with Disabilities (CRPD), which unequivocally states that '[p]ersons 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'.²²

Statistically at least, persons with disabilities constitute one of the most marginalised, socially excluded and poor groups.²³ They are disadvantaged in every sense of the word. This is worsened by systemic attitudinal, deep-seated, institutional and environmental barriers and these militate against their ability or attempts to meaningfully participate in the social, economic and political facets of society.²⁴ In most cases, it is assumed and expected that persons with disabilities are heavily dependent on their families to the extent that some are considered a burden to their caregivers. With current high levels of unemployment,²⁵ many of those who live with disabilities tend to be perceived as an economic burden especially in rural areas because they are unable to contribute productively to the running of the homestead. These notions are prominent in rural areas where causes of disability are often associated with witchcraft or wrongdoing towards the ancestors. It is because of these perceptions that persons with disabilities are ostracised and in the case of women and girls; sexually violated and often without recourse.

In 2009, the Short-Term Emergency Recovery Programme (STERP) was launched by the government and this policy indirectly addressed disability through financial support to add onto the disability allowance.²⁶ Furthermore, the Medium-Term Plan (MTP), Zimbabwe's national economic and development strategy from 2011 to 2015 also provided for the issuing of grants to assist the upkeep of persons with disabilities. However, this national policy was limited in that it did not invest in the

21 Choruma (n 15 above) 11.

22 See art 1 CRPD.

23 Choruma (n 15 above).

24 R Lang & D Charowa *DFID scoping study: Disability issues in Zimbabwe* (2007) 28.

25 Zimbabwe National Statistics Agency (n 17 above). See also '93,4 percent Zimbabweans are employed: ZIMSTAT' *The Zimbabwe Mail* 27 May 2018 <https://www.thezimbabwemail.com/business/934-percent-zimbabweans-are-employed-zimstat/> (accessed 15 November 2019). Nonetheless, the employment statistics which is estimated at between 5,18% and 90% are highly contested.

26 SA Nilsson 'Disability rights in Zimbabwe' <http://www.msc.st/docs/HRBA-Disability-Zimbabwe-revised-2011-01-30.doc> (accessed 26 November 2019).

economic empowerment of persons with disabilities or provide initiatives for income generation.²⁷

The importance of the right to vote cannot be overemphasised regardless of whether one is a person with a disability or not.²⁸ It is the choice of every citizen to choose whoever they want to represent their interests at all levels of government. Voting is essentially a manner in which an individual asserts his/her place in society.²⁹ This is of significance to persons with disabilities because their interests are usually not represented adequately at a governmental level. When such a process is denied to an already disadvantaged group because of accessibility or practical challenges, the level of their expression and participation in society is also limited.

More recently, during the 2018 elections several attempts were made to include persons with disabilities in the political process. An example of such was the provision of disability-friendly electoral booths. This can be considered as a progressive step in relation to persons with disabilities' right to vote. Furthermore, there was the assisted-voter programme which significantly enhanced the participation of persons with disabilities in the elections. Although due to these attempts, 55 000 voters were assisted in one way or another, some concerns were raised that the assisted-voter programme was a tool to intimidate voters into casting votes in a certain direction.³⁰ These concerns are legitimate because we respect the sanctity of voting and once more than one person is in the booth, it degrades that sanctity and exposes the process of voting to abuse.

In as much as these attempts are a step in the right direction, it is important to note that not all disability is physical and that there are some forms of disability that can be included in the voting process without it being under the umbrella of assisted voting. In September 2017, Senator Nayamaybo Mashavakure, who was the representative for persons with disabilities, appealed to the Zimbabwe Electoral Commission (ZEC) to make use of sign language and braille voter education and polling material.³¹ However, this application was dismissed by the High Court in May 2018 and the reason was that there was no need for ZEC to print ballot papers in braille because the assisted-voter programme was already in place and was deemed adequate in the inclusion of persons with disabilities in the electoral process.³² This decision can be criticised because, as already mentioned, assisted voting is susceptible to abuse and if there are other alternatives, they must be explored. Moreover, the low

27 Mandipa & Manyatera (n 14 above) 296.

28 *August v Electoral Commission* 1999 3 SA 1 (CC) para 17.

29 M Waterstone 'Political Participation for People with Disabilities' in *Critical Perspectives on Human Rights and Disabilities Law* (2011) 378.

30 The Zimbabwe 2018 Commonwealth Observer Group Report (2018) 31.

31 As above.

32 As above.

level of inclusion of persons with disabilities is also demonstrated in the small number of those who contested for public office in the 2018 harmonised elections. Out of 23 presidential hopefuls, only one candidate, Elton Mangoma was a person with a disability.³³

This is incongruent with recent efforts to build inclusive and just societies. For example, the last 40 years have been characterised by the emergence of advocacy groups particularly for the rights of persons with disabilities, both in developing and developed countries. Consequently, civil society organisations (CSOs) have been instrumental in this regard and as such constitute a critical component of the development and recognition of the rights of persons with disabilities. As such, the foundation of advocacy for civil society has been the migration from the perception of persons with disabilities from the health and charity approach to the human-rights approach.³⁴ This approach ensures the equality and inclusion of persons with disabilities in social, economic and political aspects. The impact of the work of CSOs has been such that governments have had to re-evaluate their legislation and policy in the regulation of persons with disabilities.³⁵ Furthermore, civil society has played a pivotal role in their work with bilateral and multilateral institutions in the development of policy and operational modalities which are enablers to the successful inclusion of persons with disabilities in all areas of life.

Legal and policy framework is the basis upon which we can determine if political processes, like the election of representatives for or standing for election for a public office, are inclusive of disability rights in a society and therefore democratic. The right to universal and equal suffrage is enshrined in inter alia, the Universal Declaration of Human Rights³⁶ (UDHR); the International Covenant on Civil and Political Rights (ICCPR);³⁷ and the CRPD. The CRPD is the first contemporary international legal instrument to depart from a health or charity-based approach to an inclusive, human-rights approach to disability. This methodology confers persons with disabilities with rights equal to their able-bodied counterparts, and this is embedded in their right to participate in the country's political activities.³⁸

Secondly, the UDHR was adopted in 1948 by the United Nations (UN) as the first non-binding international legal document which recognises inalienable rights of all human beings. Article 21 of the UDHR provides that 'everyone has the right to take part in the government of his country, directly or through freely chosen representatives'.³⁹ Although

33 Commonwealth (n 30 above) 31.

34 Commonwealth (n 30 above).

35 Lang & Charowa (n 24 above) 13.

36 Adopted 10 December 1948, UNGA Res 217 A (III).

37 Adopted 16 December 1966, entered into force 23 March 1976 999 UNTS 171.

38 Cogburn (n 13) 19.

39 Art 21 UDHR.

specific groups like persons with disabilities are not explicitly mentioned in the UDHR, the word 'everyone' in article 21 is read to be inclusive of every human being, regardless of whether they are able-bodied or not, rich or poor, educated or not. The UDHR therefore plays a pivotal role since it guarantees access to fundamental rights to all human beings.

The ICCPR adds with equal force that all people have a right to participate directly or indirectly in government and public affairs and this covers not only the election of representatives, but the right to stand for election for public office. However, like the UDHR, the ICCPR also does not explicitly refer to disability, but prohibits discrimination '... on any ground such as race, colour, sex ... or other status'.⁴⁰ The words used in the ICCPR show that it does not provide a closed list of grounds upon which discrimination can be founded. With that said, a logical conclusion that can be drawn from it is that disability can be considered as another status to support a claim of unlawful discrimination under the ICCPR.

The CRPD contains comprehensive rights of persons with disabilities. It also codifies their invaluable voting rights. It adopts an expansive definition of disability which goes beyond physical to include sensory, intellectual and psychosocial disabilities. Article 6 of the CRPD importantly recognises the marginalisation of women with disabilities especially in political and public life. The fact that the CRPD has an estimated 90 per cent member state ratification demonstrates broad consensus on the rights enunciated in the Treaty.⁴¹ Article 29 of the CRPD recognises and protects the right of persons with disabilities to fully participate in political and public life, that is as voters or candidates. This provision upholds the right to take part in political life in broader terms including 'participation in nongovernmental organisations and association concerned with the public and political life of the country'.⁴²

The CRPD also protects and promotes the right to equal recognition before the law, including legal capacity of persons with disabilities.⁴³ In as much as most countries have ratified the CRPD; legal barriers to political participation remain for persons with one or more forms of disability for many countries. As a result, persons with disabilities tend to be dependents with minimal independence, regardless of their age, thereby side-lined from public life because of these legal barriers and stigma.⁴⁴ This argument is best illustrated by the case below.

40 Art 26 ICCPR.

41 See the CRPD www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html (accessed 15 November 2019).

42 Art 29 CRPD.

43 Art 12 CRPD.

44 Atkinson et al (n 3 above) 380.

In *Bujdosó v Hungary*,⁴⁵ six Hungarian nationals were placed under partial and general guardianship due to their intellectual disabilities and their names were also removed from the electoral register. This meant that they were unable to cast their vote in the parliamentary and municipal elections in 2010 and therefore disenfranchised.⁴⁶ They took exception against this and contended that they were able to understand politics and were entitled at law to participate in elections regardless of their status.⁴⁷ They also argued that the ban was unjustifiable under article 29 of the CRPD, when read conjunctively with article 12 of the same instrument. Their major submission was that the restriction was discriminatory as it was motivated by disability. Alternatively, the six were excluded 'on the basis of a perceived or actual psychosocial or intellectual disability, including a restriction pursuant to an individualised assessment'.⁴⁸

The Committee on the Rights of Persons with Disabilities' approach reiterates the view that people with intellectual disabilities are unable to participate in political discourse in most jurisdictions. The Committee has expressed its position regarding how the plight of people with intellectual disabilities was considered by most state parties to the CRPD. It has also demonstrated its apprehension of the exclusion of people with intellectual or psychosocial disabilities from voting⁴⁹ and the exclusion of persons who are under some form of 'guardianship'.⁵⁰

It is clear from the above discussion that international law enjoins states to respect, protect and fulfil the rights of persons with disabilities. In the main, persons with disabilities have unequivocal rights to participate at all levels of political and public life especially when their interests are directly or indirectly involved. Therefore, states must refrain from any unjust limitation(s) or interference with access to political rights of persons with disabilities. States are also discouraged from enforcing discriminatory laws and instead are urged to adopt legal frameworks to enhance political participation of persons with disabilities. Therefore, since Zimbabwe is a signatory to the CRPD, it must align all domestic laws with this international standard to ensure that persons with disabilities are not left on the margins of society by safeguarding their voting rights.

In the regional context, the African Charter on Human and Peoples' Rights [1981/1986] (ACHPR) is instructive on the matter. The ACHPR is a binding regional legal instrument adopted by the Organisation for

45 Communication No 4/2011, views adopted on 9 September 2013 (20 September 2013) UN Doc CRPD/C/10/D/4/2011.

46 Para 2.

47 Para 3.

48 Art 2 CRPD.

49 See Concluding Observations on the initial report of China adopted by the Committee at its 8th session, 17-28 September 2012, CRPD (15 October 2013) UN Doc CRPD/C/CHN/CO/1 (2013) para 45.

50 CRPD (n 49 above) para 35.

African Unity (OAU) in Kenya⁵¹ on 27 June 1981. It entered into force on 21 October 1986. It is also known as the 'Banjul Charter'. This instrument secures inalienable human and peoples' rights and duties. For example, article 1 mandates states to 'recognize the rights, duties and freedoms' and enjoins them to 'adopt legislative or other measures to give effect to them'.⁵² Article 2 confers these rights and freedoms to every individual regardless of 'race, ethnic group, colour, sex, language, religion, political or any other opinion, natural and social origin, fortune, birth or other status'. This provision prohibits discrimination on the basis of listed grounds. Unlike section 56 of the Constitution its scope is broad because of the term 'or other status'. As such, we also read in 'disability' under the ACHPR. Article 13 of the ACHPR states succinctly that:

Every citizen shall have the right to participate freely in the government of his country, either directly or through freely chosen representatives in accordance with the provisions of the law.⁵³

Article 13 of the ACHPR therefore is in tandem with the UDHR, ICCPR and CRPD since it encompasses political rights. Article 19⁵⁴ also states with equal force and sagacity that all peoples shall be equal; they shall enjoy the same respect and shall have the same rights. Nothing shall justify the domination of a people by another'. The ACHPR importantly creates an enforcement mechanism through the establishment of the African Commission on Human and Peoples' Rights (African Commission) to promote human and peoples' rights and ensure their protection.⁵⁵

The African Charter on Democracy, Elections and Governance (2007/2012) (ACDEG) also provides guidance on the matter. The Democracy Charter or ACDEG was adopted in Ethiopia on 30 January 2007 and entered into force on 15 February 2012. It places emphasis on

51 Now the African Union (AU).

52 The African Commission on Human and Peoples' Rights considered art 1 of the ACHPR in several communications: *Commission Nationale des Drois de l'Homme et des Libertes v Chad Institute for Human Rights and Development in Africa v Angola* (2000) AHRLR 66 (ACHPR 1995) para 20; *International Pen and Others (on behalf of Saro-Wiwa) v Nigeria* (2000) AHRLR 212 (ACHPR 1998); *Jawara v The Gambia* (2000) AHRLR 107 (ACHPR 2000) para 46 (holding that: 'Article 1 gives the Charter the legally binding character always attributed too international treaties of this sort. Therefore, a violation of any provision of the Charter automatically means a violation of article 1. If a state party to the Charter fails to recognize the provisions of the same, there is no doubt that it is in violation of this article. Its violation, therefore, goes to the root of the Charter.');

Lawyers for Human Rights v Swaziland (2005) AHRLR 66 (ACHPR 2005); *Zimbabwe Human Rights NGO Forum v Zimbabwe* (2005) AHRLR 128 (ACHPR 2005) para 164, 215; *Egyptian Initiative for Personal Rights and Interights v Egypt* (2011) AHRLR 90 (ACHPR 2011).

53 *Constitutional Rights Project v Nigeria* (2000) AHRLR 227 (ACHPR 1999); *Jawara* (n 52 above); *Lawyers for Human Rights v Swaziland* (n 52 above); *The Nubian Community in Kenya v Kenya* Communication 317/06 (2015); *Purohit v The Gambia* (2003) AHRLR 96 (ACHPR 2003).

54 *Malawi African Association v Mauritania* (2000) AHRLR 149 (ACHPR 2000); *Gunme v Cameroon* (2009) AHRLR 9 (ACHPR 2009).

55 See art 30 ACHPR.

'good governance, popular participation, the rule of law and human rights'.⁵⁶ Its objectives are captured in article 2 and include the holding of 'regular free and fair elections to institutionalize legitimate authority of representative government as well as democratic change of governments'.⁵⁷ Article 6 enjoins state parties to 'ensure that citizens enjoy fundamental freedoms and human rights taking into account their universality, interdependence and indivisibility'. Article 8 requires states to 'eliminate all forms of discrimination based on political opinion, gender, ethnic, religious and racial grounds as well as any other form of intolerance'.⁵⁸ It also mandates countries to 'adopt legislative and administrative measures to guarantee the rights of women, ethnic minorities, migrants, persons with disabilities, refugees and displaced persons, and other marginalized and vulnerable social groups'.⁵⁹ As such, this peremptory obligation is in tandem with international standards discussed above.

Article 8(2) may be construed as imposing a positive obligation on states to initiate practicable measures in place to enable persons with disabilities to vote. The Democracy Charter's choice of words is instructive. The use of the word 'shall' is indicative of a binding obligation. Article 10(3) like the ACHPR and section 56 of the Constitution enjoins states to 'protect the right to equality before the law and equal protection by the law as a fundamental precondition for a just and democratic society'. Chapter 7 of the Charter contains substantial rules on democratic elections in Africa. Article 31 adds with equal force and mandates states to promote participation of social groups with special needs like people with disabilities in the governance process. Another positive addition is the Protocol to the African Charter on Human and Peoples' Rights of Persons with Disabilities which concretises the rights of persons with disabilities in Africa.

Consequently, the international and regional orders envisage an egalitarian and just world, where everyone including persons with disabilities is endowed with rights to participate in political activities and therefore can vote. This recognition is infused with human-rights principles and must trickle down to change domestic regulatory frameworks which are still informed by a welfare approach. The above discussion also highlights that more must be done to guarantee and implement voting rights of persons with disabilities in Zimbabwe. The next section considers how national law purports to achieve this endeavour.

56 See the Preamble Democracy Charter.

57 See arts 2(3) and 3(4) of the Democracy Charter respectively.

58 Art 8(1) of the Democracy Charter.

59 Art 8(2) Democracy Charter.

3 National framework on persons with disabilities

The previous section examined some background considerations and relevant international instruments on voting rights of persons with disabilities in Zimbabwe. It did so by *inter alia*, providing empirical evidence and a definition of disability. Resultantly, this part builds on and discusses national and regional perspectives on disability voting rights in Zimbabwe. It specifically seeks to answer the legal question whether or not voting rights of persons with disabilities⁶⁰ are equally protected in our law. The article coincides in time with a new legal culture which breaks away from a bleak past to one based on justification⁶¹ and founding principles and values.⁶² It therefore examines the issue from the lens of the 2013 Constitution and appropriate electoral laws like Electoral Act (Chapter 2:3); the ACHPR; the ACDEG; the Southern Africa Development Community (SADC); Principles and Guidelines Governing Elections (SADC Principles); and the African Union Declaration on Principles on Principles Governing Democratic Elections in Africa 2002.⁶³ The paper also considers disability laws like the Disabled Persons Act (DPA).⁶⁴ We start this section by providing a crisp summary of challenges faced by persons with disabilities in elections.

Zimbabwe achieved a democratic milestone in 1980 when all eligible citizens cast their vote. This first historic universal election signalled a move towards good governance. However, the neo-colonial period is also characterised by contested political rights. Although our laws guarantee everyone the right to vote; persons with disabilities still encounter enormous electoral related challenges even in the post 2013 constitutional dispensation.

This regressive paradigm is captured by Munemo⁶⁵ who records an avalanche of electoral hurdles. These include *inter alia*, lack of privacy in the voting process; being assisted to vote by total strangers; lack of braille ballots or enlarged print for easy reading; unavailability of magnifying material; inaccessible polling stations; being prevented from voting for different reasons; lack of information on the electoral procedures; lack of trained personnel to help people with visual impairment; lack of transport

60 This term will be used synonymously with 'vulnerable and special interest group'.

61 See secs 2, 44, 45, 46 of the Constitution.

62 Sec 3 of the Constitution.

63 Hereinafter referred to as 'the Democracy Charter'.

64 [Chapter 17: 01]. Other statutes like the Mental Health Act [Chapter 15:12]; War Victims Compensation Act [Chapter 11:16]; Criminal Law (Codification and Reform) Act [Chapter 9:23]; Social Welfare Assistance Act [Chapter 17:06]; and State Service (Disability Benefits) Act [Chapter 16:05] complete the disability framework, but they are not directly relevant to political rights.

65 ET Munemo 'Enhancement of access and inclusion of people with visual impairments in the electoral process in Zimbabwe' PhD Thesis, Zimbabwe Open University, 2015. See also B Virendrakumar et al 'Disability-inclusive elections in Africa: A qualitative systematic review' (August 2017).

to polling stations; and fear of political violence on the part of the visually impaired.⁶⁶

The subject under review in this study has been considered by other researchers, but in a broader context.⁶⁷ In the main, most empirical research findings in Zimbabwe record with concern that: 'Access and inclusion of [persons] with disabilities in the electoral processes seems to be regarded as a charity issue rather than a human rights issue'.⁶⁸ Consequently, this aspect of conventional wisdom is an affront to a potentially transformative polity and gives rise to vital questions. At the heart of the deliberation is the extent to which laws guarantee voting rights of persons with disabilities. In our considered view, the legal system in respect to the issue under review straddles between progression and regression. We note the general optimism encapsulated in the Constitution's text, and scepticism that most (if not all) statutes passed before its adoption are misaligned with its imperatives. Resultantly, we survey these key instruments and thereafter discuss barriers persons with disabilities encounter at different stages of the election cycle.

3.1 The Constitution

The Constitution of Zimbabwe Amendment (No 20) Act, 2013⁶⁹ marks a significant shift from 'welfare' to 'human rights based' approach in the context of vulnerable and special-interest groups.⁷⁰ Practically speaking, the scope of the 2013 Constitution as it relates to voting rights is more liberalised and improved compared to its predecessor, the 1979

66 Munemo (n 65 above) 4.

67 E Sackey 'Disability and political participation in Ghana: An alternative perspective' (2014) 17 *Scandinavian Journal of Disability Research* 366; International Foundation for Electoral Systems *Elections in Zimbabwe: Frequently asked questions* (2013); Inclusive International *CRPD compliance Analysis: Kenya. A country-level review of compliance with CRPD article 29* (2015); WA Oluchina 'The right to political participation for people with disabilities in Africa' (2015) 3 *African Disability Rights Yearbook* 309; J Fiala-Butora et al 'The democratic life of the union: Toward equal voting participation for Europeans with disabilities' (2014) 55 *Harvard International Law Journal* 71; J Ballington (ed) *The implementation of quotas: African experience* (2004) 125; CEDAW General Recommendation 23: Political and public life (1997) UN Doc A/52/38 para 5; M Schulze *A handbook on the human rights of persons with disabilities: Understanding the UN Convention on the Rights of Persons with Disabilities* (2009) 14; European Agency for Fundamental Rights 'The right to political participation of persons with intellectual disabilities and with mental health problems in the European Union' (2010) 15-21; MK Mbondenyei 'The right to participate in the government of one's country: An analysis of article 13 of the African Charter on Human and Peoples' Rights in the light of Kenya's 2007 political crisis' (2009) 9 *African Human Rights Law Journal* 183; African Commission on Human and Peoples' Rights 'Working group on older persons and people with disabilities' <http://www.achpr.org/mechanisms/older-disabled/> (accessed 26 November 2019); H Combrinck 'Everybody counts: The right to vote of persons with psychosocial disabilities in South Africa' (2014) 2 *African Disability Rights Yearbook* 75.

68 Munemo (n 65 above) 3.

69 For ease of reference the term 'Constitution' or '2013 Constitution' will be used.

70 Munemo (n 65 above).

Constitution. Moreover, the adoption of the Constitution embodies the country's commitment towards obligations enshrined in the CRPD and it can be argued that this constitutional embodiment constitutes partial fulfilment of voting rights for the special groups under consideration in this article. We draw lessons from article 4(a) of the CRPD which mandates the adoption of appropriate legislative initiatives for the implementation of the rights recognised in the Convention. Moreover, article 4(b) of the CRPD requires states to take positive steps to reform existing laws that perpetuate discrimination against persons with disabilities. It enunciates the fundamental rights of 'everyone' including persons with disabilities.⁷¹ Notwithstanding this, the scope of the present article is limited only to constitutional provisions relating to voting rights of persons with disabilities. And in this regard it is essential to note that the Constitution is the supreme law of the land.⁷² In the main, section 2 of the Constitution aptly states that:

- (1) This Constitution is the supreme law of Zimbabwe and any law, practice, custom or conduct inconsistent with it is invalid to the extent of the inconsistency.
- (2) The obligations imposed by this Constitution are binding on every person, natural or juristic, including the State and all executive, legislative and judicial institutions and agencies of government at every level, and must be fulfilled by them.

Thus, by virtue of the operation of the provision cited above, all electoral laws, conduct and practices must comply with the indomitable law in the country. The justification for this is that the Constitution imposes a duty on the state and every person to respect, protect, promote and fulfil fundamental rights.⁷³ As such, the Constitution has been hailed as progressive in the context of disability rights. This averment is supported by Manatsa⁷⁴ whom after having conducted an extensive review of disability legislation called for its alignment with the Constitution. His study presents a compelling argument for a human rights-based approach to disability. In the main, Manatsa draws a comparison between the Lancaster House (1979) and 2013 Constitution and highlights weaknesses in the repealed Constitution. Several constitutional provisions can also be cited to reinforce the view that the new legal order calls for an inclusive, equal, just, free and fair society. These include the Preamble which unequivocally states in part, that:

71 As above.

72 As above.

73 Sec 44 of the Constitution.

74 P Manatsa 'Are disability laws in Zimbabwe compatible with the provisions of the United Nations Convention on the Rights of Persons with Disabilities (CRPD)?' (2015) 4 *International Journal of Humanities and Social Science Invention* 25.

We the people of Zimbabwe,

United in our diversity by our common desire for freedom, justice and equality

...

Recognising the need to entrench democracy, good, transparent and accountable governance and the rule of law,

Reaffirming our commitment to upholding and defending fundamental human rights and freedoms,

...

Determined to overcome all challenges and obstacles that impede our progress,

Cherishing freedom, equality, peace, justice, tolerance, prosperity and patriotism in search of new frontiers under a common destiny,

...

Resolve by the tenets of this Constitution to commit ourselves to build a united, just and prosperous nation, founded on values of transparency, equality, freedom, fairness, honesty and the dignity of hard work.

Resultantly, it can be argued that the Preamble contains a remarkable constitutional vision. The elimination of all barriers for persons with disabilities to exercise their enshrined right to vote comports with this constitutional directive. Constitutionally speaking, persons with disabilities must generally be accorded all inalienable rights subject to justifiable and reasonable legal limitations. This logic justifies the need to take positive measures to ensure the realisation of rights. This comes after several researchers have revealed various challenges associated with the political rights persons with disabilities. Although cited briefly above they will be ventilated further below.

Cognisant of this, the Constitution enlists the welfare and rights of persons with disabilities as a national priority.⁷⁵ For example, section 22(1) provides with force and brevity that:

- (1) The State and all institutions and agencies of government at every level must recognize the rights of persons with physical or mental disabilities, in particular their right to be treated with respect and dignity.
- (2) The State and all institutions and agencies of government at every level must, within limits of resources available to them, assist persons with physical or mental disabilities to achieve their full potential and to minimize the disadvantages suffered by them.
- (3) In particular, the State and all institutions and agencies of government at every level must –
 - a) ...

75 See Chap 2 of the Constitution.

- b) Consider the specific requirements of persons with all forms of disability as one of the priorities in development plans;
- c) Encourage the use and development of forms of communications suitable for persons with physical or mental disabilities;
- d) ...

In the same spirit, the Constitution also enjoins the state to ‘promote and advance the use of all languages used in Zimbabwe, including sign language, and must create conditions for the development of those languages’.⁷⁶ This provision is intrinsically connected to the right to vote because it makes it possible especially for visually-impaired citizens to get essential voting information and thus exercise their vote.

The Constitution contains an elaborate Declaration of Rights (DoR) and imposes a duty on ‘the state and every person, including juristic persons, and every institution and agency of the government at every level must protect, promote and fulfil the rights’ enshrined in the Constitution.⁷⁷ Importantly, section 83 contains the ‘rights of persons with disabilities’ and they are progressively realisable.⁷⁸ Unlike its predecessor that erroneously listed ‘physical disability’ as a ground for discrimination, the 2013 Constitution stipulates disability as an independent to found discrimination.⁷⁹ This is in tandem with article 29 of the CRPD discussed above. The former position not only ignored other manifestations of disability, but was premised on an erroneous welfare model.⁸⁰

Section 67 of the 2013 Constitution further stipulates that ‘every Zimbabwean citizen has the right to free, fair and regular elections for any elective public office established in terms of this Constitution or any other law’,⁸¹ and ‘to make political choices freely’.⁸² It is a constitutional requirement that elections must be ‘conducted by secret ballot’.⁸³ The state is mandated to:

[T]ake all appropriate measures, including legislative measures, to ensure that all eligible citizens, that is to say the citizens qualified under the Fourth

76 Sec 6(4) of the Constitution.

77 Sec 44 of the Constitution.

78 Section 83 provides that: ‘The State must take appropriate measures, within the limits of the resources available to it, to ensure that persons with disabilities realize their full mental and physical potential, including measures-

(a) to enable them to become self-reliant;

(b) to enable them to live with their families and participate in social, creative or recreational activities;

(c) to protect them from all forms of exploitation and abuse;

(d) to give them access to medical, psychological and functional treatment;

(e) to provide special facilities for their education; and

(f) to provide State-funded education and training where they need it.’

79 Sec 56(3) of the Constitution.

80 Munemo (n 65 above).

81 Sec 67(1)(a) of the Constitution.

82 Sec 67(1)(b) of the Constitution.

83 Sec 155(1)(b) of the Constitution.

Schedule, are registered as voters; ensure that every citizen who is eligible to vote in an election or referendum has an opportunity to cast a vote, and must facilitate voting by persons with disabilities or special needs.⁸⁴

Finally, the Constitution is the 'ultimate' law. Principally, it confers obligations on both natural and juristic persons. Its promulgation has opened a window of opportunity in the persons with disabilities realm since it recognises their voting rights. It marks a significant shift from a conservativist to a conventionally sound approach anchored on human rights and the rule of law. However, the discourse may appear utopian if key structural reforms are not adhered to. The subsequent section grapples with relevant statutes.

In our view, the language used in some constitutional provisions like section 83 falls short when pitted against conventional human-rights language. The manner in which it is couched exposes it to criticism that it does not create rights, but gives directives relating to be taken by relevant parties to meet the 'needs of persons with disabilities'. As such, the Constitution must use appropriate language which reinforces voting rights of persons with disabilities. In its present state it fails to achieve the intended purpose of ensuring the enjoyment of equal voting rights.

3.2 The Disabled Persons Act (DPA)

The Disabled Persons Act is also couched in orthodox language. In our view, it falls squarely in the category of law which must be re-examined. The statute makes provision for the welfare and rehabilitation of disabled persons, provides for the appointment and functions of a Director of Disabled Persons' Affairs⁸⁵ and the establishment and functions of a National Disability Board.⁸⁶ According to section 2 of the Act, 'disabled person' covers:

[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.⁸⁷

The National Disability Board is endowed with expansive functions.⁸⁸ They include amongst others, competence to develop policies and measures to adhere and give practical effect to international standards

84 Sec 155(2)(a) & (b) of the Constitution.

85 Sec 3 of the Act.

86 Sec 4 of the Act.

87 Sec 2 of the Act.

88 See generally sec 5 of the Act.

relating to the rights of persons with disabilities.⁸⁹ We also take note of the need to ‘prevent discrimination against disabled persons resulting from or arising out of their disability’.⁹⁰ Although the Act appears to be in sync with section 56 of the Constitution and international instruments, it is, however, embodied in an impugned statute. We say so because the Act promotes a welfare approach to disability rights. It must be overhauled or reformed to be in tandem with contemporary human rights-based approaches.

3.3 Electoral Act Chapter 2:13⁹¹

The Electoral Act fleshes out electoral law as informed by the Constitution. Section 3(b) of the Act confers citizens with several invaluable rights. It codifies international imperatives since it guarantees citizens’ political rights. It also importantly acknowledges the need to facilitate the right indiscriminately.⁹² This principle of democratic elections comports with section 56(3) of the Constitution which states that:

Every person has the right not to be treated in an unfairly discriminatory manner on such grounds as their nationality, race, colour, tribe, place of birth, ethic or social origin, language, class, religious belief, political affiliation, opinion, custom, culture, sex, gender, marital status, age, pregnancy, *disability* or economic or social status, whether they were born in or out of wedlock. (Our emphasis)

Section 57 of the Act regulates the manner of voting.⁹³ Firstly, voting must be by ballot and must be conducted in a manner that is stipulated in the electoral law. Secondly, it must contain the names of the nominated candidates in alphabetical order. However, most persons with disabilities find it cumbersome if not impossible to cast their vote in the way prescribed in section 57(c)(i); (ii) and (iii) of the Act. On a positive note, the Act has created a window of opportunity for these to receive assistance from persons of their choice or those assigned to them by officials at the polling station. Moreover section 59 of the Act regulates voting by ‘illiterate or

89 Sec 5(b)(iii) of the Act. Note, however, that the Act uses the term ‘welfare and rehabilitation’ and is silent about fundamental rights and freedoms as has become a norm. It is our guided submission that this statute falls at the first hurdle when pitted against the spirit and objects of the 2013 Constitution (see secs 2, 3, 22, 44, 45, 46, 56, 83 and the whole of Chapter 4 for contextual construction). The new constitutional order envisages a transformational-egalitarian, just, tolerant and peaceful society. It peremptorily requires everything (laws, practices, conduct and custom) to comport to it without any condition whatsoever.

90 Sec 5(b)(iv) of the Act.

91 The discussion is cognisant with Amendment 6/18.

92 Sec 3(b)(i) of the Act.

93 Sec 57 of the Electoral Act.

physically handicapped voters'.⁹⁴ In our view, the impugned provision flouts international and constitutional standards discussed in this paper. Although this provision purports to guarantee the rights of persons with disabilities, it is couched on the language which falls short of constitutional requirements.

Section 59(1)(a) of the Act confers an illiterate or physically handicapped voter with a right to receive assistance from a person of their choice. This provision obliges the presiding officer to facilitate this arrangement. The voter may also be assisted by two electoral officers or employees of the ZEC and a member of the ZRP. There is no indication in the Act to suggest that the 'helper' must be a registered voter, but he or she must identify himself or herself to the presiding officer by producing proof of identity and complete requisite forms as prescribed in section 59(1)(b) of

- 94 Sec 59 of the Electoral Act states that: (1) Upon request by a voter who is illiterate or physically handicapped and cannot vote in the way set out in section 57, a presiding officer shall –
- (a) permit another person, selected by the voter, to assist the voter in exercising his or her vote; or
 - (b) in the absence of a person selected by the voter, assist the voter in exercising his or her vote in the presence of two other electoral officers or employees of the Commission and a police officer on duty.
 - (2) A person permitted to assist a voter in terms of subsection (1)(a) –
 - (a) need not be a registered voter but shall not be a minor, electoral officer, accredited observer, chief election agent, election agent or a candidate in the election; and
 - (b) shall identify himself or herself to the presiding officer by producing proof of identity, and shall complete and sign the register referred to in subsection (3); and
 - (c) shall not be permitted to assist more than one voter in any election.
 - (3) For the purposes of subsection (2)(b), every presiding officer shall keep a special register in which shall be recorded the name of every person whom the presiding officer permits to assist a voter in terms of subsection (1)(a), relevant particulars of the proof of identity produced by that person, and the name of the voter assisted by that person.
 - (4) A presiding officer permitted to assist a voter in terms of subsection (1)(b), together with the other persons there mentioned, shall there and then mark the ballot paper in accordance with the voter's wishes and place the ballot paper in the ballot box, and if the wishes of the voter as to the manner in which the vote is to be marked on the ballot paper are not sufficiently clear to enable the vote to be so marked, the presiding officer may cause such questions to be put to the voter as in his or her opinion, are necessary to clarify the voter's intentions.
 - (5) No person other than –
 - (a) the person selected by the voter in terms of subsection (1)(a) shall take part in assisting an illiterate or physically handicapped voter, and no person who is entitled to be in a polling station shall attempt to ascertain how the voter is voting:
Provided that, in the case of a voter who is visually impaired, the presiding officer shall observe the casting of the vote in order to ensure that the voter's intention is respected by the person assisting him or her;
- or
- (b) the presiding officer selected by the voter in terms of subsection (1)(b) and the persons there mentioned shall assist an illiterate or physically handicapped voter.
 - (6) The presiding officer shall cause the name of every voter who has been assisted in terms of subsection (1)(a) or (b), and the reason why that voter has been assisted, to be entered on a list.

the Act. This person can only assist one voter. There is also guidance in the Act how the presiding officer can assist the voter.

The Act prescribes that the presiding officer:

Shall there and then mark the ballot paper in accordance with the voter's wishes and place the ballot paper in the ballot box, and if the wishes of the voter as to manner in which the vote is to be marked on the ballot paper are not sufficiently clear to enable the vote to be so marked, the presiding officer may cause such questions to be put to the voter as in his or her opinion, are necessary to clarify the voter's intentions.

Statutory protection is afforded to persons with disabilities in the context of voting. This purpose is achieved in several ways. Firstly, the Act restricts persons who should render assistance to persons with disabilities to those who were duly selected by the voter, following a laid-out procedure. From the wording of the statute this appears to be a peremptory obligation since negative wording is employed. The Act states in uncertain terms that:

No person other than the person selected by the voter in terms of subsection (1)(a) shall take part in assisting an illiterate or physically handicapped voter, and no person who is entitled to be in a polling station shall attempt to ascertain how the voter is voting.

However, this rule is not cast in stone. There is a requirement that the presiding officer should guarantee the protection, respect and promotion of the voting rights of persons with disabilities.

The electoral law is clear in the case of visually-impaired voters where the presiding officer must 'observe the casting of the vote in order to ensure that the voter's intention is respected by the person assisting him or her'. In our view, by virtue of conferring a right to choose people who can assist them on voting day (to cast their vote) on persons with disabilities, the electoral law appears to be guaranteeing their rights as enjoined in the Constitution. Moreover, the law mandates the presiding officer to create a register of all voters with disabilities. In our considered view, this requirement is in tandem with the Constitution, but practically speaking a lot needs to be done as highlighted in this case study.

From an implementation perspective, the Act is also accompanied by subsidiary legislation.⁹⁵ Read cumulatively with other electoral laws, they are also geared towards the promotion, protection and respect of voting rights of persons with disabilities in the country. In the main, we argue that although the Constitution and other statutes recognise the rights of persons with disabilities, a lot more can still be done to achieve legal dictates on

95 See Electoral Act; Consolidated Electoral Regulations 2018; Electoral Regulations 2005; Electoral (Special and Postal voting) Regulations, 2013; Electoral (Voting Registration) regulations 2013.

disability rights in elections. Moreover, there are pertinent obligations placed on the ZEC and other stakeholders to make sure voting rights of persons with disabilities are attained. We emphatically reiterate the need to consider some of the issues discussed below.

4 Are voting rights of people with disabilities equally protected under legislation?

Consequently, the legal issue for determination is whether or not the voting rights of persons with disabilities are equally protected in our law. The answer to this legal question is not clear-cut. As a preliminary point, we take into account a study conducted by Munemo which revealed that there were 700 000 potential voters with disabilities in 2008. It further recorded that only 25.6 per cent of persons with disabilities managed to vote that year with a staggering 75 per cent failing due to physical and infrastructural barriers.⁹⁶ It also reveals that: 36.7 per cent of persons with disabilities were not registered on the voters' roll; 16.5 per cent were unwilling to vote; 11.75 per cent were afraid of political violence; and 25.66 per cent filed electoral related complaints.⁹⁷ According to Virendrakumar⁹⁸ electoral barriers manifest themselves in three layers, but interrelated stages in the electoral cycle: a pre-election period; an election period; and a post-election period respectively.

The preliminary stage can also be regarded as a preparatory phase where 'support for an accessible election' is peremptory. Peculiar challenges that relate to it include: pre-election assessments that do not address election access issues; discriminatory election law; limited budgetary allocated for reasonable accommodations; inaccessible polling centres selected; poll workers not trained on administering the vote to persons with disabilities; difficulties in securing a national identification card; voter registration conducted in inaccessible locations; voter education and information on political party platforms or candidates not distributed in accessible formats; persons with disabilities not included as observers; and a lack of persons with disabilities' experience in advocacy for voting rights.

Furthermore, persons with disabilities encounter enormous challenges during the election period. These range from electoral observers' failure to monitor access issues; political parties failing to address issues important to voters with disabilities or recruit candidates with disabilities; party manifestos that are not in accessible formats; inaccessible polling stations; security forces not sensitised on how to provide a safe environment for

96 Munemo (n 65 above) 5.

97 Munemo (n 65 above).

98 B Virendrakumar et al *Disability-inclusive elections in Africa: A qualitative systematic review* (2017).

voters with disabilities; media outlets failing to disseminate information in accessible formats; and an inaccessible complaints adjudication process.

The final stage in Virendrakumar's conceptualisation is the post-electoral period. Challenges that have been identified encompass the fact that persons with disabilities are usually left out in the 'lessons learned' process; unfamiliarity with electoral rights; civic education that does not address the rights of persons with disabilities and is not distributed in accessible formats; and selection criteria for election commissioners that is not disability inclusive. Cognisant of these concerns, the Institute for Democracy and Electoral Assistance developed an election toolkit which contains guidelines to promote, protect, respect and fulfil voting rights of persons with disabilities. As such, electoral laws must be assessed taking into account legal questions below.⁹⁹

In Zimbabwe, the electoral law confers voting rights on persons with disabilities.¹⁰⁰ As discussed above, these voting rights are legally actionable. Legally speaking, section 56 of the Constitution and the Electoral Act outlaws discrimination based on the ground of disability. In principle, this is in tandem with the international legal framework which saliently provides for equal rights and opportunities to vote for persons with disabilities, without any unreasonable restrictions. Conversely, as will be seen below, the right to vote is accompanied by a bundle of duties, which if unfulfilled renders it a futile academic exercise.

Moreover, the legal framework also facilitates voter registration for persons with disabilities as prescribed.¹⁰¹ The international order inductively calls on states to eliminate discrimination in electoral practices. Consequently, this legal imperative urges countries to ensure persons with disabilities' access to national identification documents and that adequate infrastructure is availed. In Zimbabwe, the plight of persons with disabilities arguably reached zenith on the eve of the 2018 harmonised elections when the Zimbabwe Electoral Commission (ZEC) introduced the Biometric Voter Registration system. Although this novel registration model created positive opportunities in our electoral system, it has been acutely criticised by several stakeholders including civil society organisations (CSOs) and persons with disabilities respectively. The major premise lodged against it is that it violated the law since it failed to consider the special needs of persons with disabilities.

99 See D Toccinardi & M Wally 'International obligations for elections: Guidelines for legal frameworks' (2014) 303.

100 Arts 25-26 ICCPR.

101 Arts 2.2 and 25 ICCPR.

Another shortfall flowing from this dispensation relates to the legal provisions to safeguard the secrecy of the vote for persons with disabilities.¹⁰² The secrecy of the vote of this special group is controversial. In our view, there are two equally important considerations. Firstly, there is an acknowledgement at law that persons with disabilities must exercise their right to vote without coercion or undue influence. Secondly, some of them may face intractable barriers such that there is need for another person to assist them to exercise their right to vote. In the subsequent case, the extent of involvement of the aide becomes a crucial issue. In our country, the subject of voting aides has caused heated debates. Allegations range from the fact that the previous regime erroneously used members of the Zimbabwe Republic Police (ZRP), ZEC and agents to facilitate the voting process. The argument is made against ‘assisted voting’ in the context of persons with disabilities mainly that it may seriously jeopardise the secrecy of the vote. This premise is discussed further below.

The law also purports to realise the voting rights of persons with disabilities through provisions that require polling stations to be accessible to this group.¹⁰³ Although Zimbabwe has not yet domesticated the CRPD, its domestic laws still require polling stations to be accessible to persons with disabilities. In the preceding discourse, we discussed constitutional provisions and emphasised the need to align major disability laws with the Constitution which is the supreme law of the land. Practically speaking, these laws must be amended or repealed to infuse constitutional dictates. In the election’s context, there is need to require disability institutions to take certain steps and work collaboratively with the ZEC to facilitate access to polling stations. As the situation currently stands, this may be impossible due to the welfare innuendos imbedded in the impugned laws discussed in this article.

In principle persons with disabilities are also granted an equal right to stand for political office.¹⁰⁴ We reiterate the point that equality is a cross-cutting theme in the legal architecture. Consequently, that is why the law imposes a duty on the state to eliminate discrimination in the ground of disability. Notwithstanding, persons with disabilities still find it difficult to stand for office because of barriers like limited infrastructure, violence and so on. The 2018 post-election violence evinces this point.

Whether or not there are measures to support elected officials with disabilities to effectively exercise their mandate is subject to debate.¹⁰⁵ However, a holistic analysis of the Constitution and other statutes may support the view that elected officials with disabilities receive support to execute their mandate. However, there is a difference between what the

102 Art 25 ICCPR; art 29 CRPD.

103 Art 2.2 ICCPR; art 29 CRPD.

104 Art 25 ICCPR; art 29 CRPD.

105 Art 2.2 ICCPR; art 27.1 CRPD.

law says and what happens in practice. The other issue relates to the question if persons with intellectual disabilities and those under guardianship are enfranchised.¹⁰⁶ Equally so, the law also provides special measures for women with disabilities to exercise their electoral rights.¹⁰⁷ The Electoral Amendment Act and Electoral Regulations make provision for special voting.

In our law, persons with disabilities have the inalienable right to freedom of association.¹⁰⁸ The Constitution bestows this right on 'everyone'. In the context of disability especially voting rights, it is important to enable persons with disabilities to associate freely, lobby and advocate for their right to vote. In practice, this has manifested itself through disability associations which usually play the role of watchdogs during elections.

Furthermore, the Electoral law provides general guidelines on civic and voter education. There are generic provisions prescribing civic and voter education, but not specifically concerning persons with disabilities.¹⁰⁹ This issue is also controversial. Civic and voter education is regulated under the Electoral Act. A few days before the 2018 harmonised elections CSOs challenged certain sections of the Act since it barred them from sensitising the electorate. The Act does not prescribe civic and voter education concerning the right to vote. However, it has been done on an ad hoc basis. In our view, the issue of voter education is intrinsically linked to successful implementation of voting rights of persons with disabilities. Therefore, the country should act expeditiously to fulfil its legal obligations in this regard.

Our argument is buttressed by the fact that despite various interventions, persons with disabilities still encounter enormous challenges in exercising their voting rights. This observation was made by a representative of persons with disabilities in the Senate in Zimbabwe, as follows:

I have put it to ZEC that we need things like sign language, voter education material in braille and that registration centres be easily accessible. Even the tables need to be friendly to those who are physically challenged and the personnel who are conducting the registration process. [I] Personally can't see and [I] would need an electronic system that tells me the information I have entered.¹¹⁰

106 Arts 25-26 ICCPR.

107 Art 7 Convention on the Elimination of All Forms of Discrimination against Women; art 3 ICCPR.

108 Art 22 ICCPR; art 29(b) CRPD.

109 Art 25 ICCPR; art 13 UNCAC.

110 'PLWDS raise concerns over 2018 vote' *Daily News* 19 September 2017 <https://www.dailynews.co.zw/articles/2017/09/19/plwds-raise-concerns-and-2018-vote> (accessed 26 November 2013). See also the Zimbabwe Human Rights Commission www.zhrc.org.zw/your-rights/ (accessed 15 November 2019).

The averment is corroborated by others. One of them is Machakaire¹¹¹ who posits that persons with disabilities firstly face the challenge that the electoral system/practices are flawed as this group relies heavily on others to exercise their vote. We argued above that the use of voting aides may affect the secrecy of the vote especially when members of the security services are involved. In our view, persons with disabilities should give free, prior and informed consent in relation to the parties who will assist them on Election Day. The author further argues that this is a cause for concern since there are almost 125 000 people in Zimbabwe who are blind.¹¹² The second challenge he cites concerns voting booths that are not fit for purpose since they do not have ramps to enable access to people with wheel chairs.¹¹³ This claim is supported by Mbanje¹¹⁴ who argues with brevity that:

[V]oting rights for people living with disability continue to be trampled on as there are no measures and facilities to ease the voting process, a situation which has forced this group to get assistance from aides.¹¹⁵

According to other reports¹¹⁶ challenges facing persons with disabilities are deep-seated and generated controversy during the constitutional making process that led to the 2013 Constitution.¹¹⁷ For example, The Voice of America published an article in March 2013 where it alleged that some persons with disabilities lacked identity documents.¹¹⁸ If this averment is correct, it implies some citizens never participated in the referendum. Therefore, this proves as cogent the argument that voting rights of persons with disabilities still face enormous challenges in our jurisdiction.

Furthermore, the European Union Observer Mission Final Report on the Republic of Zimbabwe's Harmonised Elections 2018¹¹⁹ has added to the list of challenges. In the main, it found that 'persons with disability

111 'Challenges facing voters with disabilities' *Daily News* 27 May 2018 <https://www.dailynews.co.zw/articles/2018/05/27/challenges-facing-voters-with-disabilities> (accessed 26 November 2019).

112 As above.

113 As above.

114 'People living with disability demand full voting rights' *News Day* 9 July 2018 <https://www.newsday.co.zw/2018/07/people-living-disability-demand-full-voting-rights/> (accessed 15 November 2019).

115 Mbanje (n 113).

116 See Voice of America 'Zimbabweans living with disabilities lack identity documents: Won't vote in referendum' (5 March 2013) <https://reliefweb.int/report/zimbabwe/zimbabweans-living-disabilities-lack-identity-documents-wont-vote-referendum> (accessed 26 November 2019).

117 As above.

118 As above.

119 This report is available at http://www.veritaszim.net/sites/veritas_d/files/EU%20Election%20Observers%20Final%20Report%20Zimbabwe%202018-.pdf (accessed 15 November 2019).

have reserved representation but further administrative reform could help improve their access to a secret ballot'.¹²⁰

Another issue that the EU Observer's Report raises involves Zimbabwe's failure to align its domestic laws with the CRPD. This follows the country's accession to this legal instrument in 2013. This subsequent claim confirms Manatsa's findings that disability laws¹²¹ are misaligned with the new constitutional order. As already stated above, the argument is that these laws reflect welfare rather than a rights-based perspective as required by the Constitution. Although the Zimbabwe ZEC and the government argues that it is committed to upholding the Constitution and thus promoting disabilities rights, the EU found that braille ballot papers, tactile ballot guides or other assistive measures have never been provided for persons with visual and other impairments¹²² and there were difficulties in gaining access to some polling stations.

Another issue relating to voting rights of persons with disabilities which arose after the 2018 harmonised elections concerns the election of two members of Senate, one man and one woman, to represent persons with disabilities. The elections were conducted pursuant to Statutory Instrument 126 of 2018, the Electoral (Prescribed Associations and Institutions) Notice, 2018 which set out a list of institutions and private voluntary organisations which were entitled to participate in the electoral challenge. It was amended by Statutory Instrument 138A, the Electoral Notice which removed 18 duplications from the list. The European Union observed that a total of 170 delegates were invited to participate, of whom 134 were present on the day. There was some speculation that the lack of full participation may have been due to the violence, which had taken place in the City on 1 August.

It also noted that the franchise of this election does not extend to persons with disabilities, as only representations of prescribed bodies may nominate candidates and vote. This is therefore a source of grievance to some persons with disabilities, as the electorate for the two senatorial positions is very small. An argument is made that the election could be conducted in concert with the general harmonised elections with persons with disabilities all eligible to vote for their representative.¹²³

120 European Union Observers Final Report (n 119 above) 31.

121 For example, the Disabled Persons Act, 1992.

122 European Union Observers Final Report (n 119 above) 31.

123 European Union Observers Final Report (n 119 above) 32.

5 Recommendations

We concur with the findings of the European Union's Observer Report that Zimbabwe must incorporate the CRPD into domestic law.¹²⁴ This must be done in accordance with the 2013 Constitution. This step will guarantee that voting rights of persons with disabilities are promoted and protected as peremptorily enjoined in article 1 of the CRPD.

Secondly, we acknowledge with concern the decision of the High Court in July 2018 where the court held that braille was impractical as levels of braille literacy are low amongst those with visual impairments.¹²⁵ The court missed a brilliant opportunity to change the disability landscape in the country.

Furthermore, we argue that the High Court's decision stunted legal precedent and should have followed the 2008 Supreme Court decision which struck down provisions of the Electoral Act which required that persons requiring assistance to cast their vote should be assisted by the Zimbabwe Republic Police (ZRP) officers and others on electoral duty, denying the voter any choice of assistance.¹²⁶

Practically speaking, the legislature must amend disability laws to ensure their compliance with the Constitution. At the time of writing, we ascertained that the Attorney-General's Office had produced a first draft of the Persons with Disabilities Bill which was submitted to the Ministry of Public Service, Labour and Social Welfare and relevant stakeholders. However, we do not anticipate a long wait before public release of the Bill since it should be approved by the Cabinet Committee on Legislation and then the Cabinet.

We reiterate the need for collaborative partnerships amongst stakeholders to ensure that focus is not on physical disability at the expense of other manifestations.

Moreover, the government of Zimbabwe should take practical measures to address all the barriers at different stages (pre-election period, election period and post-election period) of the election cycle, as discussed above. Firstly, the government and relevant stakeholders should address access-related issues, repeal discriminatory laws, ensure that financial resources are available to promote reasonable accommodation, train poll workers to administer the vote to persons with disabilities, facilitate access to identity documents, address issues related to voter education and include persons with disabilities as electoral observers.

124 European Union Observers Final Report (n 119 above) 31.

125 European Union Observers Final Report (n 119 above) 32.

126 As above.

Additionally, political parties should recruit persons with disabilities as candidates, ensure that manifestos are in accessible format, security forces must provide a safe environment for persons with disabilities and media outlets must provide information in accessible format and overall there must be an accessible adjudication process. Finally, persons with disabilities must be involved in the aftermath of the election.

6 Conclusion

In sum, Zimbabwe seeks to build an egalitarian and inclusive society as espoused in the 2013 Constitution. Although the Constitution's text is infused with a transformative culture and underlined by a human rights-based approach to disability; the legal system (mostly implementing statutes) is still largely repugnant in that it promotes a welfare model. As such, our study concludes that persons with disabilities still continue to live in the periphery of society as their voting rights are unrealised. We surveyed the international and national legal framework and cited pressing barriers related to the issue under review. Realistically speaking, the article may create a platform for constructive debate and importantly legislative reforms in this realm as the country prepares for the next harmonised elections in 2023. The legislature appears to be heeding the call for legislative reform as it is in the process of drafting the Persons with Disabilities Bill 2019.¹²⁷ Notwithstanding this, the authors are not privy to the contents of the Bill as it has not been released for public comment.

127 Correspondence with legislative watchdog Veritas (on file with the authors).

SECTION B: COUNTRY REPORTS

TCHAD

Serge Marcellin Tengho*

Summary

According to the results of the General Census of Population conducted in 2009 (2018 projection), the Chadian population is 15, 1 million. According to the report of the National Union of Persons with Disabilities of 2014, Persons with disabilities are 1 691 116, that is 14% of the total population; the most prevalent forms of disabilities include sensory disabilities, motor disabilities and visual disabilities.

The Republic of Chad signed the United Nations Convention on the Rights of Persons with Disabilities (CRPD), as well as its Optional protocol on 26 September, 2012. The CRPD was ratified 20 June 2019 by the Chadian government. The Optional Protocol was adopted at the National Assembly 26 September, 2012. The Constitution of the Republic of Chad contains no provision dealing directly with disabilities. The term disability does not openly appear in the Constitution. Nevertheless, the Constitution provides for the right to equality for all, including persons with disabilities. The rights to employment, education, ect, for all are also guaranteed by the preamble of the Constitution. The Republic of Chad has numerous pieces of legislation that directly address disability. The key ones are the Law n°007/PR/2007, of 7 May 2007 on the protection and promotion of the rights of persons with disabilities, which has not yet been ratified; the decree 136/PR/PM/MCFAS/94 of 16 June 1994 that instituted the National Day of Persons with Disability celebrated on 7 February every year.

The policies that directly address persons with disabilities are: (1) the national policy and its action plan; (2) the national policy of social welfare and its action plan; and (3) the national strategy on the protection of vulnerable children and the national policy on protection of children as well as its action plan including programmes affecting directly people with disabilities.

* Serge Marcellin Tengho est Etudiant en doctorat à l'Université de Dschang, Cameroun.

Other than ordinary courts or tribunals, the Chad Republic has no official body that specifically addresses the violation of the rights of people with disabilities. The Republic of Chad has had a National Human Rights Commission since 9 September 1994. It is autonomous, neutral and endowed with a legal entity. It enjoys administrative, technical and financial autonomy and independence of action. The Republic of Chad also has a Human Rights Federation which organises actions on the promotion and protection of persons with disabilities. There are numerous organisations that represent and advocate for the rights and welfare of persons with disabilities in the Republic of Chad, represented by Maison Notre Dame de Paix de Moundou Association, the Kabalaye Equipment and Rehabilitation Centre of N'djamena, and Handicap Santé which is an NGO.

In the Republic of Chad, the Ministry of National Education and Higher Education; the Ministry of Social Work, National Solidarity and the Family; the Ministry of Human Rights and the Promotion of Freedoms; the Ministry of Women, Early Childhood Protection and National Solidarity are ministers that are involved in promoting and protecting disability rights. Persons with disabilities in the Republic of Chad face many problems such as the lack of doctors specialised in re-education and rehabilitation. Where access is concerned, persons with disabilities have difficulties to access to public buildings, public transport, education, vocational training, health care, employment justice and other social structures; in practice, very little is done to ensure access for persons with disabilities.

The Chadian Government shall strengthen and speed up the implementation of its national policies and programmes for the implementation of disability rights.

1 Les indicateurs démographiques

1.1 Quelle est la population totale de la République du Tchad?

Le Tchad est un pays d'Afrique Centrale, situé au cœur du continent entre les 7^{ème} et 24^{ème} degré de latitude Nord et les 13^{ème} et 24^{ème} degré de longitude Est. Il couvre une superficie de 1 284 000 km².¹ Selon le Ministre de l'économie et de la Planification du Développement, l'évolution des indicateurs démographiques montre que la population du Tchad recensée en 2009 qui était de 11,1 millions d'habitants (densité de 8,6 habitants au Km)² avec un taux annuel moyen d'accroissement intercensitaire de 3,6% et un taux annuel moyen d'accroissement sans les réfugiés de 3,4% selon le Recensement Général de la Population et de l'Habitat (RGPH2) de 2009; aurait atteint 12,3 millions d'habitants en 2012 et passerait à 13,7 millions en 2015 (année d'évaluation des Objectifs du Millénaire pour le Développement) et atteindrait 15,1 millions d'habitants en 2018.

1 République du Tchad: Politique nationale genre (Décembre 2011)¹⁶.

1.2 Méthodologies employées en vue d'obtenir des données statistiques sur la prévalence du handicap en République du Tchad. Quels sont les critères utilisés pour déterminer qui fait partie de la couche des personnes handicapées au Tchad?

La République du Tchad n'a pas encore effectué un recensement général de personnes handicapées. Cependant, la Deuxième Enquête Tchadienne sur la santé de la famille (EDSF/PAPFAM) de 2012 ainsi que l'EDS-MICS de 2014/2015 ont produit quelques données statistiques disponibles sur le handicap. Ces études sont loin d'être exhaustives. En admettant que la personne handicapée soit « toute personne se trouvant dans l'incapacité d'assurer par elle-même en tout ou partie des nécessités d'une vie individuelle ou sociale normale du fait d'une déficience congénitale ou acquise, de ses capacités physiques, sensorielles et mentales »,² la Loi N°007/PR/2007 du 9 Mai 2007 portant protection des personnes handicapées distingue cinq catégories de personnes handicapées à savoir: les personnes handicapées physiques/moteur, les personnes handicapées auditives; les handicapées mentales; visuelles et les polyhandicapées. De plus, l'enquête fait une distinction entre le handicap sévère et le handicap modéré sans autant approfondir les critères de distinction.

1.3 Quel est le nombre total et le pourcentage des personnes handicapées en République du Tchad?

Selon le Recensement Général de la Population et de l'Habitat (RGPH2) de 2009, l'effectif des personnes handicapées représente 1,1%. Elles sont estimées à 119.353 personnes. En 2014, le rapport de l'Union Nationale des Associations des Personnes Handicapées au Tchad (UNAPHT) effectué suite au forum sur le handicap estime à 1 691 116 le nombre de personnes handicapées au Tchad, soit 14% de la population. Cependant, selon les estimations de l'Organisation Mondiale de la Santé (OMS), 15% de la population mondiale vit avec un handicap, sous une forme ou une autre.

Selon l'EDS-MICS 2014-2015, dans l'ensemble, au Tchad, 3,5% de la population présentent un handicap. Dans la majorité des cas, il s'agit d'un handicap modéré ou d'une déficience légère ou partielle (2,4% contre 1,1% pour un handicap sévère). L'extrapolation de la prévalence moyenne de 3,5% dans la population de l'échantillon à l'ensemble de la population du Tchad, estimée à 13 670 084 habitants en 2015 selon les projections de l'INSEED de 2014, donnerait un nombre de handicapés toutes catégories confondues d'environ 478 453.

NB: le RGPH2 est effectué au Tchad depuis 2009 pendant cette période le pays a traversé plusieurs conflits armés, des attaques terroristes et bien d'autres événements qui ont eu leurs répercussions sur la population. Donc l'effectif de personnes handicapées pourrait être au-delà de celui de la RGPH2.

1.4 Quel est le nombre total et le pourcentage des femmes handicapées en République du Tchad?

Selon le Recensement Général de la Population et de l'Habitat de 2009, l'effectif des femmes handicapées est de 53 310, soit un pourcentage de 0,99% de la population totale du Tchad.

2 Article 2 de la Loi N°007 2007/PR portant protection des personnes handicapées au Tchad.

Le Tchad a organisé en 2014/2015, une Enquête Démographique et de Santé, combinée à l'enquête par Grappes à Indicateurs Multiples (EDS-MICS). Portant sur un échantillon de 17 892 ménages, ce n'est que dans les 2/3 des ménages c'est-à-dire dans deux ménages sur trois sélectionnés que celle-ci a finalement eu lieu. Après analyse, les résultats ont montré que dans l'ensemble, 3,5% de la population tchadienne présente au moins un handicap dont 4% chez les hommes et 3% chez les femmes.³ Il s'en suit donc que, transplanté au niveau national on constate qu'aucune étude récente n'a été menée jusqu'ici pour présenter le taux de prévalence du handicap tant chez les hommes, les femmes que chez les enfants.

1.5 Quel est le nombre total et le pourcentage des enfants handicapés en République du Tchad?

Selon toujours le RGPH2, l'effectif des enfants handicapés est de 53 310, soit un pourcentage de 0,99% de la population totale du Tchad. Des études récentes, aucune ne présente le pourcentage du nombre d'enfants vivant avec un handicap en République du Tchad.

1.6 Quelles sont les formes de handicaps les plus répandues en République du Tchad?

Les résultats de l'Enquête EDS-MICS de 2014-2015 montrent que selon le type de handicap le pourcentage de population souffrant de déficience sensorielle est plus élevé que le pourcentage souffrant de déficience motrice (2% contre 1,3%). En outre, on remarque que la déficience visuelle (1,3%) surtout sous la forme modérée (1% contre 0,2% sous la forme sévère) et la déformation ou les difficultés à se servir des membres inférieurs ou supérieurs (0,9%), en majorité sous la forme modérée (0,7% contre 0,2% sous la forme sévère) sont les handicaps qui ont été les plus fréquemment déclarés au cours de l'enquête. Le pourcentage de population ayant déclaré, comme handicap, la perte de certaines extrémités du corps est très faible (0,1%). Il en est de même pour les troubles du comportement (0,2%).

Par rapport à l'EDST-II 2004, on constate que la prévalence est passée de 5,3% à 3,5%. Cependant, des erreurs de collecte ayant pu se produire et du fait des erreurs de sondage, il serait prématuré de conclure à une diminution de la prévalence des handicaps entre les deux enquêtes.

2 Obligations internationales

2.1 Quel est le statut de la Convention des Nations Unies relatives aux Droits des Personnes Handicapées (CDPH) en République du Tchad? Le Tchad a-t-il signé et ratifié la CDPH, Fournir le (s) date (s). Le Tchad a-t-il signé le protocole facultatif? Fournir le (s) date (s).

La République du Tchad a signé la Convention des Nations Unies relative aux Droits des Personnes Handicapées (CDPH) en date du 26 septembre 2012 et le

3 Réunion Régionale des Nations Unies sur la Mesure du handicap et les Statistiques à l'appui de l'Agenda 2030 pour le Développement Durable et le Programme Mondiale 2020 pour le Recensement de la Population pour l'Afrique. Tenue du 15 au 17 novembre 2006 à Kampala, Ouganda, 8.

Président de la République a promulgué la loi N°0024/PR/2018 portant ratification de la convention relative aux droits des personnes handicapées suite à la délibération de l'Assemblée Nationale en sa séance du 30 octobre 2018. Concernant le protocole facultatif de ladite convention, le Tchad a procédé à sa signature le 26 septembre 2012. Lors de l'adhésion à cette convention, la République du Tchad n'a formulé aucune déclaration, encore moins la moindre réserve, ni introduit une quelconque déclaration impérative.

2.2 Si le Tchad 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? Votre pays a-t-il soumis son rapport? Sinon quelles sont les raisons du retard telles qu'avancées par la branche gouvernementale en charge?

Vu que le Tchad a ratifié ladite convention en date du 9 novembre 2018⁴ et que les instruments de ratification ne sont pas encore déposés au Secrétariat des Nations Unies, on ne peut parler de la soumission du rapport. Car il faut deux ans après la ratification avant de soumettre un rapport. La branche gouvernementale chargée de la soumission du rapport est le Comité Interministériel Chargé du Suivi des Instruments Internationaux en matière des Droits de l'Homme, présidé par le Ministère de la Justice et des Droits Humains.

2.3 Si le Tchad 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 du Tchad. Y'avait-il des effets internes découlant du processus de rapport liés aux questions handicapées au Tchad?

Le Tchad vient de ratifier la Convention relative aux droits des personnes handicapées, il n'est redevable d'aucun rapport. Le délai de soumission des rapports pour le Tchad court à partir de la date de ratification.

Vu que rien n'a encore été décidé pour la soumission du rapport, il est donc clair qu'il n'y a pas jusqu'ici des observations finales ou des recommandations au sujet du rapport. Quant aux effets internes, les handicapés sont encore en attente.

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 du bien-être de l'Enfant, le Tchad 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? Était-il fait mention des droits des handicapés dans le rapport de la

4 Loi N°0024/PR/2018 Autorisant le Président de la République à ratifier la Convention Relative aux Droits des Personnes Handicapées

Revue Périodique Universelle (RPU) des Nations Unies du Tchad? Si oui, quels étaient les effets de ces observations ou recommandations?

Dans son rapport sur les Droits de l'Homme, la République du Tchad a fait mention du droit des personnes handicapées dans son rapport soumis aux organes de traités des nations Unies et de l'Union Africaine.⁵

En l'espèce, il est précisé dans ce rapport que la loi interdit la discrimination à l'égard des personnes handicapées de toutes catégories confondues. Ainsi, les recommandations faites pendant la présentation du rapport du Tchad relatif à la Charte Africaine relative aux Droits et du bien-être de l'Enfant sont relatives entre autre à la ratification de la convention relative aux droits des personnes handicapées, la prise du décret d'application de la loi 07/PR/2019, portant protection des personnes handicapées. Ce décret est adopté cette année 2019. Le code de protection de l'enfant qui est révisé et en instance d'adoption.

Le gouvernement gère des programmes éducatifs, d'emploi et thérapeutiques pour les personnes handicapées. Les enfants handicapés physiques peuvent fréquenter des établissements d'enseignement primaire, secondaire et supérieur. Le gouvernement a apporté un soutien à des écoles pour enfants handicapés visuels ou mentaux.⁶

Le Gouvernement dans la présentation de son Rapport d'Examen Périodique Universel (EPU) devant le Conseil des Nations Unies aux Droits de l'Homme ait validé le 15 mars 2019, représenté par Monsieur Djimet Arabi, Garde des Sceaux, Ministre de la justice et des droits humains a fait mention de la situation des droits de l'homme de façon générale dans le pays et a évoqué quelques avancées faites en faveur des droits des personnes handicapées. Cependant, il a informé le conseil des enjeux sécuritaires concernant le terrorisme dans la région du Sahel, de la complexité de cette lutte en rappelant la mutualisation des moyens avec le G5 (Mauritanie, Mali, Burkina-Faso, Niger et Tchad). Outre le terrorisme, le ministre a relayé les nombreux autres défis du Tchad notamment ceux liés aux changements climatiques, la dégradation environnementale consécutive au dérèglement climatique et bien d'autres défis relatifs à la promotion des droits de l'homme.

2.5 Y'avait il un quelconque effet interne sur le système légal du Tchad après la ratification de l'instrument international ou régional au 2.4 ci-dessus?

Après ratification des instruments internationaux ou régionaux, ceux-ci ont débouché sur un effet direct sur le système législatif tchadien à travers l'adoption du nouveau code de procédure pénale le 20 décembre 2016 par les députés tchadiens au palais de la démocratie de Gassi à N'Djamena. Bien plus, on aura la loi N°001/PR/2017 portant nouveau code pénal, ainsi que la loi N°007 2007/PR portant protection des personnes handicapées.

5 Tchad: Rapport sur les Droits de l'Homme (2017) 20.

6 (Comme-ci-dessus) 21. A ce niveau, ce rapport ne fait qu'énoncer sans toutefois donner des exemples palpables.

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 225 de la Constitution du Tchad a consacré la primauté des traités ou accords internationaux sur les lois nationales en ces termes: « les Traités ou Accords régulièrement ratifiés ont, dès leur publication, une autorité supérieure à celle des lois nationales, sous réserve pour chaque Accord ou Traité de son application par l'autre partie ». Ainsi, dans le système moniste en vigueur dans les pays francophones comme la République du Tchad, 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.

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 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 interne.

3 Constitution

3.1 La constitution du Tchad contient-elles 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 du Tchad ne contient aucune disposition concernant directement le handicap. Cependant certaines dispositions constitutionnelles abordent la question. Le titre V traitant des rapports entre le pouvoir exécutif et le pouvoir législatif en son article 127 alinéa 2 énonce que la loi fixe les règles concernant « la promotion du genre, des jeunes et des personnes handicapées ». Le titre VII qui porte sur le Haut conseil des collectivités autonomes et des chefferies traditionnelles en son article 172 alinéa 1 précise que la Commission Nationale des Droits de l'Homme a pour mission de « formuler des avis au gouvernement sur les questions relatives aux droits de l'Homme, y compris la condition de la femme, les droits de l'enfant et des personnes handicapées ».

3.2 La constitution du Tchad contient-elle des dispositions concernant indirectement le handicap? Si oui énumérez les dispositions et expliquez comment chacune d'elles traite indirectement du handicap.

La Constitution tchadienne proclame et réaffirme dans son préambule son attachement aux principes des Droits de l'Homme tels que définis par la charte des

Nations Unies de 1945, la Déclaration Universelle des Droits de l'Homme de 1948 et de la Charte Africaine des Droits de l'Homme et des Peuples (CADHP) de 1981 comme faisant 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 des mesures de protection.

L'article 13 de la Constitution du Tchad consacre le principe d'égalité et de non-discrimination en proclamant solennellement que « les tchadiens des deux sexes ont les mêmes droits et les mêmes devoirs. Ils sont égaux devant la loi ». L'article 44 de la Constitution dispose également que « l'Etat s'efforce de subvenir aux besoins de tout citoyen qui, en raison de son âge ou de son inaptitude physique ou mentale, se trouve dans l'incapacité de travailler, notamment par l'institution d'organisme à caractère social ». Ce principe de non-discrimination consacré par la loi fondamentale est applicable à tous, y compris aux personnes handicapées.

4 Législation

4.1 La République du Tchad a-t-elle une législation concernant directement le handicap? Si oui, énumérez la législation et expliquez comment la législation aborde le handicap.

En date du 7 mai 2007, le Tchad a voté une loi, celle N°007/PR/2007 portant protection des personnes handicapées. Cette loi contient notamment des dispositions relatives aux droits à l'éducation et à la formation ainsi qu'aux droits à l'insertion socio-économique des personnes handicapées. Le décret 136/PR/PM/MCFAS/94 du 16 juin 1994 portant institution d'une journée nationale des personnes handicapées le 7 février de chaque année, et l'arrêté 377/MEN/DG/95 du 04 décembre 1995 portant exonération des élèves et étudiants handicapés et des parents handicapés, des frais d'inscription et de scolarité sont autant de marques traduisant l'intérêt que le gouvernement tchadien, résolument engagé à bâtir un Etat de Droit respectueux des Droits Humains, porte la question du bien-être des personnes handicapées.

De façon générale en matière d'atteinte à l'intégrité de la personne humaine, la loi N°001/PR/2017 du 8 mai 2017 portant Code Pénal: l'article 320 inclut parmi les atteintes volontaires à l'intégrité corporelle, ceux qui auront exposé ou fait exposer, délaisser ou fait délaisser un enfant ou un incapable majeur hors d'état de se protéger lui-même en raison de son état physique ou mental, seront pour ce seul fait, condamnés à un emprisonnement de six mois à cinq ans et à une amende de 50.000 à 500.000 franc CFA. L'article 350 réprime le viol ou toute tentative de viol en son paragraphe C en énonçant que « la peine est un emprisonnement de dix à vingt ans lorsque le viol a été commis sur une personne particulièrement vulnérable en raison d'une maladie, d'une infirmité, d'une déficience physique ou psychique ou à l'état de grossesse et que cet état est apparent ou connu de l'auteur des faits ». Ceci parce que les femmes continuent de faire l'objet au Tchad d'importantes discriminations auxquelles s'ajoutent des violences, et notamment des viols, Cette loi punit l'exploitation frauduleuse de la faiblesse ou de l'ignorance de certains groupes vulnérables comme les enfants ou les femmes handicapés.

4.2 Le Tchad a-t-il une législation concernant indirectement le Handicap? Si oui, énumérez la principale législation et expliquez comment elle réfère au handicap.

Toutes les lois au Tchad sont fondées sur le principe d'égalité.

Les lois et les réglementations du travail interdisent la discrimination en matière d'emploi et de salaire fondée sur la race, la couleur, la religion, le sexe, l'âge, l'origine nationale, la citoyenneté ou l'appartenance à un syndicat.

5 Décisions des cours et tribunaux

5.1 Les cours (ou tribunaux) dans votre pays ont-ils jamais statué sur une question relative au handicap? Si oui, énumérez le cas et fournir un résumé pour chacun des cas en indiquant quels étaient les faits; la (les) décisions (s), la démarche et l'impact (le cas échéant) que ces cas avaient entraînés.

Etant donné que ne disposant pas d'un répertoire de jurisprudence, il est difficile de répertorier les cas qui ont été jugés devant les Tribunaux avec les conséquences éventuelles. A cet effet, nous n'avons donc pas trouvé des décisions de justice rendues concernant le handicap.

6 Politiques et programmes

6.1 Le Tchad 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.

Après la signature de la Convention Internationale relative aux Droits des Personnes Handicapées (CDPH), le gouvernement tchadien s'est vite lancé dans la mise sur pied de certains programmes. Il s'agit entre autres d'un Plan National de Développement (PND), comprenant un axe sur l'amélioration de la qualité de vie de la population ciblant spécifiquement les jeunes et les personnes Handicapées, avec comme objectif l'accès à un emploi productif, décent et durable.

A travers le projet d'Amélioration de la qualité de vie et de l'Inclusion des enfants, Jeunes Handicapés et Personnes Vulnérables au Tchad (INCLUJIPH), le gouvernement tchadien par le concours de l'Agence Française de Développement compte améliorer l'inclusion et la qualité de vie des personnes handicapées en réduisant les barrières à l'accès aux services, à la participation sociale et au développement économique au Tchad.

L'année dernière, plus de 123 millions de francs CFA ont été accordés au consortium constitué de l'ONG Handicap Santé et de la Maison Notre Dame de la Paix de Moundou pour un programme d'opérations chirurgicales. Le public visé est constitué de femmes et d'enfants handicapées, ou de victimes d'accidents divers. Il s'agit ici de la signature d'une convention entre l'AFD et le Ministre de la

santé publique représentés respectivement par l'Ambassadeur de France au Tchad, Philippe Lacoste, et du Directeur de l'Agence Française de Développement au Tchad, Olivier Cador et le Ministre tchadien de la Santé Publique, Aziz Mahatma Saleh en octobre 2018.

Dans le volet éducatif, les enfants handicapés physiques peuvent fréquenter des établissements d'enseignement primaire, secondaire et supérieur. Le gouvernement a apporté un soutien à des écoles pour enfants handicapés visuels ou mentaux.

Le Tchad 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 Ministère des Micro-crédits pour la Promotion de la Femme et de la Jeunesse créé en 2006 vise à développer des projets ou financer des projets afin de lutter contre la pauvreté et, surtout d'améliorer les conditions de vie des femmes et des jeunes. Il s'agit du 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 tchadienne. Ce programme a également ciblé les personnes vivant avec un handicap.

Dans son rapport intitulé « Vision 2030, le Tchad que nous voulons » (2017), le Ministère de l'Économie et de la Planification du Développement prévoit la mise en œuvre et le suivi des stratégies nationales de protection sociale et de la couverture sanitaire universelle, incluant l'encadrement des personnes vulnérables et à besoin spécifiques (enfants, jeunes, femmes retraités et personnes handicapées) et leur réinsertion dans les filières socio-économique.

7 Organismes en charge des personnes handicapées

7.1 En dehors des cours ou tribunaux ordinaires, le Tchad 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 du Tchad, d'organisme officiel s'intéressant spécifiquement aux violations des droits des personnes handicapées.

7.2 En dehors des cours ou tribunaux ordinaires, le Tchad 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. Il est en outre chargé du suivi de la mise en œuvre des organes de traités portant sur la protection et a promotion des Droits de l'Homme y compris les droits des personnes handicapées.

8 Institutions Nationales des Droits de l'Homme (Commission des Droits de l'Homme ou Ombudsman ou Protecteur du Citoyen)

- 8.1 Le Tchad 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 Droit de l'Homme ou l'Ombudsman ou le Protecteur du citoyen du a jamais abordé des questions relatives aux droits des personnes handicapées.**

Les textes fondamentaux sont basés sur la loi N°031/PR/94 portant création de la Commission Nationale des Droits de l'Homme. La Commission a été créée le 9 septembre 1994; avec son siège à N'Djamena, elle a commencé ses activités en 1996. Elle était chargée du suivi de la mise en œuvre des instruments de droits de l'homme ratifiés par la République du Tchad. La CNDH a reçu plusieurs plaintes sur des cas de violation de droits de personnes handicapées.

Mais actuellement la CNDH a été reformée par l'adoption de la loi N°028/PR/2018 du 29 octobre 2018, portant attribution, organisation et fonctionnement de la CNDH, pour la rendre conforme aux principes de Paris, de la catégorie A. Ainsi, la constitution de la 4^{ème} République énonce dans son article 171 qu'« il est institué une Commission Nationale des Droits de l'Homme. La Commission Nationale des Droits de l'Homme (CNDH) est une autorité administrative indépendante ».

L'article 172 définit la mission de la CNDH ainsi qu'il suit:

- Formuler des avis au Gouvernement sur les questions relatives aux droits de l'Homme, y compris la condition de la femme, les droits de l'enfant et des handicapés ;
- assister le Gouvernement et les autres institutions nationales et internationales pour toutes les questions relatives aux droits de l'Homme au Tchad en conformité avec la Charte des Droits de l'Homme et des Libertés Fondamentales;
- participer à la révision de la législation en vigueur et à l'élaboration de nouvelles normes relatives aux droits de l'Homme, en vue de la construction de l'Etat de droit et du renforcement de la démocratie ;
- procéder à des enquêtes, études, publications relatives aux droits de l'Homme;
- aviser le Gouvernement sur les ratifications des instruments juridiques internationaux relatifs à la torture, au traitement inhumain et dégradant.

Elle bénéficie d'une autonomie en vertu de l'article 173 qui stipule que « la Commission Nationale des Droits de l'Homme (CNDH) est autonome quant aux choix des questions qu'elle examine par auto-saisine. La Commission est entièrement libre de ses avis qu'elle transmet au Président de la République et dont elle assure la diffusion auprès de l'opinion publique ».

Enfin, selon l'article 174 « ses règles d'organisation et de fonctionnement ainsi que la composition de la Commission Nationale des Droits de l'Homme sont déterminées par la loi ».

9 Organisation des personnes handicapées (OPH) et autres Organisations de la Société Civile

9.1 Avez-vous au Tchad 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 de la Maison Notre Dame de Paix de Moundou (AMNDP): il s'agit d'une association tchadienne créée depuis 1995 (Création du centre en 1979) à Moundou, région située au Sud du Tchad. C'est un centre de rééducation fonctionnelle, d'appareillage et de réinsertion, avec un effectif d'environ 32 professionnels permanents au centre et une capacité d'accueil de 77 lits, 35 000 patients pris en charge, 20 000 matériels fabriqués comme les cannes, les tricycles, les orthèses et les prothèses⁷.

Le CARK a été fondé par le SECADEV (Secours Catholique et Développement) qui est une ONG Nationale créée en 1983 par le Diocèse de N'Djamena. Le Centre d'Appareillage et de Rééducation de Kabalaye est créé en 1981 pour faire face aux besoins de réadaptation des victimes d'après la guerre qu'a connue le Tchad en 1979. Les personnes handicapées identifiées dans le cadre du projet bénéficient de services de réadaptation ciblés (60% hommes; 40%femmes; 50% moins de 18 ans; 30% jeunes de 20 à 30 ans)⁸.

L'ONG Handicap Santé est basée en France mais intervient au Tchad. Elle organise et réalise des missions chirurgicales orthopédiques et plastiques à Moundou au Tchad au profit des enfants handicapés physiques pris en charge par le MNDP en partenariat avec l'hôpital régional de Moundou. Un effectif de 4099 personnes ont déjà été opérées de 1982 jusqu'en 2017⁹.

9.2 Dans les pays de votre région, les OPH sont-elles organisées ou coordonnées au niveau national et/ou régional?

Au niveau national, l'Union Nationale des Associations des Personnes Handicapées du Tchad (UNAPHT), est un réseau des Organisations des Personnes Handicapées (OPH) du Tchad toutes catégories confondues; moteurs, sensoriels (malentendants et non-voyants), mentaux et lépreux. Elle est née de la volonté manifeste des Organisations des Personnes Handicapées le 13 janvier 1996 et a eu son autorisation de fonctionner du ministère de l'administration du territoire sous le Folio n°2466 du 27 novembre 2006. Elle est régie par les statuts et le règlement intérieur. Durant son parcours, l'Union a subi des difficultés d'ordre organisationnel qui l'on amené à se restructurer à travers ses textes de base. C'est ainsi que le 19 octobre 2001, ses textes de base ont été amendés aboutissant à l'élection des nouveaux organes le 24 novembre 2001. Lors du congrès tenu du 4 au 6 février 2006 ainsi qu'au congrès de mars 2013 et celui de 13 au 14 mars 2018, ceux-ci ont abouti à l'élection des nouveaux organes et ont redéfini les orientations de l'Union.

7 Humanité et Inclusion: Lancement du projet INCLUJIPH (10 avril 2018) 13.

8 (Comme ci-dessus) 11.

9 (Comme ci-dessus).

Cadre de concertation idéal et d'action, l'UNAPHT est un réseau ouvert au monde extérieur, en vue de mener des actions concrètes pour la consolidation des organisations membres. L'UNAPHT a pour ambition de fédérer autour d'elle des personnes, des institutions qui considèrent que les personnes handicapées ne vivent pas dans un monde à part mais qu'elles font partie intégrante de la société, de la communauté. En effet, il existe au sein des pays de l'Afrique Centrale, un organe régional de coordination des OPH, à savoir la Fédération d'Afrique Centrale des Associations des Personnes Handicapées (FACAPH); Central Africa Eastern Federation of Disabled (CAFOD). Cette organisation sous régionale a été créée pour regrouper les réseaux nationaux des OPH de cette sous-région Afrique Centrale.

9.3 Si le Tchad a ratifié la CDPH, comment a-t-il assuré l'implication des Organisation des Personnes Handicapées dans le processus de mise en œuvre?

Les OPH sont régulièrement invités pour donner leur point de vue aux conférences et séminaires organisés par le gouvernement ou même lors des points de presse.¹⁰ L'ensemble des OPH présentes sont régulièrement conviées à exposer leurs problèmes et recommandations lors de la journée nationale des personnes handicapées.

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 n'ont ménagé aucun effort pour que le gouvernement tchadien procède à la ratification de la Convention des Nations Unies relatives aux Droits des Personnes Handicapées. Ceci à travers des actions de plaidoyer, de sensibilisation. Elles disposent à travers une association dénommée Voix des Personnes Handicapées d'une tranche radiodiffusée à la RNT afin de sensibiliser et d'informer la communauté sur la question du handicap. En dehors de cela, elles mènent des activités de conférence débat, sportives et autres pour solliciter des gouvernants l'instauration d'une législation qui prend en compte la situation des personnes en situation de handicap du Tchad. Ces actions ont commencé à porter leur fruit. C'est ainsi qu'une loi a été promulguée, la convention relative aux droits des personnes handicapées est ratifiée, l'implication des personnes handicapées à travers leur représentant dans certaines institutions notamment le Conseil Economique, Social et Culturel (CESC),¹¹ la Commission Nationale des Droits de l'Homme (CNDH).¹² Il est également à noter que le processus du décret d'application de la loi 007 portant protection des personnes handicapées est dans sa phase finale avec son passage devant le conseil de ministre et surtout la mise en place d'un comité paritaire interministériel pour son toilettage avant son adoption en conseil de ministre.

10 Comme le jour de la fête nationale des personnes handicapées au Tchad. Ou encore comme le point de presse animé par le président de l'Association d'Entraide des Handicapés Physiques au Tchad sous le thème: « la situation des personnes handicapées sur la route de N'gueli » tenu le vendredi 11 juin 2014.

11 Ordonnance N°022/PR/2018 portant Attributions, composition, organisation et fonctionnement du Conseil Economique, Social et Culturel.

12 Loi N°028/PR/2018 du 22 novembre 2018 portant attribution, organisation et fonctionnement de la Commission Nationale 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 qu'il convient de combler. La plupart des OPH ne disposent pas d'un siège pour se réunir. Les adhérents sont en majorité de personnes vulnérables sans qualification professionnelle et vivant dans la précarité extrême. Beaucoup ne possèdent pas les capacités techniques requises 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 audiovisuelles par leurs leaders notamment, lors de la commémoration de la Journée internationale des Personnes Handicapées célébrée chaque année le 3 décembre, ou encore pendant la journée nationale des personnes handicapées. Enfin, ces OPH n'adoptent pas une approche proactive, laissant aux départements ministériels l'initiative de programmer les consultations sur la question du handicap. Leurs actions ne portent véritablement pas du fait également des querelles de leaderships qui les minent.

9.6 Y'a-t-il des exemples pouvant servir de modèles pour la participation des OPH?

Non, il n'existe pas un exemple pour la participation des OPH pouvant servir de modèle.

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?

Nous pouvons noter par exemple l'adoption et la ratification de la Convention des Nations Unies relative aux Droits des Personnes Handicapées (CDPH), la loi N°07/PR/2007 portant protection des personnes handicapées au Tchad. Les personnes handicapées ont été associées dans tous les processus pour parvenir à ces résultats.

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, à cette évaluation nécessite une expertise externe en vue d'identifier les besoins réels des personnes vivant avec handicap afin de formuler un plan stratégique et un plan d'action pour faciliter leur inclusion socioéconomique. Un appui technique de partenaires au développement est important pour le renforcement de capacités des OPH et surtout dans le cadre des techniques du plaidoyer et du lobbying pour leur promotion dans tous les secteurs (économique, politique, social etc). 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 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 devraient être représentés dans tous les secteurs et à tous les niveaux pour faciliter leur inclusion. Actuellement les OPH sont représentées dans le Conseil Economique Social et Culturel (CESC), dans les organes en charge du suivi et de la mise en œuvre d'instruments de droits de l'homme ratifiés par la République du Tchad notamment, par les ministères en charge de la promotion et de la protection des droits de l'Homme; du ministère de la femme, de la protection de la petite enfance et de la solidarité nationale; et surtout au niveau de la Commission Nationale des Droits de l'Homme. Les personnes en situation de handicap doivent consulter régulièrement sur les aspects intéressants leur vie et surtout à l'occasion de formulation et de la mise en œuvre des programmes, projets de développement.

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?

Le Centre National d'Appui à la Recherche ou (CENAR) fondé en 1991 est un centre de recherche public dont le siège est situé à N'Djamena, la capitale du Tchad. Ce Centre est un établissement public à caractère administratif, il est affilié au Ministère chargé de l'Enseignement supérieur, de la Recherche scientifique et technique. Les chercheurs de cet établissement n'ont pas à ce jour conduit ou publiés 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) spécifique(s) 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 personnes handicapées demande l'implication de plusieurs départements ministériels, comme le Ministère de l'Education Nationale et des Enseignements Supérieurs qui s'efforcent de faciliter pour les élèves handicapés l'accès à l'éducation. Le Ministère des Droits de l'Homme et de la Promotion des libertés qui est chargé d'appliquer la politique gouvernementale en matière des Droits de l'Homme, surtout celle liées aux personnes handicapées.¹³ Le Ministère de l'Action Sociale, de la Solidarité Nationale et de la Famille intervient dans la promotion et la protection des droits des femmes vulnérables ainsi que dans la protection des personnes handicapées. Il est érigé une direction

13 Ce ministère existe depuis 2005 au Tchad et a à sa tête un Ministre, un Secrétaire Général et un Secrétaire Général Adjoint. Il comprend cinq directions: la direction des droits civils et politiques, la direction des personnes vulnérables ou on retrouve les personnes handicapées, la direction des droits économiques sociaux et culturels, la direction de la promotion et la vulgarisation des droits de l'homme qui traite aussi des problèmes des personnes handicapées et la direction des études; des législations et du contentieux.

des personnes handicapées au sein du Ministère de la Femme, de la Protection de la Petite Enfance et de la Solidarité Nationale dont le rôle est de « Coordonner, suivre et évaluer les activités de services ainsi que les associations y afférentes placées sous sa responsabilité »¹⁴. Suite aux recommandations de la Conférence Nationale Souveraine, cette Direction de Réinsertion des Personnes Handicapées est créée et est placée sous la tutelle du Ministère de la Femme, de la Protection de la Petite Enfance et de la Solidarité Nationale. Cette structure a pour attributions de:

- l'élaboration et la mise en œuvre des programmes et projets en faveur des personnes handicapées;
- la protection juridique et sociale des personnes handicapées;
- la vulgarisation des instruments juridiques nationaux et internationaux relatifs aux personnes handicapées;
- la contribution à la ratification des textes juridiques internationaux en faveur des personnes handicapées;
- la promotion de la réinsertion et de la réadaptation à base communautaire des personnes handicapées;
- le développement d'un partenariat avec les organisations œuvrant en faveur des personnes handicapées;
- le suivi/évaluation des activités des organisations des personnes handicapées (associations, groupements, ONG)
- l'élaboration d'un programme d'information et de sensibilisation sur les causes et conséquences du handicap;
- la définition des normes et procédures de création des structures de prise en charge des personnes handicapées;
- la participation à la collecte et l'analyse des données statistiques sur les types de handicap.

Toutes les actions réalisées en faveur des personnes doivent être coordonnées par cette structure étatique. Mais, il faut reconnaître que cette coordination des actions est limitée, faute des moyens.

11 Préoccupations majeures des droits de l'homme relatives aux personnes handicapées

11.1 Quels sont les défis contemporains des personnes handicapées au Tchad? 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 psychiatrie¹⁵ et des Centres

14 Décret N°780/PR/PM/MFFSN/2018 portant organisation du Ministère de la Femme, de la Famille et de la Solidarité Nationale article 12.

15 Dans www.makaila.fr portant sur les médecins à problème du Tchad, il est établi qu'en date du 18 juillet 2012 ou cet article a été écrit, on dénombrait un seul psychiatre au Tchad. Il y avait même encore un sérieux problème car ce dernier est rongé par l'alcool et tout semble lui échappé aussi bien dans son service que dans ses fonctions intellectuelles.

d'internement de ces personnes. Mais, il n'existe pas au Tchad des rituelles liés à certaines catégories des personnes handicapées.

En termes de défis, la pauvreté extrême de la population tchadienne affecte les groupes vulnérables et spécifiquement les personnes handicapées. Ces derniers pour la plupart vivant de la mendicité, dorment dans la rue. C'est pour cette raison que les associations des personnes handicapées 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 ne disposent pas des facilités pour transporter les usagers handicapés. Ils prétextent que leurs bus n'ont pas de rampe d'accès pour les fauteuils roulants ou que les handicapés mettent du temps pour monter ou descendre. Il arrive parfois que le fauteuil roulant d'une personne décédée soit récupéré par un autre handicapé. Pour avoir une maison en location par exemple, il faut s'assurer que le lieu soit le plus accessible possible, c'est-à-dire pas d'escalier; rampe; toilettes accessibles, entrée et salle assez grande pour qu'un fauteuil puisse passer.

On peut noter dans le même registre l'exclusion propre de la part de certaines personnes handicapées parce que disent-elles, sont rejetées de la société; tout comme la population a des préjugés au sujet du handicap qui est tantôt une maladie contagieuse ; héréditaire voire une malédiction. L'inclusion de ces derniers ne passera que par la rupture de ces barrières afin de permettre une meilleure inclusion de ces derniers sur presque tous les plans.

Par ailleurs, on enregistre que l'autonomisation économique, la mobilité et l'accessibilité des personnes handicapées à certains établissements publics constituent un véritable défi auquel des solutions doivent être trouvées.

A ajouter à ce registre la question du respect des droits des femmes en situation de handicap. En effet l'accès aux soins de santé notamment la santé sexuelle et reproductive n'est pas une chose aisée pour ces femmes et filles en situation de handicap. D'autant plus qu'il se pose d'abord de difficultés dues à l'accès physique, ensuite celles ayant trait à l'accueil et à la communication pour une catégorie de ces femmes.

11.2 Comment le Tchad répond-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. Pour répondre au souci d'accessibilité aux bâtiments publics, le projet du Décret d'application de la Loi N°07/PR/2007 sur la protection des personnes handicapées, prévoit des solutions pour la construction des édifices publics qui prennent en compte ces besoins spécifiques. L'article 32 du projet dispose que : « l'Etat et les collectivités territoriales décentralisées, les entreprises et les établissements publics et privés œuvrent à l'aménagement de l'environnement, à l'adaptation des moyens de communication et d'information, à la facilitation des déplacements des personnes handicapées et leurs accès aux prestations. Les parcs de stationnement intérieurs et extérieurs dépendant des bâtiments publics et privés ouverts au public sont aménagés de nature à ce qu'ils permettent de réserver des places pour le stationnement des moyens de transport utilisés par les personnes handicapées ».
- **Accès au transport public:** 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 la 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 équipées pour des rampes 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. Cependant, le projet du Décret d'application de la loi 007/PR/2007 portant sur la protection des personnes handicapées semble être un début de solution à cette difficulté.

- **Accès à l'éducation:** des programmes pour personnes handicapées ont déjà été mis sur pieds. Bien plus, en attendant l'effectivité du projet de décret portant application de la loi 007 de 2007, cette loi énonce en son article 13 que: « les élèves et étudiants handicapés et ceux des parents handicapés bénéficient d'une assistance de l'Etat et des collectivités Territoriales Décentralisées dans le cadre de leur scolarité »; tout comme l'article 14 prescrit qu': « il est institué en faveur des personnes handicapées sensorielles un enseignement de courte durée adapté à leur état en vue leur préparer une bonne réinsertion dans une classe normale ». On comprend que le gouvernement tchadien vole au secours des personnes handicapées sur le volet scolaire.
- **Accès à la formation professionnelle:** la formation professionnelle est du ressort du Ministère de la Formation Professionnelle et de la Promotion des Métiers ainsi que du Ministère des Femmes, de la Famille et de la Solidarité Nationale. Cependant, il faut retenir que ce sont les centres spécialisés de formations professionnelles qui ont beaucoup plus une visibilité, mais faut-il reconnaître que c'est le gouvernement qui leur crée les conditions pour qu'ils exercent. Dans le registre des centres de formations spécialisés, on peut citer le Centre de Formation Professionnelle pour Jeunes Sourds (CFPJS), qui effectue des formations en menuiserie et en couture; la Coordination des Associations et Groupement des Femmes Handicapés du Tchad (CAGFHT) qui fait aussi des formations en couture pour des jeunes femmes.
- **Accès à l'emploi:** à l'occasion de la célébration de la journée mondiale de lutte contre la pauvreté, le 17 octobre 2018, la Banque Mondiale a tiré la sonnette d'alarme. Selon elle, la pauvreté augmentera en 2019, pour atteindre un taux de 39,8% (presque 40%). Quant au taux de chômage, il est estimé à 47% de la population active.¹⁶ Les personnes handicapées appartenant à la frange de la population la plus favorisée touchée par le chômage de masse. Le code du travail tchadien consacre le principe de non-discrimination en matière d'emploi. Toutefois, il faut reconnaître que l'insertion des personnes handicapées dans le monde de l'emploi reste encore une équation difficile à résoudre surtout dans le secteur privé. Avec le projet du Décret d'application, ce problème sera résolu. C'est dans ce sens que le celui-ci prévoit en son article 15 que « l'Etat et les Collectivités Territoriales Décentralisées ont le devoir de créer des conditions incitatives en vue de favoriser l'emploi des personnes handicapées dans les secteurs public ou privé ». A cet effet, ils leur doivent protection contre toute forme d'exploitation et traitement discriminatoire dans l'exercice de leur fonction.
- **Accès à la détente et au sport:** les personnes handicapées ne participent pas vraiment dans les activités socio-culturelles. Le projet du décret d'application de la loi 007 de 2007, définit que les personnes handicapées seront intégrées dans les activités socio-culturelles et y participeront au même titre que les personnes valides. A ce titre, elles bénéficieront des avantages qui en résulteront et recevront en conséquence une formation dans les domaines musical, théâtral et sportif, etc.
- **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 juridique et judiciaire permettra aux personnes handicapées de saisir plus souvent les juridictions internes.
- **Accès aux soins de santé:** le gouvernement tchadien jusqu'ici ne ménage aucun effort pour la prise en charge des personnes handicapées. Mais, l'accès aux soins de santé sera davantage renforcée par à la mise en application du projet de décret d'application. En ce sens « Les personnes handicapées démunies bénéficient de la réduction des frais des soins et de rééducation dans toutes les structures de santé

16 A lire dans tchadrevolution.over-blog.com; « Tchad: le pire s'annonce, le taux de pauvreté atteindra 40% en 2019 ».

publiques Un arrêté conjoint des Ministères de la Santé Publique et de l'Action Sociale fixe les modalités et taux de réduction.

11.3 Le Tchad 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.

Au sujet des subventions ou autre moyen de revenu en vue de soutenir les personnes handicapées, le ministre des micro-crédits pour la promotion de la femme et de la jeunesse fait souligner qu'en 2013, les actions se sont traduites par des dépenses de 3 milliards 500 millions de FCFA pour financer les secteurs tels que le commerce, l'agriculture et l'informel.¹⁷ Concernant l'octroi de crédits, le ministre rappelle que le taux de remboursement oscille autour de 4%.¹⁸ Il a rappelé que ces crédits ne sont pas des dons car les populations sont sensibilisées à cet effet. Les dons sont plutôt octroyés aux personnes vivant avec un handicap, martèle le ministre.¹⁹ Il s'en suit donc que les personnes handicapées sont le plus pris en compte.

11.4 Les personnes handicapées ont-elles un droit de participation à la vie politique, (représentation politique et leadership, vote indépendant etc) au Tchad?

La constitution Tchadienne garantit à tous les citoyens tchadiens majeurs, y compris les personnes handicapées, la libre jouissance de leurs droits civiques et politiques. La République du Tchad a également ratifié en date du 9 juin 1995, le Pacte International sur les Droits Civiles et Politiques qui accorde à tout citoyen le droit de jouir pleinement et sans discrimination des droits civils et politiques.

Concernant la représentation politique, il y a lieu de constater que les personnes handicapées étaient représentées dans le gouvernement de 2013-2015 par le Ministre de la Communication, Porte-parole du Gouvernement Monsieur SYLLA Bakary. Dans la législature actuelle, il y a un déficient visuel qui siège à l'Assemblée Nationale. Les OPH sont représentées également dans le Conseil Economique Social et Culturel (CESC).

11.5 Catégories spécifiques expérimentant des questions particulières/vulnérabilités:

- **Femmes handicapées:** Outre les garanties constitutionnelles et conventionnelles, la Convention sur l'Élimination de toutes les formes de Discrimination à l'égard des Femmes, le Protocole de Maputo portant sur la protection juridique des femmes en général, l'Etat partie a pensé aux mesures spécifiques protégeant les femmes y compris celles handicapées. Il y a la création au sein du ministère de l'action sociale, de la famille et de la solidarité nationale de la direction en charge de la promotion de la femme et du genre. En collaboration étroite avec ses partenaires, celle-ci a mis sur pied une Politique Nationale Genre et une stratégie nationale de lutte contre les violences basées sur le genre notamment la lutte contre les mutilations génitales féminines. On note aussi la création du ministère des micro-projets pour la promotion de la femme et de la jeunesse qui lutte contre la pauvreté et cherche à

17 Rapport de la mission conjointe de promotion des Droits de l'Homme en République du Tchad, du 11 au 19 mars (2013) 31.

18 Comme ci-dessus.

19 Comme ci-dessus.

améliorer les conditions de vie des femmes et des jeunes, surtout les handicapés de cette catégorie.

- **Enfants handicapés:** la République du Tchad 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 gouvernement gère des programmes éducatifs, d'emploi et thérapeutiques pour les personnes handicapées. En cela donc, les enfants handicapés physiques peuvent fréquenter des établissements d'enseignement primaire, secondaire et supérieur. Le gouvernement a apporté un soutien à des écoles pour enfants handicapés visuels et mentaux. Le gouvernement assure aussi une prise en charge médicale pour les enfants handicapés.
- **Prisonniers souffrant de déficience mentale:** la surpopulation carcérale (comme le cas de la prison centrale de Ndjamenà conçue pour accueillir 300 détenus, on dénombre environ 1300; ou encore même celui d'Amsinéé conçue pour accueillir 303 détenus compte de nos jours plus de 2000) demeure un problème grave au Tchad²⁰. Les mineurs ne sont pas séparés des prisonniers adultes masculins et les enfants sont quelques fois incarcérés avec leurs mères détenues. Les ONG locales indiquent que la nourriture, les installations sanitaires et les soins de santé n'étaient pas adéquats alors que la loi spécifie qu'un médecin doit se rendre dans chaque prison trois fois par semaine; mais cette disposition n'est souvent pas respectée. A ce jour, les prisons ne disposent pas d'un médecin généraliste affecté à titre permanent. Ainsi, les prisonniers ne disposent pas de soins appropriés en raison du déficit en personnel qualifié en psychiatrie au sein de l'établissement carcéral. La construction d'un hôpital de psychiatrie est nécessaire pour prendre en charge tous les patients.

12 Perspective future

12.1 Y'a-t-il des mesures spécifiques débattues ou prises en compte présentement dans votre pays au sujet des personnes handicapées?

Le plus grand vœu des personnes handicapées tchadienne à l'heure actuelle est l'autonomisation économique pour leur permettre d'être indépendantes; Pour ce il est impératif de ratifier le projet du décret d'application de la loi 007 de 2007 qui leur permet d'obtenir des avantages en termes des transports, des soins médicaux, d'éducation de leurs enfants, d'accessibilité aux édifices administratives; portant protection des personnes handicapées au Tchad. Il faut y ajouter la mise en œuvre de la convention relative aux droits des personnes handicapées et son protocole facultatif.

12.2 Quelles réformes légales sont proposées? Quelle réforme légale aimeriez-vous voir dans votre pays? Pourquoi?

Le Tchad vient d'adopter et de ratifier la Convention relative aux droits des personnes Handicapées (CDPH), il est important que la législation nationale s'adapte à cette convention pour prendre en compte toutes les dispositions pertinentes concernant le handicap. Il s'agit notamment de:

- Code du travail;
- Code électoral;
- Le code Pénal et bien d'autres textes.

Aussi, est-il important que l'Etat adopte des stratégies et élabore des programmes et projets spécifiques qui devraient prendre en compte les besoins spécifiques exprimés par les personnes vivant avec handicap.

La loi sur l'aide juridique et l'assistance judiciaire au Tchad adopté le 3 avril 2019 devrait garantir explicitement la gratuité de tous les frais d'honoraires, des huissiers ou des expertises, pour les recours exercés par les personnes handicapées.

Etant donné que la jeunesse handicapée tchadienne bénéficie des programmes sur le plan scolaire, l'Etat devrait mettre en place une législation spécifique concernant l'accès à l'éducation des enfants handicapés par la préparation d'un environnement scolaire favorable (création des centres de formation professionnelle et d'éducation spécifiques aux handicapés).

L'Etat serait bien inspiré 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 médicaux, etc.

Summary

According to the World Health Organization (WHO), the Malian population is 18,1 million. Persons with disabilities are 2 247 500, that is 15% of the total population. According to the 2003 household survey, the most prevalent forms of disabilities include visual, motor disabilities, cerebral driving handicap, intellectual disabilities and psychosocial handicap and albinism.

The Republic of Mali signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD), as well as its Optional protocol on 15 May 2007. The CRDP and the Optional Protocol have been ratified on 7 April, 2008. Through the CRDP Art. 35, the Republic of Mali was supposed to submit its country report on 24 June 2019.

Through Art. 2 the Constitution of Mali, all Malians are born and remain free and equal in rights and duties. Any discrimination based on disability is therefore prohibited. In addition, the Constitution indirectly addresses disabilities through Art. 1 affirms that 'the human person is sacred and inviolable. Every individual has the Right to life, liberty, security and integrity of his or her person.'

The Republic of Mali has an important pieces of legislation that directly address disability. The key one is the Law 2018-027, of 12 June 2018 on the Rights of Persons with Disabilities.

The policies that directly address persons with disabilities are: The Policy of Solidarity (since 1993) which aims to reduce inequalities, provide social protection and promote the socio-economic development of vulnerable groups such as persons with disabilities and the National Special Education Policy (1999).

* Associate researcher at 'Les Afriques dans le Monde' (LAM)/Science Po Bordeaux.

Mali has the following programmes: The National program of Rehabilitation on Community Basis (RBC) since 1998 is to raise the awareness of families of children with disabilities, their rehabilitation and their rehabilitation at home; the Health and Social Development Program, the Ten-Year Health and Social Development Plan (2014-2023); and the Strategic Plan for the Promotion of Persons with Disabilities (2015-2024).

Other than ordinary courts or tribunals, the Republic of Mali does not have an official body which specifically addresses the violation of the Rights of people with disabilities. The Republic of Mali has a National Human Rights Commission, since 2016. There are numerous organisations that represent and advocate for the rights and welfare of persons with disabilities in Mali, represented by the Malian Federation of Associations of Disabled persons which is an umbrella body of around 20 organisations. In Mali, the Ministry of Solidarity and Humanitarian Action is in charge of people with disabilities. The Ministry develops and implements policies and strategies in favour of disabled people. Persons with disabilities encounter multiple levels of exclusion and discrimination. As far as access is concerned, although laws provide for access to public buildings, employment, in practice, very little is done to ensure access for persons with disabilities.

The Republic of Mali should conduct reliable specific household census of persons with disabilities, taking into account women, children and elderly persons with disabilities.

1 Les indicateurs démographiques

1.1 Quelle est la population totale de la République du Mali?

Selon l'Organisation Mondiale de la Santé, la population totale de la République du Mali est en 2017 de 18,1 millions d'habitants.¹

1.2 Méthodologie employée en vue d'obtenir des données statistiques sur la prévalence du handicap en République du Mali. Quels sont les critères utilisés pour déterminer qui fait partie de la couche des personnes handicapées en République du Bénin?

Selon Handicap International en 2017, le Mali compte un peu plus de 2,7 millions de personnes handicapées sur un total de 18,1 millions d'habitants.²

1 Handicap International (HI), Information fédérale –Fiche Pays Mali – 2017 09 FR, p.1 https://www.handicapinternational.be/sites/default/files/paginas/bijlagen/201710_fp_mali_fr.pdf 1 (18/09/2019).

2 Handicap International (HI), Information fédérale –Fiche Pays Mali – 2017 09 FR, p.1 https://www.handicapinternational.be/sites/default/files/paginas/bijlagen/201710_fp_mali_fr.pdf (18/09/2019) (Comme ci-dessus) 1.

1.3 Quel est le nombre total et le pourcentage des personnes handicapées en République du Mali?

Il y a environ 2 247 500 personnes en situation de handicap³ (soit 15% de la population) au Mali.⁴

1.4 Quel est le nombre total et le pourcentage des femmes handicapées en République du Mali?

Aucun recensement récent au niveau national n'a été mené sur le nombre total et le pourcentage de femmes en situation de handicap en République du Mali

1.5 Quel est le nombre total et le pourcentage des enfants handicapés en République du Mali?

Aucun recensement récent au niveau national n'a été mené sur le nombre total et le pourcentage d'enfants en situation de handicap en République du Mali.

1.6 Quelles sont les formes de handicap les plus répandues en République du Mali?

Par déductions nous pouvons considérer que les formes de handicap les plus répandues au Mali sont les handicaps mentaux (paralysie cérébrale, retards de développement neurologiques et/ou psychomoteurs chez les enfants selon Handicap International de 2017), le handicap moteur, la malvoyance, l'albinisme.

2 Obligations internationales

2.1 Quel est le statut de la Convention des Nations Unies relative aux Droits des Personnes Handicapées (CDPH) en République du Mali? La République du Mali a-t-il signé et ratifié la CDPH? Fournir le(s) date(s). La République du Mali a-t-il signé et ratifié le Protocole facultatif? Fournir le(s) date(s).

La République du Mali a signé la Convention Relative aux Personnes Handicapées (CRDPH), ainsi que le Protocole facultatif se rapportant à la CRDPH, le 15 mai 2007. Les CRDPH et le Protocole ont été ratifiés le 7 avril 2008. La République n'a formulé aucune réserve, ni introduit une quelconque déclaration interprétative.⁵

3 'Mali, Adoption du Projet de loi relatif aux Droits des Personnes Handicapées' <http://proadiph.org/Mali-Adoption-du-Projet-de-loi-relatif-aux-Droits-des-Personnes-Handicapees.html> (Consulté le 18/09/2019).

4 M Mateso 'Afrique : le cri de détresses des personnes handicapées, abandonnées à leur sort' https://www.francetvinfo.fr/monde/afrique/mali/afrique-le-cri-de-detresse-des-personnes-handicapees-abandonnees-a-leur-sort_3054361.html (Consulté le 18/09/2019).

5 Nations Unies Collections des Traités https://treaties.un.org/pages/viewdetails.aspx?src=treaty&mtmsg_no=iv-15-a&chapter=4&lang=en (Consulté le 18/09/2019).

- 2.2 Si la République du Mali 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 du Mali a-t-il soumis son rapport? Sinon quelles sont les raisons du retard telles qu'avancées par la branche gouvernementale en charge?**

Conformément à l'article 35 de la CDPH, la République du Mali était tenue de soumettre son rapport initial dans un délais de deux ans; soit le 30 juin 2010. La République du Mali a soumis son rapport, le 24 juin 2019.⁶

- 2.3 Si la République du Mali 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 du Mali. Y'avait-il des effets internes découlant du processus de rapport liés aux questions handicapées du Mali?**

Le Comité n'a pas encore examiné le rapport; celui-ci ayant été soumis que très récemment (24 juin 2019).

- 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 du Mali 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 personnes handicapées dans le rapport de la Revue Périodique Universelle (RPU) des Nations Unies de la République du Mali? Si oui, quels étaient les effets de ces observations ou recommandations?**

Comité des droits de l'homme

La République du Mali n'a soumis que deux rapports relatifs au Pacte international relatif aux droits civils et politiques; le premier le 14 août 1979 et publié le 19 septembre 1979. Le second a été soumis le 3 janvier et publié le 13 janvier 2003.⁷ Cependant, la Constitution malienne de 1992, actée le 7 juin 2017, mentionne dans son article 2 que toute discrimination fondée sur le handicap est prohibée.⁸

6 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019).

7 OHCHR 'State party's report CCPR/C/1/Add.49, 1979' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=frInternational (Consulté le 18/09/2019).

8 Constitution de juin 2017, article 2.

Comité pour l'élimination de la discrimination à l'égard des femmes

- La République du Mali ne fait pas mention spécifique des droits des personnes en situation de handicap dans son rapport soumis le 27 avril 2015, publié le 29 avril 2015.⁹
- Le 27 novembre 2015, le Comité demande à ce que les femmes handicapées aient accès aux services de santé, à l'éducation, à l'eau, à l'assainissement, à l'alimentation, au logement et à des activités rémunérées.¹⁰
- Le Comité demande à ce que les femmes handicapées bénéficient de budgets spéciaux pour l'éducation, le développement rural et la santé.¹¹
- En matière de participation à la vie politique et publique le Comité constate avec inquiétude que les femmes en situation de handicap n'ont toujours pas droit de vote en vertu de l'Article 28 de la Loi électorale n° 06-44 du 4 septembre 2006,¹² et qu'elles obtiennent encore difficilement les documents pour voter.¹³
- En matière d'emploi, le Comité demande l'application du régime national de protection de la santé pour les femmes handicapées.¹⁴
- En matière de santé, le Comité s'inquiète de l'insuffisance du financement en matière de santé et aux difficultés des femmes handicapées à bénéficier de soins de santé de bases.¹⁵ Il est donc demandé au Mali d'accroître les budgets pour la santé de base.¹⁶
- Pour les femmes handicapées, il a été adopté en 2015 le plan stratégique décennal et le plan d'action visant à promouvoir les droits socioéconomiques des personnes handicapées, et élaboré un projet de loi sur la protection sociale des personnes handicapées, visant spécifiquement les femmes et les filles handicapées.¹⁷
- Le Comité recommande la finalisation de la loi sur la protection sociale des personnes handicapées, la mise en place d'un mécanisme de vérification de son application et la condamnation contre les actes de discrimination contre les femmes et les filles en situation de handicap et leurs indemnisation. Il préconise un recensement des personnes handicapées, ventilé par âge, par sexe et par région. Des activités de sensibilisation doivent être menées pour promouvoir les droits des

- 9 OHCHR 'Rapport de l'Etat partie CEDAW/C/MLI/6-7, 29/04/2015' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 18/09/2019).
- 10 OHCHR 'Liste de points et de questions concernant les sixième et septième rapports périodiques (présentés en un seul document) du Mali CEDAW/C/MLI/Q/6-7, 27/11/2015, p. 6' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 18/09/2019).
- 11 OHCHR 'Rapport de l'Etat partie CEDAW/C/MLI/6-7, 29/04/2015, p. 6' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 18/09/2019) (n 9 Comme ci-dessus).
- 12 OHCHR 'Rapport de l'Etat partie CEDAW/C/MLI/6-7, 29/04/2015, p. 10' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 18/09/2019) (Comme ci-dessus).
- 13 OHCHR 'Rapport de l'Etat partie CEDAW/C/MLI/6-7, 29/04/2015, p. 10' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 18/09/2019) (Comme ci-dessus).
- 14 OHCHR 'Rapport de l'Etat partie CEDAW/C/MLI/6-7, 29/04/2015, p. 11' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 18/09/2019) (Comme ci-dessus).
- 15 OHCHR 'Rapport de l'Etat partie CEDAW/C/MLI/6-7, 29/04/2015, p. 12' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 18/09/2019) (Comme ci-dessus).
- 16 OHCHR 'Rapport de l'Etat partie CEDAW/C/MLI/6-7, 29/04/2015, p. 12' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 18/09/2019) (Comme ci-dessus).
- 17 OHCHR 'Rapport de l'Etat partie CEDAW/C/MLI/6-7, 29/04/2015, p. 13-14' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 18/09/2019) (Comme ci-dessus).

femmes et des filles en situation de handicap. Enfin, l'accès à la justice, à la vie politique, à l'éducation et à des activités génératrices de revenus sont encouragés.¹⁸

Comité de droits économiques, sociaux et culturels

- La République du Mali a fait mention spécifique, dans son rapport publié le 27 juillet 2018 des personnes en situation de handicap.¹⁹
- Le Comité exprime des préoccupations sur l'absence de loi de lutte contre la discrimination et recommande une meilleur prévention pour lutter contre la discrimination dont sont victimes les personnes en situation de handicap.²⁰

Commission africaine des Droits de l'Homme et des Peuples

Selon le 45^{ème} Rapport d'activités de la Commission africaine des Droits de l'Homme et des Peuple, présenté-conformément à l'Art. 54 de la Charte Africaine des Droits de l'Homme et des Peuples, lors de la 60^{ème} Session ordinaire, la République du Mal fait partie des 12 pays étant à jour ses rapports d'activités périodiques.²¹

- La République du Mali fait mention spécifique des personnes en situation de handicap, dans son rapport périodique à la Commission Africaine des Droits de l'Homme et des Peuples (CADHP), 2001-2011.
- Le Mali a ratifié la Convention relative aux Droits des personnes handicapées et son Protocol facultatif.²²
- La République du Mali a mis en place le Parlement des Enfants sous la tutelle du Ministère de la Promotion de la Femme, de l'Enfant et de la Famille. Les enfants handicapés peuvent être membres de ce Parlement des enfants.²³
- Le Mali indique que les Associations et Organisations de la Société civile contribuent à la promotion et la promotion des droits de l'homme, notamment des droits des personnes en situation de handicap.²⁴
- La République du Mali a procédé au recrutement de plusieurs jeunes diplômés en situation de handicap dans la fonction publique. L'Agence Nationale Pour l'Emploi

18 OHCHR 'Rapport de l'Etat partie CEDAW/C/MLI/6-7, 29/04/2015, p. 14' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 18/09/2019) (n 9 Comme ci-dessus).

19 OHCHR 'Rapport initial soumis par le Mali en application des articles 16 et 17 du Pacte attendu en 1990 E/C.12/MLI/1, 27/07/2018, p. 42' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 18/09/2019).

20 OHCHR 'Observations finales concernant le rapport initial du Mali E/C.12/MLI/CO/1, 06/11/2018, p. 3' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 18 septembre 2019).

21 ACHPR '45eme Rapport d'activités de la Commission des Droits de l'Homme et des Peuples, 10 mai-13 novembre 2018, p. 8' http://www.achpr.org/files/activity-reports/45/45th_activity_report_fre.pdf (Consulté le 18/09/2019).

22 ACHPR 'Rapport périodique du Mali à la Commission Africaine des Droits de l'Homme et des Peuples relatif à la mise en œuvre de la Charte Africaine des Droits de l'Homme et des Peuple, 2001-2011, 20/04/2016, p. 12' <http://www.achpr.org/fr/states/mali/reports/2nd-2001-2011/> (Consulté le 18/09/2019).

23 ACHPR 'Rapport périodique du Mali à la Commission Africaine des Droits de l'Homme et des Peuples relatif à la mise en œuvre de la Charte Africaine des Droits de l'Homme et des Peuple, 2001-2011, 20/04/2016, p. 22' <http://www.achpr.org/fr/states/mali/reports/2nd-2001-2011/> (Consulté le 18/09/2019) (Comme ci-dessus).

24 ACHPR 'Rapport périodique du Mali à la Commission Africaine des Droits de l'Homme et des Peuples relatif à la mise en œuvre de la Charte Africaine des Droits de l'Homme et des Peuple, 2001-2011, 20/04/2016, p. 23' <http://www.achpr.org/fr/states/mali/reports/2nd-2001-2011/> (Consulté le 18/09/2019) (Comme ci-dessus).

(ANPE) au Mali a organisé plusieurs sessions de formation en vue de faciliter leur insertion socioprofessionnelle.²⁵

Examen Périodique Universel²⁶

- La République du Mali a mentionné les organisations de la société civile qui contribuent à la promotion et à la protection des droits des personnes handicapées, en page 9, dans son rapport examiné le 3 novembre 2010.²⁷
- Dans son rapport examiné le 22 janvier 2013, la République du Mali mentionne, en page 9, les Droits des Personnes Handicapées.²⁸
- En page 14, l'Afrique du Sud félicite le Mali pour la création de l'institution nationale des droits de l'homme et à interroger le Mali sur la formation de prise en charge des enfants handicapés et leur insertion dans le système scolaire ordinaire.²⁹

2.5 Y'avait-il un quelconque effet interne sur le système légal de la République du Mali après la ratification de l'instrument international ou régional au 2.4 ci-dessus?

La ratification de la CRDPH et du Protocol facultatif par la République du Mali, a eu pour effet, avec la loi n°2017 – 31/AN-RM portant révision de la Constitution du 25 février 1992, de voir citer dans l'article 2, le terme 'handicap'.³⁰ La mention 'les femmes handicapées se voient automatiquement refuser le droit de vote à cause de leur handicap'³¹ a été retirée.

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?

Selon l'article 139 de la Loi n°2017-31/AN-RM portant révision de la Constitution du 25 février 1992 les traités ou accords ratifiés ont une autorité supérieure à celle des lois dès leur publication.

25 ACHPR 'Rapport périodique du Mali à la Commission Africaine des Droits de l'Homme et des Peuples relatif à la mise en œuvre de la Charte Africaine des Droits de l'Homme et des Peuple, 2001-2011, 20/04/2016, p. 69' <http://www.achpr.org/fr/states/mali/reports/2nd-2001-2011/> (Consulté le 18/09/2019) (Comme ci-dessus).

26 OHCHR 'Examen périodique universel – Mali' <https://www.ohchr.org/FR/HRBodies/UPR/Pages/MLIndex.aspx> (Consulté le 18/09/2019).

27 OHCHR 'Rapport national soumis en Accord avec le Paragraphe 15 A) de l'annexe à la Résolution 5/1 du Conseil des Droits de l'Homme (A/HRC/WG.6/2/MLI/1), 14/04/2008, p. 9' <https://www.ohchr.org/FR/HRBodies/UPR/Pages/MLIndex.aspx> (Consulté le 18/09/2019).

28 OHCHR '(Rapport national présenté conformément au paragraphe 5 de l'annexe à la résolution 16/21 du Conseil des droits de l'homme (A/HRC/WG.6/15/MLI/1), 4/12/2012, p. 9' <https://www.ohchr.org/FR/HRBodies/UPR/Pages/MLIndex.aspx> (Consulté le 18/09/2019).

29 OHCHR 'Rapport du Groupe de travail sur l'Examen périodique universel (A/HRC/8/50), 13/06/2008, p. 14' <https://www.ohchr.org/FR/HRBodies/UPR/Pages/MLIndex.aspx> (Consulté le 18/09/2019).

30 Loi n°2017 – 31/AN-RM portant révision de la Constitution du 25 février 1992, Art. 2

31 Loi électorale n°06-044 du 4 septembre 2006 consolidée (modifiée par la loi n°2011-085 du 30 décembre 2011 et la loi n°2013-017 du 21 mai 2013).

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.

La ratification de la CDPH vaut son incorporation dans la législation malienne; une procédure n'a pas semblé nécessaire. Dans l'Article 2 de la Constitution de 2017 de la République du Mali, est incorporé le terme 'handicap'. A la suite de longs plaidoyers de la Fédération Malienne des Personnes Handicapées (FEMAPH) auprès du gouvernement, est adoptée à l'unanimité, le 10 mai 2018 à l'Assemblée Nationale, la Loi portant protection des personnes vivant avec un handicap. Elle a été inscrite au Journal Officiel le 18 juin 2018,³² mais 'le texte n'est pas encore traduit dans les faits.'³³

3 Constitution

3.1 La constitution de la République du Mali 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 du Mali contient des dispositions concernant directement le handicap; tous les Maliens naissent et demeurent libres et égaux en droits et en devoirs. Toute discrimination fondée sur le handicap est donc prohibée (Art 2).

3.2 La constitution de la République du Mali contient-elle des dispositions concernant indirectement le handicap? Si oui énumérez les dispositions et expliquez comment chacune d'elles traite indirectement du handicap.

La loi n°2017 – 31/AN-RM portant révision de la Constitution du 25 février 1992, proclame dans son préambule son adhésion à la Déclaration Universelle des Droits de l'Homme, la Convention sur l'élimination de toutes formes de discrimination à l'égard des femmes, la Convention contre la torture et autres peines ou traitements cruels, inhumains ou dégradant, la Convention relative aux droits de l'enfant et la Charte Africaine des Droits de l'Homme et des Peuples. Dans son article 1 la Constitution affirme que 'la personne humaine est sacrée et inviolable. Tout individu a droit à la vie, à la liberté, à la sécurité et à l'intégrité de sa personne'.

32 Journal Officiel de la République du Mali 'Loi n° 2018-027 du 12 juin 2018 Relative aux Droits des personnes vivant avec un handicap, p. 863-865' https://www.ilo.org/dyn/natlex/natlex4.detail?p_lang=fr&p_isn=107353&p_country=MLI&p_count=1 (Consulté le 18/09/2019).

33 N Kane 'Mali : loi relative aux personnes handicapées, les concernés attendent son application' Hémicycles d'Afrique (9 juin 2018) <https://hemicyclesdafrique.com/mali-loi-relative-aux-personnes-handicapees-les-concernes-attendent-son-application/> (Consulté le 18/09/2019).

4 Législation

4.1 La République du Mali a-t-elle une législation concernant directement le handicap? Si oui énumérez la législation et expliquez comment la législation aborde le handicap.

La République du Mali a une législation spécifique relative aux droits des personnes vivant avec un handicap; la loi n°2018-027 du 12 juin 2018.³⁴ adopte les principes généraux tels que:

- (a) Le respect de la dignité intrinsèque, de l'autonomie individuelle, y compris la liberté de faire ses propres choix, et de l'indépendance des personnes handicapées;
 - (b) La non-discrimination;
 - (c) La participation et l'intégration pleines et effectives dans la société;
 - (d) Le respect de la différence et l'acceptation des personnes handicapées comme faisant partie de la diversité humaine et de l'humanité;
 - (e) L'égalité des chances;
 - (f) L'accessibilité;
 - (g) L'égalité entre les hommes et les femmes;
 - (h) Le respect du développement des capacités de l'enfant handicapé et le respect du droit des enfants handicapés à préserver leur identité.³⁵
- Loi n°99-041/P-RM du 12 août 1999 portant Code de Prévoyance sociale en République du Mali favorable à la protection et à la promotion des personnes vivant avec un handicap.³⁶
 - Loi d'orientation sur l'éducation en faveur des personnes handicapées (Loi n°99-046 du 28 décembre 1999)³⁷ (Art. 46, 47 et 55).³⁸

34 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 10' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (n 6 Comme ci-dessus).

35 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 10' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (n 6 Comme ci-dessus).

36 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 10' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (n 6 Comme ci-dessus); Journal officiel de la République du Mali <http://ilo.org/dyn/natlex/docs/SERIAL/58650/45533/F225184647/MLI-58650.pdf> (Consulté le 18/09/2019).

37 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 11' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (Comme ci-dessus).

38 Loi 99-046 AN RM, portant loi d'orientation sur l'éducation <https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/97009/114926/F-568307560/MLI-97009.pdf> (Consulté le 18/09/2019).

- Loi n°02-016 du 03 juin 2002 fixe les règles générales de l'urbanisme qui tiennent compte des personnes en situation de handicap doivent avoir accès aux établissements recevant du public.³⁹
- Loi n°2017-021/P-RM du 14 juin 2017 portant modification de la loi n°92-020 du 23 septembre 1992 portant Code de Travail en République du Mali: 'Le droit au travail et à la formation est reconnu à chaque citoyen, sans discrimination. Est interdite toute discrimination sur la base de critères comme l'invalidité, le handicap' (Article 4).⁴⁰

4.2 La République du Mali a-t-elle une législation concernant indirectement le handicap? Si oui énumérez la principale législation et expliquez comment elle réfère au handicap.

La République du Mali a une législation concernant indirectement le handicap:

- Article 1 de la Constitution du 25 février 1992 dispose que : 'la personne humaine est sacrée et inviolable. Tout individu a le droit à la vie, à la liberté, à la sécurité et à l'intégrité de sa personne';

Loi n°01-80 du 20 août 2001 portant Code de procédure pénale en République du Mali (Modifiée par la Loi n°2013-016 du 21 mai 2013).

.

5 Décisions des cours et tribunaux

5.1 Les cours (ou tribunaux) de la République du Mali 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.

Nous n'avons pas trouvé de décisions de justice portant sur le handicap.

6 Politiques et programmes

6.1 La République du Mali 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.

- Politique de solidarité mise en place par le gouvernement malien dès 1993 en faveur des personnes handicapées;

39 Journal Officiel de la République du Mali <http://extwprlegs1.fao.org/docs/pdf/mli153270.pdf> (Consulté le 18/09/2019).

40 Journal Officiel de la République du Mali <https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/104701/127819/F1627870706/MLI-104701.pdf> (Journal Officiel de la République du Mali) (Consulté le 18/09/2019).

- Politique nationale en matière d'éducation spéciale (1999).⁴¹

Article 46 - L'éducation spéciale a pour objet de donner des soins éducatifs appropriés aux enfants et aux adolescents handicapés afin de leur permettre de conquérir ou de reconquérir leur autonomie intellectuelle, physique et morale et de s'insérer harmonieusement dans le contexte social.

Article 47 - L'éducation spéciale s'adresse aux grands handicapés.

Article 55 - Les handicapés légers sont accueillis dans les différents ordres et types d'enseignement. Ils reçoivent les mêmes apprentissages que les apprenants non handicapés en même temps qu'ils bénéficient de soins éducatifs spéciaux.⁴²

- Programme National de Réadaptation à Base Communautaire (1998)⁴³ ayant pour objectif de procéder à la sensibilisation des familles des enfants handicapés, à leur rééducation et à leur réadaptation à domicile.
- Programme de Développement sanitaire et social (PRODESS),⁴⁴ qui prône l'intégration socio-économique des personnes handicapées.
- Programme AMO qui appuie les personnes en situation de handicap dans le prise en charge de leurs problèmes de santé.
- Handicaisse qui favorise l'accès des personnes handicapées au crédit/épargne; elle n'est pas encore fonctionnelle.
- Plan décennal de développement sanitaire et social (PDDSS) 2014-2023,⁴⁵ dont les orientations sont la promotion de l'intégration socio- économique des personnes handicapées et l'appareillage et la rééducation de plusieurs personnes handicapées.
- Plan stratégique pour la promotion des personnes handicapées 2015-2024 qui concerne la promotion socioéconomique des personnes handicapées.⁴⁶

6.2 La République du Mali 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.

La République du Mali a des politiques et des programmes qui englobent indirectement le handicap.⁴⁷

41 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 11' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (n 6 Comme ci-dessus).

42 Loi 99-046 AN RM, portant loi d'orientation sur l'éducation <https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/97009/114926/F-568307560/MLI-97009.pdf> (Consulté le 18/09/2019) (n 38 Comme ci-dessus).

43 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 14' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (n 6 Comme ci-dessus).

44 'Plan décennal de développement sanitaire et social (PDDS) 2014-2023' http://www.sante.gov.ml/docs/PDDSS_2014-2023.pdf (Consulté le 18 septembre 2019).

45 'Plan décennal de développement sanitaire et social (PDDS) 2014-2023' http://www.sante.gov.ml/docs/PDDSS_2014-2023.pdf (Consulté le 18 septembre 2019) (Comme ci-dessus).

46 MA Traoré 'Promotion des personnes handicapées: en attendant la mise en route du plan stratégique 2015-2024' (23 décembre 2015) Bamada.net <http://bamada.net/promotion-des-personnes-handicapees-en-attendant-la-mise-en-route-du-plan-strategique-2015-2024> (Consulté le 18 septembre 2019).

47 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 11' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (n 6 Comme ci-dessus).

- Institutionnalisation du mois de la solidarité et de la lutte contre l'exclusion (dont les personnes handicapées) par Décret n°01- 468/P-RM du 27 septembre 2001. Les types d'intervention de solidarité,⁴⁸ étant les activités de promotions des personnes handicapées.⁴⁹
- Politique nationale de formation professionnelle (2008) en faveur des personnes handicapées.⁵⁰
- Politique nationale de l'emploi (2015) en faveur des personnes handicapées empêchées de travailler.⁵¹
- Politique nationale de protection sociale (2016),⁵² permettant aux personnes handicapées de bénéficier en priorité des services publics et privés.⁵³

7 Organismes en charge des personnes handicapées

7.1 En dehors des cours ou tribunaux ordinaires, la République du Mali 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.

Non, en dehors des cours ou tribunaux ordinaires, la République du Mali ne dispose pas d'un organisme officiel qui s'intéresse spécifiquement à la violation des droits des personnes handicapées.

7.2 En dehors des cours ou tribunaux ordinaires, la République du Mali 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 République du Mali a un organisme officiel qui, bien que n'étant pas spécifiquement en charge de la violation des droits des personnes en situation de handicap s'y attèle tout de même: la Commission Nationale des Droits de l'Homme (CNDH).

48 B Sankaré 'Octobre, mois de la Solidarité du Mali. Il fallait y penser !' (23 octobre 2018) maliweb.net <https://www.maliweb.net/societe/octobre-mois-de-la-solidarite-au-mali-il-fallait-y-penser-2783098.html> (Consulté le 18/09/2019).

49 'Réponse au questionnaire' https://www.ohchr.org/Documents/Issues/Disability/.../civil.../DPOs_Mali_FRA.docx (Consulté le 18/09/2019).

50 'Politique nationale de Formation professionnelle' https://www.ilo.org/dyn/natlex/natlex4.detail?p_lang=en&p_isn=103134&p_count=9&p_classification=09 (Consulté le 18/09/2019).

51 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 11' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (n 6 Comme ci-dessus) 11; Y Bourdet, K Dabitaou, AS Dembélé 'Croissance, emploi et politiques pour l'emploi au Mali' (Bureau International du Travail) https://www.ilo.org/wcmsp5/groups/public/---ed_emp/documents/publication/wcms_244833.pdf (Consulté le 18/09/2019).

52 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 11' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (Comme ci-dessus).

53 'Politique nationale de protection sociale, juin 2015, p. 8-9' <http://extwprlegs1.fao.org/docs/pdf/mli173766.pdf> (Consulté le 18/09/2019).

8 Institutions Nationales des Droits de l'Homme (Commission des Droits de l'Homme ou Ombudsman ou Protecteur du Citoyen)

- 8.1 La République du Mali est-elle dotée 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 la République du Mali n'a jamais abordé des questions relatives aux droits des personnes handicapées.**

La République du Mali a une Commission des droits de l'homme (CNDH) créée par la Loi n°2016-036 du 7 juillet 2016 (Art. 1)⁵⁴ et le Décret n° 2016-0853/P-RM du 8 novembre 2016.⁵⁵ C'est 'l'institution nationale des droits de l'homme et le mécanisme national de prévention de la torture,⁵⁶ dont le siège est à Bamako (Article 2).⁵⁷ La mission de la CNDH est de protéger et promouvoir les droits de l'homme ainsi que de prévenir la torture et autres peines ou traitements cruels, inhumains et dégradants.⁵⁸ Elle reçoit des plaintes individuelles ou collectives à propos de violation des droits de l'homme au Mali (Article 28).⁵⁹ La CNDH oriente les plaignants et leur offre une assistance juridique. Elle mène des enquêtes sur les questions de violation des droits de l'homme.⁶⁰ Enfin, elle mène des actions de sensibilisation, d'information et de communication dans le but d'instaurer la culture des droits de l'homme. Elle promeut la recherche, l'éducation. La CNDH ne mentionne pas explicitement les personnes en situation de handicap.

- 54 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, Annexe 2 – Loi N°2016-036/du 7 juillet 2016 portant création de la Commission Nationale des Droits de l'Homme p. 44-49' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (n 6 Comme ci-dessus).
- 55 Journal Officiel de la République du Mali 'Loi n° 2016-036/du 7 juillet 2016 portant création de la Commission Nationale des Droits de l'Homme, p. 1228 – 1231' https://www.ilo.org/dyn/natlex/natlex4.detail?p_lang=fr&p_isn=103127&p_count=12&p_classification=01 (Consulté le 18/09/2019).
- 56 'Loi n° 2016-036/du 7 juillet 2016 portant création de la Commission Nationale des Droits de l'Homme' <https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/103127/125062/F-21441908/MLI-103127.pdf> (Consulté le 18/09/2019).
- 57 Journal Officiel de la République du Mali 'Loi n° 2016-036/du 7 juillet 2016 portant création de la Commission Nationale des Droits de l'Homme' <https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/103127/125062/F-21441908/MLI-103127.pdf> (Consulté le 18/09/2019) (Comme ci-dessus).
- 58 Journal Officiel de la République du Mali 'Loi n° 2016-036/du 7 juillet 2016 portant création de la Commission Nationale des Droits de l'Homme, Art 3' <https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/103127/125062/F-21441908/MLI-103127.pdf> (Consulté le 18/09/2019) (Comme ci-dessus).
- 59 Journal Officiel de la République du Mali 'Loi n° 2016-036/du 7 juillet 2016 portant création de la Commission Nationale des Droits de l'Homme, Art 6' <https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/103127/125062/F-21441908/MLI-103127.pdf> (Consulté le 18/09/2019) (Comme ci-dessus).
- 60 Journal Officiel de la République du Mali 'Loi n° 2016-036/du 7 juillet 2016 portant création de la Commission Nationale des Droits de l'Homme, Art 4' <https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/103127/125062/F-21441908/MLI-103127.pdf> (Consulté le 18/09/2019) (n 56 Comme ci-dessus).

Cependant, la CNDHL a organisé un séminaire sur la Convention relative aux droits des personnes handicapées.⁶¹

9 Organisation des personnes handicapées (OPH) et autres Organisations de la Société Civile

9.1 Avez-vous en République du Mali des organisations qui représentent et défendent les droits et le bien-être des personnes handicapées? Si oui énumérez chaque organisation et décrivez ses activités.

En République du Mali, il existe des organisations qui représentent et défendent les droits et le bien-être des personnes handicapées, telles que:

- L'Association Emploi Intégration des Handicapés pour le Développement (EIHD) – créé en 1992 – défendant l'intégration socioéconomique et professionnelles des personnes en situation de handicap.⁶²
- L'association Malienne de Lutte contre les Déficiences Mentales chez l'Enfant (AMALDEME), créée en 1980 a pour mission qui promeut les personnes vivant avec un handicap mental, à travers l'autonomisation, la scolarisation, l'apprentissage professionnel et la réinsertion sociale par le travail.⁶³
- L'association Malienne des Sourds (AMASOURD) contribue à la promotion de l'éducation des jeunes déficients auditives.
- L'Union Malienne des Aveugles (UMAV), créée en 1972 sous l'appellation *Association malienne pour la promotion sociale des aveugles*, qui aide à la prévention de la cécité, la scolarisation des enfants aveugles, et la réadaptation en milieu urbain et rural.
- La Fondation Ismaïla Konate, créée en 2010, appuie les programmes d'insertion socio-économique des personnes en situation de handicap à double.⁶⁴
- L'Association Malienne pour la protection des Albinos (AMPA) fondée en 2013 et enregistrée comme association le 4 juin 2015 afin d'« améliorer les conditions de vie des personnes vivant avec l'albinisme et de faciliter leur intégration sociale et économique au sein des communautés.⁶⁵

61 'Plan stratégique 2010-2014, p. 10; 14-15' <http://www.bristol.ac.uk/media-library/sites/law/migrated/documents/malistrategicplan.pdf> (Consulté le 18/09/2019).

62 'Emploi Intégration des Handicapés pour le Développement (EIHD)' <https://amisdumali.com/eihd.htm> (Consulté le 18/09/2019).

63 'Déficience intellectuelle au Mali: l'AMALDE' (1 décembre 2012) <http://ladeficiencintellectuelledanslemonde.com/2012/12/01/deficience-intellectuelle-aumali-lamalaldeme/> (Consulté le 18/09/2019).

64 'Fondation Ismaïla Konaté' <https://sites.google.com/site/handicapactionmali/nos-soutiens/fondation-ismaela-konate> (Consulté le 5 août 2019).

65 VOICE <https://voice.global/fr/partenaires/proseda-sensibiliser-sur-albinisme-aumali/> (Consulté le 18/09/2019).

9.2 Dans votre région, les OPH sont-elles organisées ou coordonnées au niveau national et/ou régional?

Il existe environ 467 Organisations de Personnes Handicapées (OPH) au Mali, depuis 2017, une vingtaine d'entre elles sont affiliées à la Fédération Malienne des Associations de Personnes Handicapées (FEMAPH), qui existe depuis 1982.⁶⁶

9.3 Si la République du Mali a ratifié la CDPH, comment a-t-elle assurée l'implication des Organisations des personnes handicapées dans le processus de mise en œuvre?

La FEMAPH en tant que membre du programme de développement sanitaire et social (PRODESS), participe aux journées d'évaluation, au comité technique et comité de suivi du PRODESS avec les ministres de la Santé et l'Hygiène Publique, de la Solidarité de l'Action Humanitaire et la reconstruction du Nord, de la promotion de la femmes, de l'enfant et de la Famille, les partenaires techniques et financiers de la société civile.⁶⁷

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 permis aux personnes en situation de handicap de participer aux activités d'élaboration et de suivi du Cadre Stratégique de Réduction de la pauvreté et des Objectifs du Millénaire pour le Développement, et également dans l'élaboration des documents pour la mise en place des organes du programme de Réadaptation à Base Communautaire (RBC).⁶⁸

9.5 Quels sont, le cas échéant les obstacles rencontrés par les OPH lors de leur engagement dans la mise en œuvre?

Le manque de moyen financier et de personnel qualifié sont les premiers obstacles que rencontrent les OPH au Mali.⁶⁹ La méconnaissance ou la mauvaise

66 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, Annexe 2 – Loi N°2016-036/du 7 juillet 2016 portant création de la Commission Nationale des Droits de l'Homme' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f [Consulté le 18/09/2019] (n 6 Comme ci-dessus); MA Traoré 'Fédération malienne des personnes handicapées: que d'acquis' 29 août 2017 <http://malijet.co/societe/federation-malienne-des-personnes-handicapees-que-dacquis> (Consulté le 18/09/2019).

67 OHCHR 'Réponse aux questions de la rapporteuse spéciale sur les droits des personnes handicapées, 18 mai 2016' https://www.ohchr.org/Documents/Issues/Disability/.../States/PM%20Mali_ENG.docx (Consulté le 18/09/2019); Lire également 'Fédération malienne des personnes handicapées: que d'acquis' <https://niarela.net/societe/federation-malienne-des-personnes-handicapees-que-dacquis> (Consulté le 18/09/2019).

68 OHCHR 'Réponse aux questions de la rapporteuse spéciale sur les droits des personnes handicapées, 18 mai 2016' https://www.ohchr.org/Documents/Issues/Disability/.../States/PM%20Mali_ENG.docx (Consulté le 18/09/2019) (n 68 Comme ci-dessus).

69 'Déficience intellectuelle au Mali: l'AMALDE' (1 décembre 2012) <http://ladedficienceintellectuelledanslemonde.com/2012/12/01/deficience-intellectuelle-au-mali-lamal-deme/> (Consulté le 18/09/2019) (n 64 Comme ci-dessus).

interprétation des textes juridiques sont aussi un problème ainsi que l'analphabétisation est aussi un autre obstacle.

9.6 Y'a-t-il des exemples pouvant servir de 'modèles' pour la participation des OPH?

Les OPH collaborent et mutualisent leurs subventions pour mettre en œuvre des projets en faveur des personnes en situation de handicap.⁷⁰

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?

Les OPH sont engagées dans la promotion de l'intégration socio-économique/professionnelle, la mise en œuvre d'actions de formation, d'appui à la recherche d'emploi, d'appui psychologique et la recherche d'activités génératrices de revenu en faveur des personnes handicapées. Les OPH promeuvent l'autonomisation, la scolarisation, l'apprentissage et la réinsertion sociale par le travail. Elles ont aussi participé à la création d'établissements scolaires et à la réadaptation en milieu urbain et rural.

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?

Le Projet d'Appui à l'Autonomisation des Organisations de Personnes Handicapées, financé par l'USAID a permis de réaliser des activités sur la période d'avril 2014 à mars 2016 pour un montant de trois millions trois cent soixante mille francs (3 360 000) Frcfa.⁷¹ Mais la plupart des OPH ont un grand besoin de capacité financière et de soutien.

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 devraient être représentées dans les organes en charge de la mise en œuvre des instruments internationaux ou régionaux et avoir un peu plus la parole.

70 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, Annexe 6, p. 56-58' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (n 6 Comme ci-dessus).

71 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, Annexe 2 – Loi N°2016-036/du 7 juillet 2016 portant création de la Commission Nationale des Droits de l'Homme' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (n 6 Comme ci-dessus).

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?

· La loi n° 02-065 du 18 décembre 2002 a créé le Centre National d'Appareillage Orthopédique du Mali (CNAOM), un établissement public national à caractère scientifique et technologique. Le CNAOM a pour mission de fournir les prestations spécialisées en matière d'orthopédie et de rééducation.⁷²

Cet établissement travaille sur la réadaptation fonctionnelle qui consiste à supprimer ou limiter les obstacles qui entravent l'activité et la participation des personnes en situation de handicap.⁷³

· L'Institut d'Etudes et de Recherche en Géronto-gériatrie de la Maison des Aînés (IERGG-MA) qui mène des recherches sur les personnes âgées en situation de handicap et appuie à l'amélioration de leur condition de vie. Ces personnes âgées vivant avec un handicap 'bénéficient de consultations gratuites en ophtalmologie, en cardiologie, en rhumatologie, en kinésithérapie, médecine générale et urologie.'⁷⁴

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).

Le Ministère de la Solidarité et de l'Action Humanitaire est en charge des personnes en situation de handicap. Il élabore et met en œuvre la politique nationale dans: 'les domaines de la lutte contre la pauvreté, du développement humain durable, de l'action et de la protection sociale et de la promotion des

72 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, Annexe 2 – Loi N°2016-036/du 7 juillet 2016 portant création de la Commission Nationale des Droits de l'Homme' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (n 6 Comme ci-dessus); M Diarra 'Centre national d'appareillage orthopédique du Mali (CNAOM): La 16^e session ordinaire du Conseil d'orientation tenue hier' (22 mars 2019) Maliweb.net <https://www.maliweb.net/societe/centre-national-dappareillage-orthopedique-du-mali-cnaom-la-16e-session-ordinaire-du-conseil-dorientation-tenue-hier-2810333.html> (Consulté le 18/09/2019).

73 M Keïta 'Centre national d'appareillage orthopédique du Mali (CNAOM): de belles perspectives pour 2019!' (Bamada.net, 25 mars 2019) <http://bamada.net/centre-national-dappareillage-orthopedique-du-mali-cnaom-de-belles-perspectives-pour-2019> (Consulté le 18/09/2019).

74 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, Annexe 2 – Loi N°2016-036/du 7 juillet 2016 portant création de la Commission Nationale des Droits de l'Homme' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (n 6 Comme ci-dessus).

personnes âgées.⁷⁵ Ce ministère est en charge de l'élaboration et la mise en œuvre des politiques et stratégies en faveur des personnes handicapées.⁷⁶ Il est composé de la Direction Nationale du Développement Social (DNDS), de la Direction Nationale de la Protection Sociale et de l'Economie Solidaire (DNPSES) et des Directions régionales et services subrégionaux.⁷⁷

11 Préoccupations majeures des droits de l'homme relatives aux personnes handicapées

11.1 Quels sont les défis contemporains des personnes handicapées en République du Mali? (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.

- En février 2017, le Comité scientifique pour la Promotion de l'Emploi des personnes handicapées faisait valoir qu'en dépit de l'adhésion du Mali à la Convention n°159 du BIT sur la réadaptation professionnelle et l'emploi des personnes handicapées le marché de l'emploi et la fonction publique restaient toujours difficile d'accès.⁷⁸
- Les textes concernant la promotion des droits des personnes handicapées sont mal interprétés et insuffisamment vulgarisés. L'analphabétisation est également un obstacle.
- Les infrastructures adaptées aux personnes en situation de handicap sont insuffisantes.

75 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, Annexe 2 – Loi N°2016-036/du 7 juillet 2016 portant création de la Commission Nationale des Droits de l'Homme' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (Comme ci-dessus).

76 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, Annexe 2 – Loi N°2016-036/du 7 juillet 2016 portant création de la Commission Nationale des Droits de l'Homme' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (Comme ci-dessus).

77 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, Annexe 2 – Loi N°2016-036/du 7 juillet 2016 portant création de la Commission Nationale des Droits de l'Homme' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (Comme ci-dessus).

78 'Violation des droits à l'emploi des personnes handicapées au Mali: les organisations des personnes handicapées comptent récidiver des actions de manifestation pour se faire entendre' (16 février 2017) bamada.net <http://bamada.net/violation-des-droits-a-emploi-des-personnes-handicapees-au-mali-les-organisations-des-personnes-handicapees-comptent-recidiver-des-actions-de-manifestation-pour-se-faire-entendre> (Consulté le 18/09/2019).

- Les ressources financières en faveur des personnes handicapées sont insuffisantes.⁷⁹
- Les personnes en situation de handicap sont toujours victimes de préjugés, stéréotypes et pratiques dangereuses. En mai 2018 les associations de défense des albinos ont dénoncé une recrudescence des crimes rituels contre les albinos.⁸⁰

11.2 Comment la République du Mali répond-elle aux besoins des personnes handicapées au regard des domaines ci-dessous énumérés?

La République du Mali répond aux besoins des personnes en situation de handicap sur plusieurs axes:

- L'Article 54 de la Loi n° 02-016 du 3 juin 2002 oblige à une meilleure accessibilité des personnes en situation de handicap aux établissements recevant du public.⁸¹ En 2015, la République du Mali a ratifié le Traité de Marrakech 'visant à faciliter l'accès des personnes aveugles, des déficients visuels et des personnes ayant d'autres difficultés de lecture des textes imprimés aux œuvres publiés'.⁸²
- Dans des contextes de conflits armés, de crises humanitaires ou de catastrophes naturelles, les personnes en situation de handicap bénéficient d'une prise en charge gratuite. La Direction Nationale du Développement Sociale (DNDS), dépendant du Ministère de la Solidarité et de l'Action Humanitaire (MSAH) dispose d'une base de données répertoriant le nombre de personnes vivant avec un handicap déplacées dans les régions.⁸³
- En matière d'autonomie de vie et d'inclusion dans la société, l'Etat a financé, en octobre 2015, le Plan Stratégique pour la Promotion Socio-économique des personnes handicapées- 2015-2024.⁸⁴ Enfin, le Code des Impôts et le Code des douanes prévoient des exonérations pour les personnes handicapées.⁸⁵
- La Constitution du Mali garantit sans discrimination la liberté d'expression et d'opinion à tout individu (Art. 4). Le gouvernement malien s'engage également à la formation d'interprètes-traducteurs en faveur des personnes sourdes et muettes.⁸⁶

79 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 24' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (n 6 Comme ci-dessus).

80 'Une petite fille albinos assassinée au Mali' (V.O.A Afrique, 14 mai 2018) <https://www.voafrique.com/a/une-jeune-albinos-assassin%C3%A9e-au-mali-%C3%A0-l-approche-des-%C3%A9lections/4393575.html> (Consulté le 18/09/2019).

81 Journal Officiel du Mali <http://extwprlegs1.fao.org/docs/pdf/mli153270.pdf> (Consulté le 18/09/2019).

82 Journal Officiel de l'Union Européenne 'Traité de Marrakech', 27 juin 2013 [https://eur-lex.europa.eu/legal-content/FR/TXT/PDF/?uri=CELEX:22018A0221\(01\)&from=EN](https://eur-lex.europa.eu/legal-content/FR/TXT/PDF/?uri=CELEX:22018A0221(01)&from=EN) (Consulté le 18/09/2019).

83 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 15' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (n 6 Comme ci-dessus).

84 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 16' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (Comme ci-dessus).

85 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 17' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (Comme ci-dessus).

86 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 17' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (Comme ci-dessus).

- La République du Mali porte une attention particulière aux personnes en situation de handicap en matière d'éducation.⁸⁷
- La République du Mali garantit en matière de santé le dépistage et interventions précoces pour les personnes en situation de handicap dont les enfants en situation de handicap, et une meilleure prise en charge pour les personnes handicapées en général.
- Le 4 mai 2019 a été organisée la Journée inclusive du mérite sportif afin de valoriser la participation des personnes en situation de handicap, de promouvoir leurs droits à la participation 'toujours faiblement pris en compte'.⁸⁸
- La République du Mali favorise une meilleure intégration des personnes handicapées dans le domaine de l'accès à la fonction publique (Art 18).⁸⁹

11.3 La République du Mali accorde-t-il des subventions pour handicap ou autre moyen de revenu en vue de soutenir les personnes handicapées?

L'Institut National de Prévoyance accorde une subvention annuelle à plusieurs associations de personnes en situation de handicap. De 2008 à novembre 2017, cette structure a accordé des rentes, des pensions et des subventions.⁹⁰

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 du Mali?

L'article 27 de la Constitution de la République du Mali garantit à tous les citoyens en âge de voter, sans discrimination, leurs droits civils et politiques. La loi n°2016-048 du 17 octobre 2016 modifiée par le Loi n° 2018-014 du 23 avril 2018 portant loi électorale garantit à toute personne en situation de handicap un droit de participation à la vie politique (Art 92).⁹¹

87 OHCHR (Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 20) https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (Comme ci-dessus).

88 M Koumaré 'La journée inclusive du mérite sportif des personnes handicapées du Mali' (West African Regional Portal on the Rights of People with Disabilities) <http://proadiph.org/La-Journee-inclusive-du-merite-sportif-des-personnes-handicapees-du-Mali.html?lang=en> (Consulté le 18/09/2019).

89 'Loi n°02-053 du 16 décembre 2002 portant statut général des fonctionnaires' <http://www.droit-afrique.com/upload/doc/mali/Mali-Loi-2002-53-statut-general-fonctionnaires.pdf> (Consulté le 18/09/2019).

90 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 17' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (n 6 Comme ci-dessus).

91 Journal Officiel de la République du Mali <http://www.matcl.gov.ml/sites/default/files/public/LOI%20N%C2%B02016-048%20DU%2017%20OCTOBRE%202016%20MODIFIEE%20PAR%20LA%20LOI%20N%C2%B02018-014%20DU%2023%20AVRIL%202018%20PORTANT%20LOI%20ELECTORALE.pdf> (Consulté le 18/09/2019).

11.5 Catégories spécifiques expérimentant des questions particulières/vulnérabilité:

Les femmes en situation de handicap

La République du Mali déploie des efforts sur la question de la promotion des femmes en situation de handicap à travers:

- Les financements du Fonds d'Appui à la Formation professionnelle et à l'Apprentissage (FAFPA);
- Les programmes de renforcement de capacités des femmes handicapées (alphabétisation, formation professionnelle);
- L'appareillage et l'accès aux aides techniques (béquilles, cannes, tricycles, moto tricycles).⁹²
- Le Mali met l'accent sur la sensibilisation des acteurs de la santé sur la prise en charge des femmes vivant avec un handicap en Santé de la Reproduction (SR), la formation en alphabétisation dans les langues nationales.⁹³
- Les femmes en situation de handicap s'organisent en associations qui sont fédérées en Union Malienne des Associations et Comités des Femmes Handicapées qui regroupent tous les types de handicap.⁹⁴ Toutefois ces femmes continuent à être marginalisées.

Les enfants en situation de handicap. Dans un souci d'amélioration des conditions de vie et d'insertion sociale des enfants vivant avec un handicap, la République du Mali a créé une synergie d'actions entre les différents ministères et une mobilisation de ressources financières.⁹⁵ Selon la Loi n°99-046 du 28 décembre 1999, modifiée, portant Loi d'Orientation sur l'Education qui dispose respectivement en ses articles 47 et 55 que l'éducation spéciales s'adresse aux grands handicapés (Art.47) et que les handicapés légers reçoivent les mêmes apprentissages que les apprenants non handicapés en même temps qu'ils bénéficient de soins éducatifs spéciaux (Art. 55).⁹⁶ A travers la Loi n°99-046 du 28 décembre 1999, la République du Mali a mis en place le Programme de l'Education

92 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 17' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (Comme ci-dessus).

93 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 17' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (Comme ci-dessus).

94 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 17' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (Comme ci-dessus).

95 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 13' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (Comme ci-dessus).

96 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 13' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (Comme ci-dessus) 13; Loi 99-046 AN RM, portant loi d'orientation sur l'éducation <https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/97009/114926/F-568307560/MLI-97009.pdf> (Consulté le 18/09/2019) (n 38 Comme ci-dessus).

(PRODEC) qui favorise la discrimination positive des bacheliers handicapés en matière d'attribution de bourses d'études à l'extérieur du Mali.⁹⁷

Les personnes en situation de handicap déplacées. Les victimes de conflits armés, de crises humanitaires ou de catastrophes naturelles bénéficient d'une prise en charge gratuite en termes d'assistance. Ces groupes sont répertoriés dans une base de données construite par la DNDS qui précise le nombre de personnes en situation de handicap déplacées. Handicap International dans le cadre de l'aide humanitaire a formé une vingtaine de personnes handicapées sur le secours d'urgence.

Les personnes âgées en situation de handicap bénéficient d'une meilleure prise en charge en matière de santé, et ce de manière globale à travers des consultations médicales gratuites.

12 Perspective future

12.1 Y'a-t-il des mesures spécifiques débattus ou prises en compte présentement en République du Mali au sujet les personnes handicapées?

A propos de la participation à la vie politique, des réflexions sont en cours afin de rendre les procédures de vote des personnes en situation de handicap plus inclusives de manière à garantir la confidentialité du processus.

12.2 Quelles réformes légales sont proposées? Quelle réforme légale aimeriez-vous voir en République du Mali? Pourquoi?

Outre l'amplification de la mise en œuvre de la Convention relative aux droits des personnes handicapées, la République du Mali devrait se munir d'urgence d'un recensement spécifique des personnes handicapées fiable et récent, tenant compte des femmes, des enfants et des personnes âgées handicapés, à l'instar de ce qui est fait pour les personnes en situation de handicap déplacées. Une étude précise des formes de handicap serait également utile afin de mieux appréhender les besoins des personnes handicapées. Bien qu'il existe deux centres médicaux en faveur des personnes en situation de handicap, la République du Mali pourrait se doter d'un laboratoire en sciences humaines et sociales afin de mener des recherches spécifiques sur la question des personnes en situation de handicap et collaborer avec d'autres laboratoires internationaux.

97 OHCHR 'Rapport Initial et périodique du Mali sur la mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées, 2008-2018, p. 13' https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?Lang=f (Consulté le 18/09/2019) (n 6 Comme ci-dessus).

RÉPUBLIQUE DU BURUNDI

Gerard Emmanuel Kamdem Kamga*

Summary

According to the 2008 census, Burundi has a population of 8 053.574 inhabitants. However, according to a projection by the Institut de Statistiques et D'Etudes Economiques du Burundi (ISTEEBU) the population of the country in 2019 is estimated to be at 12.044.164 inhabitants. The percentage of people with disabilities is unknown. The Republic of Burundi signed the United Nations Convention on the Rights of Persons with Disabilities (CRPD) on 26 April 2007 and ratified it on 26 March 2014. The Optional Protocol to the Convention on the Rights of Persons with Disabilities was signed and ratified in the same period. The Constitution of Burundi refers to disability. Article 22 reaffirms the protection and equality of everyone before the law and that no one may be subject to discrimination including among others on the ground of disability. The Republic of Burundi has numerous pieces of legislation that directly frame disability. The key ones are Law 1/03 of 10 January 2018 on the protection and promotion of the rights of people with disabilities in Burundi. Similarly, Law 1/20 of 3 June 2014 amending Law 1/22 of 18 September 2009 on the Electoral Code addresses disability. In the same vein, decree 100/216 of 4 August 2011 relating to the structure, functioning and missions of the Ministry of national solidarity frames disability. The policies that directly address persons with disabilities are: the National policy of people with disabilities and its action plan; the National policy in favour of orphans and other vulnerable children. Other than ordinary courts or tribunals, Burundi has an official body that specifically addresses the violation of the rights of persons with disabilities. It is the National Committee of the Rights of People with Disabilities / Comité National des Droits des Personnes Handicapées (CNDHP)] provided for by article 38 of Law 1/03 du 10 January 2018 on the protection and promotion of the Rights of persons with disabilities in Burundi.

* Postdoctoral Research Fellow, Faculty of Law, Department of Public, University of the Free State, Bloemfontein. email: gerard.emmanuel@gmail.com.

The Republic of Burundi has an Independent National Human Rights Commission [Commission Nationale Indépendante des Droits de l'Homme (CNIDH)] setup by Law 1/04 of 5 January 2011. There are numerous organisations that represent and advocate for the rights and welfare of persons with disabilities in Burundi. These include among others, the Network of Centre for Persons with Disabilities in Burundi [Réseau des Centres pour Personnes Handicapées au Burundi (RCPHB)], the Network of Associations of Persons with Disabilities in Burundi [le Réseau des Associations des Personnes Handicapées au Burundi (RAPHB)], the Union of Persons with Disabilities of Burundi [l'Union des Personnes Handicapées du Burundi (UPHB)] and the Federation of Associations of Persons with Disabilities of Burundi [la Fédération des Associations des Personnes Handicapées du Burundi (FAPHB)]. In Burundi, the Ministry of National Solidarity, of the rights of the Human Person and Gender deals with disability. Its Department of Social Integration is in charge of ensuring the protection of vulnerable peoples including persons with disabilities. Persons with disabilities enjoy little or no access to work, for many of them are unemployed. In addition, there is no specific process aimed at facilitating their employment in the public sphere as well as in private settings. As far as access is concerned, persons with disabilities have difficulties to access public buildings, public transport, education, vocational training, health care and other basic needs. The Burundian Government shall initiate measures to enhance the political participation of persons with disabilities in state affairs. In addition, there is a need to introduce the teaching of the rights of persons with disabilities at schools and universities across the country.

1 Les indicateurs démographiques

1.1 Quelle est la population totale du Burundi?

Les résultats du dernier Recensement Général de la Population et de l'habitat du Burundi en 2008 indiquaient que la population Burundaise était de 8 053.574 habitants. Cependant, selon les données de l'institut de statistiques et d'études économiques du Burundi (ISTEEBU), la population totale du Burundi en 2019 en termes de projection s'élève à 12.044.164 d'habitants.¹

1.2 Méthodologie employée en vue d'obtenir des données statistiques sur la prévalence du handicap au Burundi. Quels sont les critères utilisés pour déterminer qui fait partie de la couche des personnes handicapées au Burundi?

Au terme des dispositions de l'article 3 de la loi N°01/03 du 10 Janvier 2018 portant promotion et protection des droits des personnes handicapées au Burundi, « la personne handicapée est toute personne qui présente des incapacités physiques, mentales, intellectuelles ou sensorielles durables dont l'interaction durable avec

1 Burundi population. <https://countrymeters.info/fr/Burundi> (consulté le 31 juillet 2019).

diverses barrières peut porter atteinte à leur pleine et effective participation à la société sur la base de l'égalité avec les autres. » En réalité, il y'a une absence de méthode d'où l'absence de données statistiques désagrégées relatives au handicap. Ceci est dû au fait qu'il n'y a pas eu de recensement des personnes handicapées dans le pays; recensement qui aurait permis de déterminer le taux de prévalence du handicap. Pour aller plus loin, le dernier recensement de la population entière du Burundi remonte à l'année 2008 et de nos jours, le nombre exacte d'habitants du pays fait plutôt l'objet d'estimations. Dans ces conditions, il n'a pas été possible d'obtenir des données statistiques sur la prévalence du handicap dans le pays.

1.3 Quel est le nombre total et le pourcentage des personnes handicapées en République du Burundi ?

Le nombre total et le pourcentage des personnes en situation de handicap au Burundi reste méconnue faute des statistiques fiables. Ainsi selon le document de politique nationale de l'emploi de 2014, 10 pour cent de la population Burundaise est handicapée.² Toutefois, selon les estimations de l'Organisation Mondiale de la Santé (OMS) et de la Banque Mondiale 15% de la population mondiale est atteinte d'un handicap, soit environ plus d'un milliard de personnes en situation de handicap vivant à travers le monde. De ces 15%, à peu près 80% seraient dans les pays en développement, d'après la Banque Mondiale. En appliquant la formule de 15% sur les 12.044.164 d'habitants que compte le pays actuellement, le nombre de personnes en situation de handicap au Burundi serait d'environ 1.806.624; et si on se réfère aux 80% de la Banque Mondiale,³ ce nombre peut facilement être revu à la hausse.⁴

1.4 Quel est le nombre total et le pourcentage des femmes handicapées en République du Burundi?

Une étude exhaustive qui tiendrait en compte toutes les catégories de handicap fait défaut. En plus, il y a des parents qui cachent toujours leurs enfants handicapés à la maison.⁵

1.5 Quel est le nombre total et le pourcentage des enfants handicapés en République du Burundi?

Information non disponible. Il semblerait qu'il n'y ait pas encore une étude exhaustive spécifiant le pourcentage des enfants handicapés au Burundi. En plus, il y a des parents qui cachent toujours à la maison leurs enfants handicapés.⁶ Toutefois, si l'on s'en tient à une étude de l'UNICEF de 2002, il y aurait eu 10 577 enfants physiquement et mentalement handicapés au Burundi avec diverses

2 Le Document de politique nationale de l'emploi file:///D:/my%20papers/In%20Progress/burundi%20country%20report/UNDP-GOV-bi-povred-employment-report-PNE.pdf, 32. (consulté le 2 Août 2019).

3 Rapport mondial sur le handicap, Organisation mondiale de la santé et Banque Mondiale (2012) https://www.who.int/disabilities/world_report/2011/fr/ (Consulté le 13 Aout 2019).

4 Mémoire sur La Problématique des Personnes Handicapées Au Burundi Année 2013 <https://webcache.googleusercontent.com/search?q=cache:xJ3p4Sdcl38J:https://assoraphb.files.wordpress.com/2013/06/memorandum-sur-la-problematique-des-personnes-handicapees-au-burundi-annee-2013.doc+&cd=1&hl=en&ct=clnk&gl=za> (Consulté le 31 Juillet 2019).

5 Burundi – Droits de la personne handicapée <http://www.ldgl.org/burundi-droits-de-la-personne-handicapee/> (Consulté le 20 Juillet 2019).

6 Comme ci-dessus.

catégories de handicaps telles que: défauts d'élocution, traumatismes physiques liés à la guerre, maladies mentales, infirmités physiques, cécité et surdité.⁷

1.6 Quelles sont les formes de handicap les plus répandues en République du Burundi?

Il n'y a pas encore une étude exhaustive qui tient en compte toutes les catégories de handicap. En plus, certains parents cachent toujours à la maison leurs enfants handicapés.⁸

Toutefois, certaines associations représentant les personnes en situation de handicap au Burundi observe que ces personnes rencontrent beaucoup de problèmes liés à la nature spécifique du handicap qui sont entre autres la surdité, la mutité, la cécité, le handicap mental, le handicap physique et des cas complexes de handicap.⁹

2 Obligations internationales

2.1 Quel est le statut de la Convention des Nations Unies relative aux Droits des Personnes Handicapées (CDPH) en République du Burundi? La République du Burundi a-t-il signé et ratifié la CDPH? Fournir le(s) date(s). La République du Burundi a-t-il signé et ratifié le Protocole facultatif? Fournir le(s) date(s).

Le Burundi a signé la Convention des Nations Unies relative aux Droits des Personnes Handicapées (CDPH) le 26 Avril 2007 et a par la suite ratifié le même document le 26 Mars 2014. Le protocole facultatif se rapportant à la Convention relative aux droits des personnes handicapées a également été signé et ratifié les mêmes dates.

2.2 Si la République du Burundi 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 du Burundi a-t-il soumis son rapport? Sinon quelles sont les raisons du retard telles qu'avancées par la branche gouvernementale en charge?

Conformément à l'Article 35 de la CDPH, la République du Burundi était tenue de soumettre son rapport initial dans un délai de deux ans, soit à la date du 26 Mars 2016 compte tenu du fait que c'est le 26 Mars 2014 que le pays a ratifié la CDPH. Quant à la branche du gouvernement responsable de la soumission du rapport, nous n'avons pu obtenir d'information à ce sujet. En ce qui est du rapport la

7 Burundi <http://www.axl.cefan.ulaval.ca/afrique/burundi.htm>. (Consulté le 28 Juillet 2019).

8 Comme ci-dessus.

9 Union des personnes handicapées du Burundi (UPHB) <http://www.uphb.bi/index.php/presentation/organisation/4-historique> (Consulté le 20 Juillet 2019).

République du Burundi ne figure pas dans la base de données des Nations Unies regroupant les Etats ayant soumis leur rapport.¹⁰

2.3 Si la République du Burundi 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 du Burundi. Y'avait-il des effets internes découlant du processus de rapport liés aux questions handicapées du Burundi?

la République du Burundi ne figure pas dans la base de données des Nations Unies regroupant les Etats ayant soumis leur rapport.¹¹

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 du Burundi 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 République du Burundi? Si oui, quels étaient les effets de ces observations ou recommandations?

Oui, la République du Burundi a fait mention spécifique du droit des personnes handicapées dans ses rapports les plus récents. Ainsi dans son rapport national présenté le 13 Novembre 2017 conformément au paragraphe 5 de l'annexe à la résolution 16/21 du Conseil des droits de l'homme, le Burundi a mentionné spécifiquement les droits des personnes en situation de handicap. Dans la section D du rapport, il est fait mention expresse des avancées significatives du Burundi notamment avec la ratification de la Convention relative aux droits des personnes handicapées et son protocole facultatif par la loi n°1/07 du 26 mars 2014 et le Protocole facultatif à la Convention contre la torture et autres peines ou traitements cruels, inhumains ou dégradants en septembre 2013. Il convient de mentionner que cette ratification des conventions et protocoles avait été recommandée par le Conseil des droits de l'Homme en 2013. Le même rapport fait également mention spécifique du handicap en soulignant les dispositions de l'article 22 de la constitution du Burundi sur la protection et l'égalité de tous les citoyens devant la loi ainsi que l'interdiction de discrimination du fait de son origine, de sa race et autre et notamment du fait d'un handicap physique ou mental.¹²

De façon similaire, lors de la 50ème Session Ordinaire de la Commission Africaine des Droits de l'Homme et des Peuples qui s'est tenue du 24 Octobre au 05 novembre 2011 à Banjul en Gambie, la République du Burundi a soumis un rapport sur l'état des droits de l'homme conformément à l'article 62 de la Charte

10 States Parties Reports <https://www.refworld.org/type,STATEPARTIESREP,CRPD,,,0.html#SRTop41>(consulté le 31 Juillet 2019).

11 Comme ci-dessus.

12 United Nations Human Rights Council, Universal Periodic Review – Burundi <https://www.ohchr.org/EN/HRBodies/UPR/Pages/BIIndex.aspx> (consulté le 12 Aout 2019).

africaine. Ce rapport qui couvre la période allant de 2002 à 2010 constitue la résultante combinée des 2ème, 3ème, 4ème et 5ème rapports qui auraient dû être soumis en 2002, 2004, 2006 et 2008 fait également allusion au handicap. Il fait mention de l'article 22 de la loi constitutionnelle de la République du Burundi sur la protection et l'égalité de tous les citoyens devant la loi ainsi que l'interdiction de discrimination à quelque titre que ce soit, notamment du fait d'un handicap physique ou mental.¹³ L'article 18 du même rapport sur le droit à la protection de la famille fait également allusion au handicap en spécifiant que « *les personnes âgées ou handicapées ont également droit à des mesures spécifiques de protection en rapport avec leurs besoins physiques ou moraux.*» Plus loin, le même article 18 souligne le manque d'assistance spéciale dû aux personnes en situation de handicap; une situation supprimer ceci depuis lors résolue avec la mise en place du ministère de la solidarité nationale qui s'occupe des questions de handicap.¹⁴

2.5 Y avait-il un quelconque effet interne sur le système légal de la République du Burundi après la ratification de l'instrument international ou régional au 2.4 ci-dessus?

La ratification de la Convention Relative aux Droits des Personnes Handicapées (CRDPH) et du Protocole facultatif, par le Burundi a eu pour effet immédiat, la reconnaissance officielle des organisations des personnes en situation de handicap et ensuite l'adoption de la Loi N°01/03 du 10 Janvier 2018 portant promotion et protection des droits des personnes handicapées au Burundi.

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?

Selon l'article 292 de la constitution du Burundi, les traités ne prennent effet qu'après avoir été régulièrement ratifiés et sous réserve de leur application par l'autre partie pour les traités bilatéraux et de la réalisation des conditions de mise en vigueur prévues par eux pour les traités multilatéraux. Eu égard à cette disposition constitutionnelle, l'on peut logiquement envisager que les cours et tribunaux du Burundi peuvent directement appliquer les dispositions des traités internationaux.

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.

La Convention des Nations Unies relative aux Droits des Personnes Handicapées (CDPH) a effectivement été incorporée dans la législation nationale notamment par le biais de la Loi N°01/03 du 10 Janvier 2018 portant promotion et protection des droits des personnes handicapées au Burundi.

13 Commission africaine des droits de l'homme et des peuples, Burundi: 2ème Rapport Périodique, 2001-2010 https://www.achpr.org/fr_states/statereport?id=72 (consulté le 12 Aout 2019).

14 Comme ci-dessus.

3 Constitution

3.1 La constitution de la République du Burundi 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 du Burundi contient une disposition relative au handicap. Selon l'Article 22 qui réaffirme la protection et l'égalité de tous les citoyens devant la loi, nul ne peut être l'objet de discrimination du fait notamment de son origine, de sa race, de son ethnie, de son sexe, de sa couleur, de sa langue, de sa situation sociale, de ses convictions religieuses, philosophiques ou politiques, du fait d'un handicap physique ou mental, du fait d'être porteur du VIH/SIDA ou toute autre maladie incurable. Il s'agit de comprendre ici que la loi la loi s'applique de façon uniforme à tous les citoyens sans aucune distinction. Ceci dit le fait de discriminer une personne en raison de son handicap serait constitutive d'infraction donnant lieu à des sanctions.

3.2 La constitution de la République du Burundi contient-elle des dispositions concernant indirectement le handicap? Si oui énumérez les dispositions et expliquez comment chacune d'elles traite indirectement du handicap.

La Constitution de 2018 proclame dans son préambule son attachement au respect des droits fondamentaux de la personne humaine tels qu'ils résultent des textes internationaux relatifs aux droits de l'homme ratifiés par le Burundi d'une part et réaffirme son attachement à la cause de l'unité africaine conformément à l'Acte Constitutif de l'Union Africaine d'autre part. L'article 13 de la constitution réaffirme que tous les burundais sont égaux en mérite et en dignité. Tous les citoyens jouissent des mêmes droits et ont droit à la même protection de la loi. La constitution de façon implicite interdit toute discrimination dont toute personne handicapée au Burundi pourrait être victime. Une fois de plus le caractère sacré de la personne humaine est mis en avance et ceci s'applique à tous les citoyens sans exception.

4 Législation

4.1 La République du Burundi a-t-elle une législation concernant directement le handicap? Si oui énumérez la législation et expliquez comment la législation aborde le handicap.

La République du Burundi a une législation concernant directement le handicap. Il s'agit de la loi N°1/03 du 10 janvier 2018 portant promotion et protection des droits des personnes handicapées au Burundi.¹⁵ Cette législation a pour objectif selon

15 Loi n°1/03 du 10 janvier 2018 portant promotion et protection des droits des personnes handicapées au Burundi (Consulté le 29 Juillet 2019).

l'article 1 de promouvoir et de protéger les droits de la personne handicapée pour son intégration effective afin que sa dignité soit préservée. En ce qui est du champs d'application de cette loi telle que prévue par l'article 2, elle s'applique à toutes les catégories de personnes en situation de handicap ainsi qu'à ceux ou celles intervenants dans la vie de la personne handicapée.

Une autre législation abordant le handicap est la loi N° 1/ 20 du 3 juin 2014 portant révision de la loi N°1/22 du 18 septembre 2009 portant code électoral.¹⁶ L'Article 50(b) autorise un vote par procuration au profit des femmes en couche, des malades et des handicapés qui, en raison de leur état de santé ou de leur condition physique, sont dans l'impossibilité absolue de se déplacer jusqu'au lieu du scrutin.

Dans le même ordre d'idées, le décret N°100-216 du 4 août 2011 portant structure, fonctionnement et missions du ministère de la solidarité nationale, des droits de la personne humaine et du genre aborde également le handicap. L'article 14 de ce décret mentionne les missions du Département de l'Intégration Sociale quant à la protection et l'exécution des programmes liés au handicap.

4.2 La République du Burundi a-t-il une législation concernant indirectement le handicap? Si oui énumérez la principale législation et expliquez comment elle réfère au handicap.

On peut dire qu'au Burundi, toute législation est guidée par le principe de l'égalité de tous et s'applique à tous les citoyens sans exception y compris les personnes handicapées. C'est dans ce sens qu'on peut conclure que la plupart des lois du pays concernent indirectement le handicap.

5 Décisions des cours et tribunaux

5.1 Les cours (ou tribunaux) de la République du Burundi 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.

Cette information est indisponible

16 Commission électorale nationale indépendante <https://www.ceniburundi.bi/-Code-electoral-> (Consulté le 29Juillet 2019).

6 Politiques et programmes

6.1 La République du Burundi 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.

Le 3 décembre 2018, lors de la célébration de la Journée Internationale des Personnes Handicapées, le Burundi a validé la Politique Nationale des Personnes Handicapées et de son Plan d'Actions. Au cours de cet événement, le ministre des Droits de la Personne Humaines, des Affaires Sociale et du Genre a souligné le fait que le gouvernement du Burundi a initié des écoles pilotes pour une éducation inclusive, des programmes de réadaptation médicale et l'aménagement de certains lieux publics pour l'accessibilité aux personnes en situation de handicap de même que l'accès à l'information pour les personnes malentendantes à travers la Radiotélévision Nationale du Burundi (RTNB).¹⁷ Parlant de l'autonomisation des personnes en situation de handicap, le ministre a précisé que le gouvernement du Burundi a mis en place le Centre National d'Appareillage et de Rééducation des personnes handicapées (CNAR) à Gitega, ainsi qu'un Centre National de Réinsertion Socioprofessionnelle (CNRSP) de Bujumbura à Jabe avec une antenne dans la Province de Ngozi pour la formation des jeunes vivant avec le handicap. Il a ajouté que l'appui matériel et financier est donné aux associations et centres pour personnes en situation de handicap sans oublier l'assistance individuelle et l'octroi du matériel de mobilité à ces personnes (les prothèses, orthèses, béquilles, tricycles, chaises roulantes et chaussures orthopédiques).¹⁸

Comme autres politiques et programmes englobant directement le handicap, en 2008 le Conseil des Ministres du Burundi a adopté la politique nationale en faveur des orphelins et des autres enfants vulnérables, un document publié sous l'égide du Ministère De La Solidarité Nationale, du Rapatriement, de La Reconstruction Nationale, des Droits De La Personne Humaine et du Genre. Dans sa préface, ce document réaffirme l'engagement du gouvernement Burundais en collaboration avec ses partenaires non gouvernementaux à mettre en œuvre un certain nombre de mesures parmi lesquelles réadapter physiquement les enfants en situation de handicap.¹⁹ Dans sa partie introductive, le document de politique nationale en faveur des orphelins et des autres enfants vulnérables souligne les objectifs du Ministère de la Solidarité Nationale, du Rapatriement, de la Reconstruction Nationale, des Droits de la Personne Humaine et du Genre qui sont entre autres d'initier et suivre les programmes de protection des membres les plus vulnérables de la population avec une attention particulière pour les jeunes et les personnes en situation de handicap.²⁰ Les enfants en situation de handicap y sont inclus parmi les groupes cibles.

17 Validation de la Politique Nationale des Personnes Handicapées et de son plan d'actions. <http://www.droitshumains.gov.bi/validation-de-la-politique-nationale-des-personnes-handicapees-et-de-son-plan-dactions/> (Consulté le 31 Juillet 2019).

18 Validation de la Politique Nationale des Personnes Handicapées et de son plan d'actions. <http://www.droitshumains.gov.bi/validation-de-la-politique-nationale-des-personnes-handicapees-et-de-son-plan-dactions/> (Consulté le 31 Juillet 2019).

19 Politique nationale en faveur des orphelins et des autres enfants vulnérables https://hivhealthclearinghouse.unesco.org/sites/default/files/resources/iiep_burundi_politique_orphelins.pdf (Consulté le 20 Juillet 2019).

20 Comme ci-dessus.

6.2 Le Burundi 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.

La République du Burundi a ratifié la convention sur l'interdiction de l'emploi, du stockage, de la production et du transfert des mines antipersonnel et sur leur destruction, une convention qui n'englobe pas directement le handicap. Dans son rapport de transparence 2006-2017 le Burundi précise que la Direction de l'Action Humanitaire contre les Mines et Engins non explosés doit s'atteler à la poursuite de la mise en application du Plan d'Action National d'Assistance aux Victimes des Mines/Restes Explosifs de Guerre et autres personnes en situation de handicap. A part cette précision, les politiques générales au Burundi sont d'ordre non discriminatoires.

7 Organismes en charge des personnes handicapées

7.1 En dehors des cours ou tribunaux ordinaires, la République du Burundi a-t-elle un organisme officiel qui s'intéresse spécifiquement à la violation des droits des personnes handicapées? Si oui décrire l'organe, ses fonctions et ses pouvoirs.

En dehors des cours ou tribunaux ordinaires, il y'a au Burundi un Comité National des Droits des Personnes Handicapées (CNDHP), organe prévu à l'article 38 de la loi N°1/03 du 10 janvier 2018 portant promotion et protection des droits des personnes handicapées dont les missions sont déterminées par un décret qui reste attendue.

7.2 En dehors des cours ou tribunaux ordinaires, la République du Burundi 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.

Non en dehors des cours ou tribunaux ordinaires, il n'existe pas au Burundi un organisme officiel de ce genre.

8 Institutions Nationales des Droits de l'Homme (Commission des Droits de l'Homme ou Ombudsman ou Protecteur du Citoyen)

8.1 La République du Burundi est-elle dotée 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 la République du Burundi n'a jamais abordé des questions relatives aux droits des personnes handicapées.

Il existe au Burundi une Commission Nationale Indépendante des Droits de l'Homme (CNIDH) créée par la loi n°1/04 du 5 janvier 2011. Cette commission a entre autre comme missions, d'apporter ou faciliter l'assistance judiciaire aux victimes des violations des droits de l'homme en particulier les femmes, les enfants et les personnes vulnérables. L'on peut sous-entendre que les personnes vulnérables ainsi mentionnées incluraient des personnes handicapées.²¹ Donc l'on estime que bien que n'étant pas exclusivement dédiée à la question du handicap, l'on peut dire sans risque de se tromper que les missions de la commission incluent également la promotion et la protection des droits des personnes handicapées.

Le mandat de la commission comprend notamment la défense des droits de l'homme telles que recevoir des plaintes et enquêter sur les violations des droits de l'homme; effectuer des visites régulières, notifiées ou inopinées dans tous les lieux de détention et formuler des recommandations à l'endroit des autorités compétentes à l'effet d'améliorer le traitement et la situation des personnes privées de liberté; prévenir la torture et autres peines ou traitements cruels, inhumains ou dégradants, conformément aux normes universelles, régionales ou nationales pertinentes; lutter contre les viols et les violences basés sur le genre; saisir le Ministère Public des cas de violation des droits de l'homme; apporter ou faciliter assistance judiciaire aux victimes des violations des droits de l'homme en particulier les femmes et les enfants et les personnes vulnérables; attirer l'attention du gouvernement sur tous les cas de violation des droits de l'homme quelque soit le lieu où ils se produisent et proposer toutes les mesures de nature à favoriser la protection de ces droits.²²

Ce mandat s'étend également à la promotion des droits de l'homme telle qu'organiser des séminaires et atelier de formation sur les droits de l'homme; assurer la promotion du droit de la femme et de l'enfant à travers notamment: l'éducation, l'information et la communication; effectuer des campagnes d'information et de sensibilisation sur les droits de l'homme sur tout le territoire national; participer à l'élaboration et à la mise en œuvre des programmes d'éducation des droits de l'homme; vulgariser les instruments nationaux et internationaux de promotion et de protection de droits en mettant l'accent sur les droits civils et politiques, les droits économique et socioculturels, les droits de la

21 Commission Nationale Indépendante des Droits de l'Homme (CNIDH) <https://cnidh.bi/mandat> (Consulté le 29/07/2019).

22 Commission Nationale Indépendante des Droits de l'Homme <https://cnidh.bi/mandat> (Consulté le 31 Juillet 2019).

femme et de l'enfant ; contribuer à la promotion des principes d'égalité et de non-discrimination tels que garantis par la constitution ; effectuer des études et des recherches sur les droits de l'homme ; et donner des avis et recommandations aux pouvoirs publics sur des questions touchant les droits de l'homme.²³

A la question de savoir si la commission a jamais abordé des questions relatives aux droits des personnes handicapées, cette information n'est pas disponible.

9 Organisation des personnes handicapées (OPH) et autres Organisations de la Société Civile

9.1 Avez-vous en République du Burundi des organisations qui représentent et défendent les droits et le bien-être des personnes handicapées? Si oui énumérez chaque organisation et décrivez ses activités.

Il y a quelques associations et centres qui s'occupent de la prise en charge des personnes handicapées. Ces centres et associations se regroupent en quatre grands réseaux dont le Réseau des Centres pour Personnes Handicapées au Burundi (RCPHB), le Réseau des Associations des Personnes Handicapées au Burundi (RAPHB) l'Union des Personnes Handicapées du Burundi (UPHB)²⁴ et la Fédération des Associations des Personnes Handicapées du Burundi (FAPHB).

Le Réseau des Centres pour Personnes Handicapées au Burundi (RCPHB) est né de l'initiative des centres de vouloir travailler ensemble, afin de trouver des solutions relatives aux besoins des personnes en situation de handicap. Les premières réunions de discussions pour la faisabilité de ce réseau ont commencé en octobre 2006. Le réseau a finalement obtenu l'ordonnance Ministérielle « N°530/665 du 04/07/2007 » portant agrément de l'association sans but lucratif dénommée : « Réseau des Centres pour personnes handicapées du Burundi » « R.C.P.H.B ». ²⁵ Le principal rôle du RCPHB est de promouvoir et de défendre les intérêts de ses institutions membres auprès des décideurs et d'offrir également un espace d'échanges et de concertation afin de trouver des solutions communes aux problèmes communs des centres notamment en ce qui concerne la prise en charge des personnes handicapées qui les fréquentent et l'amélioration de la qualité des services offerts. Depuis sa création, le Réseau a assuré la représentation des centres au cours de différents ateliers stratégiques. Il est également reconnu par différents Ministères comme partenaire important pour la question du handicap. Il participe également à l'organisation de la Journée Internationale de la Personne Handicapée du 3 décembre et est aussi membre de la Décennie Africaine pour les Personnes Handicapées. Le Réseau rassemble actuellement 13 centres pour personnes handicapées sur le territoire national.²⁶

23 Comme ci-dessus.

24 Mémoire sur La Problématique des Personnes Handicapées Au Burundi Année 2013 <https://webcache.googleusercontent.com/search?q=cache:xJ3p4SdcI38J:https://assoraphb.files.wordpress.com/2013/06/memorandum-sur-la-problematique-des-personnes-handicapees-au-burundi-annee-2013.doc+&cd=1&hl=en&ct=clnk&gl=za> (Consulté le 31 Juillet 2019).

25 Mission du Réseau des Centres pour Personnes Handicapées du Burundi. <http://rphburundi.over-blog.com/article-mission-du-reseau-des-centres-pour-personnes-handicapees-du-burundi-49968553.html> (Consulté le 31 Juillet 2019).

26 Comme ci-dessus.

L'Union des Personnes Handicapées du Burundi « UPHB », a été créée le 25 avril 1989, enregistrée et agréée par l'Ordonnance Ministérielle N°550/208/89 du 8 août de cette même année. Elle est pionnière du mouvement associatif des personnes handicapées au Burundi. L'UPHB a évolué avec le temps du statut d'association à celui de collectif d'Organisations de Personnes Handicapées (OPH) depuis 2010 et actuellement, elle compte une trentaine d'OPH implantées dans toutes les provinces du pays et formant ainsi le collectif UPHB. L'organisation a son propre siège construit dans le respect des normes d'accessibilité. Ses Partenaires sont entre autres la Fondation Liliane (une ONG internationale intervenant dans la promotion des droits des enfants et jeunes handicapés), le Gouvernement du Burundi à travers le Ministère des Droits de la Personne Humaine, des Affaires Sociales et du Genre (MDPHASG), Humanité Inclusion (ex Handicap International), les organisations partenaires locales, La Fédération des Associations des Personnes Handicapées du Burundi (FAPHB), Le réseau des Centres des Personnes Handicapées du Burundi (RCPHB), l'Ambassade de France, l'Organisation Mondiale des Personnes Handicapées (OMPH), le Forum Africain pour les Personnes Handicapées, l'Office du Haut-Commissaire des Droits de l'Homme (OHCDH), la FACAPH, l'UNICEF, etc.. L'UPHB est une organisation qui a une vision, une mission, une devise, des valeurs, des objectifs précis et une stratégie d'intervention adaptée.

Ses principaux objectifs consiste à Rassembler toutes les organisations de personnes handicapées du Burundi qui le souhaitent et le demandent ; défendre les intérêts de ses organisations membres et de toute personne handicapée ; plaider pour la participation et l'inclusion des personnes en situation de handicap dans tous les domaines de la vie communautaire et nationale; appuyer les pouvoirs publics à mettre en place et à appliquer une législation spéciale favorable à la promotion et à la protection des droits des personnes handicapées; assurer le renforcement des capacités de ses membres; contribuer à l'autonomisation et à l'insertion socio-économique des personnes handicapées; développer la coopération avec les autres organisations sur le plan national, régional et international visant la promotion des droits humains.

En terme de stratégie d'intervention, L'UPHB met en œuvre ses interventions en faveur des personnes en situation de handicap (enfants, jeunes et adultes) résidant sur tout le territoire national en collaboration avec les OPH membres et ses Organisations Partenaires œuvrant au niveau local. Elle possède également une administration qui organise régulièrement des réunions statutaires ainsi que celles de coordination de son personnel. Au niveau des réunions statutaires, il y en a eu des réunions ordinaires mais aussi celles extraordinaires pour les membres du Comité Exécutif National. L'Assemblée générale s'est également tenue pour une évaluation semestrielle de l'état d'avancement des activités mais aussi pour les élections de nouveaux organes conformément aux nouveaux statuts. Pour les ressources humaines, l'UPHB a un personnel permanent ainsi que le personnel bénévole. Parmi le personnel permanent, l'équipe s'élève à un effectif de 10 personnes. Il s'agit d'un Directeur Exécutif, un Responsable administratif et Financier, un Coordinateur National du programme d'Appui à l'Autonomisation des enfants handicapés (PAE), un Directeur du Centre de services, une chargée de programme au niveau du PAE, un Chargé des Formations au niveau du Centre de services, un Secrétaire Comptable, deux agents d'entretien et un chauffeur.²⁷

La Fédération des Associations des Personnes Handicapées du Burundi (FAPHB) un autre réseau d'association dont le but et les objectifs sont la promotion, et la protection des droits des personnes en situation de handicap du

27 Union des Personnes Handicapées du Burundi <http://www.uphb.bi/images/pdf/RAPPORT2017.pdf> (Consulté le 31 Juillet 2019).

Burundi. Ses fonctions et activités sont plus ou moins similaire à celles des associations sus-mentionnées.

9.2 Dans votre région, les OPH sont-elles organisées ou coordonnées au niveau national et/ou régional?

Il y'a quelques associations et centres qui s'occupent de la prise en charge des personnes handicapées. Ces centres et associations se regroupent en trois grands réseaux dont le Réseau des Centres pour Personnes Handicapées au Burundi (RCPHB), le Réseau des Associations des Personnes Handicapées au Burundi (RAPHB) et l'Union des Personnes Handicapées du Burundi (UPHB).²⁸

9.3 Si la République du Burundi a ratifié la CDPH, comment a-t-elle assuré l'implication des Organisations des personnes handicapées dans le processus de mise en œuvre?

Au cours de la validation de la Politique Nationale des Personnes Handicapées et de son Plan d'Actions le 3 décembre 2018 par le gouvernement du Burundi, le ministre des Droits de la Personne Humaines, des Affaires Sociale et du Genre a réaffirmé l'appui matériel et financier du gouvernement aux associations et centres pour personnes en situation de handicap sans oublier l'assistance individuelle et l'octroi du matériel de mobilité aux personnes handicapées.²⁹

Toutefois, en dépit de cette observation, l'on doit retenir de manière générale qu'il y' a encore beaucoup de problèmes de mise en œuvre de la CDPH au Burundi.

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 à travers la Fédération des Associations des Personnes Handicapées du Burundi (FAPHB) mènent des actions de plaidoyer, de sensibilisations à travers différents projets et en collaboration avec les autorités gouvernementales. C'est grâce à cette mobilisation que la loi N°1/03 du 10 janvier 2018 portant promotion et protection des droits des personnes handicapées au Burundi a été adoptée.

9.5 Quels sont, le cas échéant les obstacles rencontrés par les OPH lors de leur engagement dans la mise en œuvre?

Les obstacles rencontrés par les OPH lors de l'engagement dans la mise en œuvre ont été la non prise en compte de leurs suggestions par le gouvernement Burundais à la suite des concertations ayant abouti au vote et à la promulgation de la loi N°1/03 du 10 janvier 2018 portant promotion et protection des droits des personnes

28 Mémoire sur La Problématique des Personnes Handicapées Au Burundi Année 2013 <https://webcache.googleusercontent.com/search?q=cache:xJ3p4SdcI38J:https://assoraphb.files.wordpress.com/2013/06/memorandum-sur-la-problematique-des-personnes-handicapees-au-burundi-annee-2013.doc+&cd=1&hl=en&ct=clnk&gl=za> (Consulté le 31 Juillet 2019).

29 Validation de la Politique Nationale des Personnes Handicapées et de son plan d'actions. <http://www.droitshumains.gov.bi/validation-de-la-politique-nationale-des-personnes-handicapees-et-de-son-plan-dactions/> (Consulté le 31 Juillet 2019).

handicapées au Burundi.³⁰ Ainsi en ce qui concerne l'éducation par exemple, les spécificités de chaque handicap ne sont pas prises en compte en matière de supports pédagogiques et de personnel enseignant. A titre illustratif, Il est fait mention des cas où on attribue aux élèves en situation de handicap des points dans le cours de sport sans qu'ils aient fourni l'effort, les considérant comme des inaptes. Pourtant, il y a des sports adaptés à une déficience donnée.³¹

9.6 Y a-t-il des exemples pouvant servir de 'modèles' pour la participation des OPH?

Oui il y'a des exemples.

Certaines personnes en situation de handicap sont encadrées par quelques centres et associations qui s'occupent de leur prise en charge. Il se trouve que ces personnes en général et les jeunes en situation de handicap en particulier ne sont pas représentés dans les organes de prise de décision. La Fédération des Associations des Personnes Handicapées du Burundi (FAPHB) indique que cela a des impacts négatifs sur la mise en pratique des projets de développement du pays puisque les jeunes handicapés ne s'y trouvent pas impliqués. Il donne l'exemple des centres-jeunes qui sont implantés dans différentes communes du pays.³² Les actions menées par cette organisation vise à sensibiliser les autorités publique pour une plus grande prise en compte de la situation des personnes en situation de handicap dans la conduite des affaires de l'Etat. Le rôle de sensibilisation et les différents plaidoyers par les OPH ont porté des fruits au fil des années. Les exemples notoires sont la reconnaissance par les organisations des personnes en situation de handicap envers le Gouvernement du Burundi pour certaines mesures initiées visant à alléger la souffrance de ces personnes. Ces mesures sont entre autres la gratuité de l'accès à l'enseignement primaire, l'accès gratuit aux soins de santé pour les enfants de moins de 5 ans, l'accès gratuits aux soins pour les femmes enceintes et accouchement gratuit, l'appui aux initiatives des organisations et centres des personnes en situation de handicap par le Ministère de la Solidarité Nationale, Droits de la Personne Humaine et du Genre, et l'acceptation des enfants en situation de handicap pour passer le concours national (enfants aveugles et sourds).³³

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?

L'adoption et la promulgation de la loi N°1/03 du 10 janvier 2018 portant promotion et protection des droits des personnes handicapées au Burundi demeure

30 Jeunes vivant avec un handicap, Des capacités sportives mises à rude épreuve <http://burundi-eco.com/jeunes-vivant-avec-un-handicap-des-capacites-sportives-mises-a-rude-epreuve/#.XUArClh97cs> (Consulté le 31 Juillet 2019).

31 Jeunes vivant avec un handicap, Des capacités sportives mises à rude épreuve <http://burundi-eco.com/jeunes-vivant-avec-un-handicap-des-capacites-sportives-mises-a-rude-epreuve/#.XUArClh97cs> (Consulté le 31 Juillet 2019).

32 Comme ci-dessus.

33 Mémoire sur La Problématique des Personnes Handicapées Au Burundi Année 2013 <https://webcache.googleusercontent.com/search?q=cache:xJ3p4Sdcl38J:https://assoraphb.files.wordpress.com/2013/06/memorandum-sur-la-problematique-des-personnes-handicapees-au-burundi-annee-2013.doc+&cd=1&hl=en&ct=clnk&gl=za> (Consulté le 31 Juillet 2019).

un aboutissement positif grâce à l'implication des OPH dans le processus de mise en œuvre de la CRDPH.

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?

Nous croyons qu'il faille mettre une plus grande pression sur le gouvernement et les pouvoirs publics pour une plus grande promotion et protection des droits des personnes handicapées.

En plus, La question des capacités des personne handicapé doit être considérée Il faut également une forte mobilisation financière pour couvrir certains retards dans le domaine du handicap ainsi qu'un plus grand plaidoyer et une sensibilisation accrue afin que la cause des personnes en situation de handicap soit entendue partout où besoin sera.

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 au travers de la FAPHB devraient être représentées dans les organes en charge de la mise en œuvre des instruments internationaux ou régionaux, et plus particulièrement parties prenantes dans la rédaction et la présentation du rapport conformément à l'Art. 35 de la CDPH. Il conviendrait également de développer dans les universités Burundaises des modules d'enseignement sur les Droits des personnes en situation de handicap et sensibiliser les populations sur la dignité de ces personnes et sur le respect de leurs droits.

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?

Non.

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).

Au Burundi, le ministère de la Solidarité Nationale, des Droits de la Personne Humaine et du Genre aborde le handicap. Le Département de l'Intégration Sociale est chargé d'assurer la protection des personnes vulnérables en difficultés y compris des handicapés et autres personnes nécessiteuses, d'élaborer et d'exécuter le programme de formation et de réadaptation pour une réinsertion Socio-Professionnelle des handicapés et d'organiser l'éducation spécialisée notamment

par la création et la multiplication des écoles pour handicapés mentaux ou sensoriels.³⁴

11 Préoccupations majeures des droits de l'homme relatives aux personnes handicapées

11.1 Quels sont les défis contemporains des personnes handicapées en République du Burundi? (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.)

Les défis contemporains auxquels sont confrontés les personnes en situation de handicap au Burundi sont l'accès à un emploi autonomisant, la très grande majorité de ces personnes étant au chômage. En outre, il n'existe pas de mesures spécifiques favorables au recrutement des personnes en situation de handicap tant dans la Fonction Publique que dans le secteur privé.

Comme autre défis, il y'a de cela quelques années, une ministre faisait clairement allusion aux pratiques et coutumes discriminatoires, à savoir des croyances qui font qu'il y ait des personnes en situation de handicap victimes de violence sexuelles, la chasse aux albinos, des employeurs qui ne recrutent pas parmi leur personnel les personnes en situation de handicap, certaines infrastructures sociales qui restent inaccessibles aux personnes en situation de handicap, et des parents qui n'envoient pas leurs enfants en situation de handicap à l'école ou qui ne les traitent pas au même titre que les bien portants.³⁵

11.2 Comment la République du Burundi répond-t-il aux besoins des personnes handicapées au regard des domaines ci-dessous énumérées?

- **Accès aux bâtiments publics**

L'installation des rampes pour faciliter le déplacement des handicapés dans les bâtiments publics demeure un vœu qui malheureusement n'est toujours pas réalisé.

- **Accès au transport public**

Les personnes en situation de handicap au Burundi ne bénéficient toujours pas de mesures spécifiques qui leurs seraient favorables quant au transport public. Néanmoins, la loi N°1/03 du 10 janvier 2018 portant promotion et protection des droits des personnes handicapées au Burundi stipule en son article 14 que l'Etat veille à la disponibilité et à la qualité des services de réadaptation des personnes en situation de handicap afin de leur permettre d'atteindre et de conserver un niveau optimal d'autonomie et de renforcer le soutien aux initiatives privées en la matière.

34 Décret n°100-216 du 4 août 2011 portant structure, fonctionnement et missions du ministère de la solidarité nationale, des droits de la personne humaine et du genre.

35 Burundi – Droits de la personne handicapée <http://www.ldgl.org/burundi-droits-de-la-personne-handicapee/> (Consulté le 31 Juillet 2019).

Plus loin, l'article 32 stipule que toute personne handicapée bénéficie de l'exonération des frais de dédouanement, de l'impôt et autres taxes sur véhicule ou tous matériels conçus pour personne handicapée.

- **Accès à l'éducation**

La mesure de la gratuité de l'accès à l'enseignement primaire pour les enfants handicapés est une initiative importante des pouvoirs publics; même si la jouissance effective requiert encore des aménagements spécifiques. Il y'a un défaut crucial d'équipements pédagogiques qui font défaut dans les écoles pilotes. L'éducation inclusive au Burundi reste donc un défi car les experts en la matière sont rares et le plus souvent, viennent de l'étranger pour un coût très onéreux.

- **Accès à la formation professionnelle**

Ce qui vient d'être mentionné dans la section précédente s'applique également à la formation professionnelle.

- **Accès à l'emploi**

L'article 31 de la loi N°1/03 du 10 janvier 2018 portant promotion et protection des droits des personnes handicapées au Burundi dispose que toute personne handicapée jouit de ses droits fondamentaux en particulier dans le domaine de l'emploi. Il est précisé qu'aux fins de l'entretien et de la sauvegarde de l'emploi des personnes handicapées, l'employeur est tenu de maintenir la personne handicapée sur son lieu de travail s'il décide de licencier une partie de son personnel pour motif économique ou pour tout autre motif raisonnable. Le texte mentionne également que tout fonctionnaire ou salarié victime d'un handicap l'empêchant de poursuivre l'exercice de son travail habituel, quelle que soit la cause, est maintenue à son poste initial ou affecté à un autre poste vacant qui peut lui être attribué selon ses aptitudes et la spécificité de son handicap et après sa réadaptation au cas échéant. Au cas où aucun emploi ne peut lui être trouvé, le même article informe que les dispositions légales relatives aux régimes de pensions et risques professionnels lui sont applicables.

Cependant, en dépit de ces dispositions pertinentes, l'on doit reconnaître que la pratique c'est tout autre chose. Les personnes en situation de handicap au Burundi demeurent marginalisées en ce qui concerne l'accès à l'emploi. La plupart du temps, leur éducation et formation professionnelles ne coïncident pas avec les demandes réelles du marché de travail.

- **Accès à la détente et au sport**

L'article 33 de la loi N°1/03 du 10 janvier 2018 portant promotion et protection des droits des personnes handicapées dispose que toute personne handicapée a le droit d'être intégrée dans les activités sportives, culturelles et de loisir dans la limite de ses conditions physique, mentale et sensorielle. Mais dans la pratique il reste énormément de choses à réaliser pour concrétiser ces dispositions.

- **Accès aux soins de santé**

L'article 55 de la constitution du Burundi reconnaît à tous les citoyens le droit aux soins de santé. Le problème est de mettre sur pied les conditions qui rendent la jouissance du droit aux soins de santé pour les personnes handicapées. Les pouvoirs publics ont pris une mesure garantissant l'accès gratuit aux soins de santé pour les enfants de moins de 5 ans, mesure ayant permis à bon nombre d'enfants d'accéder à une réadaptation appropriée. Il en est de même de l'accès gratuit aux soins pour les femmes enceintes et accouchement gratuit. Cette mesure a certainement contribué à limiter des cas de handicap qui seraient liés à une

mauvaise prise en charge des femmes enceintes et des accouchements dans les milieux non hospitaliers.³⁶

11.3 La République du Burundi accorde-t-il des subventions pour handicap ou autre moyen de revenue en vue de soutenir les personnes handicapées?

La loi N°1/03 du 10 janvier 2018 portant promotion et protection des droits des personnes handicapées au Burundi prévoit que l'Etat participe à la hauteur de ses moyens disponibles à la solidarité internationale en faveur des personnes handicapées. Par ailleurs on peut noter l'appui aux initiatives des organisations et centres des personnes en situation de handicap par le Ministère de la Solidarité Nationale, Droits de la Personne Humaine et du Genre ainsi que l'acceptation des enfants handicapés pour passer le concours national (enfants aveugles et sourds).³⁷

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 du Burundi?

Oui les personnes en situation de handicap ont un droit de participation à la vie politique. L'Article 50 (b) de la loi n° 1/ 20 du 3 juin 2014 portant révision de la loi n°1/22 du 18 septembre 2009 portant code électoral³⁸ va jusqu'à autoriser un vote par procuration au profit des malades et handicapés qui, en raison de leur état de santé ou de leur condition physique, sont dans l'impossibilité absolue de se déplacer jusqu'au lieu du scrutin. Néanmoins, il y'a un problème concernant la représentativité politique des personnes handicapées. Contrairement à d'autres pays de la sous-région qui prévoit un taux de représentation, les personnes en situation de handicap au Burundi ne sont pas représentées dans les instances politiques du pays telles que le Parlement, le Sénat, le Gouvernement et les Conseils nationaux.

11.5 Catégories spécifiques expérimentant des questions particulières/vulnérabilité:

- **Femmes en situation de handicap**
Information non disponible.
- **Enfants en situation de handicap**
Accès à l'école et aux soins de santé.

36 Memorandum Sur La Problématique des Personnes Handicapées au Burundi Année 2013 <https://webcache.googleusercontent.com/search?q=cache:xJ3p4SdcI38J:https://assoraphb.files.wordpress.com/2013/06/memorandum-sur-la-problematique-des-personnes-handicapees-au-burundi-annee-2013.doc+&cd=1&hl=en&ct=clnk&gl=za> (Consulté le 30 Juillet 2019).

37 Memorandum Sur La Problématique des Personnes Handicapées au Burundi Année 2013 <https://webcache.googleusercontent.com/search?q=cache:xJ3p4SdcI38J:https://assoraphb.files.wordpress.com/2013/06/memorandum-sur-la-problematique-des-personnes-handicapees-au-burundi-annee-2013.doc+&cd=1&hl=en&ct=clnk&gl=za> (Consulté le 30 Juillet 2019).

38 Commission électorale nationale indépendante <https://www.ceniburundi.bi/-Code-electoral-> (Consulté le 31 Juillet 2019).

12 Perspective future

12.1 Y'a-t-il des mesures spécifiques débattues ou prises en compte présentement au Burundi au sujet les personnes handicapées?

Oui, quant à la représentativité politique des personnes en situation de handicap dans les instances étatiques.

En effet, elles ne sont pas représentées dans les institutions politiques du pays (Parlement, Sénat, Gouvernement, Conseils nationaux, etc.) Ceci est difficilement compréhensible car c'est au sein de ces institutions que se joue l'avenir du pays et des Hommes. Par rapport aux pays membres de la Communauté Est Africaine, le Burundi est le dernier pays en matière de représentativité politique des personnes en situation de handicap car les autres pays membres de l'EAC ont des politiques internes de promotion des personnes en situation de handicap. Dans ces pays, ces personnes sont représentées au sein des deux chambres du parlement de leur pays, ainsi que dans le parlement de la Communauté Est Africaine. Les personnes en situation de handicap participants dans ces institutions sont cooptées parmi les personnes en situation de handicap elles-mêmes.³⁹

12.2 Quelles réformes légales sont proposées? Quelle réforme légale aimeriez-vous voir au Burundi? Pourquoi?

Le développement de l'enseignement du Droit des personnes en situation de handicap dans les grandes écoles et universités du Burundi. La mise en œuvre effective de la Convention des Nations Unies relative aux Droits des Personnes Handicapées CDPH ou tout autre instrument international, la sensibilisation des populations en général et des décideurs en particulier sur la prise en compte des mesures en faveur de la dignité des personnes en situation de handicap.

39 Memorandum Sur La Problématique des Personnes Handicapées au Burundi Année 2013 <https://webcache.googleusercontent.com/search?q=cache:xJ3p4SdcI38J:https://assoraphb.files.wordpress.com/2013/06/memorandum-sur-la-problematique-des-personnes-handicapees-au-burundi-annee-2013.doc+&cd=1&hl=en&ct=clnk&gl=za> (Consulté le 30 Juillet 2019).

RÉPUBLIQUE DU CONGO

Marianne Séverin* & Chretien Fontcha**

Summary

According to the World Bank (WB), the Congolese population is 5.2 million. No recent census has been conducted on people with disabilities. According to the United Nations Development Programme (UNDP), the most prevalent forms of disabilities include visual, motor disabilities (lower and upper limbs), visual and auditory disabilities. The Republic of Congo signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD), as well as its Optional protocol on 30 March 2007. The CRDP and the Optional Protocol have been ratified on 14 February 2014. The Republic of Congo did not submit its country report which was supposed to be submitted on 2 October 2016. Through Art 31 the elders and persons with disabilities are entitled to protective measures in relation to their physical, moral or other needs, with a view to their full development under conditions laid down by law. The State has a duty to promote the presence of people with disabilities in national and local institutions and administrations. The Republic of Congo has an important piece of legislation that directly addresses disability, Law 009/92, of 22 April 1992 on the rights of people with disabilities.

The policies that directly address persons with disabilities are: The National Social Action Policy Programme (2018-2022). Congo has the following programmes: The National Action Plan for Persons with Disabilities which aims to promote the socio-economic development of persons with disabilities, their education, a better detection of the causes of disabilities, social protection, professional training for people with disabilities.

Other than ordinary courts or tribunals, the Republic of Congo does not have an official body which specifically addresses the violation of the rights of people with disabilities. They have had a National Human Rights Commission, since 2015.

* Associate researcher at « Les Afriques dans le Monde » (LAM)/Science Po Bordeaux.

** PhD Candidate at the University of Dschang.

There are numerous organisations that represent and advocate for the rights and welfare of persons with disabilities in Congo, represented by the National Union of Disabled People of Congo which is an umbrella body of 10 important organisations.

In Congo, the Ministry of Social Affairs and Humanitarian Action are in favour of persons with disabilities, with the Advisory Council for Persons with Disabilities. Disabled people still encounter multiple levels of exclusion and discrimination. Most are yet to acquire their identity cards, and cannot access education. The Republic of Congo should equip itself with a reliable specific household census on persons with disabilities, taking into account women, children and elders with disabilities. It should increase the promotion of disability rights especially in the rural areas.

1 Les indicateurs démographiques

1.1 Quelle est la population totale de la République du Congo?

Selon la Banque Mondiale, la population totale de la République du Congo est, en 2017, de 5,2 millions d'habitants.¹

1.2 Méthodologie employée en vue d'obtenir des données statistiques sur la prévalence du handicap en République du Congo. Quels sont les critères utilisés pour déterminer qui fait partie de la couche des personnes handicapées en République du Congo?

La République du Congo n'a effectué aucun recensement récent ce qui ne permet pas d'y déterminer la méthodologie employée en vue d'obtenir des données statistiques sur la prévalence du handicap.

1.3 Quel est le nombre total et le pourcentage des personnes handicapées en République du Congo

Aucun recensement récent n'a été mené sur le nombre total et le pourcentage des personnes handicapées en République du Congo.

1.4 Quel est le nombre total et le pourcentage des femmes handicapées en République du Congo?

Aucun recensement récent n'a été mené sur le nombre total et le pourcentage des femmes handicapées en République du Congo.

1 Banque Mondiale (BM) 'République du Congo – Vue d'ensemble' <https://www.banquemondiale.org/fr/country/congo/overview> (consulté le 27/09/2019).

1.5 Quel est le nombre total et le pourcentage des enfants handicapés en République du Congo?

Aucun recensement récent n'a été mené sur le nombre total et le pourcentage d'enfants handicapés en République du Congo.

1.6 Quelles sont les formes de handicap les plus répandues en République du Congo?

Selon le programme des Nations Unies pour le Développement (PNUD) les formes de handicap les plus répandues en République du Congo sont les handicaps moteurs (membres inférieurs et supérieurs), auditifs² et visuels.

2 Obligations internationales

2.1 Quel est le statut de la Convention des Nations Unies relative aux Droits des Personnes Handicapées (CDPH) en République du Congo? La République du Congo a-t-il signé et ratifié la CDPH? Fournir le(s) date(s). La République du Congo a-t-il signé et ratifié le Protocole facultatif? Fournir le(s) date(s).

La République du Congo a signé la Convention Relative aux Personnes Handicapées (CRDPH), ainsi que le Protocole facultatif se rapportant à la CRDPH, le 30 mars 2007. Les CRDPH et le Protocole ont été ratifiés le 14 février 2014. La République du Congo n'a formulé aucune réserve, ni introduit une quelconque déclaration interprétative.³

2.2 Si la République du Congo 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 du Congo a-t-il soumis son rapport? Sinon quelles sont les raisons du retard telles qu'avancées par la branche gouvernementale en charge?

La branche du gouvernement responsable de la soumission du rapport est le ministère des affaires sociales. Conformément à l'article 35 de la CDPH, la République du Congo était tenue de soumettre son rapport initial dans un délai de deux ans; soit le 2 octobre 2016. La République du Congo n'a soumis aucun rapport.⁴ Cependant, la République du Congo a institué dans sa nouvelle

2 Cabinet Afrobarometer Sénégal 'Rapport d'étude sur la perception des populations face aux élections législatives 2012 et locales 2013 au Congo' https://www.undp.org/content/dam/congo/docs/Publications/UNDP-CG-Rapport_Enquete_Percep-2012.pdf (consulté le 27/09/2019).

3 Nations Unies Collections des Traités 'Protocole facultatif se rapportant à la Convention relative aux droits des handicapés' (New York, 13 décembre 2006) https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15-a&chapter=4&clang=_fr (Consulté le 27/09/2019).

4 OHCHR https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/countries.aspx?CountryCode=COG&Lang=FR (Consulté le 27/09/2019).

Constitution (entrée en vigueur le 25 octobre 2015), un Conseil Consultatif des personnes vivant avec handicap.⁵

2.3 Si la République du Congo 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 du Congo. Y'avait-il des effets internes découlant du processus de rapport liés aux questions handicapées du Congo?

Le Comité n'a pas encore examiné le rapport; la République du Congo n'ayant pas rendu le document conformément à l'article 35 de la CDPH au 2 octobre 2016.

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 du Congo 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 République du Congo? Si oui, quels étaient les effets de ces observations ou recommandations?

Comité contre la torture

La République du Congo n'a pas soumis récemment de rapport initial au titre de l'Article 19 de la Convention contre la torture et autres peines cruels, inhumain ou dégradation comme prévu au 15 mai 2019.⁶

Comité pour l'élimination de la discrimination à l'égard des femmes

La République du Congo a soumis son rapport initial au titre de l'article 18, alinéa 1 de la Convention sur l'Élimination de toutes les formes de Discriminations à l'égard des Femmes (CEDEF/CEDAW), le 27 avril 2017 (publié le 15 mai 2017).⁷ Y est fait mention spécifique du droit des personnes en situation de handicap:

5 Constitution de la République du Congo 'Article 234' <https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/100814/121082/F1693068911/COG-100814.pdf> (Consulté le 27/09/2019)

6 OHCHR 'Convention contre la torture autres peines ou traitements cruels, inhumains ou dégradants(CAT)' https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 27/09/2019).

7 OHCHR 'Convention sur l'élimination de toutes les formes de discrimination à l'égard des femmes (CEDAW) - Rapport de l'Etat partie' (CEDAW/C/COG/7)'https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/countries.aspx?CountryCode=COG&Lang=FR (Consulté le 27/09/2019). Le prochain rapport doit être soumis le 9 novembre 2022.

En matière d'éducation

- La loi n°009-92 du 22 avril 1992 portant statut, protection et promotion de la personne handicapée est toujours d'actualité.⁸
- En principe, il n'existe aucun texte au Congo qui discrimine les enfants vivant avec handicap en matière d'éducation.⁹

Dans la liste de points et de question concernant le septième rapport périodique du Congo (14 mars 2018), il est demandé à la République du Congo de fournir des renseignements sur les mécanismes mis en place et les mesures prises pour prévenir le danger que présentent les politiques d'ethnisation et de régionalisation pour les femmes handicapées.¹⁰

En réponse, la République du Congo a affirmé, le 14 août 2018, au terme de l'Article 15 de la Constitution du 25 octobre 2015, que tous les citoyens congolais sont égaux devant la loi et ont droit à la protection de l'Etat. 'Nul ne peut être favorisé ou désavantagé en raison de son origine familiale, ethnique, de sa condition sociale, de ses convictions politiques, religieuses, philosophiques ou autres.'¹¹

Comité de droits économiques, sociaux et culturels

Le comité économique et social a 'acté l'absence du rapport initial du Congo attendu en 1990' (4 juin 2012).¹²

- Le comité a listé les points se rapportant aux dispositions générales du Pacte (art. 1^{er} à 5) en faisant mention spécifique des personnes handicapées, en indiquant quels droits leurs ont été reconnus et si la loi portant protection des droits des personnes handicapées définit la notion d'aménagement raisonnable. Il est également demandé au Congo de donner des informations, dont des données statistiques, sur l'impact de la mise en œuvre du Plan d'action national pour les personnes handicapées de 2009 pour ce qui est de l'exercice par les personnes handicapées de leur droit de travail, à la santé et à l'enseignement, et enfin de renseigner sur l'impact des mesures ciblées visant à réduire le chômage chez les personnes handicapées.¹³

8 OHCHR 'Convention sur l'élimination de toutes les formes de discrimination à l'égard des femmes (CEDAW) - Rapport de l'Etat partie' CEDAW/C/COG/7, 15/05/2017 p. 18' https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/countries.aspx?CountryCode=COG&Lang=FR (Consulté le 27/09/2019) (n 7 Comme ci-dessus).

9 OHCHR 'Convention sur l'élimination de toutes les formes de discrimination à l'égard des femmes (CEDAW) - Rapport de l'Etat partie' CEDAW/C/COG/7, 15/05/2017 p. 19' https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/countries.aspx?CountryCode=COG&Lang=FR (Consulté le 27/09/2019) (Comme ci-dessus).

10 OHCHR 'Convention sur l'élimination de toutes les formes de discrimination à l'égard des femmes (CEDAW) - Liste de points et de questions concernant le septième rapport périodique du Congo' CEDAW/C/COG/Q/7, 19/03/2018 p. 1' https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/countries.aspx?CountryCode=COG&Lang=FR (Consulté le 27/09/2019).

11 OHCHR 'Convention sur l'élimination de toutes les formes de discrimination à l'égard des femmes (CEDAW) - Liste de points et de questions concernant le septième rapport périodique du Congo' CEDAW/C/COG/Q/7, 19/03/2018 p. 2' https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/countries.aspx?CountryCode=COG&Lang=FR (Consulté le 27/09/2019).

12 OHCHR 'Pacte international relatif aux droits économiques, sociaux et culturels' https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 27/09/2019).

- Le comité a également listé les points se rapportant aux dispositions générales du Pacte (art. 6 à 15) en interrogeant sur les mesures prises pour encourager les employeurs à recruter des personnes handicapées (Art. 6 -Droit du travail),¹⁴ et sur le pourcentage de personnes bénéficiant des divers régimes de sécurité sociale pour le handicap (Art. 9 - Droit à la sécurité sociale).¹⁵

L'International Disability Alliance (IDA), lors de la 49^e session du CDESCR (13-30 novembre 2012), a fait plusieurs recommandations faisant mention spécifique des personnes vivant avec handicap, suite à la signature de la Convention relative aux Droits des personnes handicapées et son Protocole Optionnel en 2007, par la République du Congo; prendre des mesures pour consulter et impliquer activement les personnes handicapées et leurs organisations représentatives dans l'élaboration de la législation et des politiques concernant l'éducation, l'emploi, la protection sociale, la santé, la protection contre la violence, conformément à l'article 4(3) de la CDPH.¹⁶

Comité des droits de l'enfant

Le Rapport de l'Etat partie doit être remis le 12 novembre 2019. En 2010 la République du Congo a respecté la date d'échéance de soumission de rapport (11 novembre 2010), qui a été publié le 18 septembre 2012.¹⁷

Commission africaine des Droits de l'Homme et des Peuples

Selon le 45^{ème} Rapport d'activités de la Commission africaine des Droits de l'Homme et des Peuple, présenté-conformément à l'Article. 54 de la Charte Africaine des Droits de l'Homme et des-Peuples, lors de la 60^{ième} Session ordinaire, la République du Congo a plus de trois (3) rapports en retard.¹⁸

- 13 OHCHR 'Pacte international relatif aux droits économiques, sociaux et culturels – Liste des points à traiter établie en l'absence du rapport initial du Congo, attendu en 1990' E/C.12/COG/Q/1, 4/06/2012, p. 2 https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 27/09/2019).
- 14 OHCHR 'Pacte international relatif aux droits économiques, sociaux et culturels – Liste des points à traiter établie en l'absence du rapport initial du Congo, attendu en 1990' E/C.12/COG/Q/1, 4/06/2012, p. 3 https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 27/09/2019) (Comme ci-dessus).
- 15 OHCHR 'Pacte international relatif aux droits économiques, sociaux et culturels – Liste des points à traiter établie en l'absence du rapport initial du Congo, attendu en 1990' E/C.12/COG/Q/1, 4/06/2012, p. 3 https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 27/09/2019) (Comme ci-dessus).
- 16 OHCHR 'Pacte international relatif aux droits économiques, sociaux et culturels – info des organisations de la société civile (International Disability Alliance (IDA) 12-30/11/2012, p. 1 https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/countries.aspx?Lang=fr (Consulté le 27/09/2019).
- 17 OHCHR 'Convention relative aux droits de l'enfant – Rapport de l'Etat parti' https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/countries.aspx?CountryCode=COG&Lang=FR (Consulté le 27/09/2019 2019).
- 18 ACHPR '45eme Rapport d'activités de la Commission des Droits de l'Homme et des Peuples' p. 8' https://www.achpr.org/fr_activityreports/viewall?id=49 (Consulté le 27/09/2019 2019). La République du Congo a exactement 5 rapports d'activité en retard (Cf Commission Africaine des Droits de l'Homme et des Peuples (CADHP) 'Etats parties à la Charte africaine' <https://www.achpr.org/statepartiestotheafricancharter> (Consulté le 27/09/2019 2019).

Examen Périodique Universel¹⁹

La République du Congo a mentionné les personnes handicapées dans son Rapport national, examiné le 14 septembre 2018:

En adéquation avec le Document de Stratégie de Réduction de la Pauvreté pour la période 2012-2016, un cadre stratégique sur la scolarisation des enfants handicapés. Par décret n° 2010-298 du 1 avril 2010 un comité de coordination de suivi et d'évaluation du Plan d'action national des personnes handicapées a été mis en place.²⁰

Dans le Rapport du Groupe de travail sur l'Examen périodique universel du 28 décembre 2018, le Mozambique,²¹ l'Indonésie,²² la République d'Iran,²³ l'Italie²⁴ et Maurice²⁵ ont félicité le Congo d'avoir ratifié la Convention relative aux droits des personnes handicapées.

La Chine et Cuba ont pris acte des efforts consentis par le Congo pour l'amélioration de son institutionnel en ce qui concerne les droits des personnes handicapées.²⁶

La République du Congo a été félicitée par l'Egypte, le Gabon et la République démocratique du Lao pour la promotion et la protection des droits des personnes handicapées.²⁷

- 19 OHCHR 'Examen périodique universel – Congo' <https://www.ohchr.org/FR/HRBodies/UPR/Pages/CGIndex.aspx> (Consulté le 27/09/2019).
- 20 OHCHR 'Conseil des Droits de l'Homme Groupe de travail sur l'Examen périodique universel Trente et unième session - Rapport national présenté conformément au paragraphe 5 de l'annexe à la résolution 16/21 du Conseil des droits de l'homme' A/HRC/WG.G/31/COG/1, 5-16/11/2018, p. 13' <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G18/276/48/PDF/G1827648.pdf?OpenElement> (Consulté le 27/09/2019).
- 21 OHCHR 'Conseil des droits de l'homme Quarantième session – Rapport du Groupe de travail sur l'Examen périodique universel' A/HRC/40/16*, 25/02-22/03/2019, p 5 <https://www.ohchr.org/FR/HRBodies/UPR/Pages/CGIndex.aspx> (Consulté le 27/09/2019).
- 22 OHCHR 'Conseil des droits de l'homme Quarantième session – Rapport du Groupe de travail sur l'Examen périodique universel' A/HRC/40/16*, 25/02-22/03/2019, p 9 <https://www.ohchr.org/FR/HRBodies/UPR/Pages/CGIndex.aspx> (Consulté le 27/09/2019) (Comme ci-dessus).
- 23 OHCHR 'Conseil des droits de l'homme Quarantième session – Rapport du Groupe de travail sur l'Examen périodique universel' A/HRC/40/16*, 25/02-22/03/2019, p. 9 <https://www.ohchr.org/FR/HRBodies/UPR/Pages/CGIndex.aspx> (Consulté le 27/09/2019) (Comme ci-dessus).
- 24 OHCHR 'Conseil des droits de l'homme Quarantième session – Rapport du Groupe de travail sur l'Examen périodique universel' A/HRC/40/16*, 25/02-22/03/2019, p. 9 <https://www.ohchr.org/FR/HRBodies/UPR/Pages/CGIndex.aspx> (Consulté le 27/09/2019) (Comme ci-dessus).
- 25 OHCHR 'Conseil des droits de l'homme Quarantième session – Rapport du Groupe de travail sur l'Examen périodique universel' A/HRC/40/16*, 25/02-22/03/2019, p. 10 <https://www.ohchr.org/FR/HRBodies/UPR/Pages/CGIndex.aspx> (Consulté le 27/09/2019) (Comme ci-dessus).
- 26 OHCHR 'Conseil des droits de l'homme Quarantième session – Rapport du Groupe de travail sur l'Examen périodique universel' A/HRC/40/16*, 25/02-22/03/2019, p. 7 <https://www.ohchr.org/FR/HRBodies/UPR/Pages/CGIndex.aspx> (Consulté le 27/09/2019) (Comme ci-dessus).
- 27 OHCHR 'Conseil des droits de l'homme Quarantième session – Rapport du Groupe de travail sur l'Examen périodique universel' A/HRC/40/16*, 25/02-22/03/2019, p. 8, 9 <https://www.ohchr.org/FR/HRBodies/UPR/Pages/CGIndex.aspx> (Consulté le 27/09/2019) (Comme ci-dessus).

Le Ghana a félicité le Congo d'avoir fait une priorité l'intégration des droits des personnes en situation de handicap.²⁸

La Mauritanie et le Nigeria ont pris note des efforts du Congo dans la protection des personnes handicapées.²⁹

Le Sénégal a salué la création du comité de coordination, de suivi et d'évaluation du Plan d'action national pour les personnes handicapées et particulièrement la scolarisation des enfants en situation de handicap.³⁰

2.5 Y'avait-il un quelconque effet interne sur le système légal de la République du Congo après la ratification de l'instrument international ou régional au 2.4 ci-dessus?

La ratification de la CRDPH par le Congo le 14 février 2014 a eu pour effet de citer explicitement dans la Constitution de 2015 les personnes vivant avec handicap:

- Article 31 - Les personnes âgées et les personnes vivant avec handicap ont droit à des mesures de protection en rapport avec leurs besoins physiques, moraux ou autres, en vue de leur plein épanouissement dans les conditions déterminées par la loi.³¹

L'Etat a le devoir de promouvoir la présence de la personne vivant avec handicap au sein des institutions et administrations nationales et locales.³²

- Article 234 - Il est institué un Conseil consultatif des personnes vivant avec handicap.³³

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?

Selon l'Article 223 de la Constitution de 2015 'les traités ou les accords, régulièrement ratifiés ou approuvés, ont dès leur publication, une autorité supérieure à des lois, sous réserve, pour chaque accord ou traité de son application par l'autre Partie'.³⁴ Non au Congo il n'y a pas encore de cas où le tribunal a appliqué les dispositions d'un traité international.

28 OHCHR 'Conseil des droits de l'homme Quarantième session – Rapport du Groupe de travail sur l'Examen périodique universel' A/HRC/40/16*, 25/02-22/03/2019, p. 8 <https://www.ohchr.org/FR/HRBodies/UPR/Pages/CGIndex.aspx> (Consulté le 27/09/2019) (Comme ci-dessus).

29 OHCHR 'Conseil des droits de l'homme Quarantième session – Rapport du Groupe de travail sur l'Examen périodique universel' A/HRC/40/16*, 25/02-22/03/2019, p. 10 <https://www.ohchr.org/FR/HRBodies/UPR/Pages/CGIndex.aspx> (Consulté le 27/09/2019) (Comme ci-dessus).

30 OHCHR 'Conseil des droits de l'homme Quarantième session – Rapport du Groupe de travail sur l'Examen périodique universel' A/HRC/40/16*, 25/02-22/03/2019, p. 11 <https://www.ohchr.org/FR/HRBodies/UPR/Pages/CGIndex.aspx> (Consulté le 27/09/2019) (Comme ci-dessus).

31 Constitution du 25 octobre 2015 de la République du Congo.

32 Constitution du 25 octobre 2015 de la République du Congo (Comme ci-dessus).

33 Constitution du 25 octobre 2015 de la République du Congo (Comme ci-dessus).

34 Constitution du 25 octobre 2015 de la République du Congo (Comme ci-dessus).

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.

La ratification de la CDPH vaut son incorporation dans la législation congolaise ; une procédure n'a pas semblé nécessaire ; dans la Constitution de 2015 l'article 31 promeut les droits des personnes vivant avec handicap.³⁵

3 Constitution

3.1 La constitution de la République du Congo 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 du Congo du 25 octobre 2015 contient des dispositions concernant directement le handicap. Selon l'article 31 'Les personnes âgées et les personnes vivant avec handicap ont droit à des mesures de protection en rapport avec leurs besoins physiques, moraux ou autres, en vue de leur plein épanouissement dans les conditions déterminées par la loi. L'Etat a le devoir de promouvoir la présence de la personne vivant avec handicap au sein des institutions et administrations nationales et locales'.³⁶

L'Article 234 institue un Conseil consultatif des personnes vivant avec handicap, il donne des avis et fait des suggestions au gouvernement visant une meilleure prise en charge de la personne en situation du handicap.³⁷

3.2 La constitution de la République du Congo contient-elle des dispositions concernant indirectement le handicap? Si oui énumérez les dispositions et expliquez comment chacune d'elles traite indirectement du handicap.

La Constitution de la République du Congo du 25 octobre 2015 contient des dispositions concernant indirectement le handicap.

Le préambule affirme que:

Le peuple congolais déclare partie intégrante de la présente Constitution les principes fondamentaux proclamés et garantis par:

- la Charte des Nations Unies du 24 octobre 1945;
- la Déclaration Universelle des droits de l'homme du 10 décembre 1948;
- la Charte africaine des droits de l'homme et des peuples du 26 juin 1981.³⁸

35 Constitution du 25 octobre 2015 de la République du Congo (Comme ci-dessus).

36 Constitution du 25 octobre 2015 de la République du Congo (n 31 Comme ci-dessus).

37 Constitution du 25 octobre 2015 de la République du Congo (Comme ci-dessus).

38 Constitution du 25 octobre 2015 de la République du Congo (Comme ci-dessus).

Selon l'Article 8, la personne humaine est sacrée et a droit à la vie. L'Etat a l'obligation de la respecter et de la protéger. Chaque citoyen a le droit au plein épanouissement de sa personne dans le respect des droits d'autrui, de l'ordre public, de la morale et des bonnes mœurs.³⁹

Selon l'Article 15, tous les citoyens congolais sont égaux devant la loi et ont droit à la protection de l'Etat. Nul ne peut être défavorisé ou désavantagé en raison de son origine familiale, ethnique, de sa condition sociale, de ses convictions politiques, religieuses, philosophiques ou autres.⁴⁰

L'Article 29 garantit le droit à l'éducation et l'égal accès à l'enseignement et à la formation; la scolarité obligatoire jusqu'à l'âge de seize ans.⁴¹

4 Législation

4.1 La République du Congo a-t-elle une législation concernant directement le handicap? Si oui énumérez la législation et expliquez comment la législation aborde le handicap.

La République du Congo a une législation concernant directement le handicap.

- La loi n°009/92 du 22 avril 1992, portant statut, promotion et protection de la personne handicapée jouissent du droit à la formation, à l'accès à l'emploi et à l'orientation professionnelle.⁴² Cette loi n'était pas entrée en vigueur faute d'un décret d'application.
- L'article 31 de la constitution du 25 octobre 2015 affirme que:

Les personnes âgées et les personnes vivant avec handicap ont droit à des mesures de protection en rapport avec leurs besoins physiques, moraux ou autres, en vue de leur plein épanouissement dans les conditions déterminées par la loi. L'Etat a le devoir de promouvoir la présence de la personne vivant avec handicap au sein des institutions et administrations nationales et locales.⁴³

4.2 La République du Congo a-t-il une législation concernant indirectement le handicap? Si oui énumérez la principale législation et expliquez comment elle réfère au handicap.

La République du Congo a une législation concernant indirectement le handicap. Selon l'Article 18:

Tout citoyen a droit, en tout lieu, à la reconnaissance de sa personnalité juridique. Ce droit est reconnu par la délivrance d'un acte de naissance et de la carte nationale

39 Constitution du 25 octobre 2015 de la République du Congo (Comme ci-dessus).

40 Constitution du 25 octobre 2015 de la République du Congo (Comme ci-dessus).

41 Constitution du 25 octobre 2015 de la République du Congo (Comme ci-dessus).

42 OHCHR 'Conseil des Droits de l'Homme Groupe de travail sur l'Examen périodique universel Trente et unième session - Rapport national présenté conformément au paragraphe 5 de l'annexe à la résolution 16/21 du Conseil des droits de l'homme' A/HRC/WG.G/31/COG/1, 5-16/11/2018, p. 13' <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G18/276/48/PDF/G1827648.pdf?OpenElement> (Consulté le 27/09/2019) (n 20 comme ci-dessus).

43 Constitution 2015 de la République du Congo (n 31 Comme ci-dessus).

d'identité. Celle-ci permet entre autres, de jouir du droit de vote, d'avoir un compte bancaire et de circuler librement dans le pays.⁴⁴

5 Décisions des cours et tribunaux

- 5.1 Les cours (ou tribunaux) de la République du Congo 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.**

Nous n'avons pas trouvé de décisions de justice portant sur le handicap.

6 Politiques et programmes

- 6.1 La République du Congo 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.**

La République du Congo a des politiques et des programmes qui englobent directement le handicap.

- **Après la période 2013-2016, a été retenue une série d'activités en faveur des personnes en situation de handicap dans le Programme de politique nationale d'actions sociales (PNAS) – 2018-2022- dont l'objectif est de:**

Fournir à l'ensemble de la population un socle de protection sociale: un parquet de mesures de base en vue de réduire la vulnérabilité des ménages et des individus, de les aider à mieux gérer les risques sociaux et de leur garantir la dignité humaine.⁴⁵

- **Le Plan national d'action pour les personnes handicapées**

Ce plan s'articule autour:

- De la prévention et du dépistage précoce, de l'élaboration d'étude et l'organisation d'un système d'information dans le but d'améliorer les connaissances sur les causes de handicap et les conditions sociales des personnes handicapées et de la promotion des mesures d'intervention précoces;

44 Comité Français pour la Solidarité Internationale (CFSI) 'Au Congo Brazzaville : défendre les droits des personnes en situation de handicap' <https://www.cfsi.asso.fr/thematique/congo-brazzaville-defendre-droits-personnes-situation-handicap> (Consulté le 27/09/2019).

45 PW Douniama 'Conseil consultative des personnes vivant avec handicap: Jean De Dieu Goma nommé secrétaire exécutif permanent' Agence d'Information d'Afrique Central, 16/01/2019 <http://www.adiac-congo.com/content/conseil-consultatif-des-personnes-vivant-avec-handicap-jean-de-dieu-goma-nomme-secretaire> (Consulté le 27/09/2019)

- Du développement et de l'appui aux institutions spécialisées, aux organisations des personnes handicapées et aux communautés qui prennent en charge des personnes handicapées;
- De la scolarisation et l'alphabétisation des enfants handicapés afin de faciliter l'accès des personnes handicapées à une éducation de qualité et une scolarisation adaptée;
- De l'accès à la protection, au service public, à la santé, aux sports et loisirs, à l'information, à la culture et à la communication pour répondre aux besoins d'intégration des personnes handicapées dans la population et au développement des services offerts: (i) la formation professionnelle pour permettre aux personnes handicapées d'accéder à un emploi permanent; (ii) la mise en œuvre, le suivi et l'évaluation du plan d'action.⁴⁶

6.2 La République du Congo 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.

Programme de politique nationale d'actions sociales (PNAS) – 2018-2022- dont l'objectif est de 'fournir à l'ensemble de la population un socle de protection sociale.'⁴⁷

7 Organismes en charge des personnes handicapées

7.1 En dehors des cours ou tribunaux ordinaires, la République du Congo 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.

La République du Congo ne dispose pas d'un organisme officiel qui s'intéresse spécifiquement à la violation des droits des personnes handicapées.

7.2 En dehors des cours ou tribunaux ordinaires, la République du Congo 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 République du Congo ne dispose pas d'un organisme officiel qui, bien que n'étant pas spécifiquement en charge de la violation des droits des personnes en situation de handicap s'y attèle.

46 OHCHR 'Convention relative aux droits de l'enfant - Examen des rapports soumis par les Etats parties en application de l'article 44 de la Convention. Deuxième, troisième et quatrième rapports périodiques combinés des Etats parties devant être soumis en 2010. Congo' CRC/C/COG/2-4, 18/09/2012, p. 38 https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/countries.aspx?CountryCode=COG&Lang=FR 38 (Consulté le 27/09/2019).

47 Douniama 'Conseil consultative des personnes vivant avec handicap : Jean De Dieu Goma nommé secrétaire exécutif permanent' Agence d'Information d'Afrique Central, 16/01/2019 <http://www.adiac-congo.com/content/conseil-consultatif-des-personnes-vivant-avec-handicap-jean-de-dieu-goma-nomme-secretaire> (Consulté le 27/09/2019) (n 45 comme ci-dessus).

8 Institutions Nationales des Droits de l'Homme (Commission des Droits de l'Homme ou Ombudsman ou Protecteur du Citoyen)

- 8.1 La République du Congo est-elle dotée d'une Commission Nationale 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 la République du Congo n'a jamais abordé des questions relatives aux droits des personnes handicapées.**

La République du Congo est dotée d'une Commission Nationale des Droits de l'Homme, instituée par l'article 214 de la Constitution de 2015. Selon l'article 215, la CNDH est un organe de suivi de la promotion et de la protection des droits de l'homme.⁴⁸

9 Organisation des personnes handicapées (OPH) et autres Organisations de la Société Civile

- 9.1 Avez-vous en République du Congo des organisations qui représentent et défendent les droits et le bien-être des personnes handicapées? Si oui énumérez chaque organisation et décrivez ses activités.**

Il existe des organisations qui représentent et défendent les droits et le bien-être des personnes handicapées, en République du Congo:

- L'Association des Handicapés Physiques du Congo (AHPHYCO) dont les objectifs sont de regrouper toutes les personnes en situation de handicap, assurer une aide efficace pour la défense et les intérêts sociaux, moraux et matériels, promouvoir l'intégration effective des personnes vivant avec handicap dans la société et lutter contre les discriminations.
- Après une assemblée générale ordinaire de restructuration, avec la terminologie « personne handicapée », AHPHYCO a muté son nom et est devenue:
- L'Association Nationale des personnes Handicapées Motrices du Congo (ANHAMCO);
- L'Association Nationale des Personnes Handicapées Mentales du Congo (ANPHMC);
- L'Association Nationale des Aveugles et Déficients Visuels du Congo (ANADVC);
- L'Association Nationale des Sourds et Déficients Auditifs du Congo (ANSDACO);
- L'Association Nationale des Femmes Handicapées du Congo (ANAFHCO);
- Groupe d'Intégration des Personnes Handicapées de la Cuvette-Ouest (GIPHCO);
- L'Association des Enfants Albinos du Congo (ASEALCO);

48 Constitution 2015 de la République du Congo (n 31 Comme ci-dessus).

- Handicap 3 (H-3);
- Handicap - Secours du Congo (HASECO);
- Du Comité de Défense des droits des Personnes Handicapées (COD-PH);
- De la Ligue d'Éducation, de Formation et d'Information des Personnes Handicapées (LEFIPH).⁴⁹

9.2 Dans votre région, les OPH sont-elles organisées ou coordonnées au niveau national et/ou régional?

Dans la République du Congo, l'Union Nationale des Associations des Personnes Handicapées du Congo (UNHACO) regroupe 10 grandes associations de personnes en situation de handicap, dont 6 en tant que membres à part entière et 4 uniquement comme affiliées.⁵⁰

Créée le 30 juillet 1987 à Brazzaville, l'UNAHACO a pour objectif:

- Promouvoir l'organisation et le développement des services et des programmes de prévention, de réadaptation et de réinsertion sociale en collaboration avec les administrations locales privées ou publiques existants et les organismes internationaux;
- Stimuler les administrations et les partenaires en vue de la création des structures appropriées au profit des personnes handicapées;
- Amener les pouvoirs publics à créer et à appliquer une législation spéciale relative à la protection, à la formation, et à l'emploi des personnes handicapées;
- Renforcer la capacité des associations membres à réaliser leur programme pour l'égalisation des chances;
- Constituer un système de coordination destiné à promouvoir et à assurer un échange d'informations pour la participation dans l'égalité au niveau national, régional et international;
- Promouvoir la réalisation des projets communautaires pour le maintien des revenus et la sécurité sociale;
- Rechercher les moyens financiers, matériels et humains à la réalisation de ces objectifs.⁵¹

9.3 Si la République du Congo a ratifié la CDPH, comment a-t-elle assuré l'implication des Organisations des personnes handicapées dans le processus de mise en œuvre?

La Constitution crée un Conseil consultatif des personnes vivant avec handicap chargé d'émettre des avis sur la condition de la personne vivant avec handicap et de faire au Gouvernement des suggestions visant une meilleure prise en charge de la personne vivant avec handicap.

Dans un contexte de modernisation de structures de réadaptation, les associations et les ONG coopèrent avec le gouvernement de la République du Congo afin d'œuvrer au développement visant à accélérer l'amélioration des conditions de vie des personnes en situation de handicap.⁵²

49 JD Mbele 'La représentation des situations de handicaps au Congo-Brazzaville : une approche psychologique et socio-culturelle' Thèse non publiée, Université Lumière Lyon 2, 2008 98-101 http://theses.univ-lyon2.fr/documents/getpart.php?id=lyon2.2008.mbele_jd&part=151111#Notefn77 (Consulté le 27/09/2019).

50 Mbele (Comme ci-dessus) 99-100.

51 Mbele (Comme ci-dessus) 100.

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?

L'UNHACO a participé à l'élaboration du plan d'action national pour les personnes handicapées promulgué par le décret n°2009-171 du 18 juin 2009.⁵³

Suite à la ratification de la CRDPH et le protocole du 2 septembre 2014, les OPH ont participé à l'atelier de 'sensibilisation au document et à ses textes d'application' sur la création du Conseil Consultatif des Personnes vivant avec handicap (CCPVH) – 21 décembre 2018.⁵⁴

9.5 Quels sont, le cas échéant, les obstacles rencontrés par les OPH lors de leur engagement dans la mise en œuvre?

Les obstacles majeurs des OPH sont essentiellement d'ordre financier. Par exemple en 2014, lors du bilan d'activité, l'UNHACO a fait état de 'l'ampleur des difficultés financières [qui ne l'a] pas permis d'assurer ses missions traditionnelles en faveur des personnes handicapées au Congo.'⁵⁵

9.6 Y'a-t-il des exemples pouvant servir de 'modèles' pour la participation des OPH?

Les OPH ont participé à l'élaboration du plan d'action national en faveur des personnes en situation de handicap. A l'occasion de la Journée internationale des personnes handicapées, tous les partenaires sont mobilisés, comme l'Etat, les personnes handicapées elles-mêmes, les confessions religieuses, les ONG et associations ainsi que les bailleurs de fonds.⁵⁶

52 Douniama 'Conseil consultative des personnes vivant avec handicap : Jean De Dieu Goma nommé secrétaire exécutif permanent' Agence d'Information d'Afrique Central, 16/01/2019 <http://www.adiac-congo.com/content/conseil-consultatif-des-personnes-vivant-avec-handicap-jean-de-dieu-goma-nomme-secretaire> (Consulté le 27/09/2019) (n 45 comme ci-dessus).

53 LG Oko 'Handicapés du Congo: l'Unhaco à l'heure de la restructuration' Agence d'information d'Afrique Centrale (28 août 2014) <http://www.adiac-congo.com/node/19291> (Consulté le 27/09/2019).

54 PW Douniama 'Conseil consultatif des personnes vivant avec handicap: vulgarisation de la loi créant l'institution' Agence d'Information d'Afrique Centrale (24 décembre 2018) <http://www.adiac-congo.com/content/conseil-consultatif-des-personnes-vivant-avec-handicap-vulgarisation-de-la-loi-creant> (Consulté le 27/09/2019).

55 Douniama 'Conseil consultatif des personnes vivant avec handicap: vulgarisation de la loi créant l'institution' Agence d'Information d'Afrique Centrale (24 décembre 2018) <http://www.adiac-congo.com/content/conseil-consultatif-des-personnes-vivant-avec-handicap-vulgarisation-de-la-loi-creant> (Consulté le 27/09/2019) (Comme ci-dessus).

56 PW Douniama 'Personnes handicapées : Mise en œuvre d'une nouvelle politique nationale d'action sociale' (Agence d'information d'Afrique centrale) 4/12/2017 <http://www.adiac-congo.com/content/personnes-handicapees-mise-en-oeuvre-dune-nouvelle-politique-nationale-daction-sociale-73108> (Consulté le 27/09/2019).

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 ?

La loi n°26-2018 du 7 août 2018 qui détermine l'organisation, la composition et le fonctionnement du Conseil consultatif des personnes vivant avec handicap.⁵⁷

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 ?

Afin de développer la capacité et le soutien des OPH pour s'assurer leur engagement dans la mise en œuvre, il est urgent que le Ministères des Affaires sociales puisse créer un fond dédié aux associations et ONG. En identifiant sur des critères sérieux les OPH effectives sur le terrain, cela pourrait permettre la formation d'équipes compétentes et expérimentées en capacité d'assurer l'éducation, la formation des personnes en situation de handicap, en axant plus d'efforts dans les zones rurales.

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 devraient être beaucoup mieux représentées et agir dans les zones rurales du pays. Elles devraient également appeler à la mise en place d'un système d'assurance/pensions en faveur des personnes en situation handicap afin de les maintenir hors d'un contexte de pauvreté.

Une mise à la disposition des OPH de matériels, de moyens financiers et des ressources humaines formées est nécessaire mais difficile pour cause de ressources très limitées.

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 y a le Centre National de Réadaptation Professionnelle des Personnes Handicapées (Congo-Brazzaville), Institut psychopédagogique, Institut National des Aveugles du Congo, Institut des Jeunes Sourds de Brazzaville, Institut des déficients auditifs de Pointe-Noire.

57 Douniama 'Conseil consultative des personnes vivant avec handicap : Jean De Dieu Goma nommé secrétaire exécutif permanent' Agence d'Information d'Afrique Central, 16/01/2019 <http://www.adiac-congo.com/content/conseil-consultatif-des-personnes-vivant-avec-handicap-jean-de-dieu-goma-nomme-secretaire>(Consulté le 27/09/2019) (n 45 comme ci-dessus).

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).

Il existe le Conseil Consultatif des Personnes Vivant avec Handicap (CCPVH) qui dépend du Ministère des Affaires sociales et de l'Action humanitaire.⁵⁸ La CCPVH a: 'deux missions essentielles qui sont émettre des avis et faire des suggestions au gouvernement pour une meilleure prise en compte des personnes issues de cette catégorie sociale.'⁵⁹

11 Préoccupations majeures des droits de l'homme relatives aux personnes handicapées

11.1 Quels sont les défis contemporains des personnes handicapées en République du Congo? (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).

Les personnes en situation de handicap au Congo sont encore privées de carte d'identité. Par exemple dans les communes de Djambala et de Makoua, '70% des personnes handicapées n'ont pas cette pièce, ce qui les marginalise, les stigmatise et les prive de droit à la citoyenneté'.⁶⁰ La sous-éducation est un facteur et le taux bas de scolarisation des personnes en situation de handicap maintiennent ces dernières dans la pauvreté. Une non prise en compte des personnes vivant avec handicap dans les zones rurales est également un facteur de maintien dans la pauvreté. Le manque de formation, d'éducation est la conséquence d'un difficile accès au marché de l'emploi et par conséquent le maintien dans la pauvreté.

58 Article 234 de la Constitution 2015.

59 Douniama 'Conseil consultative des personnes vivant avec handicap : Jean De Dieu Goma nommé secrétaire exécutif permanent' Agence d'Information d'Afrique Central (16/01/2019) <http://www.adiac-congo.com/content/conseil-consultatif-des-personnes-vivant-avec-handicap-jean-de-dieu-goma-nomme-secretaire> (Consulté le 27/09/2012) (n 45 Comme ci-dessus).

60 Comité Français pour la Solidarité Internationale 'Au Congo Brazzaville: défendre les droits des personnes en situation de handicap' <https://www.cfsi.asso.fr/thematique/congo-brazzaville-defendre-droits-personnes-situation-handicap> (Consulté le 27/09/2019) (n 44 Comme ci-dessus).

Bien que les albinos soient particulièrement acceptés par la population congolaise, ces derniers sont encore victimes de discrimination. Mbele fait référence à l'expression 'bana bamaza' (enfant d'eau), lorsqu'il est question d'albinos, d'enfants de petites tailles, des autistes, etc.⁶¹ L'albinisme continue d'être profondément mal compris, aussi bien sur le plan social que médical. L'apparence physique des personnes souffrant d'albinisme est souvent l'objet de croyances et de mythes erronés découlant de la superstition, ce qui favorise leur marginalisation et leur exclusion sociale.⁶²

11.2 Comment la République du Congo répond-t-elle aux besoins des personnes handicapées au regard des domaines ci-dessous énumérés?

La République du Congo répond aux besoins des personnes en situation de handicap sur:

• La Situation de risques et d'urgence humanitaire

Avec l'aide de la branche Congo de Handicap International l'Etat congolais intervient dans les domaines de la réadaptation et de l'appareillage post-poliomyélite au profit des personnes atteintes de la poliomyélite;

• L'autonomie de vie et l'inclusion dans la société

Le ministère congolais des affaires sociales fournit aux personnes handicapées des aides pour leur autonomie de vie et l'inclusion dans la société: Appuis financiers aux activités génératrices de revenus pour améliorer les ressources des personnes handicapées, fourniture gratuite de tricycles, fauteuils roulants, les béquilles, les cannes orthopédiques et cannes blanches, les lunettes correctives, appareillage orthopédique et la mise en accessibilité des établissements scolaires recevant les élèves handicapés.⁶³

• L'éducation

Selon la loi n° 008 du 06 septembre 1990 portant réorganisation du système éducatif congolais: 'l'Etat garantit à chaque enfant une scolarité obligatoire. Cette mesure s'étend aux personnes handicapées (mentaux, sensoriels, moteurs et inadaptés sociaux.)'

Il est créé des établissements spécialisés situés essentiellement à Brazzaville;

- L'Institut Psychopédagogique de Brazzaville qui reçoit des enfants ayant des anomalies mentales;
- L'Institut des Jeunes Sourds de Brazzaville (IJSB);
- L'Institut des Aveugles du Congo (IAC) situé dans la banlieue sud de Brazzaville qui est un établissement que l'Etat congolais gère en partenariat avec l'Armée du Salut.

Le ministère des affaires sociales apporte des aides scolaires: fourniture de kits scolaires aux élèves handicapés identifiés dans les établissements scolaires, intégration individualisée dans une classe ordinaire des élèves aveugles et appui aux étudiants handicapés;⁶⁴

61 Mbele (n 49 comme ci-dessus) 114 'Les bana bamaza' seraient 'des esprits ancestraux qui de leur vivant auraient connu une mort tragique par des maladies d'ordre psychosocial ou par accidents et qui renaissent chez les vivants sous forme d'enfants spéciaux qui sont parmi les plus difficiles et les plus compliqués à élever' (cité 114).

62 Les dépêches de Brazzaville 'Albinisme' Agence d'Information d'Afrique Centrale (28/09/2018) <http://www.adiac-congo.com/content/albinisme-89600> (Consulté le 27/09/2019).

63 Ministère des Affaires Sociales et de l'Action Humanitaire, Direction Générale des Affaires Sociales du Congo, Enquête sur la situation des personnes handicapées au Congo, 2011.

L'Article 29 garantit le droit à l'éducation et l'égal accès à l'enseignement et à la formation ; la scolarité obligatoire jusqu'à l'âge de seize ans.⁶⁵

• **La santé**

- Création d'une Filière à l'Ecole Paramédical de Brazzaville pour la Kinésithérapie.
- Dans le cadre du Plan d'Action National pour les Personnes Handicapées, l'Etat avec l'aide des partenaires privés octroient des aides médicales: soins spécifiques, produits pharmaceutiques, intervention chirurgicales (pieds bots, malformations congénitales, les lunettes correctives, chaussures).⁶⁶
- Réalisation des interventions chirurgicales orthopédiques sur des malformations congénitales de l'enfant et du nourrisson.

• **L'emploi**

Les ateliers du Centre national de réadaptation professionnelle de Brazzaville et bien d'autres ont été réhabilités et leur inauguration officielle a eu lieu, vendredi 8 novembre 2002, par Mme Emilienne Raoul, ministre des Affaires sociales. Au total, l'atelier de couture; l'atelier de maroquinerie et l'atelier de menuiserie et soudure, avec une réserve d'eau d'une capacité de 1000m³ pouvant alimenter le centre pendant plus de six mois, en cas de coupure d'eau.⁶⁷

• **La liberté d'expression et l'accès à l'information**

- La diffusion à la radio et à la télévision d'États des émissions des personnes handicapées (Promo-Handi),⁶⁸
- L'Édition d'un bulletin d'information "LIAISON" spécialisée sur les questions liées au handicap.⁶⁹

11.3 La République du Congo accorde-t-il des subventions pour handicap ou autre moyen de revenu en vue de soutenir les personnes handicapées?

Il n'existe aucune subvention pour le handicap et autre moyen de revenu en vue de soutenir les personnes en situation de handicap.

64 Ministère des Affaires Sociales et de l'Action Humanitaire, Direction Générale des Affaires Sociales du Congo, Enquête sur la situation des personnes handicapées au Congo (n 63 Comme ci-dessus).

65 Ministère des Affaires Sociales et de l'Action Humanitaire, Direction Générale des Affaires Sociales du Congo, Enquête sur la situation des personnes handicapées au Congo (Comme ci-dessus).

66 Ministère des Affaires Sociales et de l'Action Humanitaire, Direction Générale des Affaires Sociales du Congo, Enquête sur la situation des personnes handicapées au Congo (n 63 Comme ci-dessus).

67 P Ngalibo 'Congo-Brazzaville: Centre de réadaptation professionnelle des personnes handicapées: Réhabilitation de trois ateliers' <https://fr.allafrica.com/stories/200211140710.html> (Consulté le 27/09/2019).

68 Mbele 'La représentation des situations de handicaps au Congo-Brazzaville: une approche psychologique et socioculturelle', Thèse de doctorat de psychologie, 28/06/2008 http://theses.univ-lyon2.fr/documents/getpart.php?id=lyon2.2008.mbele_jd&part=151111#Notefn (Consulté le 27/09/2019) (n 49 Comme ci-dessus) 77.

69 Mbele 'La représentation des situations de handicaps au Congo-Brazzaville: une approche psychologique et socioculturelle', Thèse de doctorat de psychologie, 28/06/2008 http://theses.univ-lyon2.fr/documents/getpart.php?id=lyon2.2008.mbele_jd&part=151111#Notefn (Consulté le 27/09/2019) (Comme ci-dessus) 77.

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 du Congo?

L'article 18 de la Constitution de 2015 stipule que 'Tout citoyen a droit, en tout lieu, à la reconnaissance de sa personnalité juridique.'⁷⁰

11.5 Catégories spécifiques expérimentant des questions particulières/vulnérabilité:

• Femmes

L'Article 232 de la Constitution du 25 octobre 2015 a institué un Conseil consultatif des femmes afin d'émettre des avis sur la condition de la femme et de faire au gouvernement des suggestions visant à promouvoir l'intégration de la femme au développement.⁷¹ Cependant dans la pratique, la société reste encore ignorante des droits des femmes en situation de handicap. Par exemple dans un contexte d'obtention d'une carte nationale d'identité à laquelle toute personne en situation de handicap a le droit, mais qui lui est refusée dans les administrations, une couturière explique ceci 'Ma sœur m'avait demandé de trouver 2 000 FCFA à remettre à un policier pour avoir la carte nationale d'identité'.⁷²

Le 3 décembre 2016, lors de la Journée Internationale des personnes handicapées le Ministère des Affaires sociales, de l'Action humanitaire et de la Solidarité, reconnaissait que:

Si parmi ces femmes, ces hommes, et ces enfants vivant avec handicap, certains sont pleinement intégrés dans la société, participent et contribuent activement à tous les domaines de la vie, il existe encore une majorité qui se heurte aux nombreux obstacles qui l'empêche de jouir, comme les autres membres de la société, d'un accès équitable dans tous les domaines parmi lesquels; l'éducation, l'emploi, les transports et la participation à la vie sociale et politique.⁷³

• Les enfants handicapés.

Réponse à la recommandation figurant au paragraphe 57 des observations finales du Comité:

- Les cinq établissements d'éducation spécialisée sont tous concentrés à Brazzaville et Pointe Noire, ce qui pénalise déjà les enfants résidant dans les zones rurales et dans les villes secondaires.⁷⁴

70 Constitution du 25 octobre 2015 de la République du Congo (n 31 Comme ci-dessus).

71 Constitution du 25 octobre 2015 de la République du Congo (Comme ci-dessus).

72 Comité Français pour la Solidarité Internationale (CFSI) 'Au Congo, les personnes handicapées luttent pour l'obtention de la carte nationale d'identité' <https://www.cfsi.asso.fr/thematique/congo-personnes-handicapees-luttent-obtention-carte-nationale-identite> (Consulté le 27/09/2019) (n 44 Consulté le 27/09/2019).

73 V Lékoumou 'Congo : le gouvernement œuvre pour l'inclusion des personnes vivant avec handicap au processus de développement' Portail 242.Info (2016) https://www.portail242.info/Congo-le-gouvernement-oeuvre-pour-l-inclusion-des-personnes-vivant-avec-handicap-au-processus-de-developpement_a2189.html (Consulté le 27/09/2019).

74 OHCHR 'Convention relative aux droits de l'enfant - Examen des rapports soumis par les Etats parties en application de l'article 44 de la Convention. Deuxième, troisième et quatrième rapports périodiques combinés des Etats parties devant être soumis en 2010. Congo' CRC/C/COG/2-4, 18/09/2012, p. 83 https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/countries.aspx?CountryCode=COG&Lang=FR 38 (Consulté le 27/09/2019) (n 46 Comme ci-dessus) 83.

- En matière d'éducation il a été demandé une mise en œuvre effective des mesures spécifiques relatives à l'éducation des pauvres, des filles, des autochtones, des enfants handicapés et autres marginalisés.⁷⁵ Cette demande prouve donc que les enfants en situation de handicap 'souffrent d'exclusion sociale. N'ayant pas accès à l'école et ne pouvant pas travailler, ils vivent de la mendicité dans les rues alors que l'article 30 de la Constitution congolaise accorde une protection spéciale pour les personnes handicapées. Des initiatives ont été prises par le gouvernement pour améliorer la prise en charge de ces personnes, mais pour le moment, les résultats ne sont pas vraiment satisfaisants.⁷⁶

- **Les personnes en situation de handicap déplacées.**

Selon le Plan de Réponse Humanitaire et de Relèvement, le Ministère des Affaires Sociales et Humanitaire coordonne les partenaires humanitaires afin de fournir une assistance d'urgence, la protection et les services sociaux de base aux populations vulnérables dans les localités les plus affectées et à soutenir l'opérationnalisation des mécanismes de coordination mis en place à différents niveaux.⁷⁷ La stratégie de mise en œuvre est de mettre à la disposition des populations nouvellement accessibles dans les zones affectées, des articles ménagers essentiels et autres biens de première nécessité pour améliorer leurs conditions de vie, de procéder à la distribution de bâches ou matériaux pour la construction, réhabilitation ou l'extension de leurs abris. Certaines familles auront besoin d'un appui de la communauté pour la construction, réhabilitation ou extension des habitations (familles avec femme chef de ménage, personnes du troisième âge ou vivant avec handicap).⁷⁸

Selon le Rapport du Groupe de travail sur l'Examen Périodique Universel – Congo – (distribué le 28 décembre 2018), il a été confirmé que des efforts ont été consacrés : 'à l'accueil des réfugiés dans le département du Pool. Le Haut-Commissariat des Nations Unies pour les réfugiés avait mis en place un plan d'aide humanitaire en 2017 en vue d'appuyer les efforts du Gouvernement.'⁷⁹

Personnes âgées en situation de handicap.

Selon l'Article 31 de la Constitution du 25 octobre 2015 - les personnes âgées ont droit à des mesures de protection en rapport avec leurs besoins physiques, moraux

- 75 OHCHR 'Convention relative aux droits de l'enfant - Examen des rapports soumis par les Etats parties en application de l'article 44 de la Convention. Deuxième, troisième et quatrième rapports périodiques combinés des Etats parties devant être soumis en 2010. Congo' CRC/C/COG/2-4, 18/09/2012, p. 134 https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/countries.aspx?CountryCode=COG&Lang=FR38 (Consulté le 27/09/2019) (Comme ci-dessus).
- 76 Humanium 'Enfant de République du Congo. Concrétiser les Droits de l'Enfant en République du Congo' <https://www.humanium.org/fr/republique-du-congo/> (Consulté le 27/09/2019).
- 77 'Département du Pool : Plan de réponse humanitaire et relèvement' (Février 2018) <https://www.humanitarianresponse.info/en/operations/congo/document/d%C3%A9partement-du-pool-plan-de-r%C3%A9ponse-humanitaire-et-rel%C3%A8vement-f%C3%A9vrier-2018> (Consulté le 27/09/2019).
- 78 'Département du Pool : Plan de réponse humanitaire et relèvement' (Février 2018) <https://www.humanitarianresponse.info/en/operations/congo/document/d%C3%A9partement-du-pool-plan-de-r%C3%A9ponse-humanitaire-et-rel%C3%A8vement-f%C3%A9vrier-2018> (Consulté le 27/09/2019) (n 78 Comme ci-dessus).
- 79 OHCHR 'Conseil des Droits de l'Homme Groupe de travail sur l'Examen périodique universel Trente et unième session - Rapport national présenté conformément au paragraphe 5 de l'annexe à la résolution 16/21 du Conseil des droits de l'homme' A/HRC/WG.6/31/COG/1, 5-16/11/2018, p. 3' <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G18/276/48/PDF/G1827648.pdf?OpenElement> (Consulté le 27/09/2019) 3 (n 20 comme ci-dessus).

ou autres, en vue de leur plein épanouissement. Le droit de créer des établissements socio-sanitaires privés est garanti. Ceux-ci sont régis par la loi.⁸⁰

12 Perspective future

12.1 Y'a-t-il des mesures spécifiques débattus ou prises en compte présentement en République du Congo au sujet les personnes handicapées?

La mise en œuvre des commissions techniques du Conseil Consultatif des Personnes Vivant avec Handicap bénéficie d'une meilleure coordination en matière d'assemblage de documents fondamentaux, d'une élaboration d'un règlement intérieur, d'un plan d'action et d'un budget triennal.⁸¹

12.2 Quelles réformes légales sont proposées? Quelle réforme légale aimeriez-vous voir en République du Congo? Pourquoi ?

Alors qu'il est constaté une meilleure implication de le République du Congo notamment avec la création d'une institution phare tel que le Conseil Consultatif des Personnes vivant avec handicap et l'accent mis sur l'éducation, la formation et la réadaptation des personnes en situation de handicap dont les enfants, il serait important qu'il y ait une véritable prise en compte des personnes handicapées sur tout le territoire congolais et non majoritairement en zones urbaines. Les personnes handicapées issues des zones rurales doivent bénéficier d'encore plus d'attention. La question de la participation des personnes en situation de handicap à la vie politique doit être réglée au plus vite et notamment en permettant à toutes les personnes handicapées d'avoir une carte d'identité, un extrait de naissance et un accompagnant spéciale en prévision du respect de leurs droits civiques et politiques.

Alors qu'un 5^e recensement est en cours, il est souhaité que celui-ci prenne en considération le groupe des personnes en situation de handicap afin de permettre l'accès à des données fiables et très récentes afin d'avoir une meilleure cartographie.

Le Conseil consultatif des femmes et le Conseil consultatif des personnes vivant avec handicap devraient travailler de concert afin de tenir compte des spécificités de la protection et promotion des droits des femmes et filles en situation de handicap.

En matière de recherche en sciences sociale et humaines, il serait intéressant de mener une réforme de la recherche académique afin que celle-ci soit plus en adéquation avec les réalités du terrain. Ceci pourrait permettre de bénéficier et de partager l'expertise de plus de chercheurs sur la question des droits et des personnes en situation. Il serait également judicieux d'encourager des étudiants de Master et doctorat à mener leurs recherches sur ces questions, à l'instar de Jean Didier Mbele, ayant fait une recherche doctorale intitulée 'La représentation des situations de handicap au Congo-Brazzaville : une approche psychologique et socio-

80 Article 31 de la Constitution du 25 octobre 2015

81 Ganga Mickemby 'La machine de travail du conseil consultatif des personnes vivant avec handicap véritablement en marche' Groupe Congo Médias (8/08/2019) <https://groupecongomedias.com/congo-machine-de-travail-conseil-consultatif-personnes-viv-ant-handicap-veritablement-marche/> (Consulté le 27/09/2010) (n 66 comme ci-dessus)

culturelle'.⁸² Bien que datant de 2008, elle reste d'actualité et mériterait une réactualisation suite à la ratification en 2014 de la CRDPH par la République du Congo. Cependant, il existe un ouvrage publié en 2015, sur la situation du handicap au Congo-Brazzaville de Victor Mboundou et Joseph Mbandza qui décrit le quotidien des personnes en situation de handicap et les fréquentes violations de leurs droits.

82 Mbele 'La représentation des situations de handicaps au Congo-Brazzaville : une approche psychologique et socio-culturelle' Thèse non publiée, Université Lumière Lyon 2, 2008 98 at 101 http://theses.univ-lyon2.fr/documents/getpart.php?id=lyon2.2008.mbele_jd&part=151111#Notefn77 (Consulté le 27/09/2019) (n 49 comme ci-dessus).

SOUTH SUDAN

*Innocentia Mgijima-Konopi, * Theophilus Odaudu** & Reshoketswe Mapokgol****

1 Population indicators

1.1 What is the total population of South Sudan?

According to the fifth South Sudan Census conducted before the country's independence in 2011, South Sudan had a population of 8 260 490 in 2008.¹ In 2016 the South Sudan National Bureau of Statistics estimated the population to have increased to 12 230 730.²

1.2 Describe the methodology used to obtain the statistical data on the prevalence of disability in South Sudan. What criteria are used to determine who falls within the class of persons with disabilities in South Sudan?

The 2008 Census defined disability as an impairment 'that can hamper or reduce a person's ability to carry out his or her day to day activities'.³ During the Census people were asked to report whether they experience activity limitations in core domains of function, for example whether they have difficulties in seeing or

* LLB (Hons) (Witwatersrand), LLM (National University of Ireland, Galway) Programme Manager, Disability Rights Unit, Centre for Human Rights, Faculty of Law, University of Pretoria.

** LLM in Human Rights and Democratisation in Africa (Centre for Human Rights, Faculty of Law, University of Pretoria).

*** LLM in Human Rights and Democratisation in Africa (Centre for Human Rights, Faculty of Law, University of Pretoria).

1 National Bureau of Statistics 'Special interest population: Analysis from the 2008 census of population and housing' (2013) http://www.ssnbss.org/sites/default/files/2016-08/special_interest_population.pdf (accessed 22 April 2018).

2 National Bureau of Statistics 'Demographic statistics' http://www.ssnbss.org/sites/default/files/2016-08/special_interest_population.pdf (accessed 22 April 2018).

3 National Bureau of Statistics (n 1 above) 24.

hearing. This approach focuses on the 'activities' component of the International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organisation (WHO) in 2001.⁴

1.3 What is the total number and percentage of people with disabilities in South Sudan?

According to the 2008 Census, 421 285 (5.1 per cent) of the population of South Sudan were reported to have a disability.⁵ However, according to the 2016 Household Survey carried out by the Food Security and Livelihood cluster, 5.1 per cent is an extremely low number, as 15 per cent of households reported to have at least one person with a disability during the survey.⁶

1.4 What is the total number and percentage of women with disabilities in South Sudan?

The 2008 Census indicated that 5 per cent of women in South Sudan have a disability.⁷

1.5 What is the total number and percentage of children with disabilities in South Sudan?

Four per cent of the 800 000 children in South Sudan have disabilities according to a report on the 'Situation assessment of children and women in South Sudan' report published by UNICEF in 2015.⁸

1.6 What are the most prevalent forms of disability and/or peculiarities to disability in South Sudan?

The 2008 Census found the most prevalent form of disability in South Sudan to be physical impairments, which made up 28.4 per cent of disabilities, this included both the limited use of legs and the limited use of arms. Other common forms of disabilities in South Sudan include vision impairments at 23.5 per cent and blindness at 7.8 per cent; mental disabilities at 15.3 per cent; difficulty in hearing at 10.3 per cent; difficulty in speaking at 4 per cent; muteness⁹ at 2.2 per cent; loss of arms at 1.7 per cent; and lastly, loss of legs at 3.6 per cent.

4 WHO 'International classification of functioning, disability and health' (ICF) <http://www.who.int/classifications/icf/en/> (accessed 28 November 2019). 2018) 7ber 2019)t/classifications

5 National Bureau of Statistics (n 1 above) xiv.

6 B Rohwerder 'Disability in South Sudan' *Institute of Development Studies* https://reliefweb.int/sites/reliefweb.int/files/resources/Disability_in_South_Sudan.pdf (accessed 5 May 2018) 2.

7 Ministry of gender, child, social welfare, humanitarian affairs and disaster management *South Sudan national disability & inclusion policy* (2013) 8 <http://mgcswss.org/wp-content/uploads/South-Sudan-National-Disability-and-Inclusion-Policy.pdf> (accessed 22 April 2018) (NDIP).

8 UNICEF 'Situation assessment of children and women in South Sudan' (2015) 7 https://www.unicef.org/appeals/files/UNICEF_South_Sudan_Situation_Assessment_of_Children_and_Women_2015.pdf (accessed 5 May 2018).

9 National Bureau of Statistics (n 1 above) 24.

Disability was found to be more prevalent in Western Equatoria, Central Equatoria and the Upper Nile State. Other states with slightly higher prevalence were Unity and Western Bahr el Ghazal.

Difficulty in seeing, blindness, difficulty in hearing and limited use of arms were more prevalent among females. Mental disability affected both males and females almost equally although males accounted for a slightly higher percentage. Limited use of legs and loss of legs were more prevalent in males.¹⁰

2 South Sudan's international obligations

2.1 What is the status of the United Nation's Convention on the Rights of People with Disabilities (CRPD) in South Sudan? Did South Sudan sign and ratify the CRPD? Provide the date(s).

South Sudan became an independent State in 2011, they have to date not ratified the United Nation's Convention on the Rights of People with Disabilities.

2.2 If South Sudan has signed and ratified the CRPD, when is/was its country report due? Which government department is responsible for submission of the report? Did South Sudan submit its report? If so, and if the report has been considered, indicate if there was a domestic effect of this reporting process. If not, what reasons does the relevant government department give for the delay?

South Sudan is not a State Party to the United Nation's Convention on the Rights of People with Disabilities.

2.3 While reporting under various other United Nation's instruments, or under the African Charter on Human and Peoples' Rights, or the African Charter on the Rights and Welfare of the Child, did South Sudan also report specifically on the rights of persons with disabilities in its most recent reports? If so, were relevant concluding observations adopted? If relevant, were these observations given effect to? Was mention made of disability rights in your state's UN Universal Periodic Review (UPR)? If so, what was the effect of these observations/recommendations?

South Sudan has ratified the following Conventions: The Convention on the Elimination of All forms of Discrimination Against Women (CEDAW) together with its Optional Protocol; the Convention against Torture and Other Cruel Inhuman or Degrading Treatment or Punishment and its Optional Protocol; and lastly the Convention on the Rights of the Child.¹¹ The country has not submitted any communication to these bodies to date.

10 National Bureau of Statistics (n 1 above) 37.

11 United Nations Human Rights Office of the High Commissioner 'Status of ratification' <http://indicators.ohchr.org/> (accessed 5 May 2018).

South Sudan's UPR, submitted in November 2015, does not specifically mention persons with disabilities. However, in the report on education, it is stated that everyone, including persons with disabilities shall have access to education.¹² Since South Sudan's submission of the 2016 UPR report, the country has not received any concluding observations from the UN's Committee on Human Rights.

2.4 Was there any domestic effect on South Sudan's legal system after ratifying the international or regional instrument in 2.3 above? Does the international or regional instrument that had been ratified require South Sudan's legislature to incorporate it into the legal system before the instrument can have force in South Sudan's domestic law? Have the courts of South Sudan ever considered this question? If so, cite the case(s).

See 2.1 above.

2.5 With reference to 2.4 above, has the United Nation's CRPD or any other ratified international instrument been domesticated? Provide details.

The 2011 Transitional Constitution of South Sudan declared that all human-rights treaties ratified would be reflected in the country's Bill of Rights.¹³ The Bill of Rights covers CEDAW in article 55 on the right of women, article 34 on equal rights for men and women and article 33 on equality before the law. The Convention on the Rights of the Child is covered by article 56 on the rights of children. Article 32 on the rights of people to not be enslaved, article 35 against torture and article 38 on security from the death penalty speak to the Convention against Torture and Other Cruel Inhuman and Degrading Treatment or Punishment.¹⁴

3 Constitution

3.1 Does the Constitution of South Sudan contain provisions that directly address disability? If so, list the provisions and explain how each provision addresses disability.

Article 30(1) and (2) of the Constitution of South Sudan is a standalone article on disability. It sets out the rights of persons with special needs and the elderly. The article stipulates that the government at all levels has an obligation to ensure that persons with disabilities are able to enjoy their rights and freedoms on an equal basis with others. In addition, the article reaffirms that it is the States' duty to

12 HRC National report submitted in accordance with paragraph 5 of the annex to Human Rights Council resolution 16/21: South Sudan (23 August 2016) UN Doc A/HRC/WG.6/26/SSD/1 (2016) para 66.

13 Government of South Sudan 'Transitional constitution of The Republic of South Sudan' (2011) 4 <https://www.ilo.org/dyn/natlex/docs/MONOGRAPH/90704/116697/F762589088/SSD90704%202011C.pdf> (accessed 5 May 2018).

14 As above.

ensure that persons with disabilities in the country have access to suitable education, employment and public services.¹⁵ The article stresses the States responsibility to ensure access to adequate medical healthcare for persons with disabilities.¹⁶

3.2 Does the Constitution of South Sudan contain provisions that indirectly address disability? If so, list the provisions and explain how each provision indirectly addresses disability.

Article 29 on the right to education states that everyone, including persons with disabilities, has the right to receive an education.¹⁷

Article 31, on the right to health, states that all persons, including persons with disabilities have the rights to receiving adequate healthcare.¹⁸

Article 139(1)(d) on basic values and guidelines for civil service requires the government to ensure that services are provided fairly and equitably to all members of the country despite, among other issues, their physical disabilities.¹⁹

4 Legislation

4.1 Does South Sudan have legislation that directly addresses issues relating to disability? If so, list the legislation and explain how the legislation addresses disability.

South Sudan does not have such legislation.

4.2 Does South Sudan have legislation that indirectly addresses issues relating to disability? If so, list the main legislation and explain how the legislation relates to disability.

- **The Labour Act of 2017**

The Labour Act of 2017 provides a legal framework for conditions of labour, employment, labour institutions, disputes resolutions and safety in the workplace.²⁰ Section 6 of the Labour Act which addresses fundamental rights in the workplace contains a non-discrimination clause which requires the State to ensure that persons with disabilities in the workplace are not discriminated against on the basis of their disability.²¹

In section 34 of the Act, the State is required to prepare reports and provide information on the different forms of assistance offered to persons with disabilities

15 Art 30 of the Constitution.

16 As above.

17 Art 29 of the Constitution.

18 Art 31 of the Constitution.

19 Art 139 of the Constitution.

20 Labour Act of 2017.

21 Sec 6 Labour Act of 2017.

in their work place.²² Section 70 on employees with special needs, encourages ministers to promote rules that govern the hiring of persons with disabilities.²³

- **Child Act 10 of 2008**

The Child Act 10 of 2008 is aimed at extending, protecting and promoting the rights of children in South Sudan. Section 9 on non-discrimination requires the State to ensure equal treatment for all children, despite any differences, either due to disability, gender or ethnicity.²⁴

Article 2(i) requires the State to provide community-based systems of rehabilitation and supportive devices for children with disabilities. In addition, it places an obligation on the State to ensure that children with disabilities have equal access to integrated educational spaces, and that they can participate fully in family life, and recreational and sporting activities.²⁵ It is the duty of the State to ensure that they are able to integrate in communities and be self-reliant.

Section 14 on the 'right to education and wellbeing' states that all children have the right to free primary education, and that the access should not exclude children with disabilities, despite the severity of the child's disabilities.²⁶

Section 27 on the Act stipulates that children with disabilities shall be ensured access to special medical care and treatment, and to rehabilitation.²⁷

Section 36 on duties of the government, in Article 2(h), obligates the State to raise awareness on the rights of children with disabilities; on what their potential is and how they can contribute to society.

South Sudan also has a Bill of Rights which includes the right to life and human dignity in Article 11, equality before the law in Article 33, rights of children in Article 56 and many others; all of which apply to persons with disabilities as well.²⁸

5 Decisions of courts and tribunals

5.1 Have the courts (or tribunals) in South Sudan ever decided on an issue(s) relating to disability? If so, list the cases and provide a summary for each of the cases with the facts, the decision(s) and the reasoning.

There are no reported decisions of courts or tribunals.

22 Sec 34 Labour Act of 2017.

23 Sec 70 Labour Act of 2017.

24 Sec 9 Child Act of 2008.

25 Sec 36 Child Act of 2008.

26 Sec 14 Child Act of 2008.

27 Sec 27 Child Act of 2008.

28 Government of South Sudan (n 13 above) see general.

6 Policies and programmes

6.1 Does South Sudan have policies or programmes that directly address disability? If so, list each policy and explain how the policy addresses disability.

The **South Sudan disability and inclusion policy** adopted in 2013 under the Ministry of Gender, Child, Social Welfare, Humanitarian Affairs and Disaster Management directly addresses the needs of persons with disabilities.

The policy seeks to address issues pertaining to persons with disabilities:

- **Advocacy and awareness raising**

In South Sudan, people have little information on the realities of persons with disabilities. As a result, they hold negative perceptions which lead to discriminatory practices. Policy makers, government officials and community leaders also have limited awareness on disability issues. The policy therefore seeks to create greater awareness.²⁹

- **Improving accessibility**

The policy will guide the government to ensure that they create policies to eradicate the infrastructural barriers that impede persons with disabilities from accessing buildings, transportation and outdoor and indoor facilities such as schools, housing and medical facilities.³⁰

- **Ensuring active involvement and participation of persons with disabilities in the development process**

The policy will mandate the different departments of government to ensure that persons with disabilities actively engage in processes and key decision-making on policies regarding the development of the country.³¹

- **Access to healthcare**

The policy also seeks to ensure that equal access to health services and education are realised for persons with disabilities. Moreover, the policy calls for the creation of more rehabilitation services to cater for persons with disabilities.³²

6.2 Does South Sudan have policies and programmes that indirectly address disability? If so, list each policy and describe how the policy indirectly addresses disability.

The National Gender Policy is aimed at ensuring equal access to opportunities in education and other public services for women and girls including those with

29 *South Sudan national disability & inclusion policy* (n 7 above) 18.

30 As above.

31 *South Sudan national disability & inclusion policy* (n 7 above) 19.

32 *South Sudan national disability & inclusion policy* (n 7 above) 20-24.

disabilities.³³ The policy also seeks to ensure that the needs of women and girls with disabilities are incorporated into the national development agenda.³⁴

The Health Policy for the government of South Sudan seeks to provide access to the necessary medical care for all persons with disabilities.³⁵

7 Disability bodies

7.1 Other than the ordinary courts or tribunals, does South Sudan have any official body that specifically addresses the violation of the rights of persons with disabilities? If so, describe the body, its functions and its powers.

The Southern Sudan National Commission for War Disabled, Widows and Orphans was created to ensure the participation of people disabled as a result of the war, widows and orphans in the development process and ensure that they access social services.³⁶ The Commission prioritises those persons with disabilities disabled as a result of the war and not persons with disabilities in general.³⁷ No report was, however, found to assess the effectiveness of this Commission. Some critics have pointed out that having a Commission that serves a subset of persons with disabilities may create inequality amongst persons with disabilities by providing privileges to the prioritised group not enjoyed by others.

7.2 Other than the ordinary courts or tribunals, does South Sudan have any official body that though not established to specifically address the violation of the rights of persons with disabilities, can nonetheless do so? If so, describe the body, its functions and its powers.

The Public Grievances Chamber is established by section 147 of the Constitution. The Chamber has the mandate to monitor and inspect the activities of the government; it receives complaints from the public including social grievances, investigates such complaints and makes recommendations to government.³⁸ Therefore, this Chamber can address issues of violation of the rights of persons with disabilities. Complaints can be brought before it by persons with disabilities and their representative organisations as well as members of the public.

33 Ministry of Gender, Child, Social Welfare, Humanitarian Affairs and Disaster Management *The Republic of Sudan national gender policy* (2012) 21 <http://mgcswws.org/wp-content/uploads/National-Gender-Policy.pdf> (accessed 22 April 2018).

34 *The Republic of South Sudan national gender policy* (n 33 above) 42.

35 Ministry of Health *Health policy for the government of South Sudan* 38 http://www.africanchildinfo.net/clr/policy%20per%20country/south%20sudan/ssudan_health_2006-2011_en.pdf (accessed 5 May 2018).

36 As above.

37 Email communication with John Api on 4 May 2018.

38 L Moses 'Public Grievances Chamber unveils its priorities' (16 February 2012) <http://www.gurtong.net/ECM/Editorial/tabid/124/ctl/ArticleView/mid/519/articleId/6485/categoryId/1/Public-Grievances-Chamber-Unveils-Its-Priorities.aspx> (accessed 7 April 2018).

8 National human rights institutions, Human Rights Commission, Ombudsman or Public Protector

- 8.1 Does South Sudan have a Human Rights Commission or an Ombudsman or Public Protector? If so, does its remit include the promotion and protection of the rights of persons with disabilities? If your answer is yes, also indicate whether the Human Rights Commission, Ombudsman or Public Protector of South Sudan has ever addressed issues relating to the rights of persons with disabilities.**

South Sudan has a Human Rights Commission as established by section 145 of the Constitution. The Commission has the mandate to monitor and report on the protection and promotion of human rights in the country.³⁹ Even though the Constitution did not expressly mention the promotion and protection of the rights of persons with disabilities as one of the functions of the Commission, it however states that the Commission has the mandate to ‘monitor the application and enforcement of the rights and freedoms enshrined in this Constitution’ for all people which includes persons with disabilities.⁴⁰ In doing this, the Commission can proceed on its own initiative or upon a complaint made by a member of the public on the violation of any rights or freedoms.⁴¹ Since the Constitution contains provisions on the rights of persons with disabilities,⁴² it follows that its remit includes the promotion and protection of the rights of persons with disabilities. In carrying out its investigation, the Commission can issue summons or order any individual or representative of any body to appear before it or produce any document.⁴³ However, no record was found of a decision or recommendation of the Commission specifically addressing the rights of persons with disabilities in South Sudan. In its first and only report so far,⁴⁴ the Commission while reporting before the Human Rights Council, did not report on the situation relating to the rights of persons with disabilities even in the context of the war.⁴⁵ This seems to suggest that disability rights have not been on the agenda of the Commission.⁴⁶

39 Amnesty International ‘South Sudan: Conflict and impunity’ (2016) submission to the UN Universal Periodic Review, November 2016, 4 <https://www.amnesty.org/download/Documents/AFR6546322016ENGLISH.pdf> (accessed 5 April 2018).

40 Sec 146(1)(a) of the Constitution.

41 Sec 146(1)(b) of the Constitution.

42 See secs 6, 29 and 30 of the Constitution.

43 Sec 145(4) of the Constitution.

44 Amnesty International (n 46 above).

45 For the report, see the presentation by Lawrence Korbandy, Chairperson of the South Sudan Human Rights Commission before the Human Rights Council, Geneva, 24 September 2014 https://paanluelwel2011.files.wordpress.com/2014/09/lawrence-korbandy_south-sudan-human-rights-commission_pd_ss_36.pdf (accessed 10 April 2018).

46 (n 6 above) 4.

9 Disabled peoples organisations (DPOs) and other civil society organisations

9.1 Do you have organisations that represent and advocate for the rights and welfare of persons with disabilities in South Sudan? If so, list each organisation and describe its activities.

There are several organisations in South Sudan working on the rights of persons with disabilities. These include:

Humanity and inclusion (previously Handicapped International): This is an independent international aid and development organisation. It operates in situations of poverty and exclusion, conflict and disaster; providing support to vulnerable persons to improve the living conditions and promote respect for their dignity and fundamental rights.⁴⁷ Humanity and Inclusion makes interventions through humanitarian actions and development action. In South Sudan, due to the fragile nature of the State the organisation is providing both humanitarian assistance and development assistance targeted at persons with disabilities.⁴⁸

Light for the World: This is an organisation which has been working in South Sudan to promote the welfare and dignity of persons with disabilities since 2005 to ensure their full participation in the society.⁴⁹ Though its main focus is the promotion of eye health and prevention of blindness, the organisation is also involved in advocacy for the inclusion of the rights of persons with disabilities in policy formulation.⁵⁰

South Sudan Association of the Visually Impaired: This is a nongovernmental organisation founded in 2010 shortly before South Sudan gained her independence. It seeks the promotion and protection of the rights of persons with disabilities and persons with visual impairment in particular. Writing on the activities of the organisation, the organisation stated that:

[W]e advocate for recognition, protection and promotion of the rights of people with disabilities by providing reasonable accommodation and accessibility at the forefront of our advocacy, and by maintaining a gender sensitive environment, we consider nondiscrimination as a core principle. We are working to empower individuals who are blind by boosting their self-esteem and enhancing their capacities.⁵¹

Therefore, the activities of SSAVI can be summarised as awareness, advocacy, empowerment and problem solving.

47 Handicap International <https://hi.org/en/index> (accessed 20 April 2018).

48 See <https://reliefweb.int/job/2571269/administration-coordinator-south-sudan> (accessed 24 April 2018).

49 Light for the World 'Country strategy plan South Sudan' 2 https://www.light-for-the-world.org/sites/lfdw_org/files/download_files/south_sudan_strategy.pdf (accessed 9 April 2018).

50 Light for the World (n 56 above) 6. See also <http://www.lightfortheworld.nl/wp-content/uploads/2016/09/L-NL-Strategic-Plan-2016-2020.pdf> (accessed 28 November 2019).

51 Anyang (n 36 above) 2.

South Sudan Women with Disabilities Network: This is an organisation that advocates for the rights of women with disabilities in South Sudan. However, no information was found on the activities of this organisation.

9.2 In the countries in South Sudan's region (East Africa) are DPOs organised/coordinated at national and/or regional level?

Disabled People's Organisations in East Africa are largely organised at national levels. In South Sudan, for instance, DPOs are organised on cluster basis, that is, according to the different categories of disabilities. There is no single umbrella body that tends to bring all DPOs together. Though some of these DPOs have national and state branches, there is no cohesion between the national and state branches.⁵²

9.3 If South Sudan has ratified the CRPD, how has it ensured the involvement of DPOs in the implementation process?

South Sudan is yet to ratify the CRPD. Though the Constitution referred to persons with disabilities and the country has the National Disability and Inclusion Policy, and the Inclusive Education Policy, there is no specific legislation in South Sudan for the protection of the rights of persons with disabilities.⁵³ As mentioned above, DPOs were involved in the formulation of these policy documents, but there is however, no record found of a formal platform for DPOs' involvement with implementation.

9.4 What types of actions have DPOs themselves taken to ensure that they are fully embedded in the process of implementation?

In South Sudan, DPOs are actively involved in lobbying the government to ensure the implementation of disability-friendly policies. They also carry out advocacy and awareness campaigns to sensitise the public on disability rights and to garner more public support for disability inclusive policies.⁵⁴ These campaigns are carried out through seminars and workshops, publication of articles, media interviews amongst others.⁵⁵

9.5 What, if any, are the barriers DPOs have faced in engaging with implementation?

Despite the efforts of DPOs to engage with the government in the implementation process, not much has been achieved due to lack of support from the government. It is also difficult for DPOs to keep their programmes on advocacy and awareness running due to financial constraints. This has also affected the scope of outreach as advocacy activities. Activities are largely concentrated within Juba where the DPOs are mainly situated.⁵⁶ Many DPOs in South Sudan lack adequate technical expertise to strategically engage with the government and the general public;⁵⁷ there is also a lack of cohesion among the various DPOs which puts a spoke in the wheel of progress.

52 Email communication with Henry Legge on 7 May 2018.

53 Rohwerder (n 6 above).

54 As above.

55 Email communication with Ben Poggo on 2 May 2018.

56 Legge (n 44 above) 2.

57 Poggo (n 62 above).

9.6 Are there specific instances that provide ‘best-practice models’ for ensuring proper involvement of DPOs?

No data was found on existing best-practice models on ensuring proper involvement of DPOs.

9.7 Are there any specific outcomes regarding successful implementation and/or improved recognition of the rights of persons with disabilities that resulted from the engagement of DPOs in the implementation process?

As stated in 7.1 above, DPOs played an important role in the development of the Policy on Inclusive Education by the Ministry of Education. Furthermore, they advocated for the development of the National Disability and Inclusion Policy by the Ministry of Gender, Child, Social Welfare and Humanitarian Affairs. These policies protect disability rights in the country even though a lot still has to be done with regards to implementation and strengthening the legal framework.

9.8 Has your research shown areas for capacity building and support (particularly in relation to research) for DPOs with respect to their engagement with the implementation process?

Though DPOs in South Sudan are making efforts to push for the implementation of existing policies and creation of more comprehensive ones, including domestic legislation, the government does not seem to be very supportive. This, coupled with the dearth of technical knowhow in the leadership of the various DPOs makes the process of implementation slow and the achievements few.

9.9 Are there recommendations that come out of your research as to how DPOs might be more comprehensively empowered to take a leading role in the implementation processes of international or regional instruments?

Research has shown that South Sudan lacks experts who can strategically engage the government in the implementation process. Therefore, capacity building is required that if DPOs will make meaningful impact through their involvement with the implementation process. DPOs should also create a platform for synergy where they can exchange ideas and pursue a common cause with one voice.

9.10 Are there specific research institutes in the region where South Sudan is situated (East Africa) that work on the rights of persons with disabilities and that have facilitated the involvement of DPOs in the process, including in research?

No such institutions were found.

10 Government departments

10.1 Does South Sudan have a government department or departments that is/are specifically responsible for promoting and protecting the rights and welfare of persons with disabilities? If so, describe the activities of the department(s).

The Ministry of Gender, Child and Social Welfare is the government department with a mandate to protect and promote the rights and welfare of persons with disabilities.⁵⁸ The Ministry in close consultation with Disabled persons organisations (DPOs) has developed and is implementing the 2013 National Disability Policy and the Inclusive Education Policy. The Ministry is committed to the promotion of equality of previously marginalised groups and monitors the violations of the rights of women, children and persons with disabilities.⁵⁹ The Ministry is responsible for the development of social welfare, social protection and disability policies and programmes, and mainstreaming disability issues in public and private institutions.⁶⁰ However, not much could be found on the level of implementation of these objectives.

Another Ministry that promotes the rights of persons with disabilities is the Ministry of Health. Its mission is to improve the health condition of people in South Sudan and ensure quality healthcare especially the most vulnerable.⁶¹ Despite the existence of a Ministry dedicated to ensuring the implementing of Article 31 of the Constitution which provides for equal access to healthcare services, access to healthcare remains inequitable. Rohwerder reports that accessibility and affordability of health services remain a challenge for most persons with disabilities in South Sudan. Health facilities lack basic assistive technology for persons with disabilities.⁶²

The Ministry of Education, Science and Technology is a government department concerned with matters of education in South Sudan. The Ministry has formulated a National Policy on Inclusive Education to ensure inclusion of persons with disabilities in the educational system of the country. It has also spearheaded the development of a new curriculum that takes into account the needs of learners

58 M Anyang 'A presentation by the Education Secretary of South Sudan Association of the Visually Impaired' <https://worldinstituteondisabilityblog.files.wordpress.com/2016/11/mauots-presentation.pdf> (accessed 2 April 2018).

59 SIDA 'Disability rights in Sudan and South Sudan' (2014) 3 <https://www.sida.se/globalassets/sida/eng/partners/human-rights-based-approach/disability/rights-of-persons-with-disabilities-sudan-and-south-sudan.pdf> (access 17 April 2018).

60 More details can be found on the ministry's website, <http://mgcswss.org/> (accessed 3 May 2018).

61 SIDA (n 37 above).

62 Rohwerder (n 6 above).

with disabilities. Both initiatives were done in consultation with DPOs in the country.⁶³ The Transitional Constitution provides for inclusive education and the rights of persons with special needs.⁶⁴ Hence, the action of the Ministry is in keeping with these provisions.

11 Main human rights concerns of people with disabilities in South Sudan

11.1 Describe the contemporary challenges of persons with disabilities, and the legal responses thereto, and assess the adequacy of these responses.

The lack of a legislation to promote and protect the right of persons with disabilities is a challenge in the realisation of the rights of persons with disabilities. The policies in place do not adequately address the different needs of persons with disabilities and implementation of these policies has been slow. The negative attitude of the public towards persons with disabilities creates barriers for persons with disabilities to participate fully in the social, cultural and economic life of South Sudan.⁶⁵ There is limited legal recourse for persons with disabilities to vindicate their rights where such rights have been violated. Access to justice remains a concern for persons with disabilities. The Constitution in Article 14 recognises the rights of all citizens irrespective of status, to equality before the law and equal protection of the law; Article 19 contains the right to a fair hearing; and Article 20 provides for the right to seek redress in a court of law for any violation of rights. While these provisions apply to all citizens, there are barriers that impede access to justice for persons with disabilities such as inaccessible court premises and lack of reasonable accommodation. For instance, even though the Constitution in article 6 provides for the promotion of sign language for the benefit of persons with special needs, not much is being done in this regard.⁶⁶ So, even in the courts or police stations, getting a sign-language interpreter for the hearing impaired remains a challenge.⁶⁷

11.2 Do persons with disabilities have a right to participation in political life (political representation and leadership) in South Sudan?

Yes. The Constitution provides the right of all eligible citizens to vote and stand for elections and the right to form a political party. However, few persons with disabilities participate in these structures.

63 H Legge 'South Sudan UPR report – 2016: Coalition of organisations of persons with disabilities' (2016) 5 <https://uprdoc.ohchr.org/uprweb/downloadfile.aspx?filename=3454&file=EnglishTranslation> (accessed 3 April 2018).

64 Secs 29 and 30.

65 R Rieser 'Inception report: The development of a national policy for the inclusion of people with disabilities in education in South Sudan' (2014) 3 http://worldofinclusion.com/v3/wp-content/uploads/2014/01/World-of-Inclusion_South-Sudan_Inception-Report.pdf (accessed 2 April 2018).

66 Coalition of organisations of persons with disabilities *South Sudan UPR report*, (2016) 4 <https://uprdoc.ohchr.org/uprweb/downloadfile.aspx?filename=3454&file=EnglishTranslation> (accessed 20 June 2018).

67 Gilbert (n 66 above).

11.3 Are persons with disabilities' socio-economic rights, including the right to health, education and other social services protected and realised in South Sudan?

Section 37 of the Constitution provides for the economic objectives of the state which include achieving a decent standard of life for the people, promoting self-reliance and inclusive development. However, no deliberate mechanism is in place to ensure the realisation of the socio-economic rights of persons with disabilities in South Sudan. Persons with disabilities are said to be 'generally invisible in development programming'⁶⁸ as they are not considered as part of the target group.⁶⁹

The right to housing is guaranteed for all citizens under the Constitution. Article 34 provides: '(1) Every citizen has the right to have access to decent housing.' Despite this constitutional guarantee, no policy document addressing the issue of accessible housing or affirmative action programme on housing for persons with disabilities exists.

In terms of social security there is no social security programme for persons with disabilities in South Sudan.⁷⁰

Persons with disabilities in South Sudan face a lot of barriers in interacting with the physical environment. Public buildings and facilities such as schools, hospitals, offices, courts, recreational facilities are hardly accessible due to the absence of reasonable accommodation such as ramps, lifts, voice or braille facilities where needed and accessible road signs. This contributes to the social exclusion of persons with disabilities in South Sudan.⁷¹

Regarding access to public transport there is no clear policy framework on public transport taking into account the needs of persons with disabilities in South Sudan. The cost of transportation and the poor transportation infrastructure make it difficult for persons with disabilities to access services.⁷²

Article 29 of the Constitution recognises education as a right for all citizens. It is the responsibility of government at all levels to ensure that this right is guaranteed for all 'without discrimination as to religion, race, ethnicity, health status including HIV/AIDS, gender or disability'. This right is not yet realised for most persons with disabilities, especially for those living outside of Juba. This is particularly true for girls with disabilities, children with multiple disabilities and those with intellectual disabilities.⁷³ Some of the challenges to the realisation of the right to education for persons with disabilities in South Sudan are: location of the schools; negative attitudes towards students with disabilities; insecurity in some areas; lack of assistive devices; physical inaccessibility and lack of teacher experience.⁷⁴ Efforts to realise inclusive education as stated in the Education Sector Strategic Plan 2017-22 is yet to yield an appreciable result.⁷⁵

68 Rohwerder (n 6 above) 8.

69 As above.

70 NDIP (n 7 above) 11.

71 NDIP (n 7 above) 11 & 18.

72 Rohwerder (n 6 above) 3.

73 As above.

74 NDIP (n 7 above) 10-11.

75 Ministry of General Education and Instruction, Republic of South Sudan *Education Sector Strategic Plan 2014-22* (2017) 61.

In addition, there are several technical and vocational education training centres in South Sudan to enable participants to acquire employable skills for the world of work.⁷⁶ However, a clear strategy for the participation of persons with disabilities in vocational training is lacking as their special needs are often ignored.⁷⁷

Access to employment for persons with disabilities remains a challenge. Article 30 provides that government at all levels should guarantee access to suitable employment for persons with special needs. However, persons with disabilities in South Sudan continue to experience discrimination and inequalities when it comes to accessing employment. They are among the poorest and unemployed in South Sudan. A National Disability Assessment conducted in 2012 revealed that about 89.3 per cent of respondents with disabilities are unemployed.⁷⁸ This figure has not changed significantly. Women and girls face more challenges in accessing employment and vocational training.⁷⁹

Article 40(b) of the Constitution provides for the right to access recreational and sports facilities and the right to participate in these activities. No record was found on the access to recreational and sport facilities by persons with disabilities.

11.4 Case studies of specific vulnerable groups

No case study on specific vulnerable groups was found.

12 Future perspective

12.1 Are there any specific measures with regard to persons with disabilities being debated or considered in South Sudan at the moment?

In South Sudan, the current issue topping the agenda of DPOs is the adoption of a domestic legislation on the rights of persons with disabilities. Consultations are ongoing with the legislature and the executive to see to the realisation of this goal.⁸⁰

12.2 What legal reforms would you like to see in South Sudan? Why?

South Sudan should ratify the CRPD and its Optional Protocol. It should also enact a domestic legislation in line with the provisions of the Convention. This will give persons with disabilities the platform to claim their rights if violated. It is important that the legal capacity of persons with disabilities be recognised to prevent abuse, especially for persons with psychosocial disabilities.

76 UNESCO *TVET policy review South Sudan* (2014) 37 <http://unesdoc.unesco.org/images/0023/002312/231287e.pdf> (accessed 18 June 2018).

77 UNESCO (n 72 above) 39.

78 Legge (n 44 above) 5.

79 Rieser (n 65 above).

80 Legge (n 44 above).

SECTION C: REGIONAL DEVELOPMENTS

Disability rights in the African regional human rights system during 2018

Section C contains two commentaries: the first, by Anastasia Holoboff and Suzannah Phillips, examines the use of so-called ‘shadow reports’ by civil society organisations to provide information to human rights treaty bodies in their examination of reports submitted by states parties. This commentary draws on the experience of Women Enabled International in convening a coalition of civil society organisations to inform the review of South Africa’s initial state report to the Committee on the Rights of Persons with Disabilities. Given the fact that a number of African countries will have initial or periodic reports serving before this Committee in the foreseeable future, the commentary contains valuable observations as well as recommendations for potential engagement by civil society.

The second commentary focuses on the right of persons with disabilities to an adequate standard of living, which is an aspect of particular concern in the African context. Yvette Basson examines the relevant provisions of the CRPD and the African Protocol on the Rights of Persons with Disabilities respectively. While the latter is not yet in operation, it is important to gain an understanding of how the two instruments may complement each other in advancing the rights of persons of disabilities in the African region.

REGIONAL DEVELOPMENTS

LEVERAGING THE INTERNATIONAL HUMAN RIGHTS SYSTEM TO ADVANCE LOCAL CHANGE FOR SOUTH AFRICAN WOMEN WITH DISABILITIES

Anastasia Holoboff & Suzannah Phillips***

1 Introduction

Forty-nine African countries have to date ratified the Convention on the Rights of Persons with Disabilities (CRPD).¹ While the high rate of ratification is something to be celebrated, holding each state to account for their obligations under the treaty requires engagement and diligence on the part of civil society. The United Nations (UN) treaty monitoring body system is an essential mechanism to hold states to account for their duties under the treaties each state has ratified.

Every state that has ratified a human rights treaty periodically undergoes a 'review' by the treaty-monitoring body to assess whether it is complying with its obligations under the treaty, which results in recommendations² (called 'concluding observations') on what the state should do to better implement the treaty. Civil society has an important role to play in this process: every UN treaty body provides space for civil

* BFA (NYU), JD (Cardozo); Senior Legal Advisor, Women Enabled International.

** BA (Harvard), JD (Columbia); Deputy Director, Women Enabled International.

1 Convention on the Rights of Persons with Disabilities GA Res 61/106 A/RES/61/106 (13 December 2006) (CRPD); Office of the High Commissioner for Human Rights (OHCHR) 'UN Treaty body database' https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Treaty.aspx?CountryID=167&Lang=EN (accessed 15 November 2019).

2 See art 36(1) CRPD.

society to submit written information – often colloquially referred to as ‘shadow reports’ – to supplement the information shared by the government.³ Providing this supplemental information is crucial to fill in any gaps or to correct misinformation in the state’s own report, as treaty-body experts seldom have the capacity to do any independent research on an issue.

Engagement in the shadow-reporting process is one of the most important tools for civil society to use to push for the implementation of international human rights law in a way that is responsive to the specific human rights concerns of a given community, such as women with disabilities. Women with disabilities make up one in five women globally.⁴ Across the world women with diverse disabilities face increased rates of violence,⁵ routine violations of their sexual and reproductive health and rights,⁶ and enduring poverty.⁷ Yet, the majority of human rights treaties do not include articles addressing disability or gender and most state reports to treaty bodies overlook women with disabilities when discussing the country’s human rights situation. Thus, utilising the shadow-reporting system to inform the treaty bodies about the lived experiences of women

- 3 The Committee on the Rights of Persons with Disabilities (CRPD Committee) makes provision for the participation of civil society organisations in its consideration of state reports: see generally CRPD Committee ‘Guidelines on the participation of disabled persons’ organisations and civil society organisations in the work of the Committee’ CRPD/C/11/2 (14 May 2014) Annex II (Guidelines Civil Society).
- 4 World Health Organisation and World Bank *World report on disability* (2011) 28.
- 5 Women Enabled International ‘Women Enabled International Facts – The right of women and girls with disabilities to be free from gender-based violence’ (undated) <https://www.womenenabled.org/pdfs/Women%20Enabled%20International%20Fact%20-%20The%20Right%20of%20Women%20and%20Girls%20with%20Disabilities%20to%20be%20Free%20from%20Gender-Based%20Violence%20-%20ENGLISH%20-%20FINAL.pdf?pdf=GBVEnglish> (accessed 20 November 2019). See eg D Šimonović (Special Rapporteur on violence against women, its causes and consequences) ‘Report of the Special Rapporteur on violence against women, its causes and consequences on her mission to South Africa’ UN Doc A/HRC/32/42/Add.2 (14 June 2016) paras 9-10; Management Sciences for Health & UNFPA ‘We Decide – Young persons with disabilities: Equal rights and a life free of violence’ (May 2016); T Meer & H Combrinck ‘Invisible intersections: Understanding the complex stigmatisation of women with intellectual disabilities in their vulnerability to gender-based violence’ (2015) 29 *Agenda* 29; E Naidu et al ‘On the margins: Violence against women with disabilities’ Centre for the Study of Violence and Reconciliation 35 (2005) http://www.iiv.nl/epublications/2005/On_the_Margins.Pdf (accessed 20 November 2019).
- 6 Women Enabled International ‘Women Enabled International Facts – Sexual and reproductive health and rights of women and girls with disabilities’ (undated) <https://www.womenenabled.org/pdfs/Women%20Enabled%20International%20Facts%20-%20Sexual%20and%20Reproductive%20Health%20and%20Rights%20of%20Women%20and%20Girls%20with%20Disabilities%20-%20ENGLISH%20-%20FINAL.pdf?pdf=SRHREasyRead> (accessed 20 November 2019). See eg P Chappell ‘(Re)thinking sexual access for adolescents with disabilities in South Africa: Balancing rights and protection’ (2016) 4 *African Disability Rights Yearbook* 124; DisAbled Women’s Network of Canada / Réseau d’actions des femmes handicapées du Canada (DAWN Canada) ‘More than a footnote: A research report on women and girls with disabilities in Canada’ February 2019; W Holness ‘Informed consent for sterilisation of women and girls with disabilities in the light of the Convention on the Rights of Persons with Disabilities’ (2013) 27 *Agenda* at 35.
- 7 CRPD Committee General Comment 3: Women and girls with disabilities (2016) UN Doc CRPD/C/GC/3 dated 2 September 2016 para 59.

with disabilities is an essential mechanism to ensure concluding observations issued by the treaty bodies address issues of concern for women with disabilities. Doing so is a vitally important means of building both legal and cultural norms at the international and domestic levels that include women with disabilities and their issues.

This commentary will provide insight into effective civil society engagement in this process using the experience of a coalition of civil society organisations in the 2018 country review of South Africa by the Committee on the Rights of Persons with Disabilities (CRPD Committee), the expert body charged with monitoring compliance with this treaty. Using Women Enabled International's experience working with a coalition of South African disability and human rights organisations to illuminate the process, this commentary will further examine the strategic considerations during the shadow reporting process and address the importance of drawing on successful results to support domestic advocacy.⁸

2 South African shadow reports to the CRPD Committee

2.1 Background

South Africa ratified the CRPD in 2007.⁹ Accordingly in 2018 South Africa came up for its first periodic review before the CRPD Committee,¹⁰ to assess how well it was complying with its obligations under the CRPD.¹¹ Seeking to leverage this opportunity to address the pervasive

8 Further, more detailed information on the treaty body state reporting process and other UN human rights mechanisms can be found in the following publication: Women Enabled International 'accountABILITY toolkit: A guide to using UN human rights mechanisms to advance the rights of women and girls with disabilities' (2017) <https://www.womenenabled.org/atk.html> (accessed 15 November 2019).

9 Office of the High Commissioner for Human Rights 'Status of ratifications: South Africa' <http://indicators.ohchr.org/> (accessed 15 November 2019).

10 As parties to the CRPD, states are required under article 35 to submit a comprehensive report to the CRPD Committee on measures taken by the state to fulfill its obligations under the Convention. States must submit their first report within two years of ratification and at least every four years thereafter. Art 35(1)-(2) CRPD. Unfortunately, there is currently a backlog in the Committee's review of state reports which is why South Africa was only scheduled for review in 2018. This delay is due to a number of factors, including states submitting late reports, budget constraints of the Committee, and the volume of material to review.

11 The CRPD Committee, like other treaty bodies, lists their calendar of upcoming sessions on their website, along with guidelines for civil society to submit written information. If an organisation wishes to submit a shadow report, it should periodically monitor the treaty-body websites to determine when a country is coming up for review and should read the informative notes for civil society for essential information including deadlines, word-count requirements and templates for submissions <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx> (accessed 15 November 2019).

intersectional discrimination facing women and girls with disabilities¹² in South Africa, local civil society organisations Cape Mental Health, the Centre for Human Rights at the University of Pretoria, Epilepsy South Africa, Khuluma Family Counselling, Lawyers for Human Rights, Port Elizabeth Mental Health, SA Federation for Mental Health, the Teddy Bear Clinic for Abused Children and Professor Helene Combrinck from North-West University,¹³ with support from international human rights organisation Women Enabled International, decided to engage in the shadow-reporting process. Through this engagement we aimed to bring to the CRPD Committee's attention the experiences of South African women with disabilities and South Africa's failure to fulfil its duties towards them under the CRPD.

Similar to women with disabilities around the world, South African women with disabilities are discriminated against and subjected to harmful stereotypes based on both their gender and disability. South African women with disabilities, particularly black women, women in rural areas, and women with intellectual or psychosocial disabilities are regularly discriminated against and denied access to justice or essential support, services, and accommodations necessary to uphold their rights and live independent lives free from discrimination and violence.¹⁴ All women in South Africa face an extremely high risk of gender-based violence¹⁵ and for women with disabilities the risk of violence is even greater, particularly the risk of sexual violence.¹⁶ South African women with disabilities also face unique forms of discrimination in healthcare settings, especially when accessing sexual and reproductive health information and services,

12 This commentary and the CRPD Committee submissions address the situation of South African women with disabilities throughout their life cycle. Any reference to 'women with disabilities' should be interpreted to include girls with disabilities unless otherwise indicated.

13 Helene Combrinck's contributions to the submissions were made in her personal capacity and as such do not represent the views of the Faculty of Law or the North-West University.

14 See C Capri et al 'Intellectual disability rights and inclusive citizenship in South Africa: What can a scoping review tell us?' (2018) 7 *African Journal of Disability* 1 5 <https://doi.org/10.4102/ajod.v7i0.396> (accessed 15 November 2019); T Meer & H Combrinck 'Help, harm or hinder? Nongovernmental service providers' perspectives on families and gender-based violence against women with intellectual disabilities in South Africa' (2017) 32 *Disability & Society* 37; T Meer & H Combrinck 'Invisible intersections: Understanding the complex stigmatisation of women with intellectual disabilities in their vulnerability to gender-based violence' (2015) 29 *Agenda* at 14; Naidu et al (n 5 above) 35.

15 See eg Šimonović (n 5 above) paras 9-10.

16 Reasons predicted for this heightened risk for women with disabilities include: their social isolation and dependence on others, a lack of knowledge about their rights and the obstacles faced in accessing social support services and justice mechanisms. See Šimonović (n 5 above) para 30; Meer & Combrinck (n 14 above) at 38. See also General Comment 3 (n 7 above) para 33.

frequently finding that these services are unavailable, unaffordable, inaccessible, or discriminatory.¹⁷

Our coalition submitted two shadow reports to the CRPD Committee throughout the review process – one submission to the Committee’s pre-sessional working group¹⁸ to inform the list of issues¹⁹ and one in advance of the session in which the state report was reviewed.²⁰ Given the severe challenges faced by South African women with disabilities, and based on the expertise of coalition members in these areas, the coalition agreed to focus the shadow reports on the ways in which these issues play out in violation of South Africa’s obligations to respect, protect, and fulfil the rights protected under the CRPD. Both reports contained three categories of information: factual information pertaining to key issues facing women with disabilities (for example global and local statistics, domestic laws and policies, case studies); analysis of relevant international human rights legal standards; and suggested questions and recommendations.

Each report addressed the following key issues: first, how South Africa fails to fully recognise and take action to address the multiple forms of discrimination that women with disabilities experience in South Africa in violation of its obligations under article 6 of the CRPD (women with disabilities).²¹ Second, the ways in which South African women with disabilities cannot access justice on an equal basis with others due to a range of barriers, both physical and legislative, in violation of article 13 of the CRPD (access to justice).²² Third, South Africa’s failure to address the exceedingly high levels of gender-based violence experienced by women with disabilities through exercising due diligence to prevent, protect against, investigate, prosecute, and punish gender-based violence, while ensuring that women and girls have access to appropriate support services when they experience such violence, in violation of articles 15 (freedom from torture or cruel, inhuman or degrading treatment or punishment) and

17 See R Johns & C Adnams ‘My right to know: Developing sexuality education resources for learners with intellectual disabilities in the Western Cape, South Africa’ (2016) 4 *African Disability Rights Yearbook* 114; Chappell (n 6 above) 134-138; Holness (n 6 above) 36; VN Mgwili & B Watermeyer ‘Physically disabled women and discrimination in reproductive health care: Psychoanalytic reflections’ in B Watermeyer et al (eds) *Disability and social change: A South African agenda* (2006) 262-266.

18 Rule 5 of the Committee’s Rules of Procedure (2016) file:///Users/alr/Downloads/G1622964.pdf (accessed 15 November 2019), which sets out the role of the pre-sessional working group.

19 The first report to inform the List of Issues can be found on the OHCHR UN Treaty body database website at https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fCO%2fZAF%2f30268&Lang=en (accessed 15 November 2019).

20 The second report to inform the review can also be found at the OHCHR website at https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fCSS%2fZAF%2f31996&Lang=en (accessed 15 November 2019).

21 Art 6 CRPD.

22 Art 13 CRPD.

16 (freedom from exploitation, violence and abuse) of the CRPD.²³ Fourth, South Africa's failure to fulfil its duties under both articles 23 (respect for home and the family) and 25 (health),²⁴ as South African women with disabilities do not receive sufficient sexual and reproductive health and rights education and information; lack access to accessible health facilities; and face discrimination in the healthcare settings where they do have access.²⁵ Lastly, the reports addressed the lack of data collection disaggregated by disability and gender in violation of South Africa's obligations under article 31 (statistics and data).²⁶

2.2 Selecting a coalition

A key strategic consideration in submitting written information to a treaty body will be whether an organisation wants to submit information alone or in coalition with other organisations, and will depend on a range of factors, including each coalition member's mandate and the issues to be raised. Coalition shadow reports can be effective in demonstrating that the content of the report is not just the position of one organisation, but that of several, lending greater authority to the information presented. In addition, because treaty-body experts are often inundated with a large amount of information during the session, coalition shadow reports have the benefit of reducing the number of reports the committee members receive, allowing them to focus more on the content of each report.

Moreover, coalition reports allow each non-governmental organisation (NGO) to contribute according to its specific expertise, strengthening the overall impact of the advocacy. For the South Africa CRPD Committee reports, our coalition was formed to reflect members of civil society across both the disability rights and mainstream human rights fields in South Africa. Each person brought expertise in different aspects of the lived experience of South African women with diverse disabilities and was able to contribute research or anecdotal evidence from their practices into the reports. Women Enabled International, as an international NGO, provided the expertise on the international human rights treaty body processes, international law, and issues facing women with disabilities generally. By working together, we were able to emphasise to the CRPD Committee the particularly acute situation of women with disabilities in South Africa.

23 Arts 15 & 16 CRPD.

24 Arts 23 & 25 CRPD.

25 See Johns & Adnams (n 17 above) 114-118; Chappell (n 6 above) 124; Holness (n 6 above) 36; Mgwili & Watermeyer (n 16 above) 262-266.

26 Art 31 CRPD.

2.3 Engagement in the list of issues process: Setting the agenda

There are typically two stages during a treaty body's review of a state when civil society can submit a shadow report to inform the process. Treaty bodies typically send states a List of Issues, either before or after a state has submitted its report to the treaty body.²⁷ The List of Issues focuses the agenda for the state review, indicating the topics that the treaty body is most interested to focus on during the in-person dialogue. Civil society generally has the opportunity to submit information to inform the topics on the List of Issues (stage 1). States will then reply to the List of Issues, and civil society has another opportunity to provide information following the state's response (stage 2).

Choosing to submit a report at the List of Issues stage is often crucial to ensuring that the treaty body addresses one's priority issues, as the List of Issues determines in large part the focus of the dialogue²⁸ during the state's review. By submitting a shadow report to inform the development of the List of Issues, civil society can be more successful at influencing the treaty body to address their issues in the dialogue between the treaty body and the state and in the concluding observations. Failure to have one's issues included on the List of Issues does not preclude one from including those issues in subsequent shadow reports, but it can make it more of a challenge to obtain concluding observations on that issue.

To ensure that the CRPD Committee considered the unique issues facing South African women with disabilities as they related not only to article 6 (women with disabilities), but other CRPD articles as well, our coalition submitted a shadow report to the CRPD Committee pre-sessional working group for South Africa that was developing the List of Issues. Our report addressed the key issues affecting South African women with disabilities and was primarily based on published statistics and research. Successful reports are tailored to include information and questions based on one's ultimate advocacy goals. At this stage of the review process, the objective is to encourage the treaty body to interrogate what the state is doing to address the issues raised in the submission; accordingly, our coalition's submission included suggested questions for the List of Issues. For instance, 'What steps is South Africa taking to ensure the expansion of current gender-based violence services to include women with disabilities (for example, Thuthuzela Care Centres)?'

This strategy proved effective, as the CRPD Committee's List of Issues for South Africa contained 15 out of the 37 questions pertaining to women with disabilities or a related issue highlighted in our coalition's

27 Rule 48bis of the Committee's Rules of Procedure (2016) file:///Users/alr/Downloads/G1622964.pdf (accessed 15 November 2019).

28 Working Methods of Committee (2011) Part I para A file:///Users/alr/Downloads/G1145155.pdf (accessed 15 November 2019).

report.²⁹ The majority of our coalition's questions were reflected in one way or another in the List of Issues, including some specific questions about services and trainings relating to gender-based violence. For example:

Please provide information about: ... (b) Access by women and girls with disabilities to the Thuthuzela Care Centres, which provide support services for survivors of sexual offences and domestic violence, and to programmes providing psychosocial redress and legal aid for women with disabilities who are exposed to gender-based violence.³⁰

2.4 Engagement in the state party review: Session shadow report

After the state replies to the List of Issues, and before the session at which the treaty body will have a dialogue with the state party, there is the second opportunity for civil society to submit additional information or submit an initial report. Strategically if an NGO submitted information for the List of Issues, this stage presents an opportunity for civil society to provide new, updated, or expanded information pertaining to the List of Issues and responding to the state's report. It is advisable to avoid repetition of information contained in the first report unless necessary to emphasise an important point.

Accordingly, our coalition used this second opportunity to expand the coalition to include other South African disability-service providers who could provide further information about the lived experiences of South African women with disabilities. As a result, the second report contained anecdotal reports and information from mental health service providers in several provinces across South Africa and additional research to respond to the specific List of Issues released by the CRPD Committee as well as South Africa's state report. Moreover, where the objective of the first report was to inform the List of Issues, this second report sought to inform the specific recommendations the CRPD Committee would make in its concluding observations. Accordingly, the second report contained suggested questions for CRPD Committee members to pose to South Africa during their in-person dialogue and offered specific recommendations for concluding observations. Given the demands on committee members' time, providing advance questions and suggested language can be useful for committee members and an effective strategy for ensuring one's issues are addressed.

29 See CRPD Committee List of issues in relation to the initial report of South Africa CRPD/C/ZAF/Q/1 (25 April 2018).

30 CRPD Committee (n 29) para 17(b).

For example, our coalition's second report encouraged the CRPD Committee to ask South Africa what steps it was taking to respect the legal capacity of women with disabilities. We also requested that the Committee specifically recommend the amendment of a South African law that allowed third-parties to consent to sterilisation and abortion on behalf of a woman with a disability. This again proved to be a successful technique as this recommendation was reflected in the CRPD Committee's concluding observations. Specifically, the Committee called on South Africa to:

Revise the Sterilization Act (1998) and Choice on Termination of Pregnancy Act (1996), and remove provisions allowing for sterilization and termination of pregnancy under a substitute decision-making regime, and bring them into line with general comment No 1.³¹

2.5 In-person session advocacy

Following the shadow-reporting process, the treaty body will engage in an interactive, in-person dialogue with the state party's delegation informed by the state report and any civil society reports received. There is an opportunity during this in-person session in Geneva, Switzerland for civil society to engage further in both formal and informal ways. Many treaty bodies have formalised opportunities for civil society to brief them either before or during the session through country briefings open to civil society.³² It is advisable (and often required) that organisations contact the secretariat of the treaty body prior to the session to indicate a desire to participate in a country briefing.

In addition to the country briefings, civil society present in Geneva can engage in informal conversations with individual treaty-body experts during breaks in the session. These sessions may also present advocates with the opportunity to communicate directly with the state delegation, which can be useful for subsequent advocacy to ensure implementation of the concluding observations. It is especially helpful to seek out the expert(s) who have been assigned as rapporteur³³ for the country in question and/or the expert(s) who are asking questions around the relevant treaty provisions. Other advocacy strategies to consider are requesting the opportunity to hold a private thematic briefing with the treaty body during its session or holding a 'side event' during the session to raise key issues informally.

31 Concluding Observations on the initial report of South Africa, CRPD Committee (23 October 2018) UN Doc CRPD/C/ZAF/CO/1 (2018) para 33(a).

32 Working Methods of Committee (2011) Part II para E file:///Users/alr/Downloads/G1145155.pdf (accessed 15 November 2019).

33 Working Methods of Committee (2011) Part I para E file:///Users/alr/Downloads/G1145155.pdf (accessed 15 November 2019).

Following submission of our coalition's shadow reports, Women Enabled International sent an email to key CRPD Committee members notifying them of the reports and highlighting important issues. Furthermore, while no coalition members were able to be present for the treaty-body session when South Africa was being reviewed, Women Enabled International was present during another country review during the same session and had the opportunity to meet informally with the rapporteur for South Africa and advocate for the five key issues highlighted in our coalition's reports.

3 Concluding observations

The CRPD Committee published its concluding observations on the initial report of South Africa on 23 October 2018.³⁴ The principal areas of concern and recommendations to South Africa included 33 references to women with disabilities or gender.

Every issue raised in our coalition's reports was reflected in some manner in the concluding observations. Each of the five key issues that our coalition highlighted in the reports – multiple and intersecting discrimination faced by South African women with disabilities; access to justice; gender-based violence; sexual and reproductive health and rights, including forced sterilisation and forced abortion; and the lack of disaggregated data – was reflected in the final concluding observations. This success underscores that strategic engagement in the state-reporting process can play an important role in translating the often opaque language of international human rights treaties into concrete suggestions for strengthening human rights at the domestic level.

4 Conclusion

The shadow-reporting process is a critical component of the international human rights system and necessary to ensure that the rights enumerated in international human rights treaties like the CRPD lead to long-term change for individuals living in the countries that have ratified treaties.

It is incumbent on anyone who engages in the shadow reporting process to commit to advocacy aimed at ensuring implementation of the concluding observations at the country level. Implementation will vary on the country context and is most effective when considered as part of initial shadow-reporting strategy. When contemplating implementation strategies effective starting points can include developing or growing a coalition to coordinate implementation advocacy based on the concluding

34 CRPD Committee (n 30 above).

observations; engaging with local and national government, especially those officials who were engaged with the review process; and raising awareness through media strategies. Regardless of the strategy chosen, engagement of people with disabilities is essential for both long-term change and realisation of the promise made by the CRPD.

Particularly for marginalised groups, such as women with disabilities, using the international human rights system to raise awareness about priority issues and increase pressure on one's government to intensify its capacity and fulfil its obligations towards marginalised groups can be an especially effective technique. Following our successful engagement with the CRPD Committee's review of South Africa, our South African coalition members are now taking stock of how best to promote the concluding observations to effect long-term change for women with disabilities in South Africa.

REGIONAL DEVELOPMENTS

THE RIGHT TO AN ADEQUATE STANDARD OF LIVING IN THE PROTOCOL TO THE AFRICAN CHARTER ON HUMAN AND PEOPLES' RIGHTS ON THE RIGHTS OF PERSONS WITH DISABILITIES IN AFRICA

*Yvette Basson**

1 Introduction

The Protocol to the African Charter on Human and People's Rights on the Rights of Persons with Disabilities in Africa (African Disability Protocol) was adopted by the African Union (AU) on 29 January 2018.¹ The primary purpose of this instrument is to 'promote, protect and ensure the full and equal enjoyment of all human and people's rights by all persons with disabilities' on the African continent.² The Protocol is thus potentially an important step forward in the achievement of equal rights by persons with disabilities in Africa.

Although not yet in operation, the African Disability Protocol stands alongside the United Nations Convention on the Rights of Persons with Disabilities (CRPD)³ in setting out human-rights standards in respect of persons with disabilities in the African region. While there are clear differences in emphasis between the two instruments, several commonalities may also be noted. One of these areas of overlap is the inclusion of the right to an adequate standard of living, set out in article 28 of the CRPD and article 20 of the African Disability Protocol respectively. Both of these documents guarantee the recognition of this right and require of states parties to take positive steps towards its realisation. The fulfilment

* Yvette Basson, LLB, LLM, LLD, Lecturer, University of the Western Cape.

1 Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, adopted on 29 January 2018 <https://au.int/en/treaties/protocol-african-charter-human-and-peoples-rights-rights-persons-disabilities-africa> (accessed 3 September 2019). The Protocol was adopted in terms of art 66 of the African Charter on Human and Peoples' Rights (African Charter), which allows for the acceptance of additional protocols to supplement its provisions.

2 Art 2 African Disability Protocol.

3 GA Res A/RES/61/06, adopted on 13 December 2006, entered into force on 3 May 2008.

of this right takes on particular urgency in the African context, where the living standard of persons with disabilities is often reported to be dismal⁴ – a function of the disproportionately limited access to education, employment and other means of support they experience. In order to assess and compare the potential of the two human-rights instruments to address the current situation, this commentary accordingly compares the scope and content of the provisions relating to the right to an adequate standard of living and examines the obligations imposed by each instrument on states. It then provides an overview of the implementation mechanisms of the African Disability Protocol, followed by a number of conclusions.

2 General obligations of states parties

Both the CRPD and the African Disability Protocol impose general obligations on states parties related to the rights of persons with disabilities. The CRPD provides that:

States Parties undertake to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability.⁵

Thereafter, article 4 lists a number of ways in which this full realisation of human rights and fundamental rights should be achieved, inter alia through the adoption of legislative measures to recognise the rights of persons with disabilities,⁶ the abolition of discriminatory laws and policies,⁷ and the development of universally designed goods, services, equipment and facilities for use by persons with disabilities.⁸

The African Disability Protocol in turn enjoins states parties to:

[T]ake appropriate and effective measures, including policy, legislative, administrative, institutional and budgetary steps, to ensure, respect, promote, protect and fulfil the rights and dignity of persons with disabilities, without discrimination on the basis of disability.⁹

Further, article 4 of the Protocol also confirms that states parties must take steps to mainstream disability in legislation and policy,¹⁰ abolish

4 See in this regard eg LO Oyaro 'Africa at crossroads: The United Nations Convention on the Rights of Persons with Disabilities' (2015) 30 *American University International Law Review* 347 352-353.

5 Art 4 CRPD.

6 Art 4(1)(a) CRPD.

7 Art 4(1)(b) CRPD.

8 Art 4(1)(f) CRPD.

9 Art 4 African Disability Protocol.

10 Art 4(b) African Disability Protocol.

discriminatory policies and laws¹¹ and criminalise and campaign against harmful practices against persons with disabilities.¹²

On a first reading, these general ‘operational’ obligations appear very similar. Upon closer inspection, the inclusion of certain steps to be taken by states parties in the African Disability Protocol shows a clear intent to contextualise the realisation of the rights of persons with disabilities on the African continent.¹³ For example, it explicitly mentions that states parties must take budgetary steps to ensure the full implementation of the Protocol,¹⁴ whereas the CRPD does not make express mention of such a requirement. Many countries in Africa do not prioritise spending on socio-economic issues, which makes the duty to allocate resources to the implementation of the Protocol particularly significant.¹⁵

This difference in emphasis is the first of many examples where the language between the two instruments differ in subtle, yet important ways. The African Disability Protocol has been drafted bearing in mind the unique experience of persons with disabilities on the African continent¹⁶ and therefore locates certain rights in this context to a greater extent than the CRPD does.¹⁷

11 Art 4(c) African Disability Protocol.

12 Art 4(d) African Disability Protocol.

13 For a helpful overview of the drafting history of the Protocol, see LM Mute & E Kalekye ‘An appraisal of the Draft Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Persons with Disabilities in Africa’ (2016) *East African Law Journal* 68 70-76.

14 Art 4 African Disability Protocol.

15 A Odusola et al (eds) *Income inequality trends in Sub-Saharan Africa* (2017) 179.

16 This is evident from the Preamble to the Protocol, which makes reference to ‘the lack of a substantive binding African normative and institutional framework for ensuring, protecting, and promoting the rights of persons with disabilities’ and the need to establish such a framework through the African Union.

17 Examples include: the recognition in the Preamble of the maiming or killing of persons with albinism as a worrying phenomenon on the continent; the definitions of ‘harmful practices’ and ‘ritual killings’ are to be read with art 11, which addresses the duties of states parties in respect of eradication of harmful practices committed against persons with disabilities; and the undertaking to protect (amongst others) closely related family members, children and caregivers against discrimination based on their association with persons with disabilities (art 5(2)(c) Protocol).

3 The right to an adequate standard of living

3.1 Interpreting the provisions of the African Disability Protocol and the CRPD

As noted above, the right to an adequate standard of living of persons with disabilities is provided for in article 20 of the African Disability Protocol and article 28 of the CRPD respectively.

Article 20(1) provides that:

Persons with disabilities have the right to an adequate standard of living for themselves and their families, including adequate food, access to safe drinking water, housing, sanitation and clothing, to the continuous improvement of living conditions and to social protection.

It thus confirms the rights to an adequate standard of living and the related right to social protection. It also provides some insight as to the scope and content of the right to an adequate standard of living by listing certain components of this right, such as housing, adequate food and access to safe drinking water.

Article 28(1) of the CRPD sets out the following:

States Parties recognise the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realisation of this right without discrimination on the basis of disability.

The proper implementation of the right to an adequate standard of living may contribute towards persons with disabilities participating in society fully and equally with other people on a daily basis.¹⁸ In terms of the obligations created by article 28(1) of the CRPD, this means that states parties have a duty to ensure that persons with disabilities are provided with access to the means to ensure such full and equal participation. In doing so, states parties must make use of the measures listed in article 4 as discussed above. Similarly, article 20(1) of the African Disability Protocol attempts to ensure proper emphasis on the right to an adequate standard of living of persons with disabilities by incorporating specific obligations that are complemented by the general ones set out in article 4.

18 Icelandic Human Rights Centre 'The right to an adequate standard of living' <http://www.humanrights.is/en/human-rights-education-project/human-rights-concepts-ideas-and-fora/substantive-human-rights/the-right-to-an-adequate-standard-of-living> (accessed 3 September 2019).

Article 20(1) provides that an adequate standard of living *inter alia* includes access to safe drinking water and sanitation. In this regard, the African Disability Protocol provides more information on what is required, since the CRPD provides only for the access to clean water services by persons with disabilities.¹⁹ The express inclusion of these two elements, which have historically proved to be socially and politically critical,²⁰ reminds us that many persons with disabilities in Africa do not yet have access to these basic necessities (which may not be as urgent a priority in so-called 'developed' countries that are states parties to the CRPD).²¹ Access to safe drinking water and sanitation should therefore be emphasised in the 'continuous improvement of living conditions' of persons with disabilities in Africa.²²

The interpretation of the phrase 'adequate standard of living' leads to two questions: what is adequate and which elements are essential for a living standard to be regarded as adequate? In ensuring such an adequate standard of living, states parties may be expected to provide persons with disabilities with access to a range of goods and services.²³ However, it is clear that an adequate standard of living consists of more than simply having access to the necessities specifically mentioned in this article. The realisation of the right to an adequate standard of living therefore demands more from states parties than merely making these requirements available.²⁴ An exact list of the necessities contributing to the achievement of an adequate standard of living for persons with disabilities cannot readily be compiled, because the right is highly subjective and what is required must be determined on a case-by-case basis.²⁵ However, it is argued here that certain goods and services, namely those expressly enumerated in article 20(1), can clearly be considered part of the right to an adequate standard of living for persons with disabilities. This list should therefore not be seen as an exhaustive one, but rather as a guideline for the provision of certain minimum necessities. In terms of what can be considered 'adequate', this can only be determined on a case-by-case basis, since the needs of individual persons with disabilities may differ greatly.²⁶

19 Art 28(2) CRPD.

20 BS Levy & VW Sidel 'Water rights and water fights: Preventing and resolving conflicts before they boil over' (2011) 101 *American Journal of Public Health* 779.

21 Goal 6 of the United Nations Development Programme's Sustainable Development Goals highlights the challenges faced in providing access to safe drinking water and sanitation, see <http://www.africa.undp.org/content/rba/en/home/sustainable-development-goals/goal-6-clean-water-and-sanitation.html> (accessed 3 September 2019).

22 Art 20(1). See also discussion below.

23 Y Wiid 'The right to social security of persons with disabilities in South Africa' LLD thesis, University of the Western Cape, 2015 152.

24 D Moeckli & S Shah (eds) *International human rights law* (2010) 196.

25 As above.

26 The Committee on Economic, Social and Cultural Rights (Committee on ESCR) has provided guidance in determining 'adequacy' in the context of the right to housing, which may also be applicable more broadly: see Committee on CÉSCR General Comment 4: The right to adequate housing (1991) UN Doc E/1992/23 dated 13 December 1991 para 8.

3.2 Duties of states parties to ensure the right to an adequate standard of living

Both the African Disability Protocol and the CRPD impose clear obligations on states parties in the realisation of the right to an adequate standard of living. Article 20(1), read with article 20(2),²⁷ provides that states parties must provide certain goods and services in the realisation of the right. Similarly, article 28(1) of the CRPD provides that: ‘States Parties ... shall take *appropriate steps to safeguard and promote the realisation of this right*’.²⁸ It is generally accepted that the guarantee or recognition of a particular right by a state party gives rise to obligations to respect, protect and fulfil the right concerned.²⁹ Second, the general obligations incorporated in article 4 of the Protocol are also applicable to the right to an adequate standard of living of persons with disabilities.

Article 20(1) further calls for the ‘continuous improvement of living conditions’ of persons with disabilities. This commitment is also found in article 28(1) of the CRPD, although, as mentioned previously, the obligation to continuously improve living conditions on states parties is clearer in the latter. Essentially, this confirms that states parties have an obligation to ensure the progressive realisation of the right to an adequate standard of living for persons with disabilities. This is indicated by the constituent elements, such as adequate food and housing. As explained by the UN Committee on Economic, Social and Cultural Rights, ‘progressive realisation’ does not require that a right be fully implemented and realised immediately, but rather that states parties must ensure the realisation of the right over time.³⁰ States parties must therefore evaluate and monitor the standard of living of persons with disabilities within their territory and, importantly, must endeavour to constantly improve on that position.³¹

At the same time, it is noteworthy that the right to an adequate standard of living is interwoven with a prohibition of disability-based

27 Art 20(1)-(2) African Disability Protocol.

28 Emphasis added.

29 The Committee on ESCR first adopted the following analysis of state duties: ‘The right to health, like all human rights, imposes three types or levels of obligations on States parties: the obligations to *respect, protect* and *fulfil* the right.’ (Emphasis added): Committee on ESCR General Comment 14: The right to the highest attainable standard of health (2000) UN Doc E/C.12/2000/4 dated 11 August 2000 para 33. This approach has subsequently been applied extensively in respect of a range of rights.

30 Committee on ESCR General Comment 3: The nature of states parties’ obligations (1990) UN Doc E/1991/23 dated 14 December 1990 para 9; see also Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities <https://www.un.org/development/desa/disabilities/resources/handbook-for-parliamentarians-on-the-convention-on-the-rights-of-persons-with-disabilities/chapter-two-the-convention-in-detail-4.html> (accessed 3 September 2019).

31 The Committee on ESCR has further noted that states parties should move ‘as expeditiously and effectively as possible’ towards the full realisation of the right concerned and that deliberately retrogressive measures must generally be avoided – see General Comment 3 (n 30 above) para 9.

discrimination: article 20(2) contemplates the full enjoyment by persons with disabilities of this right, 'on the basis of equality'. Similarly, article 28(1) of the CRPD makes reference to safeguarding and promotion of this right 'without discrimination on the basis of disability'. Addressing disability-based discrimination is an obligation of immediate implementation, and therefore not subject to progressive realisation.³²

3.3 Related rights

The right to an adequate standard of living cannot be implemented independently of other rights. This is evidenced by the numerous links to and overlaps with other rights in the CRPD as well as the African Disability Protocol. Significantly, both documents include a reference to the indivisibility and interrelatedness of all human rights in their respective Preambles.

The right to social protection is an example of the overlap of the right to an adequate standard of living with other rights. The inclusion of the right to social protection in article 20 of the African Disability Protocol and article 28 of the CRPD is a clear indication that the two rights are interconnected and that their content may be similar. For example, both articles incorporate the need for the provision of housing to persons with disabilities in the right to an adequate standard of living,³³ and the right to social protection has historically included this as well.³⁴

Another significant link can be found between the right to an adequate standard of living and the right to life in the community as provided for in article 14 of the African Disability Protocol and article 19 of the CRPD. According to article 14(1), '[e]very person with a disability has the right to live in the community with choices on an equal basis with others'. Article 14(2) requires states parties to provide certain goods and services in the realisation of this right. These include rehabilitation services,³⁵ which in turn overlap with article 18 which specifically guarantees the right to rehabilitation services. It is submitted here that these facilities and services should therefore be added to those listed in article 20 as essential for an adequate standard of living.

32 See Committee on the Rights of Persons with Disabilities (CRPD Committee) General Comment 6: Equality and non-discrimination (2018) UN Doc CRPD/C/GC/6 dated 26 April 2018 para 12.

33 Art 20(1) African Disability Protocol and art 28(1) CRPD both include the right to housing in the right to an adequate standard of living.

34 Art 28(2) CRPD. See also the International Labour Organisation 'Social protection systems for and to prevent homelessness and facilitate access to adequate housing' (2019) https://www.un.org/development/desa/dspd/wp-content/uploads/sites/22/2019/06/ILO-Geneva-SP-and-homelessness_220519-DRAFT.pdf (accessed on 4/12/2019).

35 Art 14(20(e)).

The right to an adequate standard of living should further be interpreted with reference to the inherent dignity of persons with disabilities, which constitutes one of the general principles of the CRPD.³⁶ It is understood that an adequate standard of living can only be achieved if the person or persons in question are able to live a life of dignity through having their basic needs met.³⁷

Other rights guaranteed in the Protocol that overlap with the right to an adequate standard of living include the right to be protected from exploitation, violence and abuse in various contexts (articles 9(2)(c) and 10(2)(d)). Since persons with disabilities are substantially more likely to experience violence (including from those who are involved in their daily care),³⁸ this right is particularly important in ensuring equal participation in society. The right to barrier-free access to the physical environment (article 15(1)),³⁹ the right to education (article 16) and the right to decent work (article 19) all tie in with employment opportunities in the workplace on an equal basis with persons without disabilities. The right to participate in political and public life (article 21) also contributes towards full participation in society by ensuring that the voices of persons with disabilities are heard when making decisions relating to governance.⁴⁰

4 Implementation of the African Disability Protocol

The Protocol sets out a number of measures aimed at implementation and enforcement.⁴¹ First, states parties are required to show in their periodic reports⁴² to the African Commission on Human and Peoples' Rights (ACHPR) which measures they have taken towards the full realisation of the rights recognised in the Protocol.⁴³ Mute and Kalekye explain that the adoption of the Protocol may have a significant impact on the approach of the ACHPR to disability rights in its examination of periodic state reports: they note that the lack of a normative framework has until now necessitated a consideration of 'generalities' rather than a focus on specific

36 See art 3(a) CRPD, which closely corresponds with art 3(a) African Disability Protocol.

37 Committee on Economic Social and Cultural Rights General Comment 12: The right to adequate food (1999) dated 12 May 1999 (item 4). See also Y Wiid 'The right to social security of persons with disabilities in South Africa' LLD thesis, University of the Western Cape, 2015 150.

38 World Health Organisation 'Violence against adults and children with disabilities' <https://www.who.int/disabilities/violence/en/> (accessed 4 December 2019).

39 Significantly, art 15(2)(a) of the Protocol, which sets out the measures to be taken by states parties to 'facilitate full enjoyment' of this right, stipulates that such measures should apply to rural as well as urban settings.

40 JC Bricout & DB Gray 'Community receptivity: The ecology of disabled persons' participation in the physical, political and social environments' (2006) 8 *Scandinavian Journal of Disability Research* (2006)1.

41 Art 34 African Disability Protocol.

42 In terms of art 62 of the African Charter.

43 Art 34(1) African Disability Protocol.

aspects such as legal capacity.⁴⁴ This is accordingly one area where the advent of the Protocol may yield visibly positive results.

Further, the ACHPR will have the mandate to interpret the provisions of the Protocol⁴⁵ and may refer matters of interpretation and enforcement to the African Court on Human and Peoples' Rights.⁴⁶ This court will have the mandate to hear disputes arising from the implementation of the Protocol.⁴⁷

At the time of writing, five countries have signed the Protocol and none have ratified it.⁴⁸ The Protocol will only acquire legal effect once 15 AU member states have ratified it, which means that the Protocol is not yet binding on any of the 54 member states.⁴⁹ However, this instrument is complementary to the CRPD, which has been signed and ratified by the majority of AU member states.⁵⁰ The CRPD is also expressly referred to in the Preamble of the African Disability Protocol as an instrument that confirms the rights of persons with disabilities. The lack of ratification to date of the Protocol should thus not necessarily be seen as an absence of commitment to the rights confirmed therein; although the reasons for the lack of ratification of the Protocol are unclear, the relatively short period since its adoption must be borne in mind.

5 Conclusion

From the foregoing discussion, it becomes apparent that the importance of the right to an adequate standard of living cannot be overemphasised. Not only does the right to an adequate standard of living have a direct impact on the dignity of persons with disabilities, but the ideal of full and equal participation in society is wholly dependent on the goods and services included in the scope and content of this right. Unfortunately, the enforcement mechanisms provided for in the African Disability Protocol

44 Mute & Kalekye (n 13 above) 78.

45 Art 34(3) African Disability Protocol. The arguments against the adoption of an African regional instrument on disability rights in the form of a protocol to the African Charter included the concerns first that African human rights institutions, such as the ACHPR, have not historically paid a great deal of attention to the promotion of the rights of persons with disabilities and second, that these institutions are already under-resourced and overburdened and would therefore find it difficult to monitor the implementation. See generally Oyaró (n 4 above) 359-360, 367.

46 Art 34(4) African Disability Protocol.

47 Art 34(5) African Disability Protocol.

48 African Union 'Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa – Status list' <https://au.int/en/treaties/protocol-african-charter-human-and-peoples-rights-rights-persons-disabilities-africa> (accessed 3 September 2019).

49 Article 38(1) African Disability Protocol.

50 United Nations 'Convention on the Rights of Persons with Disabilities' https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en (accessed 3 September 2019).

remain only theoretical at this stage, since there has been no ratification of the instrument to date.

Until such time as the African Disability Protocol is ratified by AU member states, the reporting and monitoring mechanisms in the CRPD are the only way to measure the extent of implementation of the right to an adequate standard of living in member states that have ratified the CRPD. This is not an ideal situation – as mentioned previously, the African Disability Protocol has been drafted with the unique socio-economic and other challenges present in Africa in mind. This is evident in the unique details added to the African Disability Protocol that are lacking in the CRPD. The African Disability Protocol is therefore the ideal instrument to make strides in realising the right to an adequate standard of living for persons in Africa.

BOOK REVIEW

SIMON FOLEY: *INTELLECTUAL DISABILITY AND THE RIGHT TO A SEXUAL LIFE* (2019)

Charles Ngwena*

Routledge 1-184; i-vii. ISBN 978-1-138-62824-3

1 Introduction

The last two decades or so have seen a growth in literature addressing disability from a variety of revisionary perspectives, including human rights law, applied philosophy, sociology, and critical social theory in general. The growth has intensified with the adoption of the Convention on the Rights of Persons with Disabilities (CRPD) by the United Nations in 2006.¹ The literature, especially that emanating from Critical Disability Studies (CDS),² is not just revisionary but is also set on a transformative path. It evinces a sharpened disability consciousness in the manner it questions old assumptions about disability and deconstructs disablism as a deeply entrenched system of oppression analogous to racism, sexism and other status-subordinating 'isms'.³

* LLB, LLM, LLD, Barrister-at-Law, Professor, Centre for Human Rights, University of Pretoria.

1 GA Res. 61/611, adopted on 13 December 2006, and entered into force on 3 May 2008.

2 I am using 'Critical Disability Studies' as a generic description of discourses and academic programmes that seek to inflect how we think about disability with critical social theory to argue that disability is discursively created and not something comprehensible only through the intrinsic body.

3 'Disablism' or its variants such as 'ableism' or 'ablism' are terms that find favour amongst commentators who treat disability as the outcome of structural power. See, for example: IM Young *Justice and the politics of difference* (1990) 124, 145, 164; M Oliver *The politics of disablement* (1990) 77; C Ngwena 'Developing juridical method for overcoming status subordination in disablism: The place of transformative epistemologies' (2014) 30 *South African Journal on Human Rights* 275.

Across cultures, there is an acute awareness of the historical legacy of systemic exclusion of persons with disabilities and the imperative to restore human dignity and equality. The adoption of a regional treaty on disability under the African human rights system - the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa by the African Union in 2018 (the Protocol) – is part of rising inter-cultural disability consciousness.⁴ The Protocol, which emulates the CRPD,⁵ underlines that, apart from combatting negative stereotyping and prejudice, what is also required is changing radically, that is, transforming how we normatively treat persons with disabilities as social, political, economic and juridical subjects.

At the very least, a transformative approach to disability means reconceptualising disability to depart from hegemonic cultural systems that stigmatise and colonise certain forms of bodily variations as corporeal deficit in order to legitimise unequal distribution of ontological status, resources and power.⁶ Such cultural systems have produced and reproduced relations of inequality and status subordination.⁷ Transformation enjoins us to accept human diversities substantively. To achieve parity in participation, it is necessary to dismantle systemic barriers erected on the assumption of able-bodiedness. This is an essential step in building an inclusive social, political, economic and legal environment in which the equality and human dignity of persons with disabilities, including autonomous will and preferences, are protected on an equal basis with others. Simon Foley's book, *Intellectual disability and the right to a sexual life: A continuation of the autonomy/paternalism debate*, which is the subject of this review, belongs to Critical Disability Studies. It reinforces the argument for a transformative approach to disability in ways that are synergic with the goals of the CRPD and, by implication, the Protocol.

Intellectual disability and the right to a sexual life is a book written by a sociologist based in Ireland. Foley develops his arguments from a syncretic sociological archive, drawing mainly on Michel Foucault's

4 Adopted by the Thirtieth Ordinary Session of the Assembly, held in Addis Ababa, Ethiopia on 28 January 2018, available at https://au.int/sites/default/files/treaties/36440-treaty-protocol_to_the_achpr_on_the_rights_of_persons_with_disabilities_in_africa_e.pdf (accessed on 26 November 2019).

5 Though inspired by the CRPD, the Protocol is not a replica of the former. The Protocol does not detract from the protection guaranteed by the CRPD. However, in some instances it amplifies the rights guaranteed by the CRPD and in others extends the rights: L Mute & E Kalekye 'An appraisal of the Draft Protocol the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa' (2016) *East African Law Journal* 68, 84-89.

6 R Garland-Thompson 'Integrating disability, transforming feminist theory' (2002) 14(3) *National Women's Studies Association Journal* 1, 5.

7 N Fraser *Justice interruptus: Critical reflections on the 'Postsocialist' condition* (1997) 16-23; N Fraser 'Rethinking recognition' (2000) 3 *New Left Review* 107.

theory of power⁸ and Julia Kristeva's psychoanalytic concept of abjection⁹ and its application to disability by Margrit Shildrick.¹⁰ In addition, he draws on applied philosophy in general and, to a limited extent, Anglo-American jurisprudence. His arguments are also informed by empirical research findings.

Foley's main proposition is that persons with intellectual disabilities and, more specifically adults with Down syndrome, have sexual needs and that 'where necessary facilitated sex with prostitutes should be included as part of a new regime of care to ensure that their sexual needs are met'.¹¹ He makes a concerted case for reforming societal arrangements for care, especially parental care for adults with Down syndrome. The ultimate goal is to ensure that the arrangements do not continue to serve as overly paternalistic modes of care but, instead, become porous to specifically recognising and accommodating the sexual will and preferences of persons with Down syndrome and the possibility of facilitating sexual intercourse.

2 Overview of the book

The book has six chapters which are preceded by an introduction. In the introduction, Foley considers two main questions. First, he considers what constitutes an intellectual disability. Second, he addresses why the book focuses on Down syndrome. The two questions intertwine. Addressing them is a necessary underbrush-clearing exercise partly because many commentaries use 'intellectual disability' interchangeably with 'learning disability'.¹² Moreover, some commentaries use 'mental disabilities' as an all-inclusive descriptive category for mental conditions that intersect with disability. Given the heterogeneity of disabilities in the mental sphere alone, such conflation is apt to render any analysis of general application only or even questionable use.

The author highlights that his book is not just about disability but 'intellectual disability' and, more particularly, persons with Down syndrome. The cogency of his arguments, which seek to promote the sexual autonomy of persons with Down syndrome through a third-party intervention of facilitated sex, crucially depends on the reader first

8 M Foucault *Discipline and punish* (1977); *History of sexuality: Volume 1* (1978); *Power/Knowledge* (1980); *Afterword: The subject and power* (1983) in H Dreyfus & P Rabinow (eds) *Michel Foucault: Beyond structuralism and hermeneutics*.

9 J Kristeva *The powers of horror: An essay on abjection* (1982).

10 M Shildrick: *Embodying the monster: Encounters with the vulnerable self* (2003); 'Contested pleasures: The socio-political economy of disability and sexuality' (2007) 4(1) *Sexuality Research & Social Policy* 53; 'Dangerous discourses: Anxiety, desire and disability' (2007) 8(3) *Studies in Gender and Sexuality* 221; *Dangerous discourses of disability, subjectivity and sexuality* (2009).

11 p i. Foley uses the word 'prostitutes' but without intending to stigmatise. In this review, unless quoting, 'sex-workers' is used as the more acceptable lexicon in contemporary discourses on transactional sex.

12 p 1.

sufficiently appreciating differences in cognitive impairments and how they are located in differently positioned subjects.¹³

Foley subscribes to the definition of 'intellectual disability' offered by the American Association of Intellectual and Developmental Disabilities (AAIDD) and the World Health Organisation (WHO). The essence of the AAIDD's definition is that intellectual disability is a cognitive impairment (or impaired intelligence) which is biological in origin and begins before the age of 18.¹⁴ It has a lasting effect on development, resulting in significant limitation in intellectual functioning and adaptive behaviour, including the acquisition of age-appropriate social and practical skills.¹⁵ The definition of WHO is complementary.¹⁶ It formulates intellectual disability primarily in terms of cognitive impairment with a biological source manifesting before adulthood. Both definitions take into account society's role in creating an enabling or disabling environment for persons with intellectual disabilities.

Foley wants to capture the 'biological' nature of intellectual disability in a manner unobscured by the social model of disability.¹⁷ His point is not that the environment does not compound intellectual disability through failure to accommodate. Rather, it is that intellectual disability is primarily a congenital condition. It is a condition organically rooted in brain anatomy or physiology and is intrinsically limiting such that the environment can only add to the limitations.¹⁸ To underscore his argument, he says:

[A] key premise underpinning the substantive claims made and conclusions drawn [in this book] is an acknowledgement that biology does mean that intellectually disabled people will never transcend a cognitive threshold. Consequently, it is the fact that intellectual disabilities such as Down syndrome are real *pre-discursive* impairments with real consequences in the real world that informs the subject matter of this book.¹⁹

13 p 2.

14 American Association of Intellectual and Developmental Disabilities, available at <https://www.aaidd.org/intellectual-disability/definition> (accessed on 29 November 2019).

15 As above.

16 World Health Organisation available 'Definition: Intellectual disability', available at <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability> (accessed on 29 November 2019).

17 The social model is an approach to disability that prizes the environment rather than the body as the cause of disability. Though it has its variants, the more popularised version of the social model was pioneered by sociologists in Britain: V Finkelstein *Attitudes and disabled people: Issues for discussion* (1980); M Oliver *Understanding disability: From theory to practice* (1996); C Barnes *Disabled people in Britain and discrimination: A case for anti-discrimination legislation* (1991).

18 p 3.

19 p 3 (references omitted and emphasis added).

Thus, Foley argues that intellectual disability would still prevail as an impairment regardless of how society is organised.²⁰ In this way, Foley is a critic of an exclusive social model. He finds the social model to be politically important but, nonetheless, an incomplete explanation for intellectual disability. He joins other critics not so much in jettisoning the social model but decentering it in order to bring greater attention to disability as a dialectic between the body, its intrinsic limitations and the social environment. The main discontent with the social model is that it has become a meta-narrative which glosses over the complexities and diversities of disability, implicating only a disabling environment but effacing the reality of impairments and personal experiences about disability.²¹ Foley is careful to point out that even among persons with Down syndrome, cognitive impairment is not homogeneous as some have mild and others severe impairment.

According to Foley, when determining whether an appropriate balance is being struck between the freedom to make one's own choices and paternalism in context of the social care of adults with Down syndrome, embodiment is a crucial informing element. It can tell us the degree of paternalism that third parties feel they are justified in exercising, including in respect of sexuality choices. Adults with Down syndrome are appropriate subjects for Foley's sexual autonomy-recognition arguments as they epitomise a sexually disempowered historical community quintessentially at the receiving end of a 'paternalistic regime of care'.²² He explains a 'paternalistic regime of care' in the following way:

Namely, if adults with Down syndrome, or any other form of intellectual disability, either must ask permission and, or are prevented by their parents from taking control over their social/sexual lives (that is, if they are not allowed to do what they want, and particularly at night time) they are being subjected to a paternalistic regime of care.²³

His point is that, even as adults, persons with Down syndrome are socially constructed as perennial children. Consequently, they are prevented by parents from taking control of their social lives, including sexual lives. Moreover, the facial appearance of persons with Down syndrome marks them out. It comes ensconced in socially constructed 'spoiled identity'²⁴

20 p 3. Here Foley follows closely the arguments of Tom Shakespeare: T Shakespeare 'Social models of disability and other life strategies' (2004) 6 *Scandinavian Journal of Disability Research* 8, 14.

21 Shakespeare (n 20 above); T Shakespeare & N Watson 'The social model of disability: An outdated ideology' (2002) 2 *Research in Social Science & Disability* 9; D Anastasiou & JM Kauffman 'The social model of disability: Dichotomy between impairment and disability' (2013) 38 *Journal of Medicine and Philosophy* 441; E Barnes *The minority body: A theory of disability* (2016).

22 p 6.

23 As above.

24 E Goffman *Stigma: Notes on the management of spoiled identity* (1963).

and abjection', thus, reinforcing the book's argument that for this category of disability embodiment matters.

The focus on intellectual disability and Down syndrome in this book is also tied to the author's standpoint as someone who has developed a close relationship with persons with Down syndrome. The author grew up with a sister with Down syndrome and watched her grow into an adult with a need for a boyfriend. As a child and teenager, he socialised with persons with Down syndrome to a degree he regards as sufficient to adequately acquaint him with the lifeworlds of persons with disabilities. In the light of this personal connection, he felt well placed to embark on research and writing about the sexual desires of persons with Down syndrome.

In Chapter 1, Foley explains his overall methodology. Over and above engaging with published commentaries, an important methodological dimension to the book is its empirical component. The book's arguments are partly informed by findings from empirical research in the form of semi-structured interviews and focus group sessions conducted in the Republic of Ireland. The research subjects were two population groups – adults with Down syndrome who were still living at home and mothers of adult children with Down syndrome who were still providing parental care. The choice of semi-structured interviews and focus group sessions as the empirical approach was prompted by the author's objective to give direct voice to historically silenced social groups.

Chapter 1 is also taken with Foley explaining his main analytic approach, especially its place in Foucault's discourse of power and Kristeva's theory of abjection. Foucault's concept of 'discourse' is appropriated to explain that as society and community, including parents and their adult daughters and sons with Down syndrome, we are discursively created.²⁵ By this, Foucault means that how we think and how we conduct our lives, including in the sphere of sexuality, is not the free exercise it appears to be. Rather, it is an outcome of language. The choices we make are anchored in an ideology that is tied to power and knowledge that produce an 'effect'. Foley draws parallels between Foucault's omnipotent, omnipresent and omniscient 'panopticon' with the regime of parental care for adults with Down syndrome and how adults with Down syndrome, themselves, conduct their own lives.²⁶ The point of Foley's analogy is to argue that the regime of care for adults with Down syndrome mimics incarceration with parents serving as 'reluctant jailors' and their children as compliant 'prisoners' of a kind under a system of surveillance. Each group tries to do what is socially expected of it by the dominant cultural imaginary.

25 M Foucault *The archaeology of knowledge* (1972) 49.

26 Foucault *Discipline and punish* (n 8 above).

Foley's uses Kristeva's psychoanalytic concept of abjection not just as an important but also necessary tool for understanding the primordial rejection of Down syndrome in the dominant cultural imaginary. Down syndrome is perceived, even by loving parents and persons with Down syndrome, themselves, as outside the range of what is 'normal'; as something impure and abnormal. Down syndrome is constructed by the dominant cultural imaginary as something that 'disturbs identity, system and order' and, even more so, the idea of facilitated sex.²⁷

In Chapter 2, the focus is on the autonomy/paternalism debate. Foley highlights that there are no easy answers for helping us determine the right balance between autonomy and paternalism when addressing the sexual needs of a social group that, on account of cognitive impairment, is vulnerable in a real sense to sexual abuse and exploitation by its non-intellectually disabled counterparts. He concedes that paternalism is warranted but highlights that cognitive impairment creates a dilemma between the liberal ideological ethic to respect the will and preference of the subject and the obligation to concomitantly provide safeguards against the abuse and exploitation of the subject.

Foley does not argue for dispensing with paternalism. What he is most critical of is that, even taking into account the legitimate duty of parents and the state to protect a vulnerable group, intellectual disability is at the receiving end of a classificatory system which recognises differentiated citizenship among its populace and ascribes an inferior ontological status to some. Socially and legally, persons with Down syndrome are instantly marked as the *Other* and accorded a subordinate status, including in the sexual sphere.

To appreciate the extent of the othering of persons with intellectual disabilities, we only need to look at our domestic criminal justice systems, especially the regimes for regulating consent to sexual intercourse, to see that they have one striking feature in common. Nearly all proceed on the presumption of the normative exclusion of persons with intellectual disabilities from sexual citizenship. Many legal systems have historically condoned forced sterilisation and other sexuality and reproductive autonomy-suppressing sanctions in respect of persons with intellectual disabilities.²⁸

27 Kristeva (n 9 above) 4.

28 In *Buck v Bell*, 274 US 200 (1927) the Supreme Court of the United States upheld a statute of Virginia which authorised the compulsory sterilisation of the people that were diagnosed to be 'mentally retarded' for the 'protection and health of the state'. Writing for the majority, Justice Wendell Holmes famously said that: 'Three generations of imbeciles are enough': PA Lombardo 'Three generations, no imbeciles: New light on *Buck v Bell*' (1985) 60 *New York University Law Review* 30, 32; RL Burgdorf & MP Burgdorf 'The wicked witch is almost dead: *Buck v Bell* and the sterilization of handicapped persons' (1977) 50 *Temple Law Quarterly* 995.

Whereas non-intellectually disabled adults are, in a Millian sense,²⁹ presumed to be autonomous agents with a capacity to freely consent to sexual intercourse in pursuit of happiness, the opposite is deemed for their intellectually disabled counterparts. The latter are, on account of intellectual impairment, presumed to be lacking in cognitive competence to muster such capacity. Whereas non-intellectually disabled adults are not subjected to a formal test to assess competence to consent to sexual intercourse, the onus is on persons with intellectual disabilities to rebut the presumption of incompetence. The juridical justification for the presumption of incompetence has been the need to protect intellectually disabled persons from rape, sexual abuse and other forms of sexual violence or exploitation. It is glaringly apparent, however, that the legal impulse to protect a sexually exploitable class has not come with equal concern to give recognition to the sexual needs of persons with intellectual disabilities, including the possibility that they might desire sexual intercourse in the same way as their non-intellectually disabled counterparts.

Parental care has emulated legal paternalism in prioritising protection from harm over the possibility that their child with intellectual disability might wish to have sexual intercourse. Even without the intervention of the law, generally, adult children with intellectual disabilities have been cared for by their parents in ways that exclude or at least do not support the notion of autonomous sexual citizenry. Understandably, the need to protect persons with intellectual disabilities from sexual abuse and exploitation by their non-intellectually disabled counterparts together with the assumption that they cannot muster parenthood, have been the main justification for the prohibitory regimes. However, in exchange of care and protection, the price paid by persons with intellectual disabilities has been the infantilisation of their desire to have sexual intercourse. Thus, their sexual autonomy has been historically misrecognised.³⁰

In Chapters 3 and 4, Foley puts his main proposition to empirical testing. It will be recalled that the proposition is that persons with intellectual disabilities and, more specifically, adults with Down syndrome have sexual needs and that where necessary facilitated sex with sex-workers should be included as part of a new regime of care to ensure that the needs are met. The chapters highlight that adults with Down syndrome desire to have intimate partners and that their parents recognise the legitimacy of this need. However, the praxis of parenting is contradictory in that it does not accommodate this need. Adults with Down syndrome are supervised by parents in ways that do not leave room of being alone with a partner. Foley describes the relationship between parents and their adult children with Down syndrome as defined by unproductive power

29 JS Mill *On liberty* (1959).

30 Fraser *Justice interruptus* (n 7 above); Fraser 'Rethinking recognition' (n 7 above).

with the former almost serving as sovereign power and latter as ‘docile bodies’. A major explanation for the asymmetrical relationship is that both the parents and the adult children are the products of a normative social discourse that includes law and religion. The discourse constructs adults with Down syndrome as children and condemns the idea of sexuality for persons who are deemed to be asexual.

Facilitated sex was, foremost, viewed by mothers of adult children as morally reprehensible and a major breach of their paternalistic role.³¹ The mothers were prepared to accept sex work as legitimate work but not for the provision of services to their adult children. They could not imagine the ‘pimp’ and supervisory roles they would be required to play. The fact that in the dominant cultural imaginary sexual intercourse is a private act accentuated the unacceptability of facilitated sex. However, parents could possibly imagine facilitated sex if it was a ‘last resort’. Drawing on Kristeva and her adherents, Foley argues that the unequivocal rejection of facilitated sex by parents is largely explicable as psychoanalytic abjection. It is the rejection of what is ‘unclean’ and would contaminate their identity as parents and moral persons.

Chapter 5 is aptly titled ‘A modest proposal regarding the normalisation of facilitated sex’. In this chapter Foley highlights that he is not arguing for paternalism to be dismantled as it has its assured and necessary place in the care of adults with Down syndrome. However, he wants our social systems, including law, policy and parental care, to accommodate the possibility of facilitated sex where such sex meets the sexual needs of adults with Down syndrome. He wants us to reimagine society in ways that are conscious to sexual desire as something experienced not just by non-intellectually disabled persons but also by their intellectually disabled counterparts. In this new imagination, facilitated sex becomes one of the means of supporting sexual autonomy of persons with intellectual disabilities. He reminds us that we are not pre-social and that we can remake the existing social order.

Chapter 6, the last chapter, recaps Foley’s arguments. It is reminder of what *Intellectual disability and the right to a sexual life* is about.

3 Significance

Albeit in a moral rather than a human rights domain, discursively, *Intellectual disability and the right to a sexual life* speaks to the same cause as the CRPD. It makes an unequivocal demand on recognition of unqualified equality for a group whose ontological status has been historically accorded a diminished status by an ableist ideology. Foley’s book is a

31 The question of facilitated sex was only put to mothers during focus group sessions.

narrative on inclusive equality but in the sexuality sphere where it seeks to give concrete recognition to the sexuality rights of persons with intellectual disabilities not just through language but also praxis.

The right of persons with intellectual disabilities to a sexual life on an equal basis with their non-intellectually disabled counterparts has historically been a non-subject at the receiving end of implicit ableist assumptions about what a 'disabled' body or mind cannot do. The marginalisation of this right has come with official imprimatur and embedded cultural practices. Foley is right to disturb 'the order of things'.³² His arguments are counter-hegemonic. He is challenging the status quo of an Althusserian interpellated ability/disability system that asexualises persons with Down syndrome.³³ His goal is not to dismantle a paternalistic system but to fundamentally revise the manner in which the system has been normatively tied to a cultural imaginary that classifies humanity into categories with a hierarchical order for apportioning ontological status.

The arguments in *Intellectual disability and the right to a sexual life* have striking resonance with the CRPD. The book implicitly speaks to article 23 which requires states to eliminate discrimination against persons with discrimination relating to relationships on an equal basis with others.³⁴ In similar vein, it speaks to article 25 which recognises that persons with disabilities have a right to health including 'sexual health'.³⁵ Above all, Foley's book speaks to article 12 of the CRPD. This article reaffirms that persons with disabilities have the right to recognition as persons before the law.³⁶ It requires states to recognise their legal capacity in all spheres of life.³⁷ Legal capacity is not only a right to hold rights but also to exercise rights.³⁸ Cognitive impairment does not deprive one of the right to legal capacity as it is an inherent right that is not dependant on mental capacity. In anticipation of the fact that mental capacity can adversely interfere with the exercise of legal capacity, the CRPD requires states to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.³⁹ It is incumbent on states to

32 M Foucault *The order of things: An archaeology of human sciences* (1994).

33 The term 'interpellation' denotes the role played by society in creating and naming disability. It implies the 'hailing or summoning into place' of a subject by discourse. Louis Althusser, in an essay titled 'Ideological state apparatuses', first used the term to implicate and explicate a causal connection between ideology in social and political institutions and the production of subjects. The essay is published as a part of a book: L Althusser *Lenin and philosophy and other essays* (1971); S Hall 'Who needs "identity"?' in J Evans & P Redman (eds) *Identity: A reader* (2000) 15-30 at 19-21. C Ngwenya *What is Africanness? Contesting nativism in race, culture and sexualities* (2018).

34 Art 23(1) of the CRPD.

35 Art 25(a) of the CRPD.

36 Art 12(1) of the CRPD.

37 Art 12(2) of the CRPD.

38 Committee on the Rights of Persons with Disabilities General comment No 1 Article 12: Equal recognition before the law (2014) para 13.

39 Art 12(3) of the CRPD.

ensure that measures relating to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse.⁴⁰

Looked at through the lens of the CRPD, it is possible to argue that Foley's main proposition is not in fact radical but is a means of giving practical effect to what international human rights already envisages. For far too long, the mode of care for persons with intellectual disability has prioritised substitute decision-making over the will and preferences of the subject class. The placement of a duty upon society to accommodate persons with disabilities is the CRPD's most critical transformative lynchpin, providing us with the jurisprudential *raison d'être* for reconceptualising disability and instituting fundamental societal reforms.⁴¹ We can, therefore, relate to facilitated sex for persons with intellectual disability as one of the possible accommodation measures for fulfilling autonomy and achieving inclusive equality in the sexuality domain.⁴²

4 Conclusion

Foley addresses an area of social life that has been largely overlooked or even shunned from in social discourses not so much because it is so intimate and so personal but because it relates to a social group that has been historically constructed as asexual. Of course, Foley's proposal of facilitated sex raises problems of its own. Sex work and the role of the state in regulating sex work remain areas of controversy across cultures.⁴³ There is also the issue of privacy and how far third parties can go in supervising what is ultimately an intimate and personal activity. At the same time, if we agree that persons with intellectual disabilities have sexual desires that are not less human than those of their non-intellectually disabled counterparts, Foley is asking us to consider seriously the means of giving not merely rhetorical but more significantly practical recognition to the desires.

40 Art 12(4) of the CRPD.

41 The duty to accommodate is a foundational principle under the CRPD, see art 5(4) of the CRPD.

42 I use 'inclusive equality' synonymously with 'substantive equality' as a genus of equality that, unlike formal equality, addresses structural inequality and is aimed at achieving parity in participation, taking into account power relations. However, the Committee on the Rights of Persons with Disabilities inexplicably appears to draw a distinction between the two equalities. In General Comment No 6 (2018) on equality and non-discrimination CRPD/C/GC/6, para 10, the Committee seems to imply that inclusive equality is a fuller genus of equality than substantive equality in that it envisages parity in participation but so does substantive equality. See, for example: C Albertyn 'Substantive equality and transformation in South Africa' (2007) 23 *South African Journal on Human Rights* 253; C Sheppard *Inclusive equality: The relational dimensions of systemic discrimination In Canada* (2010).

43 S Tamale 'Paradoxes of sex work and sexuality in modern-day Uganda' in S Tamale (ed) *African sexualities: A reader* (2011) 145-173; J Scoular 'What's law got to do with it? How and why law matters in the regulation of sex work' (2010) 37(1) *Journal of Law and Society* 12.

Foley's book is a provocative addition to a rapidly growing canon of disability theory and praxis but for a specific class of disability – intellectual disability. It has appeal across cultures, not least because the asexualisation of persons with disabilities epitomises an area of social, political and legal life with a globally shared discursive history. The asexualisation is present in the Republic of Ireland in the same way as it is present across the African region and for substantially similar reasons.

Whilst constructed around critical social theory, Foley's book is written in an engaging and accessible style. It has appeal across disciplines, including law and human rights.