The viability of supported decision-making in protecting adolescent girls with intellectual disability from involuntary sterilisation in Nigeria

By

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Declaration

I, Anwuli Irene Ofuani, hereby declare that this thesis which I submit for the degree of Doctor Legum (LLD) in the Faculty of Law at the University of Pretoria is my original research work. I further declare that this thesis has not previously been submitted for any degree or examination at the University of Pretoria or any other institution.

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Approval

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Table of contents

Dedication

To my parents, Professor Ogo A. Ofuani and Dr Felicia N. Ofuani; and to my sister, Suzzie Onyeka.

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List of tables

List of figures

Abstract

The importance of promoting adolescent reproductive health rights is emerging in Nigeria. Accordingly, medical practice in terms of contraceptive decision-making is evolving such that adolescents who can understand the nature and consequences of a contraceptive treatment can be administered such treatment. Given that adolescent girls with intellectual disabilities are subjected to involuntary sterilisation on an unequal basis with their peers, the need for a strategy to promote their reproductive health and rights is undeniable. Supported decision-making is one strategy for promoting the legal capacity of adolescent girls with intellectual disabilities in terms of decision-making about contraception. The right to supported decision-making as expounded by Committee on the Rights of Persons with Disabilities involves providing assistance to persons with disabilities, including adolescents with intellectual disabilities, to exercise their legal capacity and make decisions affecting their lives.

This study therefore examines the viability of supported decision-making in protecting adolescent girls with intellectual disabilities from involuntary sterilisation in Nigeria. Utilising the social model of disability and Foucauldian perspectives, the study assesses the conceptions of intellectual disability, legal capacity and supported decision-making as well as the practicality of law and policy in guaranteeing supported decision-making for adolescent girls with intellectual disabilities. The study also employs empirical research, to interrogate the Committee on the Rights of Persons with Disabilities' interpretation of supported-decision making for adolescents with disabilities. It finds that adolescent girls with intellectual disabilities are susceptible to involuntary sterilisation in Nigeria. Secondly, the CRPD Committee provides little guidance on how to theorise supported decision-making for persons with intellectual disabilities who require extensive and pervasive support especially as regards determining their 'will and preference'. Thirdly, the best interests' standard and the functional approach adopted by the CRPD Committee in interpreting the implication of article 12 for children and adolescents with disabilities leaves room for abuse because the standards for determining them are indefinite. Fourthly, there is ambiguity as to the scope, models and principles of supported decision making.

Accordingly, this study recommends that legislative enactment and reform is imperative not only to promote supported decision-making but also to mitigate the involuntary sterilisation adolescent girls with intellectual disabilities. It also recommends that support measures and services be provided for persons with disabilities in general, and adolescent girls with intellectual disabilities in Nigeria. The study further recommends awareness raising and public sensitisation as well as training of policy-makers and relevant stakeholders to address negative pervasive stereotypes and beliefs about persons with disabilities. Lastly, the need for evidence based research to interrogate the applicability and standards of supported decision-making for adolescents with intellectual disabilities and to contribute to the jurisprudence on supported decision-making is emphasised.

CHAPTER ONE

INTRODUCTION

1.1. Background to the study

This study critically assesses the viability of the Convention on the Rights of Persons with Disabilities (CRPD's)[1] concept of supported decision-making as a paradigm for protecting adolescent girls with intellectual disabilities from involuntary sterilisation in Nigeria. Viability in the context of this study involves an examination into whether or not supported decision-making is practical for all levels of intellectual disability, as well as an assessment of what supported decision-making means to the respondents of the empirical component of the study. It also entails an examination of whether or not supported decision-making includes or excludes substituted decision-making for adolescent girls with extensive and pervasive intellectual disabilities particularly where their will and preferences are not discernable. An examination into the applicability and practicality of supported decision-making in this context is pertinent as adolescent girls with intellectual disabilities are highly susceptible to practices that infringe on their rights to retain their fertility. The study draws on empirical research in assessing the rights of adolescent girls with intellectual disabilities to legal capacity and supported decision-making *vis á vis* protecting them from involuntary sterilisation.

The involuntary sterilisation of girls with intellectual disabilities is an act of violence that impacts on their rights to equality and non-discrimination, bodily integrity, dignity, autonomy, physical health and mental health.[2] The CRPD contains provisions that are vital for addressing the inequality, discrimination and violation of rights that involuntary sterilisation poses for adolescent girls with intellectual disabilities. Specifically, articles 5, 12, 23 and 25 of the CRPD, which would be subsequently discussed in this chapter, are crucial in protecting girls with intellectual disabilities from involuntary sterilisation.

Some treaty monitoring bodies and United Nations (UN) Special Rapporteurs also acknowledge that involuntary sterilisation violates the human rights of persons subjected to it. For instance, the African Commission on Human and Peoples' Rights affirms that

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[1] Convention on the Rights of Persons with Disabilities (CRPD) (2006) 46 ILM 443.

[2] L Dowse 'Sterilising by stealth? Safeguarding the human rights of girls with disabilities in Australia' (2004-2005) *3 Australian Health Consumer* 5; C Stimpson 'Involuntary sterilisation of people with disabilities- a response to the senate report' (2013) 22 *Human Rights Defender* 14.

involuntary sterilisation contravenes the rights to equality, non-discrimination and physical and mental health.[3] The Committee on the Elimination of all forms of Discrimination against Women (CEDAW Committee) also affirms that involuntary sterilisation violates the rights to corporeal and mental integrity, informed consent and human dignity and should be proscribed by law.[4] Similarly, the Beijing Declaration and Platform for Action, the Committee on the Rights of the Child (CRC Committee) and the United Nations (UN) Special Rapporteur on Violence against Women have declared that involuntary sterilisation is a form of violence.[5] They also stated that involuntary sterilisation is an infringement of women and girls' rights to physical integrity and security.[6] The UN Special Rapporteur on Torture also emphasises that the involuntary sterilisation of women and girls with disabilities constitutes "torture or cruel or inhuman treatment".[7]

In Nigeria, the involuntary sterilisation of adolescent girls with intellectual disabilities appears to be a gendered issue which is reinforced by legal, cultural and social values. Negative stereotypical attitudes and assumptions that girls with intellectual disabilities are 'child-like', 'non-sexual', 'overly-sexual', 'unmarriageable' and 'reliant' as well as beliefs that intellectual disability is hereditary underpin their being involuntarily sterilised.[8]

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[3] African Commission on Human and Peoples' Rights Resolution 260 on involuntary sterilisation and the protection of human rights in access to HIV services, 5 November 2013, No 260 ACHPR/Res.260 (LIV)13 http://www.achpr.org/sessions/54th/resolutions/260/ (accessed 10 February 2015).

[4] Committee on the Elimination of Discrimination against Women (CEDAW Committee) (1999) 'General recommendation No. 24: Article 12 of the convention (women and health) ' A/54/38/Rev.1, chap. 1, para 22; Committee on the Elimination of Discrimination against Women (CEDAW Committee) (2010) 'Concluding observations of the Committee on the Elimination of Discrimination against Women: Australia' CEDAW Forty-sixth session, 12–30 July 2010, CEDAW/C/AUS/CO/7.

[5] United Nations, The Beijing Declaration and the Platform for Action: Fourth World Conference on Women, Beijing, China, (1995) A/CONF.177/20/Add.1, paras 95–96; United Nations Committee on the Rights of the Child (CRC Committee) 'Article 19: The right of the child to freedom from all forms of violence ' General Comment No.13 (2011) CRC/C/GC/13 para 16 & 21; R Manjoo 'Special Rapporteur on violence against women, its causes and consequences' Report of the Special Rapporteur on violence against women, its causes and consequences (2012) U.N. Doc. A/67/227, para. 28.

[6] R Coomaraswamy 'Violence against women (addendum): Policies and practices that impact women's reproductive rights and contribute to, cause or constitute violence against women' Report of the Special Rapporteur on violence against women, its causes and consequences E/CN.4/1999/68/ Add. para 51 http://www.unhchr.ch/Huridocda/Huridoca.nsf/0/4cad275a8b5509ed8025673800503f9d?Opendocument (accessed 10 February 2015); United Nations Committee on the Rights of the Child (CRC Committee) 'The rights of children with disabilities' General Comment No. 9 *(2007) CRC/C/GC/9* para 60.

[7] M Nowak 'Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development: Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment' (2008) A/HRC/7/3 paras 38 & 39.

[8] C Frohmader 'Dehumanised: The forced sterilisation of women and girls with disabilities in Australia' WWDA Submission to the Senate Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia (2013) 36 http://wwda.org.au/wp-content/uploads/2013/12/WWDA_Sterilisation_Sub_Summary_and_Recs.pdf (accessed 10 February 2015); G Llewellyn 'The involuntary or coerced sterilisation of people with disabilities in Australia' https://sydney.edu.au/health-sciences/cdrp/Sterilisation_Submission%2021.pdf (accessed 8 October 2016);

Anecdotal evidence suggests that over the years, sterilisation has generally been requested more for girls with intellectual disabilities than for their male peers.[9] Moreover, the Penal Code, applicable in Northern Nigeria, protects males from sterilisation to some extent by penalising 'emasculation' with a prison term of about seven years.[10] There is however no corresponding provision for females in the Penal Code thereby exposing adolescent girls with intellectual disabilities to inequality and discrimination. This situation is further exacerbated by inadequate framework, legislative or otherwise, to support them in decision-making with regards to contraception and to protect them from involuntary sterilisation.

A number of reasons have been adduced in justifying the involuntary sterilisation of girls with intellectual disabilities including eugenics, menstrual management, prevention of sexual abuse, prevention of unplanned pregnancy and socio-economic factors.[11] Historically, sterilisation was carried out on persons with disabilities to prevent them from giving birth to 'disabled' offspring like themselves. This was based on the beliefs of the eugenic movement, which sought to purify the human race and protect the social fabric of society.[12] A few respondents in the empirical component of this study which is discussed in Chapter Seven opined that preventing girls with intellectual disabilities from having children with

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Nigeria Stability and Reconciliation Programme & Inclusive Friends 'What violence means to us: Women with disabilities speak' 11-12 http://www.nsrp-nigeria.org/wp-content/uploads/2015/09/What-Violence-Means-to-us-Women-with-Disabilities-Speak.pdf (accessed 4 September 2017); AI Ofuani 'Protecting adolescent girls with intellectual disabilities from involuntary sterilisation in Nigeria: Lessons from the Convention on the Rights of Persons with Disabilities' (2017) 17 *African Human Rights Law Journal* 550, 564. See also the empirical component of this study discussed in Chapter Seven of this study.

[9] A Animashaun 'Indications for the sterilisation of the handicapped adolescent' (1978) 8 *Nigerian Medical Journal 253*-254; D Olubukola 'Intellectually retarded education in Nigeria: Past, present, and future' (2007) 22 *Essays in Education* 75; Ofuani (n 8 above) 554.

[10] Cap. P3, LFN, 2010, sections 244 & 247.

[11] L Dowse 'Moving forward or losing ground? The sterilisation of women and girls with disabilities in Australia' http://wwda.org.au/issues/sterilise/sterilise2001/steril3/ (accessed 8 October 2016); Women with Disabilities Australia (WWDA) 'WWDA policy & position paper: The development of legislation to authorise procedures for the sterilisation of children with intellectual disabilities' (2007) http://www.wwda.org.au/polpapster07.htm (accessed 28 May 2018); Frohmader (n 8 above) 36; C Frohmader 'Moving forward and gaining ground: The sterilisation of women and girls with disabilities in Australia' (2012) 6 http://wwda.org.au/wp-content/uploads/2013/12/Moving_Forward_Gaining_Ground.pdf (accessed 22 March 2014); Llewellyn (n 8 above) 3-5; L Elliott 'Victims of violence: The forced sterilisation of women and girls with disabilities in Australia' (2017) 6 *Laws*, 8; doi:10.3390/laws6030008; Ofuani (n 8 above) 551.

[12] JL Ricks & SF Dziegielewski 'Involuntary sterilization and the mentally retarded revisited' (2000) 2 *Human Rights Review* 125-126; Dowse (n 11 above); AM Stern 'Sterilized in the name of public health- race, immigration, and reproductive control in modern California' (2005) 95 *American Journal of Public Health* 1128, 1129-1130; Frohmader (n 8 above) 36; Women with Disabilities Australia (n 11 above); SL Watson & D Griffiths 'Right to life' in F Owen & D Griffiths (eds) *Challenges to the human rights of people with intellectual disabilities* (2008) 77; Intellectual Disability Rights Service (IDRS) 'The involuntary or coerced sterilisation of people with disabilities in Australia' Senate committee inquiry submission to the senate standing committee on community affairs 3 http://www.idrs.org.au/pdf/submissions/2013-Submission-on-Sterilisation-to-Senate-Inquiry.pdf (accessed 22 March 2014); Frohmader (n 11 above) 7; Elliot (n 11 above).

intellectual disabilities was a ground for sterilising them.[13] Sterilisation is also used as a contraceptive method to prevent unplanned pregnancies and to avoid the burden of taking care of children of such pregnancies.[14] Sterilising to prevent pregnancy was the most cited reason by respondents of the empirical component of this study. An argument in favour of sterilisation for fertility management is that the removal of the risk of pregnancy would improve the quality of life of the girls enabling them to venture freely into society without fear of containment by their caregivers.[15] The financial implication of caring for girls with intellectual disabilities, their potential offspring and their contraceptive needs has also been used to rationalise the sterilisation of girls with intellectual disabilities.[16] Financial incapacity was also cited as a reason to justify the sterilisation of adolescent girls with disabilities by respondents in the empirical component of this study.[17] In terms of menstrual management, sterilisation is often sought to avert menstrual hygiene concerns or concerns about phobias about blood, mood swings as well the length, heaviness, and irregularity of the periods.[18] Another reason given for sterilising women and girls with disabilities is to protect them from sexual abuse.[19]

Nonetheless, these reasons are discriminatory and in no way justify the sterilisation of girls with intellectual disabilities for the following reasons. First, it has been established that the eugenic justification for sterilisation is baseless and erroneous because many intellectual disabilities are not genetic. Hence, having an intellectual disability does not necessarily mean that an intellectually disabled person's offspring would equally have the disability.[20] Moreover, the prospect of having a child with intellectual disability is no justification for sterilisation because it is discriminatory as it allows the application of different standards for

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[13] See sections 7.2.2.4 and 7.3.2.4 of Chapter Seven of this study.
[14] SM Brady & S Grover 'The sterilisation of girls and young women in Australia: A legal, medical and social context' (1997) A report commissioned by the Federal Disability Discrimination Commissioner for the Human Rights and Equal Opportunity Commission 30-31 https://www.humanrights.gov.au/sites/default/files/content/disability_rights/hr_disab/Sterilization/sterilis.doc (accessed 28 May 2018); SM Brady 'The sterilisation of children with intellectual disabilities- defective law, unlawful activity and the need for a service oriented approach' (1998) 33 *Australian Journal of Social Issues* 155, 157-158; Elliot (n 11 above).
[15] SM Brady 'Sterilization of girls and women with intellectual disabilities- past and present justifications' (2001) 4 *Violence against Women* 432, 454.
[16] N O'Neill 'Sterilisation of children with intellectual disabilities' (1996) 2 *Australian Journal of Human Rights* 262, 266-267; Brady (n 15 above) 454; Dowse (n 11 above); Women with Disabilities Australia (n 11 above); Frohmader (n 8 above) 36; Llewellyn (n 8 above) 3-5, Intellectual Disability Rights Service (n 12 above) 7; Elliot (n 11 above).
[17] n 13 above.
[18] O'Neill (n 16 above) 266-267; Brady (n 14 above) 157-158; Brady (n 15 above) 432, 440- 443; Frohmader (n 8 above) 36; Dowse (n 11 above); Frohmader (n 11 above) 10; Elliot (n 11 above).
[19] Brady (n 15 above) 445-446; Brady & Grover (n 14 above) 30-31; Intellectual Disability Rights Service (n 12 above) 7; Frohmader (n 11 above) 8; Elliot (n 11 above).
[20] Frohmader (n 8 above) 37; Intellectual Disability Rights Service (n 12 above) 6; Elliot (n 11 above).

girls with intellectual disabilities in contrast to their peers without intellectual disabilities. Secondly, with regards to menstrual management, evidence suggests that even for girls with high support needs, menstrual issues can be successfully met with strategies generally applicable to non-disabled girls. [21] Thirdly, although sterilisation prevents pregnancy, there are other forms of contraception, which are less invasive but extremely effective in preventing pregnancy.[22] In addition, with appropriate education, support and counsel, many girls with intellectual disabilities can deal appropriately with their sexuality.[23] Furthermore, sterilisation does not prevent sexual abuse as it is a problem affecting many women and girls irrespective of disability.[24] More so, research has shown that instead of guarding against sexual abuse, sterilisation could increase susceptibility to sexual abuse because a girl who has been sterilised may be seen as a risk-free target because she cannot become pregnant. So, sterilisation could unintentionally serve to cover up the sexual abuse of girls with intellectual disabilities.[25] Besides, with adequate education, care and support, the susceptibility of girls with intellectual disabilities' to sexual abuse could be minimised.[26] Lastly, if parents and carers are provided adequate support and welfare by the government, the issue of sterilisation on the ground of financial hardship becomes baseless.[27]

Thus, involuntary sterilisation gives rise to discrimination and inequality for adolescent girls with intellectual disabilities as they are more likely to be sterilised on the basis of the grounds discussed above than their peers without disabilities.[28] It is therefore imperative that mechanisms are put in place to protect them from involuntary sterilisation. As such, this study explores whether or not providing support in decision-making to adolescent

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[21] O'Neill (n 16 above) 267; Brady & Grover (n 14 above) 31; Frohmader (n 8 above) 42; Dowse (n 11 above); Intellectual Disability Rights Service (n 12 above) 7; Elliot (n 11 above).

[22] Brady & Grover (n 14 above) 31; Brady (n 14 above) 159; R Howard & S Hendy 'The sterilisation of women with learning disabilities- some points for consideration' (2004) 50 *British Journal of Developmental Disabilities* 133, 136.

[23] O'Neill (n 16 above) 271.

[24] Brady & Grover (n 14 above) 32; Brady (n 14 above) 159; Brady (n 15 above) 441-442; Frohmader (n 8 above) 42.

[25] Brady & Grover (n 14 above) 32; Women with Disabilities Australia 'Submission to the preparation phase of the UN analytical study on violence against women and girls with disabilities*'* (2011) http://wwda.org.au/wp-content/uploads/2013/12/WWDASubUNStudyViolenceWWDDec2011.pdf (accessed 10 February 2015); Frohmader (n 8 above) 36; Intellectual Disability Rights Service (n 12 above) 8; Frohmader (n 11 above) 11; Elliot (n 11 above).

[26] Brady (n 14 above) 159-160; Frohmader (n 11 above) 11.

[27] Frohmader (n 8 above) 36; Dowse (n 11 above); Intellectual Disability Rights Service (n 12 above) 8; Women with Disabilities Australia (n 11 above).

[28] L Tilley et al 'The silence is roaring: Sterilization, reproductive rights and women with intellectual disabilities' (2012) *27 Disability & Society 413, 417;* A Roy et al 'The human rights of women with intellectual disability' (2012) 105 *Journal of the Royal Society of Medicine* 384; H Brooker 'Forced sterilisation of women and girls in Europe' https://inclusion-europe.eu/?p=5264 (accessed 27 January 2018).

girls with intellectual disabilities in terms of contraception would be theoretically effective and appropriate.

The provisions of the CRPD, particularly articles 12, 23 and 25, are crucial in protecting girls with intellectual disabilities from involuntary sterilisation. Article 23 stipulates that persons with disabilities, including children and adolescents, have the right "to retain their fertility on an equal basis with others."[29] This provision is important because it unequivocally protects women and girls with intellectual disabilities from involuntary sterilisation. Consequently, the Committee on the Rights of Persons with Disabilities (CRPD Committee) has points out that laws and policies that enable the sterilisation of persons with disabilities contravene the provisions of article 23 of the CRPD.[30] Article 23 therefore protects persons with disabilities, especially women and girls with intellectual disabilities, from discrimination by guaranteeing are not treated differently from others by being subjected to involuntary sterilisation on an unequal basis with their peers.

Similarly, article 25 recognises that persons with disabilities are entitled to enjoy 'the highest attainable standard of health without discrimination on the basis of disability'.[31] It requires health care professionals to provide the same quality of health care given to other persons to persons with disabilities "on the basis of free and informed consent."[32] This right to consent to medical treatment, including sterilisation, is intrinsically linked to legal capacity.[33] This is because the denial of legal capacity usually leads to persons with intellectual disabilities being deprived of their fundamental rights, including the right to consent to medical treatment and the right to retain their fertility.[34] As such, what makes a sterilisation voluntary or involuntary is the nature of the consent given. Consent is a 'fragile' concept for persons with intellectual disabilities because they are often considered as lacking the legal capacity to consent freely and voluntarily.[35] The concept of free and informed

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[29] Convention on the Rights of Persons with Disabilities (n 1 above) article 23(1) (c).

[30] Committee on the Rights of Persons with Disabilities 'Concluding observations on the initial report of Argentina' UN Doc CRPD/C/CHN/Co/1 para. 34.

[31] IR Pavone 'Article 25 [Health]' in VD Fina et al (eds) *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (2017) 471, 477.

[32] Convention on the Rights of Persons with Disabilities (n 1 above) article 25(d).

[33] M Pare 'Of minors and the mentally ill: Re-positioning perspectives on consent to health care' (2011) 29 *Windsor Yearbook of Access to Justice* 107, 123.

[34] Committee on the Rights of Persons with Disabilities 'Article 12: Equal recognition before the law' (General Comment No. 1) (2014) CRPD/C/GC/1 paras 3 and 8 https://daccess-ods.un.org/TMP/6734848.02246094.html (accessed 8 July 2017).

[35] A D'Espallier 'Cutting the ties: Sterilisation of persons with disabilities new perspectives after the introduction of the CRPD' (2014) 3 http://www.jus.uio.no/english/research/news-and-events/events/conferences/2014/wccl-mdc/wccl/papers/ws7/w7-despallier%20.pdf (accessed 8 November 2014).

consent which serves to determine whether a sterilisation is conducted voluntarily or against a person's will is therefore challenging for persons with intellectual disabilities.[36] For girls with intellectual disabilities who require extensive and pervasive support, consent for sterilisation often comes from parents, guardians, or medical professionals rather than from themselves. More often than not, substituted decision-making[37] is employed on the ground that it is for their protection and is deemed sufficient to justify involuntary medical treatment.[38] Denying them legal capacity in health care in the context of contraceptive decision-making therefore places them in a position of inequality and discrimination in relation to their counterparts without disabilities.

'Equality before the law' is a fundamental principle of human rights protection and is vital for the exercise of other human rights including the right to retain fertility and to make informed decisions.[39] Article 12 reiterates the right of persons with disabilities to equal recognition before the law and recognises their right to legal capacity "on an equal basis with others in all aspects of life."[40] It also requires that persons with disabilities be provided support in the exercise of their legal capacity and that such support in the exercise of their legal capacity must respect the "rights, will and preferences" of the person.[41] Article 12 reads as follows:

> Article 12 - Equal recognition before the law-
> 1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
> 2. States Parties shall recognize 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

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[36] D'Espallier (n 35 above) 16.

[37] Substituted decision-making involves a third party taking or making decisions for a person without involving or without consulting the person for whom the decision is taken or being made. See Office of the Public Advocate 'Substitute decision making' http://www.opa.sa.gov.au/making_decisions_for_others/substitute_decision_making (accessed 14 May 2016).

[38] Mental Disability Advocacy Center & the World Network of Users and Survivors of Psychiatry 'Submission to the UN Special Rapporteur on Torture on his upcoming thematic paper on torture in the context of healthcare' para 22 http://www.wnusp.net/documents/2012/2012_11_06_TortureInHealthcare_submission.doc (accessed 8 November 2014).

[38] D'Espallier (n 35 above) 16.

[39] General Comment No. 1 (n 34 above) para 1.

[40] Convention on the Rights of Persons with Disabilities (n 1 above) article 12 (1) & (2).

[41] n 1 above article12 (3) & 12 (4).

> 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 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.

The CRPD is therefore the first global human rights treaty to specifically recognise the right to legal capacity for persons with disabilities, including those with intellectual disabilities and article 12 was one of the most deliberated articles during its drafting. The deliberations revolved around the construction of legal capacity; the shift from a rebuttable presumption of legal capacity to a right to universal legal capacity; how support and supported decision-making models should be construed; and the scope of guardianship and substitute decision-making.[42]

The import of article 12 is that a person with disability is entitled to make decisions, including decisions about medical treatment, and that the person's right to decision-making cannot be displaced by that of a third party.[43] In interpreting the provisions of article 12, the CRPD Committee reaffirms that "a person's status as a person with a disability or the existence of impairment must never be grounds for denying legal capacity or any of the rights provided for in article 12."[44] The Committee establishes that the right to legal capacity is intricately linked to the fulfilment of other human rights in the CRPD, including reproductive rights.[45] Intrinsically, article 12 upholds a permanent presumption of full legal capacity to all persons with disabilities.[46] According to the Committee, article 12 does not permit the "discriminatory denial of legal capacity' of persons with disabilities but emphasises the need for support in the exercise of their legal capacity.[47] Such support must respect their "rights, will and preferences" and in no way amount to substitute decision-making.[48] The Committee further states that where it is impracticable to determine a person's will and preferences, the

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[42] CJ Sundram 'A discussion of legal capacity in the draft convention on disability' (2006) 11 http://www.mdri.org/mdri-web-007/pdf/A%20discussion%20of%20Capacity.pdf (accessed 8 July 2017); 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* 429; RD Dinerstein 'Implementing legal capacity under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The difficult road from guardianship to supported decision-making' (2012) 19 *Human Rights Brief 8*.
[43] Frohmader (n 8 above) 42.
[44] General Comment No. 1 (n 34 above) para 9.
[45] n 34 above paras 8 & 31.
[46] n 34 above para 12.
[47] n 34 above para 15.
[48] n 34 above para 17.

"best interpretation of the person's will and preferences" should be the determinant.[49] However, the Committee provides little guidance on how to determine the "will and preference" or "best interpretation of will and preference".

The CRPD Committee also acknowledges that the right to legal capacity applies to children with disabilities (including adolescents with disabilities).[50] According to the Committee, article 12 protects the equality of all persons, before the law, regardless of age, so the 'will and preferences' of children with disabilities should be respected on the same basis as those of other children.[51] The Committee also posits that article 12 should be construed along with article 7 which provides for the "evolving capacities of children" and that the "best interests of the child" should be a primary consideration in every action involving children with disabilities.[52] However, as highlighted in Chapters Four and Five, by connecting article 7 to article 12, the Committee reinforces the 'functional' approach to legal capacity for children with disabilities which it denounces for adults with disabilities.[53] Arguably, the discourse on article 12 as well as the CRPD Committee's interpretation of article 12, in general, and its application to children with disabilities, in particular, is nuanced. Accordingly, the complexities surrounding the interpretation of article 12 form the basis for the discussions in Chapters Four and Five of this study.

1.2. Explication of terminologies

In this section, the terms adolescent, sterilisation, intellectual disability and legal capacity which are central to this study are explained for better understanding of their contextual use in the study. This is because they are terms that keep evolving over time and/or whose definitions and interpretations remain contentious.

1.2.1. Adolescent

Adolescence is a social construct which characterises the transitional period that occurs after childhood and before adulthood.[54] Its meaning and the ages at which it begins and ends vary

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[49] n 34 above para 21.
[50] n 34 above para 36.
[51] n 34 above para 36.
[52] Convention on the Rights of Persons with Disabilities (n 1 above) article 7(1) & (2).
[53] General Comment No. 1 (n 34 above) para 15.
[54] MON Kunnuji 'Adolescence, young adulthood and internet use in Nigeria: A review of what is known and unknown' (2014) 3 *International Journal of Economy, Management and Social Sciences* 11, 13; Encyclopaedia Britannica 'Adolescence' https://www.britannica.com/science/adolescence (accessed 22 March 2014).

between cultures, through time and amongst individuals.[55] The World Health Organisation (WHO) identifies adolescence as the period in human development occurring from ages 10 to 19, during which several key developmental experiences occur.[56] Similarly, the United Nations Children's Fund (UNICEF) perceives the period of adolescence as a time of transition involving multi-dimensional changes- biological, psychological (including cognitive) and social.[57] In Western societies, adolescence is seen as a period in between childhood and adulthood characterised by the onset of puberty.[58] Kunnuji observes that in many African cultures, the period of adolescence is a recent experience because in the past people simply moved from childhood into adulthood.[59] It must however be noted that the construction of adolescence and when it begins or ends is culturally, socially, economically, politically and demographically contingent.[60]

There is currently no standard definition of the term "adolescent" as it varies from country to country and is usually expressed in terms of the chronological age during which adolescence occurs even though age is just one trait that describes the adolescence.[61] In many countries, including Nigeria, most adolescents are regarded as children under the law as the age of majority is customarily 18 years.

The most commonly cited definitions of 'adolescent' are the definitions by WHO and UNICEF which define adolescents as persons between 10 and 19 years of age.[62] In Nigeria,

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[55] AJ Degner 'The definition of adolescence: One term fails to adequately define this diverse time period' http://www.charis.wlc.edu/publications/charis5-3/degner.pdf (accessed 22 March 2014); MM Ikorok et al 'Adolescent problems: The implications for Nigerian public health workers' (2005) 24 *Ilorin Journal of Education* 113, 114; World Health Organisation (WHO) 'Adolescent development' http://www.who.int/maternal_child_adolescent/topics/adolescence/dev/en/ (accessed 22 March 2014).
[56] World Health Organisation 'Adolescent health' http://www.who.int/topics/adolescent_health/en/(accessed 22 March 2014); World Health Organisation (n 55 above).
[57] United Nations Children's Fund (UNICEF) 'Adolescent development: Perspectives and frameworks' http://www.unicef.org/ADAP_series_1.pdf (accessed 22 March 2014).
[58] United Nations Children's Fund (n 57 above).
[59] Kunnuji (n 54above) 13.
[60] LJ Crockett 'Cultural, historical, and subcultural contexts of adolescence: Implications for health and development' in J Schulenberg et al (eds) *Health Risks and Developmental Transitions During Adolescence* (1997) 23.
[61] American Psychological Association 'Developing adolescents: A reference for professionals' 1 http://www.apa.org/pi/families/resources/develop.pdf (accessed 22 March 2014); United Nations Population Fund (UNFPA) 'Adolescent and youth demographics: A brief overview' https://www.unfpa.org/webdav/site/global/shared/factsheets/One%20pager%20on%20youth%20demographics%20GF.pdf (accessed 22 March 2014); United Nations Children's Fund (UNICEF) 'The State of the world's children 2011: Adolescence- an age opportunity' 12 http://www.unicef.org/adolescence/files/SOWC_2011_Main_Report_EN_02092011.pdf (accessed 22 March 2014); World Health Organisation (n 55 above).
[62] World Health Organisation (n 56 above); United Nations Children's Fund (UNICEF) Handbook- Children as Advocates- strengthening child and young people's participation in advocacy fora (June 2010) http://www.unicef.org/adolescence/files/SAF_resources_childrenadvocates.pdf (accessed 22 March 2014).

the revised National Adolescent Health Policy defines an adolescent as a person within the ages of 10 and 24 years.[63] The American Academy of Paediatric Dentistry (AAPD) defines adolescents as youths between the ages of 10 to 18 years.[64] Interestingly, in the United Kingdom, a new guidance for psychologists proposes to increase the adolescent age up to 25 years.[65] It can therefore be inferred from the definitions of adolescence and adolescent, that an adolescent is a person who is experiencing the transition of life from childhood to adulthood who is within the age range of 10-24 years of age. However, for the purpose of this study, an adolescent is a person who is within the ages of 13 to 18 years, who is progressively transitioning from childhood into adulthood.

1.2.2. Sterilisation

Sterilisation refers to "surgical intervention resulting either directly or indirectly in the termination" of a person's ability to have children.[66] It differs from other methods of contraception in the sense that its effects are usually permanent because reversal requires additional surgery which is in many cases is unsuccessful.[67] Surgical methods of contraception such as tubal ligation[68] and hysterectomy[69] are examples of sterilisation procedures for women and girls.[70]

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[63] Federal Ministry of Health, National Adolescent Health Policy (1995) 1; Federal Ministry of Health, National Policy on the Health and Development of Adolescents and Young People in Nigeria, 2007, 1.

[64] American Academy of Pediatric Dentistry 'Guideline on adolescent oral health care' (2010) 35 *Council on Clinical Affairs Reference Manual 142.*

[65] 'Teenage plus: The new adolescence' The Independent 25 April 2012; 'Is 25 the new cut-off point for adulthood?' BBC News Magazine 23 September 2013; 'An adult at 18? Not any more: Adolescence now ends at 25 to prevent young people getting an inferiority complex' Daily Mail 24 September 2013; 'Adulthood extended to age 25 by child psychologists in UK' Medical Daily 24 September 2013.

[66] Women with Disabilities Australia (n 11 above); American Association for Intellectual and Developmental Disabilities 'Sterilization of persons who are mentally retarded' (1974) http://ethics.iit.edu/ecodes/node/3713 (accessed 22 March 2014); Human Rights Watch 'Sterilization of women and girls with disabilities- a briefing paper http://www.hrw.org/news/2011/11/10/sterilization-women-and-girls-disabilities (accessed 22 March 2014); Australian Institute on Intellectual and Developmental Disabilities 'The involuntary or coerced sterilisation of people with disabilities in Australia' Submission to the Senate inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia 6 http://www.aph.gov.au/DocumentStore.ashx?id=b355cde8-a8ad-4cb6-9375-70e467755ecb&subId=16187 (accessed 10 January 2018).

[67] Human Rights Watch (n 66 above); D'Espallier (n 35 above) 8.

[68] Tubal ligation involves tying or blocking a woman's fallopian tubes are clamped and blocked to permanently prevent pregnancy. See 'What is tubal ligation' https://www.webmd.com/sex/birth-control/what-is-tubal-ligation (accessed 12 February 2017); 'Tubal ligation (tubal sterilization)' https://www.emedicinehealth.com/tubal_sterilization/article_em.htm (accessed 12 February 2017).

[69] Hysterectomy involves the surgical removal of a girl or woman's uterus. See The National Women's Health Network 'Hysterectomy' https://www.nwhn.org/wp-content/uploads/2015/07/Hysterectomy.pdf (accessed 12 February 2017); 'Hysterectomy' https://www.webmd.com/women/guide/hysterectomy#1 (accessed 12 February 2017).

[70] AS Alnasser 'Sterilization among mentally retarded women' (2013) 7 *Middle East Journal of Nursing 40.*

Sterilisation could be voluntary or involuntary. Voluntary sterilisation involves terminating a person's reproductive capability by personal choice, with the person's knowledge, full and informed consent.[71] Conversely, involuntary (forced) sterilisation involves permanently ending a person's capacity to procreate against his or her will or knowledge, or without his or her consent.[72] In other words, sterilising a person after express refusal to undertake the procedure or conducting the procedure without the person's knowledge or consent, amounts to involuntary sterilisation.[73] In this study, involuntary sterilisation refers to any treatment carried out on a girl or woman without her consent or knowledge, by another person's decision, by undue influence and/or coercive or persuasive tactics, which renders her permanently incapable of reproduction. Involuntarily sterilising girls with intellectual disabilities is unlawful as the CRPD guarantees persons with disabilities, including children with disabilities, the right to retain their fertility on an equal basis with others.[74]

Some literature on sterilisation distinguish between involuntary sterilisation and coerced sterilisation.[75] Coerced sterilisation has been defined as involving the use of inducements and coercion such as monetary incentives, misinformation, force, threats and enticement to induce a person to undergo sterilisation.[76] However, the distinction made by some authors between what is 'involuntary' and what is 'coerced' are not always clear and

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[71] 'Voluntary sterilisation' https://medical-dictionary.thefreedictionary.com/voluntary+sterilization (8 September 2017).

[72] Forced sterilization http://www2.webster.edu/~woolflm/forcedsterilization.html (accessed 22 March 2014).

[73] Open Society Foundations 'Against her will: Forced and coerced sterilization of women worldwide' (2011) 4 http://www.opensocietyfoundations.org/sites/default/files/against-her-will-20111003.pdf (accessed 22 March 2014); C Frohmader 'Moving forward and gaining ground: The sterilisation of women and girls with disabilities in Australia' *(2012)* 5 http://wwda.org.au/wp-content/uploads/2013/12/Moving_Forward_Gaining_Ground.pdf (accessed 22 March 2014); D'Espallier (n 35 above) 8; Australian Institute on Intellectual and Developmental Disabilities (n 66 above) 6.

[74] Convention on the Rights of Persons with Disabilities (n 1 above) article 23(1) (c).

[75] Open Society Foundations (n 73 above) 2; Women with Disabilities Australia (WWDA) et al (2011) 'Sterilisation of women and girls with disabilities: A briefing paper' http://www.wwda.org.au/Sterilization_Disability_ Briefing_Paper_October2011.pdf (accessed 22 March 2014); Human Rights Watch (n 66 above); Frohmader (n 11 above) 5; Australian Human Rights Commission 'The involuntary or coerced sterilisation of people with disabilities in Australia' Australian Human Rights Commission submission to the senate community affairs references committee (2012) 5 https://www.humanrights.gov.au/sites/default/files/20121128_sterilisation.pdf (accessed 22 March 2014); R Sifris *Reproductive freedom, torture and international human rights: Challenging the masculinisation of torture* (2014) 7.

[76] Open Society Foundations (n 73 above) 4; F Kasiva 'Robbed of choice, forced and coerced sterilisation experiences of women living with HIV in Kenya' http://kelinkenya.org/wp-content/uploads/2010/10/Report-on-Robbed-Of-Choice-Forced-and-Coerced-Sterilization-Experiences-of-Women-Living-with-HIV-in-Kenya.pdf (accessed 22 March 2014); S Vale 'Forced and coerced sterilization: The nightmare of transgender and intersex individuals' http://impakter.com/forced-and-coerced-sterilization-an-unnecessary-intervention-in-transgender-and-intersex individuals/ (accessed 15 September 2016); Women with Disabilities Australia (WWDA et al (n 75 above); Frohmader (n 11 above) 11; Australian Human Rights Commission (n 75above); Sifris (n 75 above) 7.

convincing. ‘To coerce’ is synonymous with ‘to force’.[77] So it is unclear if the difference between coerced sterilisation and involuntary sterilisation is one of degree, or if the difference is between what is blatant and what is subtle, or between what is mild, moderate or extreme.

Involuntary sterilisation is often referred to as non-therapeutic.[78] The term ‘non-therapeutic’ is a contested and contextual term.[79] Literature on the issue suggests that “non-therapeutic sterilisation refers to sterilisation performed for reasons other than to treat a medical condition or disease” or to save a person’s life.[80] In contrast, therapeutic sterilisation is carried out to treat some “malfunction or disease or an incidental result of a surgery performed to cure a disease or correct some malfunction.”[81] Accordingly, sterilisation carried out for contraceptive purposes or for reasons other than treat a medical condition or to save a life, is non-therapeutic. However, the distinction is not clear cut and gives rise to questions such as: Is sterilisation therapeutic or non-therapeutic when an adolescent voluntarily consents to it to prevent pregnancy? Is sterilisation ‘therapeutic or ‘non-therapeutic’ if consent was not provided prior to the sterilisation? Naik suggests that for the sterilisation of a child/adolescent with intellectual disability to be therapeutic, it must be such that it would also be performed on a child without intellectual disability with same medical condition.[82] According to her, non-therapeutic sterilisation, on the other hand, involves the performance of a procedure that ordinarily would not be done on a child without disability.[83] Even though sterilisations are performed more on children or adolescent girls with intellectual disabilities, Naik’s distinction is ambiguous. She seems to suggest that if sterilisations were commonly performed on children without disabilities, for instance, in societies where it is done for

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[77] ‘Synonyms and antonyms of coerce’ https://www.merriam-webster.com/thesaurus/coerce (accessed 30 May 2018); ‘Synonyms of coerce’ https://www.collinsdictionary.com/dictionary/english-thesaurus/coerce (accessed 30 May 2018); ‘synonyms of coerce in English’ https://en.oxforddictionaries.com/thesaurus/coerce (accessed 30 May 2018).

[78] A D’Aubin ‘Working for access’ in J Turner (ed) *Living the changes* (1990) 147; Human Rights Watch (n 66 above); Frohmader (n 8 above) 22.

[79] Australian Law Reform Commission ‘Multiculturalism and the law’ Report No 57 (1992) 120 https://www.alrc.gov.au/sites/default/files/pdfs/publications/alrc57.pdf (accessed 15 September 2016); P Hammond ‘Handicapped girls under nine illegally sterilised’ Courier Mail 8 May 1993.

[80] J Fortin *Children’s Rights and the developing law* (3rd ed) (2009) 399; Intellectual Disability Rights Service (n 12 above) 3.

[81] *Secretary, Department of Health and Community Services v JWB and SMB* (Marion’s Case) (1992) 175 CLR 218 http://www.austlii.edu.au/cgi-bin/sinodisp/au/cases/cth/HCA/1992/15.html (accessed 22 March 2014); Fortin (n 80 above) 399.

[82] L Naik ‘The involuntary or coerced sterilisation of people with disabilities in Australia’ Submission to the Senate Community Affairs Committee (2012) 4-5 https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Submissions (accessed 15 September 2016).

[83] Naik (n 82 above) 5.

population control, then such sterilisations would be therapeutic. Moreover, some medical procedures do not fit neatly into both categories and the resort is often had to the counsel of medical professionals.[84]

The courts have also not been helpful in providing a clear-cut distinction between therapeutic and non-therapeutic sterilisation. The High Court of Australia in *Secretary, Department of Health and Community Services v JWB and SMB* (Marion's Case) attempted a distinction between therapeutic and non-therapeutic sterilisation. In that case, Lord Brennan opines that medical treatment is therapeutic even in the absence of consent, if done to enhance a person's physical or mental qualities while treatment that is not done to enhance a person's physical or mental qualities is non-therapeutic.[85] Again, Lord Brennan's distinction is ambiguous and unhelpful in distinguishing between therapeutic and non-therapeutic medical procedures. Indeed what procedures could be considered as enhancing a person's physical and mental attributes? It is also questionable whether sterilisations performed to enhance a person's physical or mental qualities can be considered therapeutic, if done without the person's consent. More so, what constitute a person's physical and mental qualities is subjective.

The issues highlighted above reflect the problem of delineating 'therapeutic' and 'non-therapeutic' procedures especially in the context of the medicalisation of disability and the justification of non-consensual procedures.[86] Perhaps this is why the distinction has been referred to as 'distinction without a difference',[87] 'meaningless'[88] and 'not useful'.[89] This is because in many cases the effect is the same: a girl with intellectual disability is sterilised and authorisation by law does not hide the fact that the girl "is subjected to an unnecessary and non-therapeutic medical intervention".[90] As Women with Disabilities Australia (WWDA) point out, the terms derive from a gendered and prejudiced perspective that the reproductive lives of women and girls with disabilities should be determined by law, and by legal and

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[84] Fortin (n 80 above) 400.

[85] *Secretary, Department of Health and Community Services v JWB and SMB* (Marion's Case) (n 81 above) per Lord Brennan, para 19.

[86] L Steele 'Court authorised sterilisation and human rights: Inequality, discrimination and violence against women and girls with disability' (2016) 39 *UNSW Law Journal* 1002, 1007.

[87] P De Cruz *Comparative healthcare law* (2000) 201.

[88] *Re B (A Minor)* (1988) AC 199, 204 per Lord Hailsham of St Marylebone LC.

[89] 'Sterilisation and other medical procedures on children' A report to the Attorney-General prepared by the Family Law Council (November 1994) para 1.23. https://www.ag.gov.au/FamiliesAndMarriage/FamilyLawCouncil/Documents/Sterilisation%20and%20Other%20Medical%20Procedures%20on%20Children.doc (accessed 22 March 2014).

[90] Women with Disabilities Australia (n 11 above).

medical professionals. The terms are therefore used to conceal the violation of their human rights as well as the long-lasting physiological and psychological effects of sterilisation such as stigma, premature menopause, osteoporosis, cardiovascular problems and sexual abuse.[91]

1.2.3. Intellectual disability

Intellectual disability is a term that applies to a diverse group of people and a wide spectrum of disabilities such as Down's syndrome, Fragile X syndrome, Prader-Willi syndrome and fetal alcohol syndrome, which have no essential causal link.[92] It is generally defined as a disability that occurs before the age of 18 and affects cognitive and adaptive functioning.[93] It is not a 'static condition' but an interface between individuals' abilities and social factors.[94] Intellectual disability is therefore neither a medical concept nor a social concept.[95]

As a subject of inquiry, intellectual disability has been of great interest to professionals from different disciplines. It originated from psychologists, who developed diagnostic criteria to homogenise and classify human conditions identified as intellectual disability and to categorise persons with intellectual disability based on their perceived disabilities.[96] Professionals such as educators, sociologists, philosophers and anthropologists have also been involved in examining it as a concept.[97] This multidisciplinary interest in intellectual disability, though beneficial in some instances, has resulted in problems of conceptual and definitional clarity, making it a highly contested concept.[98] As such, it is a term that is constantly changing because its interpretations and the terminologies used in describing it keep changing with time. The multidisciplinary interest has also contributed to the objectification of persons with intellectual disabilities and in emphasising their difference from other persons. Moreover, the categorisation of human conditions with one general concept involves hasty generalisation and universalisation, which could be problematic as

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[91] Women with Disabilities Australia (n 11 above); European Disability Forum (EDF) & Fundación Cermi Mujeres 'Ending forced sterilisation of women and girls with disabilities' http://www.fundacioncermimujeres.es/sites/default/files/forcedsterelisationreport.pdf (accessed 10 March 2016).

[92] *Secretary, Department of Health and Community Services v JWB and SMB* (Marion's Case) (n 81 above) para 21 per Mason CJ, Dawson, Toohey and Gaudron JJ; MB First & A Tasman *Clinical guide to the diagnosis and treatment of mental disorders* (2nd ed) (2010) 17.

[93] R Schalock et al *Intellectual disability: Definition, classification, and systems of supports* (11th ed) (2010) 5; American Psychiatric Association *diagnostic and statistical manual of mental disorders* (DSM-5) (5th ed) (2013) 33.

[94] M Rioux 'The equality-disability nexus: The history and law of mental handicap in Canada' 54 (10) Dissertation Abstracts International 3895A.

[95] Rioux (n 94 above) 3895A.

[96] R Ahlzén & M Evans *Diagnosis* (2010) 133.

[97] RM Garigiulo *Special education in contemporary society: An introduction to exceptionality* 4th ed (2010) 142.

[98] Garigiulo (n 97 above) 142.

using one general term to describe too many conditions could lead to technical vagueness or linguistic redundancy.[99]

Intellectual disability differs from other mental disabilities such as psychosocial disability and developmental disability. Psychosocial disability is the term for describing persons with mental health conditions such as depression, bipolar disorder, and schizophrenia.[100] Unlike intellectual disability, psychosocial disability may occur at any stage in life; may not permanently affect cognitive ability; may be temporary, cyclical, or episodic; and may be cured or stabilised with medication, psychotherapy or other support mechanisms.[101] What has historically invited medical/psychiatric intervention on persons with psychosocial disabilities is that during the episode of psychosocial disability, their cognitive capacities (the mental capacities to know and decide) are impaired. However, psychosocial disability is a fluctuating condition that is distinct from intellectual disability which does not have moments of fluctuation, save that it can be interpreted differently, in different contexts and at different times.

Developmental disability is wider-ranging than intellectual disability and refers to severe life-long cognitive and/or physical disabilities, which occur before the age of 22 years.[102] It usually affects one or more major life activities such as speaking, mobility, language or learning.[103] Albeit being used interchangeably, developmental disability

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[99] E McSherry 'A Foucauldian discourse analysis of intellectual disability in Irish education' unpublished PhD thesis, University of Limerick, 2013 4-5.

[100] World Network of Users and Survivors of Psychiatry 'Manual on implementation of the Convention on the Rights of Persons with Disabilities' 9 http://www.chrusp.org/home/resources (accessed 22 March 2014); Christian Blind Mission (CBM) International 'Psychosocial disabilities' http://www.cbm.org/Psychosocial-disabilities-251912.php (accessed 22 March 2014); International Association for the Scientific Study of Intellectual Disabilities 'Mental health and intellectual disabilities- addressing the mental health needs of people with intellectual disabilities' 7 http://iassid.org/pdf/mh-sirg-who-final.pdf (accessed 22 March 2014).

[101] Intellectual Disability Rights Service (IDRS) 'A step-by-step guide to section 32 applications- intellectual disability and mental illness' http://www.idrs.org.au/s32/_guide/p040_4_2_IDandMI.php#.VBK-VcKSzaY (accessed 22 March 2014); Inclusion Europe & Mental Health Europe 'Mental illness and intellectual disability' http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1277&context=gladnetcollect (accessed 22 March 2014).

[102] American Association on Intellectual and Developmental Disabilities (AAIDD) 'Frequently asked questions on intellectual disability' http://aaidd.org/intellectual-disability/definition/faqs-on-intellectual-disability (accessed 22 March 2014); Human Rights Watch 'Barriers everywhere- lack of accessibility for people with disabilities in Russia' http://www.hrw.org/sites/default/files/reports/russia0913_ForUpload.pdf (accessed 22 March 2014).

[103] American Association on Intellectual and Developmental (n 102 above); Human Rights Watch (n 102 above).

includes intellectual disability as well as non-cognitive disabilities such as cerebral palsy and epilepsy.[104]

Intellectual disability has been subject to a myriad of names, definitions and classification systems which reflect the times and contexts of their use.[105] Historically, terms such as 'feebleminded', 'moron', 'imbecile', 'idiot', 'mental deficiency', 'mental handicap', 'mental sub-normality', 'mental disability' and 'mental retardation' have been used to describe intellectual disability.[106] However, these terms have been deemed unacceptable because of their pejorative connotations and also because of their normative implications since the use of the terms also permit violations of human rights and stigma. The changes in terminology reflect the changed construct of intellectual disability and are less offensive to persons with intellectual disabilities.[107] More so, the meanings ascribed to the terms have different connotations in different countries. For instance, the term 'learning disabilities' has different meanings across the globe.[108] Hence, the terminology used is important because the language and term used to express intellectual disability can be used to perpetuate stereotypes, adversative perceptions and, invariably, stigma.[109] There is also concern over the manner in which terminology for intellectual disability is used because it can shape meanings, create realities and result in the negation of the person to whom it applies.[110] In fact, terms such as *mental deficiency* and *mental retardation* were clinical terms applied to intellectual disability that eventually became immersed into popular language as insults to degrade or depreciate a person. They resulted in negative beliefs about persons with intellectual disabilities suggesting that they were flawed, sub-human and invaluable.[111] Hence, promoting the use of positive terminology through awareness and enlightenment programmes could be effective in advancing the value and dignity of persons with intellectual

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[104] Center for Disease Control and Prevention (CDC) 'Facts about developmental disabilities' http://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html#ref (accessed 22 March 2014).

[105] P Louhiala *Preventing intellectual disability: Ethical and clinical issues* (2004) 8.

[106] Louhiala (n 105 above) 8; A Hudson & G Radler 'Psychologists and intellectual disability' *InPsych* (August 2005) http://www.psychology.org.au/publications/inpsych/disability/ (accessed 14 February 2015).

[107] S Lara 'Intellectual disability: Definition, classification and assessment' http://www.iidd.wisc.edu/sites/vanhise.lss.wisc.edu.iidd/files/a/Int_Disab_Head_lecture.ppt (accessed 22 March 2014).

[108] R Jenkins *Questions of competence: Culture, classification and intellectual disability* (1998) 8.

[109] Canadian Association for Community Living 'Definitions and terminology' http://www.cacl.ca/about-us/definitions-terminology (accessed 22 March 2014).

[110] M Bury & J Gabe *The sociology of health and illness: A reader* (2013) 280.

[111] J Simpson 'What's in a name? The language of intellectual disability' in S Melrose et al (eds) *Supporting individuals with intellectual disabilities and mental illness (2015) 8.*

disabilities as well as socially re-engineer people's attitudes towards them.[112] Nonetheless, Smith argues that an acceptable term for intellectual disability may not be achievable because over time the term would eventually become obsolete.[113]

Currently, there is no standard or universal terminology for intellectual disability. An examination of recent literature shows that the term 'intellectual disability' is predominantly used in many countries including the United States of America, Ireland and Australia while in the United Kingdom, the term 'learning disability' is used.[114] In Nigeria, terms such as such as 'mental challenge' are used by many Nigerians to denote intellectual disability while terms such as 'mental retardation' and 'intellectual disability' are used by the medical professionals. Indeed, medical professionals who trained in Nigeria mostly use the term 'mental retardation' while those who received training in the United States of America use the term 'intellectual disability'.[115] The term 'mental retardation' is also predominantly used by teachers and professionals in many schools for students with intellectual disabilities in Nigeria. An in-depth examination of how intellectual disability has been and is construed is carried out in Chapter Two.

1.2.4. Legal capacity

In most legal systems, capacity is an attribute assigned to persons deemed capable of exercising free will and choice and whose actions have legal effects. Historically, modern legal systems have treated capacity as a rebuttable presumption which, if proved to be lacking in a person, can result in a designation of incapacity to make decisions.[116] Legal capacity is the basis of persons' right to make decisions for themselves in a society[117] and it affects most areas of life, including independent living, marriage, employment, contracts, voting,

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[112] Intellectual Disability Rights Service (IDRS) 'Introduction to intellectual disability' http://www.idrs.org.au/pdf/IDRS_%20Introduction_intellectual%20disability_17Feb09.pdf (accessed 22 March 2014).

[113] JD Smith 'The myth of mental retardation: Paradigm shifts, disaggregation and developmental disabilities' (2002) 40 *Mental Retardation* 62, 64.

[114] Irish Association of Supported Employment (IASE) 'Intellectual disability' http://www.iase.ie/pages/disability_awareness/disability_awareness_i.html (accessed 22 March 2014).

[115] This was gathered from discussions with respondents of the empirical component of this study.

[116] JE Méndez 'Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment' UN A/HRC/22/53 6-7.

[117] SA Law Commission 'Assisted decision-making: Adults with impaired decision-making capacity' discussion paper 105 (2004) www.justice.gov.za/salrc/dpapers/dp105.pdf (accessed 15 September 2016).

management of property, and health care decisions.[118] It is therefore a socio-legal construct that is determined by prevailing societal beliefs which keep evolving.[119]

Legal capacity has been subject to various definitions and interpretations.[120] Minkowitz defines it as "the recognition of an individual as a person with legal rights and responsibilities, who is entitled to exercise those rights and responsibilities for him or herself."[121] To Bach and Kezner, it "reflects an individual's right to make decisions and have those decisions respected by others."[122] The European Union Agency for Fundamental Rights defines it as "the law's recognition of a person's decisions which makes him a subject of the law and a bearer of legal rights and obligations" without which his decisions will have no legal effect or validity.[123] Lewis sees it as the construct through which the law can "recognise and validate the decisions and transactions that a person makes."[124] To Quinn, legal capacity is the "epiphenomenon"; "the legal shell through which personhood", personal freedom and un-coerced interactions are advanced.[125] Accordingly, legal capacity allows persons to express their wishes in life.[126] It goes beyond decision-making, and without it, many human rights become meaningless.[127] For the purpose of this study, legal capacity is defined as the recognition of persons' 'standing' in society and before the law which enables them full access to all the rights accruing to them as human beings.

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[118] G Quinn & T Degener 'The moral authority for change: Human rights values and the worldwide process of disability reform' in G Quinn & T Degener (eds) *Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability* (2002) 14; Council of Europe Commissioner for Human Rights 'Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities' CommDH/IssuePaper (2012) 2 https://rm.coe.int/16806da5c0 (accessed 15 February 2014).

[119] CP Sabatino & E Wood 'The conceptualization of capacity of older persons in western law' *in* I Doron & A Snoden (eds) *Beyond elder law: New directions in law and aging* (2012) 35, 36.

[120] Quinn & Degener (n 118 above) 14.

[121] T Minkowitz 'The paradigm of supported decision making' https://www.academia.edu/8770379/The_Paradigm_of_Supported_Decision-Making (accessed 15 February 2014).

[122] M Bach & L Kerzner 'A new paradigm for protecting autonomy and the right to legal capacity' (2010) 159 www.lco-cdo.org/disabilities/bach-kerzner.pdf (accessed 15 February 2014).

[123] European Union Agency for Fundamental Rights 'Equality- legal capacity of persons with intellectual disabilities and persons with mental health problems' (February 2013) 9 http://fra.europa.eu/sites/default/files/legal-capacity-intellectual-disabilities-mental-health-problems.pdf (accessed 15 February 2014).

[124] O Lewis 'Advancing legal capacity jurisprudence' (2011) 6 *European Human Rights Law Review* 700.

[125] G Quinn 'Personhood and legal capacity perspectives on the paradigm shift of article 12 CRPD' 10 http://www.nuigalway.ie/cdlp/documents/publications/Harvard%20Legal%20Capacity%20gq%20draft%202.doc (accessed 22 March 2014).

[126] Quinn (n 125 above) 10; Council of Europe Commissioner for Human Rights (n 118 above) 2.

[127] Council of Europe Commissioner for Human Rights (n 118 above) 2.

Traditionally, where persons are perceived to lack decision-making capacity, their legal capacity is denied. In this regard, persons with disabilities, especially those with intellectual disabilities, have been subject to restrictions of their legal capacity.[128] Such construction of legal capacity as being contingent on cognitive, perceptual, corporeal, interactional and interpersonal capabilities discriminates based on disability.[129] However, the CRPD provides that persons with disabilities have "the right to enjoy legal capacity on an equal basis with others in all aspects of life" and that they should be provided support in exercising their legal capacity.[130] Although article 12 of the CRPD does not define legal capacity, the CRPD Committee interprets it as "the capacity to be both a holder of rights and an actor under the law" which grants persons the right to the protection of their rights by the legal system.[131] A detailed discussion of legal capacity and what it entails for adolescent girls with intellectual disabilities is set out in Chapter Four.

1.3. Problem statement and objectives of the study

The involuntary sterilisation of adolescent girls with intellectual disabilities is yet to receive attention in Nigeria. In spite of the fact that it has been subject of national and global discourse, there is little discourse on the issue in Nigeria. Past governmental contraceptive policies show that sterilisation is legal, if performed for health, eugenic, or contraceptive purposes.[132] Similarly, the empirical component of this study discussed in Chapter Seven also shows that adolescent girls with intellectual disabilities are susceptible to sterilisation. At the core of this problem of involuntary sterilisation is the societal attitude of denying girls with intellectual disabilities legal capacity with regards to contraceptive decisions because they are perceived to lack mental capacity and that it is in their best interests. Although the CRPD recognises the right of children (including adolescents) to freely express their views on all issues affecting them in keeping with their age and maturity, adolescents with intellectual disabilities in Nigeria are rarely consulted on decisions affecting their reproductive health. Even those who can make decisions for themselves are sometimes not allowed to make decisions about contraception on an equal basis with other adolescents of their age. Consequently, decision-making about contraception emanates from their parents, guardians,

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[128] Minkowitz (n 121 above).

[129] n 121 above.

[130] Convention on the Rights of Persons with disabilities (n 1 above) article 12(1) & (3).

[131] General Comment No. 1 (n 34 above) para 1.

[132] Center for Reproductive Law and Policy (CRLP) 'Women's reproductive rights in Nigeria: A shadow report' (1998) 8.

or even medical professionals, without their input or resort to their will and preferences.[133] This paternalistic attitude contributes to their exclusion and participation on issues pertaining to their lives and from society at large.

In addition, there is no coherent legal framework protecting adolescent girls with intellectual disabilities from involuntary sterilisation as policymakers in Nigeria are yet to assign any importance to the issue. Although Nigeria is a party to the CRPD and other human rights instruments guaranteeing the rights of adolescent girls with intellectual disabilities, for several years there was no existing disability law at the national level except for the Nigerians with Disability Act (NWDA), 1983[134] which is outdated. Moreover, the Discrimination against Persons with Disabilities (Prohibition) Act, 2018 which was recently signed into law[135] and the few existing laws at the state level merely pay lip service to the rights of persons with disabilities. Although the Discrimination against Persons with Disabilities (Prohibition) Act prohibits discrimination on the ground of disability,[136] non-discrimination in health care[137] and free and medical health service to persons with intellectual disability,[138] it contains no provisions prohibiting sterilisation of persons with disabilities or guaranteeing their right to legal capacity and support in decision-making.

Without legislative and policy reforms which unequivocally prohibit involuntary sterilisation and guarantee legal capacity, mitigating the sterilisation of adolescent girls with intellectual disabilities may remain unchecked. Against this backdrop, this study critically assesses whether supported decision-making is an appropriate paradigm for protecting adolescent girls with intellectual disabilities from sterilisation in Nigeria. It assesses if support in contraceptive decision-making would mitigate involuntary sterilisation. Accordingly, the study examines, through empirical research, the prevailing attitudes towards

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[133] ER Ezeome & PA Marshall 'Informed consent practices in Nigeria' (2009) 9 *Developing World Bioethics* 138, 139; YZ Lawal et al 'The doctrine of informed consent in surgical practice' (2011) 10 *Annals of African Medicine* 1, 2*;* E Chianu 'The horse and ass yoked- legal principles to aid the weak in a world of unequals' presented at the 91st Inaugural Lecture Series at the Akin Deko Auditorium, University of Benin, Nigeria on 20th September 2007.

[134] The Nigerians with Disability Act (NWDA), 1983 was originally a decree but became an Act by virtue of section 315 of the 1999 Constitution of the Federal Republic of Nigeria. Interestingly, it is yet to be repealed by any law.

[135] Discrimination against Persons with Disabilities (Prohibition) Act, 2018. The Act was passed into law in January 2019. See J Ameh 'Buhari signs bill prohibiting discrimination against persons with disability' The Punch 25 January 2019; Human Rights Watch 'Nigeria passes disability rights law- offers hope of inclusion, improved access' https://www.hrw.org/news/2019/01/25/nigeria-passes-disability-rights-law (accessed 31 January 2019).

[136] n 135 above, section (n 135 above, section (1

[137] n 135 above, section (1).

[138] n 135 above, section 5 (1).

the involuntary sterilisation of adolescent girls with intellectual disabilities in Nigeria. It also assesses the practicability of supported decision-making in protecting adolescent girls with intellectual disabilities who require extensive and pervasive support from involuntary sterilisation in Nigeria. The study also aims to assess respondents' views on the viability of the rights to legal capacity and supported decision-making in terms of contraception for adolescent girls with intellectual disabilities. It also aims to make recommendations especially in terms of mechanisms to enable the right of adolescent girls with intellectual disabilities to support in contraceptive decision-making as a means of mitigating involuntary sterilisation.

1.4. Research questions

The central research question this study seeks to investigate is: To what extent can supported decision-making be applied as paradigm in protecting the legal capacity of adolescent girls with intellectual disabilities in Nigeria with regards to contraceptive decision-making and decision-making about sterilisation? To answer this main question, a number of other questions will be addressed:

1) How has intellectual disability been conceptualised traditionally and how is it conceptualised by parents of adolescent girls with intellectual disabilities and professionals in the selected schools and hospitals?

2) What do the rights to equality and legal capacity entail for adolescent girls with intellectual disabilities?

3) What is supported decision-making and what does it entail for adolescent girls with intellectual disabilities?

4) How viable is supported decision-making for adolescent girls with intellectual disabilities, especially those with disabilities that require extensive and pervasive support with regards to contraceptive decision-making and decision-making about sterilisation in Nigeria?

5) What is the attitude of the parents and professionals working with the girls towards the involuntary sterilisation and contraceptive decision-making of adolescent girls with intellectual disabilities in Nigeria?

6) In the light of recent developments in the United Kingdom and Canada in terms of informal supported decision-making systems such as peer mentorship, micro-boards and circles of

friends, what lessons can be drawn for Nigeria with regards to promoting supported decision-making for adolescent girls with intellectual disabilities.

1.5. Methodology of the study

This study utilised descriptive and analytical approaches to appraise the data, literature and materials garnered before making inferences. It employed the mixed methods methodology which employs desk research as well as empirical research comprising qualitative and quantitative research methods. The study also relied on materials from different sources with a view to addressing the issues raised by the research questions. It used primary and secondary sources, including international and regional human rights treaties, national legislations, textbooks, journal articles, case laws, commentaries, newspapers, conferences, dissertations and online resources. However, the fact that there is little or no data on the issues of involuntary sterilisation, legal capacity and supported decision-making in the Nigerian context necessitated the need for empirical research.

The empirical component of this study was carried out in Southern Nigeria which consists of three geo-political zones- south-south, south-west and south-east. Two states from each geo-political zone were randomly selected. The states selected are Anambra, Edo, Ekiti, Imo, Lagos and Rivers states which were used in the study. A total of number of 17 schools, comprising schools for adolescents with intellectual disabilities were purposively selected from the six states. Parents of adolescent girls in the selected schools and professionals working with them in the schools, such as teachers, vocational trainers, physiotherapists and nurses, were randomly selected as participants. Similarly, two federal teaching hospitals were randomly selected from the three geo-political zones. Professionals in the hospitals that have regular dealings with adolescents with intellectual disabilities, such as gynaecologists, paediatricians, psychiatrists and psychologists, were randomly selected as participants. Questionnaires were administered to the parents and the professionals in the selected schools and hospitals. However, head teachers and consultant doctors were interviewed to get more information on the issues addressed. Audio devices were also used to record the interviews but, where the respondents refused, the interviews were manually recorded by hand notes. An in-depth discussion of the methodology for the empirical component of the study is carried out in Chapter Six.

The rights of respondents of the empirical component of the study were taken into consideration. Approval for the empirical research was granted by the Ethics Committee, Faculty of Law, University of Pretoria in accordance with the University of Pretoria's Ethics Policy. Approvals were also obtained from the relevant ministries and boards and ethics committees to enable the researcher conduct research in the selected schools and hospitals. In addition, permission was also granted by the heads of the institutions used in the study. Informed consent were also granted by the participants in the study and the participants were assured of the confidentiality of the information provided by them. Measures were also taken to protect the anonymity and privacy of respondents and institutions used in the study. These ethical considerations are discussed in detail in Chapter Six.[139]

The study also employed the socio-legal research approach. The socio-legal research approach involves the application of interdisciplinary perspectives through theoretical and empirical research in examining phenomena.[140] Socio-legal research was chosen for this study because it provided an appropriate platform to approach the research issues from a multidisciplinary perspective rather than from a purely legal perspective.

1.6. Literature review

Previous studies on how intellectual disability was and is traditionally conceptualised in Nigeria provided an insight into past and present outlooks about intellectual disability and persons with intellectual disabilities in Nigeria. Ihenacho,[141] Abang,[142] Ajuwon and Brown,[143] Etieyibo and Omiegbe,[144] Sango[145] and Imade[146] present a general historical perspective on the outlook of Nigerians towards persons with intellectual disabilities. Ofovwe and Ofovwe[147] and Atitiola et al[148] also show that that there was a pervasive negative attitude

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[139] See section 6.6 of this study.
[140] The British Library 'Socio-legal studies: An introduction to collections' http://www.bl.uk/reshelp/findhelpsubject/busmanlaw/legalstudies/soclegal/sociolegal.html (accessed 16 October 2016); V Levičev 'The synthesis of comparative and socio-legal research as the essential prerequisite to reveal the interaction of national legal systems' http://www.tf.vu.It/en/science/researchers-conference-2015/rsearchers-conference-2013 (accessed 16 October 2016).
[141] IJ Ihenacho *Introduction to special education in Nigeria: Historical and sociological perspectives* (1985) 6.
[142] B Abang 'Disablement, disability and the Nigerian society' (1988) 3 *Disability Handicap & Society* 71, 73.
[143] PM Ajuwon & I Brown 'Family quality of life in Nigeria' (2011) 56 *Journal of Intellectual Disability Research* 61, 67.
[144] E Etieyibo & O Omiegbe 'Religion, culture, and discrimination against persons with disabilities in Nigeria' (2016) 5 *African Journal of Disability* http://dx.doi.org/10.4102/ajod.v5i1.192 (accessed 12 October 2016).
[145] PN Sango 'Country profile: Intellectual and developmental disability in Nigeria' (2017) 22 *Tizard Learning Disability Review* 87.
[146] VO Imade 'Awakening hope: A critical analysis of the stigmatization of children with disabilities in Nigerian families and communities' Master of Arts thesis, York University, 2017, 31.
[147] GE Ofovwe & CE Ofovwe 'Knowledge, attitude and expectations of mothers of children with neurologic disorders attending the paediatric neurology clinic, University of Benin Teaching Hospital, University of Benin, Benin City, Nigeria' (2007) 6 *Journal of Medicine and Biomedical Research* 59, 63.

towards children with intellectual disabilities and their families resulting in stigma and social prejudices against them. However, even when they provide a historical content which is relevant to this study and was relied upon in this study, they give a general overview of the perception and attitudes about intellectual disability. This study however focuses on adolescent girls with intellectual disabilities. Ezejideaku[149] and Obiakpor et al[150] also provide an insight on how intellectual disability is constructed by the Igbo and Yoruba, respectively, through proverbs. This study relied on and built upon their work by presenting more proverbs garnered from fieldwork. The study also relied on the empirical research conducted by Abasiubong et al,[151] Chukwu and Onyeneho[152] and Ishola-Esan[153] in Lagos, Imo and Oyo states respectively, which show that intellectual disability is largely attributed to spiritual causes. This study, however, goes further by presenting findings from the empirical research conducted on parents of adolescent girls with intellectual disabilities and professionals in schools and hospitals in six states in southern Nigeria, as can be seen in Chapter Seven.

The right to legal capacity and its attendant supported decision-making is a much debated concept which affects how persons with intellectual disabilities are perceived as subjects before the law. Accordingly, there is a plethora of literature on the subject matter.[154]

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[148] O Atilola et al ‘Neurological and intellectual disabilities among adolescents within a custodial institution in south-west Nigeria’ (2014) 21 *Journal of Psychiatric and Mental Health Nursing* 31, 35.

[149] EUC Ezejideaku ‘Disability and disabled in Igbo proverbs’ (2003) 20 *Proverbium* 163.

[150] FE Obiakpor et al ‘Special education in Nigeria: Shifting paradigms’ in K Mutua and CS Sunal (eds) *Advances in research and praxis in special education in Africa, Caribbean, and the Middle East* (2012) 32.

[151] F Abasiubong et al ‘The Opinions and attitudes of mothers to mental retardation in Lagos, Nigeria’ (2008) 6 *Nigerian Journal of Psychiatry* 80.

[152] NE Chukwu & NG Onyeneho ‘Sociocultural factors associated with abuse of mentally impaired persons in Imo State, Nigeria’ (2015) 35 *International Quarterly of Community Health Education* 349, 362.

[153] HO Ishola-Esan ‘Impact of the remnants of African worldviews on perception of pastors towards ministering to persons with disabilities in Nigeria’ (2016) 20 *Journal of Disability and Religion* 103, 108.

[154] Dhanda (n 42above) 429; EW Maina ‘The right to equal recognition before the law, access to justice and supported decision making’ presented at the CRPD Conference of Parties on 2-4 September 2009 in New York http://www.un.org/disabilities/documents/COP/Edah%20Presentation%20COSP.doc (accessed 15 February 2014); Quinn (n 125 above); L Kerzner ’Paving the way to full realization of the CRPD's rights to legal capacity and supported decision-making: A Canadian perspective’ presented at the Legal Capacity Symposium From the Margins: New Foundations for Personhood and Legal Capacity in the 21st Century at the University of British Colombia, Ontario, Canada on April 2011 https://cic.arts.ubc.ca/files/2014/07/In_From_The_Margins_Paper-Lana_Kerzner-FINAL-April_22__2011__2_.pdf (accessed 15 February 2014); Dinerstein (n 42 above) 8; P Gooding ‘Supported decision-making: A rights-based disability concept and its implications for mental health law’ (2013) 20 *Psychiatry, Psychology and Law* 431; NA Kohn et al ‘Supported decision-making: A viable alternative to guardianship?’ (2013) 117 *Penn State Law Review* 1111; T Carney & F Beaupert, ‘Public and private bricolage– challenges balancing law, services and civil society in advancing CRPD supported decision-making’ (2013) 36 *University of New South Wales Law Journal* 175; E Flynn & A Arstein-Kerslake ‘The support model of legal capacity: Fact, fiction, or fantasy?’(2014) 3 *Berkeley Journal of International Law* 124; P Gooding, ‘Navigating the flashing amber lights of the right to legal capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to major concerns’ (2015) 15 *Human Rights Law Review* 45; T Carney ‘Clarifying, operationalising and evaluating supported decision making models’ (2014) 1 *Research and Practice in Intellectual and Developmental Disabilities* 46; Minkowitz (n 121 above); T Carney

The literature initially focused on interpreting the implications of article 12 of the CRPD[155] but after the CRPD Committee's General Comment No. 1 on article 12, literature contesting the CRPD Committee's construal of article 12 began to materialise.[156] Some of the literature have focused on the right to support in the exercise of legal capacity and supported decision-making for persons with intellectual disabilities.[157] The literature was of great use to this study. However, this study is an original contribution to scholarship on legal capacity because it examines the theoretic practicality of supported decision-making as a paradigm for protecting adolescent girls with intellectual disabilities from involuntary sterilisation. It marks a departure from the existing literature by assessing the views of respondents to the empirical research on the right of adolescent girls with intellectual disabilities to legal capacity and the viability of supported decision-making for them in the context of contraception. The respondents' views on the right to legal capacity and the viability of supported decision-making for the right of adolescent girls with intellectual disabilities are discussed in Chapter Seven of the study.

Several commentators have celebrated supported decision-making as representing a "paradigm shift" from substituted decision-making regimes.[158] However, this study supports the view of some scholars that implementing supported decision-making would be

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'Guardianship, citizenship and theorizing substitute decision making law' http://ssrn.com/abstract=2041103 (accessed 12 October 2017); M Browning et al 'Supported decision-making: Understanding how its conceptual link to legal capacity is influencing the development of practice' (2014) 1 *Research and Practice in Intellectual and Developmental Disabilities* 34; C Kong 'The convention for the rights of persons with disabilities and article 12: Prospective feminist lessons against the will and preferences paradigm' (2015) 4 *Laws* 709; T Carney 'Supported decision-making for people with cognitive impairments: An Australian perspective?' (2015) 4 *Laws* 37; A Arstein-Kerslake & E Flynn 'The general comment on article 12 of the Convention on the Rights of Persons with Disabilities: A roadmap for equality before the law' (2016) 20 *International Journal of Human Rights* 471; AS Kanter 'Expert opinion submitted to the Ontario Law Commission on its interim report on legal capacity, decision making and guardianship' (2016) http://www.cacl.ca/sites/default/files/uploads/Expert%20Opinon%20ASKanter%20-%20FINAL%20COPYRIGHT.pdf (accessed 12 October 2017); A Arstein-Kerslake 'Future directions in supported decision-making' (2017) 37 *Disability Studies Quarterly* http://dsq-sds.org/article/view/5070/4549 (accessed 08 July 2017); A Arstein-Kerslake *Restoring voice to people with cognitive disabilities: Realizing the right to equal recognition before the law* (Cambridge Disability Law and Policy Series) (2017); P Gooding *A new era for mental health law and policy: Supported decision-making and the UN Convention on the Rights of Persons with Disabilities* (2017).

[155] Dhanda (n 42 above) 429; Quinn (n 125 above); T Minkowitz 'Abolishing mental health laws to comply with Convention on the Rights of Persons with Disabilities' in B McSherry and P Weller (eds) *Rethinking rights based mental health laws* (2010) 151; Kanter (n 154 above).

[156] Browning et al (n 154 above) 34; Gooding (n 154 above) 45; Carney (n 154 above) 37.

[157] S Pathare & LS Shields 'Supported decision-making for persons with mental illness: A review' (2012) *Public Health Reviews 15*; N Devi 'Supported decision-making and personal autonomy for persons with intellectual disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities' (2013) 41 *Journal of Law, Medicine and Ethics* 792-806; K Glen 'Beyond guardianship: Supported decision-making by individuals with intellectual disabilities' http://supporteddecisions.org/wp-content/uploads/2015/09/Glen.Beyond-Guardianship.Briefing-Paper.pdf (accessed 12 October 2016).

[158] Arstein-Kerslake 'Future directions in supported decision-making' (n 154 above); Kohn et al (n 154 above) 1120; Dinerstein (n 42 above) 10.

challenging, especially for adolescents with intellectual disability. One area that is particularly challenging and highly contested is the interpretation of the will and preferences of persons with intellectual disabilities as provided by article 12 (3).[159] In interpreting article 12 (3), the CRPD Committee stated that "support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities" and never result in substitute decision-making.[160] However, determining the 'will and preferences' of persons with intellectual disabilities, especially girls with intellectual disabilities, is particularly challenging. As Tobin and Luke opine, "the reality is that for some women or girls with profound intellectual disability, substituted rather than supported decision-making will be inevitable, irrespective of the education or services afforded to them, or the granting of additional time in order to allow their capacities to evolve."[161] Similarly, Quinn is of the opinion that there may be circumstances where substituted decision-making would be employed in relation to persons whose will is imperceptible or to whom it is impossible to attribute a will or preference. Nevertheless, he opines that the fact that "decisions will be made 'for' and 'not' with them does not mean that substituted decision-making *as usual* is the correct response."[162] Gooding also asserts that determining the will and preferences of some persons with intellectual disability may be difficult.[163] Similarly, Arstein-Kerslake and Flynn point out that the Committee's interpretation does not adequately attend to all the situations where difficulties arise in determining a person's will and preferences.[164] As a response, the CRPD Committee states that "where, after significant efforts have been made" and it is impracticable to ascertain a person's will and preferences, the "best interpretation of will and preferences" should apply.[165] Still, the question that remains in such a situation is- how should the 'best interpretation of will and preferences' be deduced?

Undoubtedly, supported decision-making is a ground-breaking concept, but as this study highlights in Chapter Five, it is a nuanced and contested concept. The extent of the applicability of supported decision-making to children/adolescents with disabilities is not very clear. Petri observed that the Committee provides no guidelines on how to realise the

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[159] Convention on the Rights of Persons with Disabilities (n 1 above) article 12(3).

[160] General Comment No. 1 (n 34 above) para 17.

[161] J Tobin & E Luke 'The involuntary, non-therapeutic sterilisation of women and girls with an intellectual disability- can it ever be justified?' (2013) 3 *Victoria University Law and Justice Journal* 27, 37.

[162] Quinn (n 125 above) 13.

[163] Gooding (n 154 above) 54.

[164] Carney (n 154 above) 43; A Arstein-Kerslake & E Flynn 'The general comment on article 12 of the Convention on the Rights of Persons with Disabilities: A roadmap for equality before the law' (n 154 above) 482.

[165] General Comment No. 1 (n 34 above) para 21.

rights contained in article 12 of the CRPD in relation to children with disabilities.[166] This is further compounded by the CRPD Committee's interpretation of article 12 in relation to children with disabilities. Whilst acknowledging that children with disabilities have a right to equality before the law, the Committee precludes them from exercising the right by linking it to article 7 of the CRPD.[167] The Committee states that although article 12 applies to all persons, age notwithstanding, article 7 recognises the evolving capacities of children and the application of the best interests to them along with respect for their will and preference on the same basis as other children.[168] Thus, as Sandland observes, in applying 'will and preference' together with best interests to children with disabilities, the Committee seems to have merged the old paradigm of mental assessments tests and best interests with the new paradigm of support.[169]

Article 7 of the CRPD which is similar to article 12 of the CRC guarantees to children with the ability to form their own views, the right to express those views freely in all matters affecting them in accordance with their age and maturity.[170] However, as will be discussed in Chapter Five, article 12 of the CRPD goes beyond article 12 of the CRC by guaranteeing that "the will and preferences of children with disabilities are respected on an equal basis with other children."[171] As such, reference to 'the will and preferences' of children with disabilities in article 12 of the CRPD points to the application of the support paradigm to them.[172] Indeed, Sandland contends that the right to supported decision-making applies to, and is ideal for, children with disabilities.[173] In line with this, Minkowitz states that children have an 'evolving legal capacity' and should be provided with "age-appropriate support" to enable them "exercise their evolving legal capacity" and make decisions.[174] McCallum and Martin also argue that article 12 applies to children with disabilities.[175] This study subscribes to the views of Minkowitz, McCallum and Martin, Petri and Sandland in

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[166] G Petri 'Children with learning disabilities and their participation in judicial procedures– what can disability advocacy offer? (2017) 22 *Tizard Learning Disability Review* 10, 11.

[167] General Comment No. 1 (n 34 above) para 36; R Sandland 'A clash of conventions? Participation, power and the rights of disabled children (2017) 5 *Social Inclusion* 93, 96.

[168] General Comment No. 1 (n 34 above) para 36; Convention on the Rights of Persons with Disabilities (n 1 above) article 7(1) & (2).

[169] Sandland (n 167 above) 99.

[170] Convention on the Rights of the Child (1989) 28 ILM 1456, article 12.

[171] General Comment No. 1 (n 34 above) para 36; see also section 5.3 of the study.

[172] Sandland (n 167 above) 101.

[173] Sandland (n 167 above) 101.

[174] T Minkowitz 'Norms and implementation of CRPD article 12' https://papers.ssrn.com/sol3/Delivery.cfm?abstractid=2037452 (accessed 15 February 2015).

[175] R McCallum & H Martin 'Comment: The CRPD and children with disabilities' http://www.austlii.edu.au/au/journals/AUIntLawJl/2013/3.pdf (accessed 12 October 2017).

contending that the CRPD applies to adolescent girls with intellectual disabilities although with some challenges.

Most of the literature on supported decision-making also focus on adults with disabilities and overlook the fact that that children and adolescents with disabilities are also denied legal capacity on an unequal basis with other children and adolescents. The literature pay little or no attention to the potential of supported decision-making in promoting contraceptive decision-making for adolescents with disabilities including those with intellectual disabilities. Franklin and Sloper affirm this by stating that the knowledge regarding supported decision-making for adults "has remained rather polarised from that of children's participation."[176]

1.7. Theoretical framework

This section examines the theoretical framework of this study. It discusses the application of Foucault's writings and the social model of disability in analysing issues such as intellectual disability, legal capacity and supported decision-making.

1.7.1. A Foucauldian perspective

In part, this study is anchored on the critical theory of Foucault as it provides a veritable basis for analysing the issues for determination in the study. His works, particularly *Madness and civilisation*[177] and *Discipline and punish,*[178] can be considered historical examinations of the discourse on social conditions.[179]

Foucault is interested in how "the processes of exclusion" lead to the creation of certain discourses rather than others in a society.[180] According to him, "the production of discourse is at once controlled, selected, organised and redistributed by a certain number of procedures whose role is to ward off its powers and dangers, to gain mastery over its chance events, to evade its ponderous, formidable materiality."[181] He is not concerned with how

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[176] A Franklin & P Sloper 'Supporting the participation of disabled children and young people in decision-making' (2009) 23 *Children and Society* 3, 13.

[177] M Foucault *Madness and civilization: The history of insanity in the age of unreason* (1973).

[178] M Foucault *Discipline and punish: The birth of the prison* trans A Sheridan (1977).

[179] S Mills *Michel Foucault* (2003) 1.

[180] Mills (n 179 above) 67.

[181] M Foucault 'The order of discourse' in R. Young (ed) *Untying the Text: A post-structuralist reader* (1981) 52.

definitions or classifications of concepts come about, but on how they occur.[182] He argues that concepts change over time; they have a history and impetus for their use and so must be interrogated.[183] His work is therefore suitable for examining the discourse on intellectual disability, legal capacity and its attendant supported decision-making. This is because these concepts have been and are influenced by historic traditions, institutional structures and political processes which determine how a person is perceived in society. Foucault questioned traditional notions of the foundations of the 'clinic', contending that the clinic sought to classify and concretise social others.[184] Similarly, Carlson points out that intellectual disability defies a clear-cut, 'unequivocal' construction as its definitions and classifications are rife with contradictions and tensions which result in the exclusion of persons with intellectual disabilities.[185] The same can also be said for legal capacity which has been subject to various constructions which have resulted in the exclusion of persons with intellectual disabilities from acting as legal agents in their own affairs.

Foucault regards "knowledge as a form of power" and argues that "expert knowledge about human 'normality' and 'abnormality'" is the primary form of control in modern societies.[186] He does not believe that power could be defined free of its application in a social context. So, where there are "imbalances in power relations" between individuals and/or between institutions such as hospitals and schools, and/or the state, there will be production of knowledge.[187] This is because each institution had its own discourse and practice from which frameworks of knowledge were established and when these institutional discourses overlap, new forms of knowledge are created.[188] Chapter Two of this study shows that intellectual disability is a creation of imbalances in power between medical professionals and persons with intellectual disabilities resulting in the clinical construction of intellectual disability. In the same vein, power imbalances between legal professionals and persons labelled as incompetent gave rise to knowledge about the traditional conceptions to legal

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[182] B Berkovits 'Foucault, social construction and critique' in A Zaharijevic et al (eds) *Engaging Foucault vol 1* 58.
[183] Mills (n 179 above) 4.
[184] 'The contribution and impact of the work of Michel Foucault on the philosophy of law and politics' https://www.lawteacher.net/free-law-essays/general-law/jurisprudence-foucault.php (accessed 02 January 2017).
[185] L Carlson 'Docile bodies, docile minds: Foucauldian reflections on mental retardation' in S Tremain (ed) *Foucault and the government of disability* (2009) 134.135.
[186] P Conrad & KK Barker 'The social construction of illness: Key insights and policy implications' (2010) 51 *Journal of Health and Social Behaviour* S67, S 69.
[187] Mills (n 179 above) 69.
[188] McSherry (n 99 above) 84.

capacity discussed in Chapter Four. The intersection of discourses to create new forms of knowledge is also discernable from the findings in Chapter Seven.

Foucault also examined power relations within the family. He maintains that the family has its own discourse and emphasises parental control as a type of power mechanism in the familial context.[189] The parental control, which is usually exerted over children, is not essentially oppressive but involves a complex interaction between discipline and nurture.[190] This control over the child along with other intersecting discourses resulted in the distinction between the normal child and the abnormal child.[191]

Foucault's work on discourse and power is therefore appropriate for considering how knowledge about intellectual disability and legal capacity is produced, in what circumstances such knowledge is produced, whose interests it might serve, and how it is possible to think in a different way.[192]

1.7.2. The social model of disability- a functional disability model for persons with intellectual disabilities?

The prevalent approach to conceptualising disability is the social model of disability which establishes a link between disability and society. The social model of disability, which is based on 'materialist philosophy,'[193] was developed by the Union of the Physically Impaired against Segregation (UPIAS) and given prominence by Michael Oliver.[194] It was developed as a critique to the medical model of disability which identified disability as a medical problem inherent in the individual and portrayed persons with disabilities as 'lacking', in need of charity and unable to participate actively in society.[195]

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[189] n 99 above 60.

[190] M Foucault 'Polemics, politics and problematizations' in P Rabinow (ed) *Essential works of Foucault 1954-1984 vol 1- Ethics: Subjectivity and truth* trans R Hurley et al (1994) 298; M Foucault *The history of sexuality vol I: An Introduction* (2003) 110-114.

[191] McSherry (n 99 above) 62.

[192] Mills (n 179 above) 66.

[193] The model assumes according to the Marxist Philosophy that 'human nature and the resultant choices that individuals can make for themselves, are determined by the structure and ideology of society'. See R Lang 'The development and critique of the social model of disability' 10 http://www.ucl.ac.uk/lc-ccr/lccstaff/raymondlang/DEVELOPMMENT_AND_CRITIQUE_OF_THE_SOCIAL_MODEL_OF_D.pdf (accessed 13 June 2015).

[194] The term 'social model of disability' was not formulated by UPIAS in its 1976 document 'but was articulated by Michael Oliver in a paper in 1981. See C Barnes 'Understanding the social model of disability- past, present and future' in N Watson et al (eds) *Routledge Handbook of Disability Studies* (2012) 13.

[195] C Barnes 'The social model of disability: Valuable or irrelevant?' 2. http://citeseerx.ist.psu.edu/messages/downloadsexceeded.html (accessed 13 June 2015); Dewsbury et al 'The anti-social model of disability' (2004) 19 *Disability & Society* 145, 147; L McCarthy 'Disabling the medical

The social model, on the other hand, maintains that disability is not the product of biological taxonomy but is socially created by "systematic patterns of exclusion" engrained into society.[196] It emphasises that disabling environments, not impairment, disable persons with disabilities and calls for societal change in order to overturn the social, economic, political, attitudinal and cultural barriers they face.[197] The appeal of the social model therefore lies in its potential for advocating for the removal of barriers, restructuring persons with disabilities as rights holders and overcoming discrimination.[198] Although it appreciates the value of interventions centred on the individual, such as rehabilitation and employment, the social model also recognises the limitations of such interventions in empowering persons with disabilities.[199]

The social model has being acclaimed as the "big idea" of the disability rights movement; a "heuristic device" for appreciating the social nature of disability.[200] Nonetheless, the history of the disability rights movement and the early years of the development of the social model of disability show dominance by persons with physical disabilities and an emphasis on physical disabilities. This point is further buttressed by the fact that the symbol for disabilities in most countries of the world, including Nigeria, is the wheelchair, which signifies physical disability.[201] This raises the question whether the social model of disability– a model that was initially developed by and for persons with physical disabilities– is suitable for persons with intellectual disabilities and to what extent. In view of this, the merits and demerits of the model has been the subject of academic debates.

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model' (2008) 17 *Metascience* 207; M Oliver 'The social model of disability: Thirty years on' (2013) 28 *Disability and Society* 1026; Barnes (n 194 above) 14.

[196] Barnes (n 195 above) 2; World Health Organization 'ICD-10 guide for mental retardation' (1996) 20 http://www.who.int/mental_health/media/en/69.pdf (accessed 14 February 2015); K Paterson & B Hughes 'The social model of disability and the disappearing body: Towards a sociology of impairment' (1997) 12 *Disability and Society* 325, 328; J Owens 'Exploring the critiques of the social model of disability: The transformative possibility of Arendt's notion of power' (2015) 37 *Sociology of Health and Illness* 385.

[197] Union of the Physically Impaired against Segregation (UPIAS) 'Aims and policy statement' http://disability-studies.leeds.ac.uk/files/library/UPIAS-UPIAS.pdf (accessed 29 April 2015); H Hahn 'Public support for rehabilitation in programs: The analysis of US disability policy' (1986) 1 *Disability, Handicap and Society* 121,128; J Morris *Pride against prejudice: Transforming attitudes to disability'* (1991) 1-3; Lang (n 193 above) 2.

[198] JC Humphrey 'Researching disability politics, or, some problems with the social model in practice' (2000) 15 *Disability and Society* 63; T Shakespeare *Disability rights and wrongs revisited* (2014) 11.

[199] Union of the Physically Impaired against Segregation (UPIAS) *Fundamental principles of disability* (1976) 4; Barnes (n 195 above) 2; Lang (n 193 above) 2; T Shakespeare *Disability rights and wrongs* (2006) 30; Shakespeare (n 198 above) 16-17; Owens (n 196 above) 385.

[200] Barnes (n 194 above) 18; Oliver (n 195 above) 1024.

[201] AD Renteln 'Cross-cultural perceptions of disability' in SS Herr, HH Koh and LA Gostin (eds) *The human rights of persons with intellectual disabilities: Different but able* (2003) 60.

One of such merits is that it is based on the Marxist philosophy which underlines the impact of capitalism and industrialisation on persons with disabilities.[202] It highlights the oppression experienced by persons with intellectual disabilities culminating in institutionalisation, eugenics and control by the medical profession.[203] It also advocates for inclusion and non-discrimination, which are crucial for empowering persons with intellectual disabilities, who, like other disabled persons, experience marginalisation and discrimination in their lives.[204]

On the other hand, the social model was primarily developed by and for persons with physical disabilities whose experiences are fundamentally different from the experiences of persons with intellectual disabilities. This is buttressed by the fact that membership into UPIAS was only open to persons with physical disabilities and the principles, discussions and thoughts that guided the development of the social model was organised by them.[205] The terms ‘physically impaired people’ and ‘physical disability’ were also extensively used in the UPIAS founding document and principles.[206] Moreover, the UPIAS principles evidently took into consideration only persons with physical disabilities in distinguishing between ‘physical impairment’ and ‘disability’– a distinction that enabled the advancement of the social model of disability.[207] Impairment was defined in the UPIAS principles as “lacking part or all of a limb, or having a defective limb, organism or mechanism of the body.”[208] Disability was also defined “as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have *physical impairments* and thus excludes them from participation in the mainstream of social activities.”[209] Although the restriction to ‘physical disabilities’ was subsequently removed,[210] the definitions show that little or no consideration was initially given to intellectual disability and persons with intellectual disabilities.[211] Furthermore, there seems to be a hierarchy of impairments within

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[202] K Stalker ‘Theorizing the position of people with learning difficulties within disability studies- progress and pitfalls’ in N Watson et al (eds) *Routledge handbook of disability studies* (2012) 122.

[203] n 202 above 122.

[204] n 202 above 122.

[205] Union of the Physically Impaired against Segregation (n 197 above) para. 27. Although the statement called for alliances with other disabled peoples’ groups as well as non-disabled people, only persons with physical disabilities could join UPIAS at the time.

[206] Union of the Physically Impaired against Segregation (n 199 above) 4.

[207] D Race et al ‘Towards a dialogue for practice: Reconciling social role valorization and the social model of disability’ (2005) 20 *Disability and Society* 507, 514.

[208] Union of the Physically Impaired against Segregation (n 199 above) 14.

[209] Union of the Physically Impaired against Segregation (n 199 above) 14.

[210] C Barnes ‘A working social model? Disability, work and disability politics in the 21st century’ (2000) 65 *Critical Social Policy* 441, 442.

[211] Stalker (n 202 above) 122.

the disability rights movement, with persons with physical and sensory impairments dominating and persons with intellectual disabilities ranking at the lowest rung.[212] They are usually not included by other disabled people in the disability rights movement. For instance, persons with intellectual disabilities and/or their advocates are hardly included in the activities of the Joint National Association of Persons with Disabilities, (JONAPAD), the umbrella disability organisation, in Nigeria.

Another shortcoming of the social model for persons with intellectual disabilities is its failure to recognise the impact of impairment as against disability. Impairment has been defined as the "functional limitation" arising from physical, mental or sensory deficiency while "disability is the loss or limitation" of prospects to participate in society on account of social barriers.[213] Even so, disability has always existed at the intersection between impairment, society's construal of impairment as well as the political and economic contexts of disability.[214] Even as persons with intellectual disabilities are disabled by societal barriers, their intellectual impairment is also a major effect of their disability.[215] The dichotomy between impairment and disability therefore fails to appreciate that their impairment, as well as socio-economic barriers constitute disability for persons with intellectual disabilities, a view recognised by the CRPD and International Classification of Functioning, Disability and Health (ICF).[216] For persons with intellectual disabilities, stigma and discrimination are often intertwined with their impairment and the difficulties they encounter because their impairment cannot be easily resolved by "social manipulation."[217] Feminist disability authors such as Morris, French, Corker and Crow have argued that distinguishing impairment from

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[212] T Shakespeare 'Social models of disability and other life strategies' (2004) 6 *Scandinavian Journal of Disability Research* 8, 13; Stalker (n 202 above) 125.

[213] C Barnes *Disabled people in Britain and discrimination* (1991) 2.

[214] GL Albrecht et al 'The shaping of disability studies as a field: An institutional history of disability' in GL Albrecht et al (eds) *Handbook of disability studies* (2001) 24.

[215] DA Goodley 'Learning difficulties, the social model of disability and impairment: Challenging epistemologies' (2001)16 *Disability & Society* 207, 213; Race et al (n 207 above) 515-516; S Vehmas 'What can philosophy tell us about disability?' in Nick Watson et al (eds) *Routledge handbook of disability studies* (2012) 303; Shakespeare (n 198 above) 13-14.

[216] T Shakespeare & N Watson 'The social model of disability: An out-dated ideology' in SN Barnartt and BM Altmam (eds) *Research in Social Science and disability* (vol 2) (2001) 18; Shakespeare (n 212 above) 13; AM Samaha 'What good is the social model of disability?' (2007) 74 *The University of Chicago Law Review* 1251, 1262; L Terzi 'The social model of disability: A philosophical critique' *(2004) 21 Journal of Applied Philosophy* 141, 152; Convention on the Rights of Persons with Disabilities (n 1 above) preamble para e; World Health Organization *International classification of functioning, disability and health* (ICF) (2001) 18-20.

[217] S French 'Disability, impairment or something in between?' in J Swain et al (eds) *Disabling barriers, enabling environments* (1993) 17; Shakespeare (n 199 above) 22.

disability negates the experiences of persons with disabilities.[218] They argue that some impairment have significant impact on the lives of persons with disabilities irrespective structural and social settings.[219] Similarly, Degener in her discourse on the human rights model of disability acknowledges that the social model of disability neglects the impact of "pain, deterioration of quality of life and early death due to impairment and dependency."[220] For persons with intellectual disabilities, although experiences of denial of capacity, exclusion and violence are socially constructed, they remain rooted in biology and medicine.[221] Goodley contends that the "transformation" envisaged by the social model is largely untenable for persons with intellectual disabilities because of their dependence on others for support.[222] Shakespeare also argues along those lines by asserting that their impairment and the experiences arising thereof cannot be seen as purely biological or social, but as 'complex bio-social phenomena'.[223] According to Shakespeare, "context is important" as persons with disabilities are heterogeneous with diverse needs and impairments.[224] Thus, the removal of socio-economic barriers, if possible, may not necessarily signify the end of disability for persons with intellectual difficulties.

The social model also seems to have relegated the impact of "culture and cultural processes in the creation of disability."[225] In neglecting the impact of culture and cultural processes on intellectual disability, it disregards their role in shaping society which in turn impacts on how persons with intellectual disabilities are treated in the society.[226] For instance, in Northern Nigeria, disability is seen as the will of 'Allah' and persons with disabilities, including those with intellectual disabilities, are usually not socially excluded from their communities.[227] In such communities, whilst persons with intellectual disabilities may not experience socio-cultural barriers, they may experience difficulties in their daily lives because of their impairment.

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[218] Morris (n 198 above) 10; French (n 217 above) 17; M Corker *Deaf and disabled or deafness disabled?* (1998) 38; L Crow 'Including all of our lives: Renewing the social model of disability' 3-5 https://www.researchgate.net/profile/Liz_Crow/publication/246453360_Including_All_of_Our_Lives_Renewing_the_Social_Model_of_Disability/links/572e16e108aeb1c73d12936e/Including-All-of-Our-Lives-Renewing-the-Social-Model-of-Disability.pdf?origin=publication_detail (accessed 31 May 2018).

[219] D Anastasiou & JM Kauffman 'The social model of disability: Dichotomy between impairment and disability' (2013) 38 *Journal of Medicine and Philosophy* 441, 450.

[220] T Degener 'Disability in a human rights context' (2016) 5 *Laws* 35.

[221] Stalker (n 202 above) 124.

[222] Goodley (n 215 above) 213.

[223] Shakespeare (n 199 above) 132.

[224] Shakespeare (n 212above) 15.

[225] Goodley (n 215 above) 225.

[226] Goodley (n 215 above) 225.

[227] Koran 2:273; Koran 42:27; Abang (n 134 above) 73.

In response to the shortcomings of the social model, some disability authors have called for a reconstruction or abandonment of the social model of disability to include the experience of disability and impairment.[228] For instance, Morris developed a theory called "impairment effects" which she defines as "the direct and unavoidable impacts that impairments have on individuals' embodied functioning in the social world".[229] According to her, impairment and impairment effects are usually "bio-social and culturally" constructed.[230] Similarly, Swain and French call for an affirmative model of disability "borne of disabled people's experiences as valid individuals, as determining their own lifestyles, culture and identity."[231] The ICF incorporates the medical model and the social model and adopts a "bio-psycho-social approach" so as to "achieve a synthesis, in order to provide a coherent view of different perspectives of health from a biological, individual and social perspective."[232] Thus, the ICF recognises the impact of health conditions and environmental factors in the construction of disability, and that such conditions and factors interact to influence the level and extent of a person's functioning.[233] Shakespeare and Watson call for a complete abandonment of the social model because they believe that it cannot be reformed.[234] In contrast, Oliver argues that focusing on impairment de-politicises the social model of disability and will not result in the development of alternative models or approaches.[235]

Perhaps the problem with the social model of disability stems from the fact that it tries to bring together people with different disabilities, different identities, and different experiences under one model that suppresses their identities and experiences diverse needs. So, in adopting such a simplistic approach to disability, it is guilty of over-socialisation and over-generalisation.[236] As Fraser notes, creating a single identity for groups of people will amount to a denial of the complexity of their lives, their identities and affiliations.[237] Thus, an inclusive disability model or theory must recognise the interaction between impairment and society and also accommodate the experiences of persons with intellectual disabilities to ensure their equal treatment with others in the society. The human rights model of disability

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[228] Crow (n 218 above) 5.
[229] J Morris 'Disability and impairment' in J Swain et al *Disabling barriers- enabling environments* (2014) 14.
[230] n 220 above 14.
[231] J Swain & S French 'Towards an affirmation model of disability' (2000) 15 *Disability & Society* 569, 578.
[232] World Health Organization (n 216 above) 20.
[233] World Health Organization (n 216 above) 16-19.
[234] Shakespeare & Watson (n 212 above) 20.
[235] Oliver (n 195 above) 1025.
[236] M Corker & T Shakespeare 'Mapping the terrain' in M Corker & T Shakespeare (eds) *Disability/postmodernity: Embodying disability theory* (2002) 15; Terzi (n 216 above) 153.
[237] N Fraser 'Rethinking Recognition' (2000) 3 *New Left Review* 107, 112.

is such a model. Degener in advocating for the human rights model of disability states that unlike the social model, the human rights model acknowledges life circumstances of persons with disabilities and "demands them to be considered when social justice theories are developed."[238] According to her, the human rights model of disability "encompasses values for disability policy that includes human dignity", "does not require the absence of impairment" and "defies the presumption that impairment may hinder human rights capacity."[239] In as much as like the social model it recognises that the interaction between impairments and attitudinal and environmental barriers disables a person,[240] the human rights model goes beyond the social model and is a more inclusive approach as it applies to all categories of disabilities including persons with intellectual disabilities. Thus, it recognises that the removal of impairment and/or the removal of barriers on its own is not sufficient but that the provisions in human rights laws such as the right to support in the exercise of legal capacity is required. It recognises that disability is a social construct and that impairment should not be used as the basis for denying human rights.[241] Accordingly, the CRPD is an embodiment of the human rights model as it aims to ensure the full and equal enjoyment of rights by persons with disabilities and respect of human dignity.[242] It focuses on equal opportunities, non-discrimination on the basis of disability and participation in society.

1.8. Significance of the research

This study critically assesses whether supported decision-making is suitable in safeguarding the legal capacity of adolescent girls with intellectual disabilities in Nigeria with regards to decision-making about sterilisation. In doing this, it examines the prevailing attitudes of parents and professionals towards the involuntary sterilisation of adolescent girls with intellectual disabilities in Nigeria. The issue of supported decision-making with regards to decision-making for medical interventions such as sterilisation is currently a topical issue around the world but there is little scholarship on the issue in Nigeria. The study therefore contributes to existing literature by presenting a Nigerian context to the issue.

The study also assesses the theoretic practicability of supported decision-making in protecting adolescent girls with intellectual disabilities from involuntary sterilisation in

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[238] Degener (n 220 above).
[239] n 220 above
[240] Convention on the Rights of Persons with Disabilities (n 1 above) preamble (e).
[241] Committee on the Rights of Persons with Disabilities 'Article 5: equality and non-discrimination' (2018) CRPD/C/GC/6 (General Comment No. 6) para 9.
[242] n 220 above

Nigeria. Accordingly, it presents a view on the complexities envisaged in the implementation of supported decision-making in an African-Nigerian context and for adolescents with intellectual disabilities. The supported decision-making paradigm is one of the ground-breaking human rights concepts of the 21st century and yet there is lack of supporting empirical research on the issue.[243] This study fills the gaps by undertaking an empirical research to garner respondents' views on the viability of supported decision-making in the Nigerian context. So the study engages in the social auditing of law and advances a legal jurisprudence on the protection of adolescent girls with intellectual disabilities from involuntary sterilisation in Nigeria. In general, the study is expected to contribute to the development of literature on supported decision-making in Africa in general, and Nigeria, in particular.

1.9. Scope and limitations of the study

This study is limited in scope. In essence, it studies the implication of advancing supported decision-making for adolescent girls with intellectual disabilities. This means that the study focused primarily on adolescent girls with intellectual disabilities. Although adolescent boys with intellectual disabilities may be subjected to sterilisation, they are not included in the study.

The empirical component of the study is also limited in terms of its geographical scope to southern Nigeria and specifically to two states of each of the three geo-political zones in southern Nigeria. So Northern Nigeria is outside the scope of the study. Additionally, the empirical component of this study was restricted to a selection of hospitals, schools and special education centres in the selected states.[244]

Another limitation of the study is that it sets out to critically assess 'supported decision-making' at a time that the concept is still in the process of development. Thus, evaluating the application of a concept which is still unravelling and for which there is not yet a complete picture is limiting.

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[243] Advocacy for Inclusion 'Supported decision making, legal capacity and guardianship- implementing article 12 of the Convention on the Rights of Persons with Disabilities in the Australian capital territory' 32 http://www.advocacyforinclusion.org/publications/supported_decision_making_legal_capacity_and_guardianship2012final.pdf (accessed 16 October 2016).

[244] See Chapter Six on for the discussion on the methodology of the empirical component of this study.

1.10. Overview of chapters

This study is structured into eight chapters. Chapter One provides a general introduction and overview to the study. It outlines the background to the study, explains the terminologies used and examines the construct of intellectual disability, statement of the problem, methodology, theoretical framework, significance of the study, scope of the study and ethical considerations.

Chapter Two conceptualises intellectual disability. It examines how intellectual disability was and is constructed in Nigeria from the pre-colonial era to the colonial and post-colonial eras. Issues surrounding the monopoly of the classification, eventual medicalisation and diagnosis of intellectual disabilities eminent in the social construction of intellectual disabilities are discussed.

Chapter Three examines the concept of equality. It explores the theories and types of equality and their import for persons with intellectual disabilities. The chapter examines what equality entails for adolescent girls with intellectual disabilities. It also discusses sterilisation as inequality and discrimination for adolescent girls with intellectual disabilities.

Chapter Four examines the concept of legal capacity. It examines the traditional notions of intellectual disability and the CRPD's construction of intellectual disability. It also examines what legal capacity entails for adolescent girls with intellectual disabilities especially in the light of the article 12 of CRPD and the CRPD Committee's interpretation of legal capacity.

Chapter Five examines the concept of supported decision-making and what it entails for adolescent girls with intellectual disabilities. It examines the challenges in implementing supported decision-making for adolescent girls with intellectual disabilities in Nigeria.

Chapter Six contains a detailed analysis of the empirical research, the objectives of the research and its research methodology.

Chapter Seven discusses the results of the empirical research. It elaborates on the findings garnered from the data obtained from the empirical component of this research using the research questions of the study as themes for discussing the findings.

Chapter Eight consists of the summary, recommendations and final conclusion of the study. The recommendations proffered are intended to contribute to the debate on supported decision-making.

CHAPTER TWO

DECONSTRUCTING INTELLECTUAL DISABILITY

2.1. Introduction

> The changing definitions of difference constitute the history of mentally handicapped people. These definitions have always been conceived of by others, never are they the expression of a group of people finding their own identity, their own history. The assertion of difference between people is seldom neutral; it almost always implies some kind of social distance or distinction. The differences between mentally handicapped people and others have mostly been seen negatively, making them a problem to themselves and to others. Only in a few instances has the ''otherness'' of mentally handicapped people been valued positively or respected.[1]

This chapter examines the concept of intellectual disability with a view to deconstructing the ideologies inherent in the concept. The manner in which persons with intellectual disabilities are regarded in terms of their autonomy, self-determination and decision-making reflects how their disability is construed. Thus, what it means, how it is measured and who is regarded as having an intellectual disability, is historically and culturally contingent, and largely dependent on the approach adopted by a society.[2] This in turn impacts on who is regarded as having or lacking legal capacity, the type of education they receive, their eligibility for support services and on other aspects of their lives, including healthcare.[3] The construction of intellectual disability has also influenced sterilisation policies. Historically, sterilisation policies authorised the involuntary sterilisation of persons labelled as having intellectual disability in the guise of eugenics or that it was for their best interests.

This chapter, therefore, seeks to answer these questions:

a. How has intellectual disability been construed over time?

b. What is or has been the impact of such constructions of intellectual disability on persons with intellectual disabilities?

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[1] J Ryan & F Thomas *The politics of mental handicap* (Revised edition) (1987) 13.

[2] P Louhiala *Preventing intellectual disability: ethical and clinical issues (2004) 8*; A Dimopoulos *Issues in human rights protection of intellectually disabled persons* (2010) 9; L Carlson *The faces of intellectual disability* (2010) 93; S Lara 'Intellectual disability: Definition, classification and assessment' http://www.iidd.wisc.edu/sites/vanhise.lss.wisc.edu.iidd/files/a/Int_Disab_Head_lecture.ppt (accessed 22 March 2014).

[3] A Bray 'Definitions of intellectual disability- review of the literature prepared for the national advisory committee on health and disability to inform its project on services for adults with an intellectual disability' (2003) http://www.nhc.govt.nz (accessed 22 March 2014).

Accordingly, the study draws from studies by psychologists, psychiatrists, medical practitioners, legal practitioners, sociologists, anthropologists, feminists, poststructuralists and critical disability studies. It presents an account of how intellectual disability has and is construed in Nigeria. This is because most of the literature on intellectual disability depicts intellectual disability from a Western perspective. Even when an African perspective is presented, it is usually assumed that disability is always construed negatively.[4] This has resulted in cultural imperialism in the discourse of intellectual disability. As such, an examination of the historic contexts in the construction of intellectual disability is important in any discourse on intellectual disability. As Barclay points out “rethinking historical assumptions challenges us to seek more clarity into which embodied qualities constituted impairment, disability, and ability at different historical moments and in different cultural spaces.”[5]

This chapter also assesses how the standards set out in diagnostic manuals by professional organisations affect the quality of life of persons with intellectual disabilities. It argues that although the diagnostic manuals have their uses, they have become instruments of medicalisation in the lives of persons with intellectual disabilities. This has resulted in problems of conceptual and definitional clarity, thereby rendering intellectual disability a highly contested concept.[6] Thus, since intellectual disability is nuanced and constantly evolving, current approaches may not be suitable for the future. It further examines how intellectual disability has and is been construed over time the relationship between such constructions and how persons with intellectual disability have been and/or are treated.

It must be noted that terms such as ‘idiocy’, ‘idiots’, ‘imbecile’, ‘feebleminded’, ‘feeblemindedness’, ‘moron’, ‘mental deficiency’ ‘mental disorder’ and ‘mental retardation’, are used in this chapter merely to reflect the language of their time of usage. They are not a reflection of the views held in this study.

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[4] JL Barclay ‘Differently abled: Africanisms, disability, and power in the age of transatlantic slavery’ in JF Byrnes & JL Muller (eds) *Bioarchaeology of impairment and disability: Theoretical, ethnohistorical and methodological perspectives* (2017) 82.

[5] Barclay (n 4 above) 79.

[6] RM Garigiulo *Special education in contemporary society: An introduction to exceptionality* 4th ed (2010) 142.

2.2. Historic account of intellectual disability in Nigeria

The earliest recorded historical account of intellectual disability is attributed to the Egyptian Papyri of Thebes in 1552 in reference to brain damage.[7] Although intellectual disability has probably always existed as a human condition in Nigeria, there is little historical account of intellectual disability before the pre-colonial era despite evidence alluding to the existence of settlements dating back to 9000 BC.[8] This is because every community has its cultural interpretation of diseases and disabilities.[9] So what amounts to intellectual disability and the societal response to it varies from locale to locale and from culture to culture, illustrating Foucault's view that for every issue several responses can be produced.[10] So, past and prevalent cultural beliefs determine how intellectual disability is construed as well as the status of persons with intellectual disabilities.[11] Some of these cultural beliefs result in negative attitudes towards persons with intellectual disability while some result in positive attitudes.[12] There is a therefore a link between societal perceptions of intellectual disability and social disposition towards persons with intellectual disabilities. This in turn influences how the concept of personhood is denoted as well as the socio-economic organisation of the society.

Similarly, the language of people in a society also reflects their perception of intellectual disability. This is because language is the instrument through which culture is transmitted from generation to generation and provides an insight into the historic and prevalent attitudes in any given society.[13] One way of orally transmitting and preserving

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[7] JC Harris *Intellectual disability: Understanding its development, causes, classification, evaluation, and treatment* (2006) 13.

[8] T Shaw & SHG Daniels 'Excavations at Iwo Eleru, Ondo State' (1984) 14 *West African Journal of Archaeology* cited in AI Okpoko 'Archaeology and the study of early urban centres in Nigeria' (1998) 19 *African Study Monographs* 35, 48; 'Pre-Historic Nigeria: Iwo-Eleru, Akure, Ugwuelle-Uturu' http://www.nok-benin.co.uk/history_nok.htm (accessed 09 September 2016).

[9] I Illich *Limits to medicine- medical nemesis: The expropriation of health* (1976) 44; PK Dalal & T Sivakumar 'Moving towards ICD-11 and DSM-V: Concept and evolution of psychiatric classification' (2009) 51 *Indian Journal of Psychiatry* 310, 314.

[10] M Foucault 'Polemics, politics and problematizations' in P Rabinow (ed) *Essential works of Foucault 1954-1984 vol. 1- Ethics: Subjectivity and truth* trans R Hurley et al (1994) 118.

[11] M Eskay et al 'Disability within the African culture' (2012) B4 *US-China Education Review* 473, 477; S Edwardraj et al 'Perceptions about intellectual disability: A qualitative study from Vellore, South India' (2010) 54 *Journal of Intellectual Disability Research* 736.

[12] M Eskay et al 'Culture and disability' http://twren.sites.luc.edu/phil389&elps423/c&d.htm (accessed 09 September 2016).

[13] W Gellman 'Roots of prejudice against the handicapped' (1959) 25 *Journal of Rehabilitation* 4; J Kisanji 'Culture and disability: An analysis of inclusive education based on African folklore' presented at the International expert meeting and symposium on local concepts and beliefs of disability in different cultures at Bonn, Germany on 21 - 24 May 1998, 4; EUC Ezejideaku 'Disability and the disabled in Igbo proverbs' (2003) 20 *Proverbium* 163; FE Obiakpor et al 'Special education in Nigeria: Shifting paradigms' in K Mutua & CS

historical accounts through language is by way of proverbs. The use of proverbs in Nigeria dates back to the pre-colonial/pre-literate era.[14] They are statements that contain "wisdom, truths, morals, experiences, lessons, advice" and philosophies of a people passed on from one generation to another.[15] They are a veritable source of information on the perception of intellectual disability in traditional Nigerian societies.[16] So, the historical and prevalent construction of intellectual disability in Nigeria is discussed hereunder.

2.2.1. Pre-colonial era (1500-1900)

Pre-colonial Nigeria comprised diverse ethnic groups with different cultural, religious and socio-economic backgrounds.[17] There was no homogenous attitude towards disability as each ethnic group had its beliefs about disability and attitudes towards persons with disabilities were either positive or negative.[18] This reflects the construction of intellectual disability in the sixteenth to nineteenth centuries where superstitious beliefs were prevalent and attitudes towards persons with intellectual disabilities were either positive or negative depending on such beliefs.[19]

Historical accounts of two ethnic groups in Nigeria, the Igbo and the Yoruba, in Southern Nigeria, indicate that their perceptions of intellectual disability are rooted in cultural and religious beliefs. An examination of some proverbs from the Igbo and the Yoruba also provides an insight on how intellectual disability was perceived. This study focuses on the Igbo and the Yoruba because they are the two largest ethnic groups in southern Nigeria, the site of the empirical component of this study.[20]

Sunal (eds) *Advances in research and praxis in special education in Africa, Caribbean, and the Middle East* (2012) 32.

[14] O Abayomi 'Philosophical significance of Yoruba proverbs' http://www.academia.edu/3397082/Philosophical_Significance_of_Yoruba_Proverbs (accessed 30 August 2017).

[15] W Mieder 'Popular views of the proverb' (1985) 2 *Proverbium* 109, 117.

[16] Ezejideaku (n 13 above) 160-161.

[17] Library of Congress 'Country profile: Nigeria' (July 2008) https://www.loc.gov>frd>Nigeria (accessed 15 July 2016).

[18] BL Yaksat & KE Hill 'Strategies for involving parents of visually impaired children, professionals, and the wider community as partners in achieving full access to education for these children' www.icevi.org/publications/icevix/wshops (accessed 15 July 2016).

[19] GL Albrecht et al 'The shaping of disability studies as a field: An institutional history of disability' in GL Albrecht et al (eds) *Handbook of disability studies* (2001) 24-36; Harris (n 7 above) 14-17; Carlson (n 2 above) 23; RJ Franzese *The sociology of deviance: Differences, tradition, and stigma* (2009) 201; SB Richards et al *Cognitive and intellectual disabilities: Historical perspectives, current practices and future directions* (2nd ed) (2015) 8.

[20] The empirical component of this study, which is discussed in Chapters Six and Seven, was conducted in Southern Nigeria. The Yoruba are the largest ethnic group in southwest Nigeria and the Igbo (Ibo) are the

2.2.1.1. The Igbo

The Igbo in the south-east and south-south of Nigeria attributed intellectual disabilities to a variety of spiritual causes such as “curse from the gods”, witchcraft, spells, evil spirits or retribution for the wrongdoings of their parents or ancestors.[21] According to Ezejideaku and Sango, children with intellectual disabilities were considered worthless[22] and were either killed or abandoned.[23] However, this might be an overgeneralisation given that there are different degrees of disabilities. Thus, children with intellectual disability who require intermittent and limited support may not have been killed or abandoned as mild and moderate forms of intellectual disability would likely have fallen under the radar is preliterate societies. Families of persons with disabilities with extensive and pervasive support needs also resorted to traditional healers who often employed unconventional methods of treatment such as the cutting and application of herbs into the scalp of the disabled person and flogging.[24] This is similar to how ancient Greeks and Romans construed intellectual disability in terms of the spiritual and the abnormality.[25] Clearly, in ancient societies, cultural and social ideals rooted in beliefs in the ‘perfect body’ determined their attitudes towards the body considered to be flawed.[26]

Status also influenced the outlook towards intellectual disability as a person with intellectual disability from a royal or ruling clan was most likely to be treated with more respect than someone who was not from a royal or ruling clan.[27] It was also commonplace for

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largest in southeast Nigeria. See ‘Nigeria fact sheet’ https://photos.state.gov/libraries/nigeria/487468/pdfs/Nigeria%20overview%20Fact%20Sheet.pdf (accessed 28 May 2018); ‘Largest ethnic groups in Nigeria’ https://www.worldatlas.com/articles/largest-ethnic-groups-in-nigeria.html (accessed 28 May 2018). More so, the constitution permits the National Assembly to conduct its business in English as well as Hausa, Yoruba and Igbo. See The Constitution of the Federal Republic of Nigeria of 1999 Cap C23, LFN 2004, section 55. Similarly, the National Policy on Education requires that every child learn any of three Nigerian languages: Hausa, Igbo and Yoruba. See Federal Republic of Nigeria, National Policy on Education (4th ed) (2004), section 10 (a).

[21] VO Imade ‘Awakening hope: A critical analysis of the stigmatization of children with disabilities in Nigerian families and communities’ Master of Arts thesis, York University, 2017, 31; Sango ‘Country profile: Intellectual and developmental disability in Nigeria’ (2017) 22 *Tizard Learning Disability Review* 87.

[22] Ezejideaku (n 13 above) 159.

[23] Sango (n 21 above) 88.

[24] Sango (n 21 above) 87-88.

[25] Harris (n 7 above) 13; C Laes et al *Disabilities in Roman antiquity: Disparate bodies a capite ad calcem* (2013) 21.

[26] J Lorber & PY Martin ‘The socially constructed body: Insights from feminist theory’ in P Kivisto (ed) *Illuminating social life: Classical and contemporary theory revisited (6th ed) (2013) 249, 251.*

[27] This was garnered during the empirical component of this study.

wealthy or affluent families to marry wives for their male relatives with intellectual disabilities, a practice which is still on-going in some parts of Nigeria.[28]

An examination of some Igbo proverbs also shows how intellectual disability was construed:

1. ‘A muta amaghi ihe na ume omumu bu otu’
   (To beget an imbecile is as good as being barren)

2. ‘Nke onye ge ji mụa *ọzuaị*, ya mụa oshi, maka na oshi zu sia obu bo *ọzuaị*’
   (It is better to have a thieving child than an imbecile because the thieving child would steal and claim it is the imbecile that stole)

3. ‘Wạ negbu ọzuaị, ọzuaị ne egbu nwa’
   (When you beat an imbecile, it beats its own child)

4. ‘Wa tigbue ọzuaị amali wa na ọzuaị nwe ebo’
   (When you kill an imbecile, you will get to know that he or she has a clan/lineage)

5. ‘Onye mu ọzuaị ka onye aga mma’
   (The mother of an imbecile is better than the barren woman)

The reference to ‘imbecile’ in the Igbo proverbs seems to imply a form of intellectual disability requiring extensive and pervasive support and not just any intellectual disability because intellectual disability requiring intermittent support would probably have been unnoticed in pre-historic societies. The first proverb is negative as it indicates that to the Igbo, a child with intellectual disability who requires extensive support is useless and worthless such that having a child with such disability is as good as having no child at all.[29] The second proverb is negative and indicates that the Igbo consider children with intellectual disability who require extensive support useless and incapable of asserting themselves. So it is preferable to have a thief for a child than a child with intellectual disability who requires extensive support. The third proverb is also negative as it shows that persons with intellectual

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[28] IJ Ihenacho *Introduction to special education in Nigeria: Historical and sociological perspectives* (1985) 6.

[29] Ezejideaku (n 13 above) 163.

disability who require extensive support are stupid because rather than face the person beating them, they would rather beat their children.

Conversely, the fourth and fifth proverbs have some positive connotations. The fourth proverb shows that irrespective of their disability, they can rely on their families to stand up for them when they are harmed. The fifth proverb indicates that it is better to have a child with intellectual disabilities than to have no child at all (be barren).

2.2.1.2. The Yoruba

The Yoruba in South-west Nigeria had mixed attitudes towards persons with disabilities, including those with intellectual disabilities.[30] Some Yoruba ethnic groups had an altruistic attitude and believed that *Obatala,* the creator, was responsible for creating disability and charged that persons with intellectual disabilities be treated humanely.[31] However, other groups regarded persons with disabilities as “punishment from the gods” or “wrath of the gods.”[32] In communities where persons with intellectual disabilities were regarded as punishment from the gods, they were particularly treated worse than those with physical disabilities and subjected to stigma.[33]

An examination of the following Yoruba proverbs also shows that their attitude towards persons with intellectual was either negative or positive.

1. Omọgo eni ki o ma ku, kin i o pa ọmọ bi ko se ago
   (One would not lose anything if an imbecile dies)

2. Akuku bi sanju radarada ọmọ
   (It is better to be childless than have an imbecile (incomplete child))

3. Ọmọ ku, ọmọ o ye, a o si ki olọmọ ku ewu ọmọ
   (No matter how disabled a child is, the child will still bear his/her father’s name)

4. Ọmọ eni ko ni sedi bebere ki afi ileke si idi elomiran
   (No matter how one’s child is, one would not replace him/her with someone else’s child)

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[30] TB Abang ‘Disablement, disability and the Nigerian society’ (1988) 3 *Disability Handicap and Society* 71, 73.

[31] Abang (n 30 above) 73; Barclay (n 4 above) 83.

[32] Obiakpor et al (n 13 above) 32.

[33] Obiakpor et al (n 13 above) 32.

Like the Igbo proverbs, 'imbecile' in the Yoruba proverbs seems to imply a severe form of intellectual disability and not just any intellectual disability. The first and second proverbs portray negative attitudes towards persons with intellectual disabilities while the third and fourth proverbs indirectly portray positive attitudes. The first proverb indicates that the Yoruba consider persons with intellectual disabilities worthless and that their death means nothing. The second proverb points to the belief that rather than having a child with intellectual disability, it is better to be childless (like an Igbo proverb indicates). The third proverb shows that in spite of their disability, children with disabilities would always be regarded as parts of their families. The fourth proverb indicates that a child is a child irrespective of its disability.

The pre-colonial era also marked the advent of Christianity into southern Nigeria by European missionaries between 1815 and 1880.[34] Spirituality in understanding disability and Christian charity in caring for persons with intellectual disabilities were greatly emphasised in the Christian doctrine as the Bible urges Christians to "comfort the feebleminded."[35] In view of that, some Christian groups treated persons with intellectual disability as persons in need of assistance. As such, it could be argued that the Christian doctrine brought in and fostered the dependence on charity and benevolence[36] which still prevails in Nigeria today.

In contrast, disability was construed by some Christian groups in Nigeria as resulting from possession by evil spirits or demons and/or as a punishment for Adam's original sin.[37] Accordingly, persons with disabilities were subjected to prayers and services to 'cast out' the devil spirits and demons, a practice still on-going in some parts of southern Nigeria. Christian reformers like John Calvin and Martin Luther held similar viewpoints in Britain between the sixteenth and eighteenth centuries.[38]

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[34] Sango (n 21 above) 89.

[35] Thessalonians 5:14 (King James Version Bible); Ihenacho (n 28 above) 13; Sango (n 21 above) 89; M Miles 'Some influences of religions on attitudes towards disabilities and people with disabilities' (2-3) *Journal of Religion, Disability and Health* 117, 121; NL Eiesland *The disabled God: Toward a liberatory theology of disability* (1994) 73.

[36] A Downing 'Power and disability in the global south: A case study of Ghana's disability rights movement' unpublished Master's Thesis, Lund University, 2011, 7.

[37] Sango (n 21 above) 89.

[38] G Grant et al (eds) *Learning disability: A life cycle approach to valuing people* (2005) 69; Franzese (n 19 above) 201.

2.2.2. The colonial era (1900-1960)

The colonisation of Nigeria began with the control of the coastal regions of Nigeria in 1884, the conquering of the Igbos and the declaration of Lagos as a British colony in 1861 and 1882, respectively.[39] Nigeria was subsequently divided into two protectorates, the Northern protectorate and the Southern protectorate, which became amalgamated in 1914 to become Nigeria.[40]

In 1916, the Lunacy Ordinance was enacted in the southern protectorate of Nigeria.[41] The ordinance defined a lunatic as any person of "unsound mind" including "idiots."[42] The ordinance also provided for the establishment of asylums for the confinement of persons adjudged to be lunatics.[43] Likewise, in 1958, the Lunacy Act was enacted. The Lunacy Act defined a lunatic to include an "idiot" and any other "person of unsound mind".[44] It also provided that a person may be arrested and committed to an asylum if adjudged by a Magistrate to be a lunatic.[45] The scope of the Act was so wide that it could have led to broad-based applications of the law and the wrongful committal of persons without disabilities in asylums.[46]

The colonial asylums operated more as custodial centres for the confinement and seclusion of persons adjudged to be lunatics than as treatment centres.[47] Intrinsically, they were instruments of social control rather than institutions for treatment and care.[48] They were established to check resistance and eradicate the traditional beliefs of the colonised and impose the culture of the colonial government.[49] Foucault termed this application of control

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[39] 'Nigeria history' https://thecommonwealth.org/our-member-countries/nigeria/history (accessed 4 September 2017).

[40] 'Nigeria as a colony' https://www.britannica.com/place/Nigeria/Nigeria-as-a-colony (accessed 4 September 2017); Nigeria history (n 39 above); Sango (n 21 above) 89.

[41] B Ayorinde & Co 'Nigeria 'The Rashidi Yekini case and the state of mental health law in Nigeria' http://www.mondaq.com/Nigeria/x/293624/Healthcare/The+Rashidi+Yekini+Case+And+The+State+Of+Mental+Health+Law+In+Nigeria (accessed 2 January 2015).

[42] JH Sadowsky *Imperial bedlam: Institutions of madness in colonial southwest Nigeria* (1999) 28.

[43] Sadowsky (n 42 above) 29; Ayorinde & Co (n 41 above).

[44] The Lunacy Act, Cap. 112, Laws of the Federation of Nigeria, 1958, section 2.

[45] n 44 above section 13.

[46] AH Westbrook 'Mental health legislation and involuntary commitment in Nigeria: A call for reform' (2011) 10 *Washington University Global Studies Law Review* 397, 404.

[47] Sadowsky (n 42 above) 29; Ayorinde & Co (n 41 above); Westbrook (n 46 above) 402; PU Ude 'Policy analysis on the Nigerian Lunacy Act (1958): The need for a new legislation' (2015) 19 *Journal of Psychiatry* doi:10.4172/2378-5756.10003432.

[48] Ude (n 47 above) 3.

[49] P Devlieger 'Experience of disability: Sub-Saharan Africa' in GL Albrecht (ed) *Encyclopedia of Disability* (2006) 694; H Meekosha 'Contextualizing disability: Developing southern/global theory' Keynote paper

by some persons in power over others as "power relations".[50] The colonial government exerted power through the asylums to "compare, differentiate, hierarchise, homogenise, exclude and ultimately normalise" the colonised."[51] Differences in culture, language and political beliefs as well as the nonconformity to British ideologies were equated with lunacy.[52] Western medicine was utilised as a means of expounding classification systems, regulating how knowledge about lunacy or intellectual disability was constructed, and, objectifying persons deemed intellectually disabled as "objects of knowledge".[53] Colonialism was therefore a way of imposing "westocentric knowledge" on Nigerians.[54]

The colonial era also brought into Nigeria the institutionalisation policies which had flourished in Europe from the nineteenth century to the early part of the twentieth century.[55] The institutional era in Europe gave rise to the proliferation of institutions and professionals such as psychiatrists, psychologists and special education teachers, for the treatment and education of persons with disabilities.[56] It was a period that culminated in the removal of persons perceived as deviant from society to "protect society from their deviancy" resulting in the custodial care and confinement of persons diagnosed as intellectually disabled in asylums and institutions.[57] It must however be pointed out that compared to international rates, the rate of institutionalisation in Africa for intellectual disability has generally been low.[58]

The institutional era also gave rise to the use of diagnostic manuals, classification criteria and terminologies such as "idiots', 'feebleminded', 'imbeciles', which were subsequently introduced into Nigeria.[59] Consequently, the British colonial government brought with it Western ideologies and modes of treatment of disabilities including

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presented at the 4th Biennial Disability Studies Conference at Lancaster University, UK on 2nd - 4th September 2008 http://wwda.org.au/wp-content/uploads/2013/12/meekosha2008.pdf (accessed 2 February 2016).

[50] M Foucault 'The subject and power' in HL Dreyfus & P Rabinow (eds) *M Foucault: Beyond structuralism and hermeneutics* (2nd ed) (l983) 223; L Carlson 'Mindful subjects: Classification *and* cognitive disability' unpublished PhD thesis, University of Toronto, 1998, 13.

[51] M Foucault *Discipline and punish: The birth of the prison* trans A Sheridan (1977) 183.

[52] R Keller 'Madness and colonization: Psychiatry in the British and French empires, 1800-1962' (2001) 35 *Journal of Social History* 295, 306; Westbrook (n 46 above) 402; Ude (n 47 above) 3.

[53] Keller (n 52 above) 306; Ude (n 47 above) 3.

[54] Meekosha (n 49 above).

[55] Harris (n 7 above) 16; Albrecht et al (n 19 above) 24; Sango (n 21 above) 89.

[56] Harris (n 7 above) 16; Albrecht et al (n 19 above) 24.

[57] Carlson (n 2 above) 23.

[58] P Bartlett et al 'Mental health in the community: Thinking about Africa' (2011) *International Journal of Mental Health Systems* 21.

[59] Harris (n 7 above) 16.

intellectual disability.[60] As a result, the construction of intellectual disability changed from the spiritual prevalent in the pre-colonial era to the bio-medical prevalent in the colonial era resulting in the socio-medical construction of intellectual disability.

2.2.3. The post-colonial era (1960 till date)

Nigeria attained independence in 1960 and became a republic in 1963.[61] The construction of intellectual disability in post-colonial Nigeria has largely been shaped by beliefs from both the pre-colonial and colonial eras. Years of colonisation have led to assimilation of colonial values along with cultural and religious beliefs.[62] Thus, cultural and religious beliefs from the pre-colonial era along with classification criteria by educators and professional organisations which emanated from the colonial era have influenced how intellectual disability is construed.

Several post-independence studies indicate that intellectual disability is attributed to a variety of causes ranging from the medical to the biological and to the spiritual.[63] Some of such causes include natural causes, diseases, evil spirits, family curses, ancestral curses and food poisoning.[64] The empirical component of this study discussed in Chapter Seven also indicates that intellectual disability is largely attributed to biological factors as well as medical factors and spiritual factors.[65]

The variety of beliefs about the causes of intellectual disability has resulted in either positive or negative attitudes towards persons with intellectual disabilities. In instances where intellectual disability is attributed to biological and medical causes, persons with intellectual disabilities are usually treated positively and accepted as part of their society.[66] Conversely, where it is attributed to spiritual causes, persons with intellectual disabilities are treated

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[60] Ude (n 47 above) 2.

[61] Nigeria as a colony (n 41 above); Sango (n 21 above) 89.

[62] E Etieyibo & O Omiegbe 'Religion, culture, and discrimination against persons with disabilities in Nigeria' (2016) 5 *African Journal of Disability* http://dx.doi.org/10.4102/ajod.v5i1.192

[63] F Abasiubong et al 'The opinions and attitudes of mothers to mental retardation in Lagos, Nigeria' (2008) 6 *Nigerian Journal of Psychiatry* 80; PM Ajuwon & I Brown 'Family quality of life in Nigeria' (2011) 56 *Journal of Intellectual Disability Research* 61, 67; GE Afolayan 'Contemporary representations of disability and interpersonal relationships of disabled women in south-western Nigeria' (2015) 29 *Agenda: Empowering Women for Gender Equity* 54, 60; NE Chukwu & NG Onyeneho 'Sociocultural factors associated with abuse of mentally impaired persons in Imo State, Nigeria' (2015) 35 *International Quarterly of Community Health Education* 349, 362.

[64] Abasiubong et al (n 63 above) 80; Ajuwon & Brown (n 63 above) 67; Afolayan (n 63 above) 60; Chukwu & Onyeneho (n 63 above) 362.

[65] See Chapter Seven of this study.

[66] AO Okunade 'Attitude of Yoruba of western Nigeria to handicap in children' (1981) 7 *Child Care, Health and Development* 187.

negatively resulting in stigma and discrimination against them and their families.[67] The stigma attached to intellectual disability has resulted in the social exclusion of children with intellectual disabilities who are abandoned or hidden away on account of the shame and stigma experienced by their families.[68] Moreover, parents of children with intellectual disabilities usually shop for cures from hospitals, traditional healers, churches or imams to avoid such stigma.[69] Empirical research has also shown that women and girls with intellectual disabilities are typically victims of forced contraception and involuntary sterilisation.[70]

2.3. Intellectual disability: whither the names, definitions and classifications?

Two organisations in the United States of America have been prominent in proffering definitions and classifications for intellectual disability in the twentieth century. They are the American Psychiatric Association and the American Association on Intellectual and Developmental Disabilities (AAIDD). Their prominence in defining and classifying intellectual disability could be attributable to the fact that they are the oldest associations in the field of psychiatry and intellectual disability, respectively. The American Psychiatric Association, which was established in 1844, is the world's largest psychiatric organization.[71] Similarly, the AAIDD, established in 1876, is the oldest and largest interdisciplinary organisation in the field of intellectual and developmental disabilities.[72] The World Health Organisation has also produced definitions and classifications which are used by psychiatrists and psychologists worldwide, including Nigeria. The terminology, definitions and classification systems used by these organisations are examined in this section.

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[67] O Atilola et al 'Neurological and intellectual disabilities among adolescents within a custodial institution in south-west Nigeria' (2014) 21 *Journal of Psychiatric and Mental Health Nursing* 31, 35.

[68] Atilola et al (n 67 above) 35.

[69] GE Ofovwe & CE Ofovwe 'Knowledge, attitude and expectations of mothers of children with neurologic disorders attending the paediatric neurology clinic, University of Benin Teaching Hospital, University of Benin, Benin City, Nigeria' (2007) 6 *Journal of Medicine and Biomedical Research* 59, 63; Ajuwon & Brown (n 62 above) 67; Atilola et al (n 67 above) 35.

[70] Women Enabled International (WEI) et al 'NGO submission to the CEDAW committee pre-sessional working group for Nigeria (October 2016) 9 http://tbinternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/NGA/INT_CEDAW_NGO_NGA_25529_E.docx (accessed 15 September 2017); Inclusive Friends & Nigeria Stability and Reconciliation Programme (NSRP) 'What violence means to us: Women with disabilities speak' (2015) 19 http://www.nsrp-nigeria.org/wp-content/uploads/2015/09/What-Violence-Means-to-us-Women-with-Disabilities-Speak.pdf (accessed 05 July 2016).

[71] American Psychiatric Association 'About APA and psychiatry' http://www.psychiatry.org/about-apa--psychiatry (accessed 2 January 2015).

[72] American Association on Intellectual and Developmental Disabilities (AAIDD) 'About us' http://aaidd.org/about-aaidd (accessed 2 January 2015).

2.3.1. The American Psychiatric Association (APA)

The American Psychiatric Association has over the years changed the terminology from 'mental deficiency' to 'mental retardation' and recently to 'intellectual disability.' The changes in terminology were necessitated because the terms came to be regarded as negative and pejorative. In its diagnostic manuals DSM-I and DSM-II, it defined mental deficiency as "a defect of intelligence existing since birth"[73] and as "subnormal general intellectual functioning which originates during the developmental period," respectively.[74] However, DSM I and II were criticised as been too inclusive resulting in a large number of people being classified as having intellectual disability.

In its DSM-III and DSM III-R manuals, APA defined mental retardation "as significantly sub-average general intellectual functioning resulting in, or associated with, deficits or impairments in adaptive behaviour with onset before the age of 18."[75] The definitions were changed to homogenise diagnostic systems within the USA with that of other countries in the wake of research that showed psychiatric diagnoses differed significantly in Europe and the USA.[76] However, DSM-III and DSM III-R's diagnostic criteria were criticised as overly inclusive and leading to the medicalisation of 20-30% of the population who may not have had intellectual disabilities.[77]

In APA's DSM-IV and DSM-IV-TR manuals, the American Psychiatric Association defined mental retardation as "significantly sub-average intellectual functioning deficits or impairments in adaptive functioning occurring before the age of 18."[78] One of the shortcomings of DSM-IV and DSM-IV-TR was the excessive fragmentation which gave rise to the diagnosis of different disabilities simultaneously.[79] Another shortcoming was that little attention was given to the role of ethnicity and culture in the diagnostic systems such that

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[73] American Psychiatric Association *Diagnostic and statistical manual- mental disorders (DSM-1)* (1952) 23.

[74] American Psychiatric Association *DSM-II Diagnostic and statistical manual of mental disorders* (2nd ed) (1968) 14. This was classified under 'Chronic brain syndrome with mental deficiency' and 'mental deficiency' in DSM-I.

[75] American Psychiatric Association *Diagnostic and statistical manual of mental disorders* (DSM-III) (3rd ed) (1980) 36 and American Psychiatric Association *Diagnostic and statistical manual of mental disorders* (3rd ed - revised) (DSM-III-R) (1987) 28.

[76] 'Diagnostic and statistical manual of mental disorders' http://sevencounties.org/poc/view_doc.php?type=doc&id=8212&cn=18 (accessed 2 January 2015).

[77] Diagnostic and statistical manual of mental disorders (n 76 above).

[78] American Psychiatric Association *Diagnostic and statistical manual of mental disorders* (DSM-IV) (4th ed) (1994) 39; American Psychiatric Association *Diagnostic and statistical manual of mental disorders* (DSM-IV-TR) (4th ed Text Revision) (2004) 41.

[79] EG de Matos 'Importance and constraints of the DSM-IV use in the clinical practice' (2005) 27 *Revista de Psiquiatria do Rio Grande do Sul* 312.

persons not of the Anglo-western culture were susceptible to being diagnosed as having intellectual disability.[80]

In 2013, APA's DSM-5 defined intellectual disability, in its diagnostic manual, as "a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains."[81] According to DSM-5, three criteria must be met: "deficits in intellectual functions, deficits in adaptive functioning and onset of intellectual and adaptive deficits during the developmental period."[82] Although DSM-5 still utilises the same categories as the previous manuals, it does not specify an intelligence quotient (IQ) cut for the different categories of intellectual disability. It goes beyond DSM-1V by deemphasising the need for an assessment of cognitive capacity and calls for the assessment of adaptive functioning.[83] However, in spite of its claims of deemphasising the requirement of IQ testing, DSM-5 still maintains that IQ tests are the only ways to measure intellectual functioning and so should only be conducted by a certified clinician.[84] Hence the diagnosis of intellectual disability still rests on an unreliable test instrument. It also serves to perpetuate the dominance of medical practitioners over the diagnosis of intellectual disability.

DSM	YEAR	SEVERITY
DSM-I	1952	Idiocy which includes profound mental deficiency (IQ under 20); Imbecility which includes severe mental deficiency (IQ under 50); Moron which includes moderate mental deficiency (IQ from 50 to 69); Borderline intelligence which includes mild mental deficiency (IQ from 70 to 85); Mongolism
DSM-II	1968	Borderline (IQ 68-85); Mild (IQ 52-67); Moderate (IQ 36-51); Severe (IQ 20-35); Profound (IQ under 20)
DSM-III	1980	Mild (IQ 50-70); Moderate (IQ 35-49); Severe (IQ 20-34); Profound (IQ under 20).
DSM-III-R	1987	Mild (IQ 50-55 to approximately 70); Moderate (IQ 35-40 to 50-55); Severe (IQ 20-25 to 35-40); Profound (IQ below 20 or 25).
DSM-IV	1994	Mild (IQ 50-55 to approximately 70); Moderate (IQ 35-40 to 50-55); Severe (IQ 20-25 to 35-40); Profound (IQ below 20 or 25).
DSM	2004	Mild (IQ 50-55 to approximately 70); Moderate (IQ 35-40 to 50-55); Severe (IQ 20-25 to 35-40); Profound (IQ below 20 or 25).
DSM-5	2013	Mild; Moderate; Severe; Profound

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[80] VEW Kress et al 'The DSM-IV-TR and culture: Considerations for counsellors' (2005) 83 *Journal of Counselling and Development* 97, 98-99; RL Spitzer & JC Wakefield 'DSM-IV diagnostic criterion for clinical significance: Does it help solve the false positives problem?' (1999) 156 *American Journal of Psychiatry* 1856; CK Varley 'Overview of DSM-5 changes' http://www.omh.ny.gov/omhweb/resources/providers/dsm-5-overview.pdf (accessed 2 January 2015).

[81] American Psychiatric Association *Diagnostic and statistical manual of mental disorders* (DSM-5) (5th ed) (2013) 33.

[82] American Psychiatric Association (n 81 above) 33.

[83] American Psychiatric Association 'Highlights of changes from DSM-IV-TR to DSM-5' http://www.dsm5.org/Documents/changes%20 from%20dsm-iv-tr%20to%20dsm-5.pdf (accessed 2 January 2015).

[84] American Psychiatric Association (n 81 above) 33.

Table 2.1- The American Psychiatric Association's classification of intellectual disability

The APA diagnostic manuals also classify intellectual disability based on the levels of severity obtained from IQ tests. In DSM I, intellectual disability was classified into 'idiocy', 'imbecility', 'moron', and 'mongolism'. In DSM II, the classifications were 'borderline', 'mild', 'moderate', 'severe' and 'profound' However, since DSM III, intellectual disability has been classified into 'mild', 'moderate', 'severe' and 'profound'. Table 2.1 (above) shows how intellectual disability has been classified over the years.

2.3.2. The American Association on Intellectual and Developmental Disabilities (AAIDD)

Like APA, the American Association on Intellectual and Developmental Disabilities (AAIDD) also changed its terminology from the previously used 'mental retardation' to 'intellectual disability' in 2010.[85] In 1959, AAIDD defined mental retardation as "subaverage general intellectual functioning originating during the developmental period, related to impairment in maturation, learning, and social adjustment."[86] In 1961, it defined mental retardation as "subaverage general intellectual functioning that originates during the developmental period and is associated with impairment in adaptive behaviour."[87] The 1959 and 1961 definitions were considered over-inclusive because a large number of persons were diagnosed as having mental retardation especially in sub-populations where minority status, language factors, or socioeconomic background affected the IQ test scores.[88] Adaptive behaviour as it was presented in the 1959 and 1961 definitions was not actually functional for the diagnosis of mental retardation.[89]

In 1973 and 1977, respectively, AAIDD revised the definition of mental retardation to include "significantly sub-average intellectual functions existing concurrently with defects in adaptive behaviour and manifested during the developmental period."[90] The 1973 definition was revised with criticisms of the 1961 definition in mind. It placed more emphasis on the

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[85] The Association has changed its name five times from Association of Medical Officers of American Institutions for Idiotic and Feebleminded Persons in 1876; American Association for the Study of the Feebleminded in 1906; American Association on Mental Deficiency in 1933; American Association on Mental Retardation in 1987; and to American Association on Intellectual and Developmental Disabilities in 2007.

[86] RF Heber *A manual on terminology and classification in mental retardation (1959) 3.*

[87] RF Heber *A manual on terminology and classification in mental retardation* (1961) 3.

[88] JD Smith 'Twentieth-century definitions of mental retardation' http://mn.gov/mnddc/parallels2/pdf/90s/99/99-MRI-MLW.pdf (accessed 2 January 2015).

[89] Smith (n 88 above).

[90] HJ Grossman (ed) *Manual on terminology and classification in mental retardation* (1973) 11; HJ Grossman (ed) *Manual on terminology and classification in mental retardation* (revised ed) (1977) 11.

importance of adaptive behaviour.[91] It also reduced the cut-off point for mental retardation from 85 to 70 and significantly reduced the proportion of the population that could be classified as having mental retardation.[92] Although there were no substantive changes to the 1977 definition, the role of clinical judgment was given greater emphasis and allowance was given for the diagnosis of people with IQs up to 10 points above the 70 if they also showed marked deficits in adaptive behaviour.[93]

In 1983, the AAIDD defined mental retardation as "significantly sub-average general intellectual functioning resulting in or associated with, concurrent impairments in adaptive behaviour and manifested during the developmental period."[94] The definition further expanded the age in which intellectual disability might occur from the conception to 18 years of age.[95]

In 1992, the AAIDD proffered the much debated definition of mental retardation as "substantial limitations in present functioning characterised by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more adapting skills areas, which manifests before age 18."[96] It emphasised the importance of different types of support for persons with intellectual disabilities.[97] The 1992 definition was lauded as representing a significant paradigm shift in the way intellectual disability was conceptualised. Intellectual disability was not seen as a categorical trait in a person but as disability resulting from the interaction of the person with the environment.[98] This was consistent with the emerging strength of the social model of disability.[99] In spite of this, the definition's classification of supports was met with criticism especially in the psychological community and led to the revision of the AAIDD's definition.[100]

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[91] Grossman (1973) (n 90 above) 382.

[92] Grossman (1973) (n 90 above) 382.

[93] Grossman (1973) (n 90 above) 382.

[94] HJ Grossman (ed) *Classification in mental retardation* (1983) 11.

[95] Smith (n 88 above).

[96] R Luckasson et al *Mental retardation: Definition, classification, and systems of supports* (9th ed) (1992) 1. The adapting skills are communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work.

[97] Luckasson et al (n 96 above).

[98] TR Parmenter 'What is intellectual disability? How is it assessed and classified?' (2011) 58 *International Journal of Disability, Development and Education* 303, 306.

[99] Parmenter (n 98 above) 308.

[100] n 98 above 308.

In 2002, AAIDD defined mental retardation as "a disability characterised by significant limitations in both intellectual functioning and adaptive behaviour as expressed in conceptual, social, and practical adaptive skills which originates before age 18."[101]

The 2010 definition uses the term 'intellectual disability' but retains the 2002 definition.[102] This definition, although not without flaws, reflects, to some extent, the objectives of the CRPD as regards support for persons with intellectual disabilities. The definition aims to diagnose intellectual functioning based on the level of support required by a person with intellectual disability.[103]

Prior to the AAIDD's 2010 definition and classification, the diagnosis of intellectual disability had been based on clinical criteria, but the current diagnostic criteria attempt to incorporate the bio-medical aspects of intellectual disability with the social factors that are disabling. It is a 'multidimensional approach' intended to promote fresh notions of intellectual disability and reduce reliance on IQ tests and to promote support for persons with intellectual disabilities.[104] It is in line with the CRPD's concept of supported decision-making. Its reliance on supports is important because while a person may be able to function well in a supportive environment, in a less supportive environment the same person may face difficulties and consequently be diagnosed as intellectually disabled.[105] Yet, in as much as the concept of support is commendable, it may be ineffectual because policy makers and programme administrators still utilise IQ testing in determining eligibility for services.[106]

The AAIDD initially classified intellectual disability based on the levels of severity of derived from IQ tests but since 1992, it has classified intellectual disability based on the level of support needed. In 1959, intellectual disability was classified into 'borderline', 'mild', 'moderate', 'severe' and 'profound' while the 1961, 1973, 1977 and 1983 manuals, classified

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[101] R Luckasson et al *Mental retardation: Definition, classification, and systems of Supports* (10th ed) (2002) 1. It defines intelligence as 'general mental capability. It involves the ability to reason, plan, solve problems, think abstractly, comprehend complex ideas, learn quickly, and learn from experience. Although not perfect, intelligence is represented by Intelligent Quotient (IQ) scores obtained from standardised tests given by a trained professional.' Adaptive behaviour is defined as 'the conceptual, social, and practical skills that people have learned to be able to function in their everyday lives. Significant limitations in adaptive behaviour impact a person's daily life and affect the ability to respond to a particular situation or to the environment.'

[102] R Schalock et al *Intellectual disability: Definition, classification, and systems of supports* (11th ed) (2010) 5.

[103] Garigiulo (n 6 above) 152.

[104] JA Afolayan 'CHS407: Care of persons with disabilities' National Open University of Nigeria course guide 33 http://www.nou.edu.ng/uploads/NOUN_OCL/pdf/SHS/PHS%20407.pdf (accessed 14 February 2016).

[105] C Hatton 'Intellectual disabilities– classification, epidemiology and causes' in E Emerson et al (eds) C*linical psychology and people with intellectual disabilities* (2nd ed) (2012) 3, 4.

[106] R Turnbull et al 'Shakespeare Redux, or Romeo and Juliet revisited: Embedding a terminology and name change for the field of mental retardation' (2002) 40 *Mental Retardation* 65, 68.

intellectual disability into ‘mild’, ‘moderate’, ‘severe’ and ‘profound’. Since 1992, intellectual disability has been classified based on support needs as ‘intermittent’, ‘limited’, ‘extensive’, and ‘pervasive’. Table 2.2 (below) shows how intellectual disability has been classified over the years.

MANUAL	YEAR	SEVERITY
Heber	1959	Borderline (IQ 68 -84); Mild (IQ 52 - 67); Moderate (IQ 36 - 51); Severe (IQ 20 - 35); Profound (IQ less than 20)
Heber	1961	Mild (IQ 52 - 67); Moderate (IQ 36 - 51); Severe (IQ 20 - 35); Profound (IQ less than 20)
Grossman	1973	Mild (IQ 52 - 67); Moderate (IQ 36 - 51); Severe (IQ 20 - 35); Profound (IQ less than 20)
Grossman	1977	Mild (IQ 52 - 67); Moderate (IQ 36 - 51); Severe (IQ 20 - 35); Profound (IQ less than 20)
Grossman	1983	Mild (IQ 50-55 to approximately 70); Moderate (IQ 35-40 to 50-55); Severe (IQ 20-25 to 35-40); Profound (IQ below 20 or 25)
Luckasson et al	1992	Intermittent; limited; extensive; pervasive
Luckasson et al	2002	Intermittent; limited; extensive; pervasive
Schalock et al	2010	Intermittent; limited; extensive; pervasive

Table 2.2- AAIDD’S classification of intellectual disability

2.3.3. The World Health Organisation (WHO)

The World Health Organisation (WHO) still uses the term ‘mental retardation’ but the term is under consideration for a change to “intellectual disability” in the upcoming ICD-11 which “will be presented at the World Health Assembly in May 2019 for adoption by Member States and will come into effect on 1 January 2022”.[107] WHO, in its current diagnostic manual ICD-10, defines mental retardation as “a condition of arrested or incomplete development of the mind’ characterised by ‘impairment of skills manifested during the developmental period.”[108] Previously, in its ICD-9 manual, WHO defined mental retardation as “a condition of arrested or incomplete development of mind which is especially characterised by sub-normality of intelligence.”[109] Terms such as ‘high-grade defect’, ‘backwardness’, ‘sub-normality’, ‘mental deficiency’, ‘feeblemindedness’, ‘imbecile’, ‘moron’ and ‘idiocy’ were used in describing the categories of mental retardation.[110] ICD-10 classifies intellectual disability using the degree of severity which is based on intelligent quotient (IQ) tests into four categories- mild (IQ of 50 to 69); moderate (IQ of 35 to 49);

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[107] WHO releases new International Classification of Diseases (ICD 11) https://www.who.int/news-room/detail/18-06-2018-who-releases-new-international-classification-of-diseases-(icd-11) (accessed 20 December 2018).

[108] World Health Organisation (WHO) *ICD-10 guide for mental retardation* (Geneva, World Health Organization, 1996), 1. The skills include cognitive, language, motor and social abilities.

[109] World Health Organisation (WHO) *International classification of diseases- manual of the international statistical classification of diseases, injuries, and causes of death* (9th ed) (1975) 212.

[110] World Health Organisation (n 108 above) 212-213.

severe (IQ of 20 to 34); and profound (IQ less than 20).[111] In the ICD-9 manual, mental retardation is classified as mild (IQ of 50-70); moderate (IQ of 35-49); severe (IQ 20-34) and profound (IQ under 20).[112] Similarly, in the ICD-8 manual, mental retardation was classified into five categories- borderline (IQ of 68-85); mild (IQ of 52-67); moderate (IQ of 36-51); severe (IQ of 20-35) and profound (IQ under 20).[113]

The World Health Organisation classification system focuses on the medical classification of diseases and in doing so preserves the notion that intellectual disability is an 'abnormality' inherent in the person.[114] It is different from the International Classification of Functioning, Disability and Health (ICF) approach which construes intellectual disability as an interaction between the person's impairment and societal/environmental factors.[115] Besides, it relies on IQ testing which is problematic because it is unreliable in testing intelligence and could result in misdiagnosis.

2.3.4. The educational classification of intellectual disability

The educational classification of intellectual disability originated in the early 1900s as a culmination of the efforts by early educationists such as Itard and Seguin who were pioneers of special education.[116] The classification was promoted by early American teachers to aid in educating children with disabilities using unconventional curriculum teaching methods and has been retained by educators and educationalist in many parts of the world including Nigeria.[117] The classification categorises children, including adolescents, with intellectual disability into three groups for the purpose of placement in schools: 'educable', 'trainable' and 'custodial' (un-trainable).[118]

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[111] World Health Organisation (n 107 above) 2-4.
[112] World Health Organisation (n 108 above) 212.
[113] World Health Organisation (WHO) 'International classification of diseases- manual of the international statistical classification of diseases, injuries, and causes of death' (ICD-8) Vol 1, (8th ed) (1965) 154-155.
[114] M Oliver *The politics of disablement* (1990) 4.
[115] World Health Organization (WHO) 'International classification of functioning, disability and health' (ICF) (2001) 20.
[116] CA Duckett 'A study of what should characterize the education program of the mentally retarded child' (1968) Honors Theses 416 https://scholarlycommons.obu.edu/honors_theses/416 (accessed 31 May 2018); DE Cichon 'Educability and education: Filling the cracks in service provision responsibility under the Education for All Handicapped Children Act of 1975' (1987) 48 *Ohio State Law Journal* 1089, 1091; P Tremblay 'Special needs education basis: Historical and conceptual approach www.ibe.unesco.org/sites/default/files/History_Inclusive_Education.pdf (accessed 31 May 2018).
[117] Cichon (n 116 above) 1092.
[118] JR Davitz et al 'Terminology and concepts in mental retardation (1964) 39.

The educable intellectually disabled refer to those whose IQ ranges from 50-70.[119] They belong to the same category classified as mild intellectual disability in other classification systems and require minor support. They are regarded as having academic potential.[120] Traditionally, they had been regarded as 'academically inferior' because their academic performance was below average.[121] However, with individualised educational plans (IEPs), students classified as educable are performing well in school. The trainable intellectually disabled refers to children that are incapable of formal academic learning but may be trained in non-academic areas.[122] They refer to children with an IQ range of 30-50 range. They usually have secondary disabilities including sensory, visual, speech and motor impairments.[123] They usually have good personal care skills and require moderate support and supervision.[124] The custodial intellectually disabled includes children with an IQ below 35.[125] It is usually assumed that training and education is not achievable for this category of children because they are highly dependent on others.[126] They are usually unable to care for themselves and cater to their daily personal needs and usually have multiple disabilities.[127] They require very high levels of support.

Most of the schools used in the empirical component of this study use the educational classification. In place of custodial, some of the schools use the terms 'severe mentally retarded', 'uneducable' or 'dependable'. There are no standard assessment criteria in place for assessing students and it seems to be based on the teachers' assessments and information provided by parents. This arbitrary assessment could lead to misdiagnosis and students who do not have intellectual disability could be diagnosed as intellectually disabled and vice versa.

The definitions and diagnostic criteria for intellectual disability by APA and the WHO are clinically inclined. Their reliance on IQ testing means that the identification and classification are subjective and unreliable. More so, the definitions and classification systems vary. WHO classifies intellectual disability using the degree of severity based on

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[119] n 118 above 39.
[120] Garigiulo (n 6 above) 151.
[121] Davitz (n 118 above) 40.
[122] Garigiulo (n 6 above) 151
[123] R Mulligan & R Mulligan 'Mental retardation and mental deficiency' http://www.usc.edu/hsc/dental/GSPD504/MRMD.pdf (accessed 14 February 2014).
[124] Mulligan & Muligan (n 123 above).
[125] Davitz (n 118 above) 39.
[126] n 118 above 39.
[127] n 118 above 39.

intelligent quotient (IQ) tests[128] while APA uses severity codes based mainly on adaptive behaviour in the conceptual, social and practical domains as mild, moderate, severe and profound.[129] On the other hand, AAIDD classifies intellectual disability into four categories, based on the level of support needed, as intermittent, limited, extended and pervasive.[130] The educational classification system also relies on IQ testing but the criteria are not well-defined. Evidently, the classification systems are not uniform and could result in a person may be diagnosed as intellectually disabled in one system but not in another system. Perhaps, rather than trying to put persons with intellectual disability in a box by defining and classifying them, they should be accepted as persons with diverse needs like everyone else. Given that definitions have been used to deny people legal protection,[131] Smith suggests that "the most positive paradigm shift might be deconstruction" and "the best definition, may be no definition at all."[132] In addition, the definitions are imperialistic in nature; they were made by medical practitioners for persons with intellectual disabilities without consulting them or their advocacy groups. Since some of the associations like AAIDD are taking human rights into consideration, the more inclusive approach would be to involve persons with intellectual disabilities.

2.4. The construction of intellectual disability

This section examines the clinical and social constructions of intellectual disability. It examines the impact of psychological testing on the clinical construction of intellectual disability and persons with intellectual disability. It also examines the effect of labelling and stigma on persons with intellectual disability.

2.4.1. Intellectual disability as a clinical construction

Intellectual disability has largely been construed as a 'clinico-medical' entity identified by changing clinical categorisations which have characterised it as a biological problem, inherently located in the individual, which diminishes his or her other qualities.[133] It is

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[128] World Health Organization (n 108 above) 2-4.

[129] American Psychiatric Association (n 81 above) 33.

[130] Schalock et al (n 102 above) 5.

[131] AD Renteln 'Cross-cultural perceptions of disability' in SS Herr, HH Koh & LA Gostin (eds) *The human rights of persons with intellectual disabilities: Different but Able* 60.

[132] JD Smith 'The myth of mental retardation: Paradigm shifts, disaggregation and developmental disabilities' (2002) 40 *Mental Retardation* 62.

[133] Smith (n 132 above) 64; M Rapley *The social construction of intellectual disability* (2004) 31. Smith defines typology as the study of groups of individuals whose individual differences are thought to be eclipsed by underlying types and essences.

attributable to the emergence of the industrial revolution which brought with it scientific inquests into the 'normal' body and the attendant ideologies of 'utilitarianism', 'medicalisation', 'eugenics' and 'social Darwinism'.[134] In most countries, intellectual disability is largely construed clinically. Its assessment and diagnosis is largely based on the criteria in diagnostic manuals by the American Association on Intellectual and Developmental Disabilities (AAIDD), the American Psychiatric Association (APA) and the World Health Organization (WHO). In Nigeria, the WHO diagnostic manual ICD-10 is widely used by psychologists and psychiatrists in diagnosing intellectual disability while psychologists and psychiatrists trained in the USA rely on both ICD-10 and DSM-5.[135] More so, some laws and bills on disability have adopted a clinical construction of disability, by requiring the prior assessment and certification by a medical doctor for eligibility to some of the privileges in the laws and bills.[136]

The clinical construction of intellectual disability arose from the medical profession's use of clinical tools to differentiate persons with intellectual disabilities from other persons based on their impairment.[137] It owes its existence to the development of a new professional discipline- psychology - together with the proliferation of institutions for the 'feebleminded' in the nineteenth century. This corresponds with Foucault's views that the prominence of the 'clinic' in the nineteenth century is due to the reformation of 'medical discourse' and the discourse about 'disease'.[138] This reformation, according to Carlson, was the "organising principle" in the construction of medical knowledge about intellectual disability.[139] As Danforth explains, the newly emerging field of psychology borrowed metaphors from two established fields - the 'disease metaphor' from Medicine and the 'efficiency metaphor' from Engineering.[140] The two metaphors were combined to create the disease 'mental deficiency' along with the authoritative language and concepts of medicine and engineering.[141]

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[134] C Barnes 'The social model of disability: Valuable or irrelevant?' 2. http://citeseerx.ist.psu.edu/messages/downloadsexceeded.html (accessed 22 March 2014).

[135] This was garnered from discussions with doctors involved in the empirical component of this study.

[136] See section 25 of the Discrimination against Persons with Disabilities (Prohibition) Act, 2018, section 3 of the Nigerians with Disability Act 1993 and section 78 of the Nigerians with Disability Bill 2016.

[137] The term 'clinical' is used in this study to emphasise the combination of scientific and medical tools used in the construction of intellectual disability.

[138] M Foucault *The birth of the clinic* (2003) xix.

[139] L Carlson 'Docile bodies, docile minds: Foucauldian reflections on mental retardation' in S Tremain (ed) *Foucault and the government of disability* (2009) 134.

[140] S Danforth 'New words for new purposes: A challenge for the AAMR' (2002) 40 *Mental Retardation* 52.

[141] Danforth (n 140 above) 52.

Hence, the new profession reorganised the discourse about the causes, definitions and treatments of intellectual disability within an organised structure, resulting in "new forms of knowledge" about persons with intellectual disabilities.[142] This was done in a bid to gain authenticity and convince the public that psychologists possessed a superior scientific and medical knowledge base that superseded rationality, spiritual beliefs and traditional beliefs.[143] The asylums and hospitals for idiots, lunatics, imbeciles and the feeble-minded, which they established, became dominant forms of institutional treatment, education and custodial care for persons with intellectual disabilities.[144] Carlson argues that within those institutions intellectual disability was 'both found and made' and that knowledge was remade and reported'.[145] To her, the creation of new typologies gave rise to the emergence of the 'idiot', 'imbecile' and 'moral imbecile' as distinct categories of intellectual disability in the nineteenth century.[146] This occurred again in the early twentieth century, when knowledge of "feeblemindedness" was reformed and a new category of intellectual disability, the "moron," emerged.[147] The focus was on the differentiation and categorisation of a group of people so as to establish the scientific character of psychology.[148] The discourse became centred on the 'ideology' of normality and abnormality and gave rise to the construction of a person with intellectual disability as abnormal and different.[149] Ironically, the categorisation of persons with intellectual disabilities became the basis for their exclusion from society as it has served to emphasise their difference from others negatively giving rise to stereotypical labels and stigmatisation.[150]

Clinical categories derive their authority from medical professionals who define and categorise diseases. Once a clinical category is defined by the professional, it becomes "institutionalised" and controlled by medical professionals and other professionals in associated fields.[151] The professionals generate languages of description that depict the body as 'healthy or unhealthy', 'normal or abnormal', 'intelligent or unintelligent' and provide

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[142] Carlson (n 139 above) 137.
[143] Danforth (n 140 above) 52
[144] E Emerson et al *Clinical psychology and people with intellectual disabilities* (2012) 24.
[145] Carlson (n 2 above) 22.
[146] n 2 above 22.
[147] n 2 above 22.
[148] Danforth (n 140 above) 54.
[149] M Oliver 'The individual and social models of disability' a paper presented at Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians on 23 July 1990 4 http://disability-studies.leeds.ac.uk/files/library/Oliver-in-soc-dis.pdf (accessed 22 March 2014).
[150] R Bogdan and SJ Taylor 'The judged, not the judges: An insider's view of mental retardation' (1976) 31 *American Psychologist* 47; I Illich 'Body history' (1986) 6 *The Lancet* 1325, 1327.
[151] RJ Barnet 'Ivan Illich and the nemesis of medicine- The man and his message in memoriam' (2003) *6 Medicine, Health Care and Philosophy* 273, 276.

reasons for the distinctions.[152] They proclaim 'secret knowledge' about human nature and they alone possess the requisite expertise to define, diagnose, classify and determine how to treat diseases, thereby guaranteeing them legitimacy and authority, all of which serves to entrench them into society.[153] In view of this, Illich referred to the medical profession as a new type of cartel with the power to create needs they alone can satisfy.[154] In the case of psychologists, their claim of expertise over the mind and instruments to measure the mind gave them an air of professional mastery.[155] This claim to expertise is succinctly captured by the AAIDD's statement as follows:

> Clinical judgment is essential, and a higher level of clinical judgment is frequently required in complex diagnostic and classification situations… Clinical judgment is defined as a special type of judgment rooted in a high level of clinical expertise and experience and judgment that emerges directly from extensive training, experience with the person, and extensive data...[156]

Accordingly, who is construed as intellectually disabled and how such persons would function in society and the boundaries of normal and abnormal behaviour is within the psychologists' definitional control and power'.[157] This exercise of power and control by the medical profession has been termed 'medicalisation' by Illich.[158]

Medicalisation is a process where "non-medical problems" are characterised and handled as "medical problems" usually in terms of illness and disorders."[159] According to Linton, medicalisation construes human diversity as a "deviance from the norm, as a pathological condition, deficit, and personal tragedy" such that disability is structured as a medical issue.[160] Medicalisation therefore represents the medical profession's control over the organisation of "class power"- a "radical monopoly" that has created a social milieu in which persons with disabilities are labelled as incompetent and new categories of persons are created.[161] It exemplifies the control of the medical profession over discourses and knowledge about intellectual disability and over the lives of persons with intellectual

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[152] KJ Gergen *An invitation to social construction* (1999) 39.
[153] Illich (n 9 above) 46-47; I Illich et al *Disabling professions (Ideas in Progress)* (1977) 19; C Goble '50 years of NHS involvement in the lives of people with learning difficulties: A cause for celebration?' (1998) 13 *Disability & Society* 833, 834; Rapley (n 132 above) 44.
[154] Illich (n 9 above) 16.
[155] Danforth (n 140 above) 54.
[156] Schalock et al (n 102 above) 29.
[157] M Gillman et al 'what's in a Name? The implications of diagnosis for people with learning difficulties and their family carers' (2000) 15*Disability and Society* 389*;* MK Simpson 'Idiocy as a regime of truth: an archaeological study of intellectual disability through the work of Edouard Seguin, William Ireland, and Alfred Binet and TH Simon' Unpublished PhD Thesis, University of Dundee (2000) cited in Rapley (n 132 above) 42.
[158] Illich (n 9 above) 39.
[159] P Conrad 'Medicalization and social control' (1992) 18 *Annual Review of Sociology* 209.
[160] S Linton *Claiming disability: Knowledge and identity* (1998) 11.
[161] Illich (n 9 above) 43.

disabilities, all of which are embodiments of power.[162] This exercise of power by medical professionals is amplified when historically stigmatised categories such as gender, race and class are taken into consideration. The exercise of medical power in gender is particularly evident in the context of reproductive health.[163] Foucault, in discussing the exertion of medical power over the female body, contended that since the eighteenth century, the female body was analysed, qualified and disqualified and incorporated into the field of medical practices.[164] Indeed, the sterilisation of adolescent girls with intellectual disabilities is 'medicalised' and medical professionals are usually implicated since they usually play a crucial role in the performance of the sterilisation.[165] This exercise of medical power is also evident with race in the United States of America and how race served to legitimise the over-representation of African Americans in the diagnosis of intellectual disability and special education.[166]

2.4.2. Psychological testing and intellectual disability

The diagnosis of intellectual disability is usually based on the clinical assessment of 'intelligence' and 'adaptive functioning' by means of psychological tests.[167] Psychological testing involves the use of written, visual, or verbal tests to assess a person's intellectual, behavioural and emotional functioning and abilities. They are used to determine children and

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[162] N Altermark 'Powers of classification: Politics and biology in understandings of intellectual disability' (2015) 11 *Review of Disability Studies: An International Journal* 68, 70.

[163] R Sifris 'The involuntary sterilisation of marginalised women: Power, discrimination, and intersectionality' (2016) *Griffith Law Review1*-3.

[164] M Foucault *The history of sexuality* (2003) 104.

[165] *Secretary, Department of Health and Community Services v JWB and SMB* (Marion's Case) (1992) 175 CLR 218, para 50 (accessed 22 March 2014); Sifris (n 163 above) 3.

[166] N Krieger ('Shades of difference: Theoretical underpinnings of the medical controversy on black/white differences in the United States, 1830–1870' (1987) 17 *International Journal of Health Services* 259–278; DR Williams & M Sternthal 'Understanding Racial/ethnic Disparities in Health: Sociological Contributions' (2010) 51 *Journal of Health and Social Behavior* S15–S27; PL Morgan et al 'Minorities are disproportionately underrepresented in special education: Longitudinal evidence across five disability conditions' (2015) 44 *Educational research* 278–292; JD Niedenfuer 'The overrepresentation of African American students in special education: A review of the literature' (2015) *Culminating Projects in Special Education*, Paper 3; Wright et al The Other Half Hasn't Been Told: African American Males and Their Success in Special Education' (2016) 7 *Journal of African American Males* in Education 35-46; W Cavendish et al 'Troubling the problem of racial overrepresentation in special education: A commentary and call to rethink research' (2018) *Educational Review* 1-13.

[167] American Psychiatric Association (n 81 above) 33;The American Association on Intellectual and Developmental Disabilities (AAIDD) 'Frequently asked questions on intellectual disability and the AAIDD definition' http://aaidd.org/docs/default-source/sis-docs/aaiddfaqonid_template.pdf?sfvrsn=2 (accessed 4 February 2015); American Psychiatric Association 'Intellectual disability' http://www.dsm5.org/documents/intellectual%20disability%20fact%20sheet.pdf (accessed 4 February 2015).

adolescents' academic ability, school placement and the existence of an intellectual disability.[168]

The first psychological (intelligence) test, the Binet-Simon scale, was developed by Alfred Binet and Theodore Simon in 1905 to identify children having difficulties in primary schools in France.[169] The Binet-Simon scale was translated into English by Henry Goddard, the superintendent at the Vineland Training School for Feeble-minded Boys and Girls, in New Jersey for the purpose of identifying the "feeble-minded and placing them in institutions". In 1912, Henry Goddard introduced the tests to the United States for the purpose of diagnosing intellectual disability.[170] The test was later adapted by Lewis Terman, a psychologist at the Stanford University for use in America in 1916. The resultant test called the Stanford-Binet scale was widely used in the United States for many years.[171]

Psychological testing was subsequently used as a tool for eugenic purposes in the United States and other parts of the world in the twentieth century. It was believed that delinquency and unfitness were hereditary and that unfit persons in the society, including those with intellectual disabilities, should not be allowed to reproduce. Mass testing was conducted and those adjudged to be unfit were sterilised and institutionalised.[172] In present times, intelligence tests are still widely used for school placements and to determine intellectual functioning of persons.[173]

'Intelligence' is a highly contentious issue that has been the subject of different definitions which are based on the perception of the person defining it because intelligence is multidimensional and can be perceived from different perspectives.[174] The AAIDD defines it as the general mental capacity of a person which involves the capacity to reason, solve

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[168] 'Psychological tests' http://www.healthofchildren.com/P/Psychological-Tests.html (accessed 12 January 2018); DW Fiske & DC Adkins 'Psychological testing' https://www.britannica.com/science/psychological-testing (accessed 12 January 2018).

[169] KA Becker 'History of the Stanford-Binet intelligence scales: Content and psychometrics' (2003) *Stanford-Binet Intelligence Scales, Fifth Edition Assessment Service Bulletin No. 1*.

[170] Harris (n 7 above) 21.

[171] A Roige 'Intelligence and IQ testing' http://eugenicsarchive.ca/discover/connections/535eecb77095aa000000023a (accessed 4 February 2015); C Kaestle 'Testing policy in the United States: A historical perspective' http://www.gordoncommission.org/rsc/pdfs/kaestle_testing_policy_united_states.pdf (accessed 4 February 2015).

[172] M Quigley 'The roots of the IQ debate- eugenics and social control' http://www.publiceye.org/magazine/v09n1/eugenics.html (accessed 4 February 2015); MM Singleton 'The science of eugenics: America's moral detour' (2014) 19 *Journal of American Physicians and Surgeons* 122-124.

[173] American Psychiatric Association (n 81 above) 33; D Martschenko 'The IQ test wars: why screening for intelligence is still so controversial' https://theconversation.com/the-iq-test-wars-why-screening-for-intelligence-is-still-so-controversial-81428 (accessed 31 January 2018).

[174] JH Kranzler & RG Floyd *Assessing intelligence in children and adolescents- a practical guide* (2013) 3.

problems and learn.[175] It is measured in terms of the intelligence quotient (IQ) obtained from standardised IQ tests.[176]

Intelligent quotient (IQ) refers to the numeral value representing a person's intelligence in relation to the other people of the same age (known as the normative sample) who took the same test.[177] IQ is usually evaluated by dividing a person's mental age by his or her chronological age and multiplying the result by 100. In other words, IQ= "mental age/chronological age x 100."[178] The IQ for normal intelligence is between 90 and 110, placing the average (mean) IQ score at 100.[179] So an IQ of between 70 or below usually indicates limitations in intelligence and the presence of an intellectual disability.[180] However, a score of 75 may still be an indicator of intellectual disability because the "standard error of measurement for most IQ tests is approximately 5" representing a score of about "2 standard deviations below the mean."[181]

IQ tests are standardised and test a person's test scores in relation to other person's test scores.[182] Accordingly, IQ is not a total indication of a person's intelligence but an evaluation of his performance in relation to other people of the same age.[183] Examples of IQ tests for adolescents include the Wechsler Intelligence Scale for Children (WISC) children ages 6 to 16; Wechsler Adult Intelligence Scale (WAIS) for people over sixteen years of age and Stanford-Binet Intelligence Scales, Fifth Edition (SB5), which is used to evaluate the

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[175] The American Association on Intellectual and Developmental Disabilities (n 167 above).

[176] The American Association on Intellectual and Developmental Disabilities (n 167 above); S Colmar et al 'Assessing intellectual disability in children: Are IQ measures sufficient, or even necessary?' (2006) 16 *Australian Journal of Guidance & Counselling* 177, 178.

[177] American Psychological Association 'Intelligence' http://www.apa.org/topics/intelligence/ (accessed 17 September 2016); Encyclopaedia Britannica 'IQ psychology' http://global.britannica.com/science/IQ (accessed 17 September 2016).

[178] AM Colman 'Aspects of intelligence' in I Roth (ed) *The open university's introduction to psychology Vol 1* (1990) 328.

[179] American Academy of Pediatrics 'Outlook for children with intellectual disabilities' https://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Outlook-for-Children-with-Intellectual-Disabilities.aspx (accessed 17 September 2016).

[180] The American Association on Intellectual and Developmental Disabilities (n 167 above); American Psychiatric Association (n 81 above) 37.

[181] The American Association on Intellectual and Developmental Disabilities (n 167 above).

[182] T Reynolds et al 'Psychological tests and intellectual disabilities' http://communitycounsellingservices.org/poc/view_doc.php?type=doc&1d=10346&cn+208 (accessed 17 September 2016).

[183] D Garlick 'The confusing concept of IQ' psychology today' https://www.psychologytoday.com/blog/intelligence-and-the-brain/201009/the-confusing-concept-iq (accessed 17 September 2016).

level of global intellectual functioning among individuals with neuro-developmental disorders.[184]

Notwithstanding the wide usage of IQ tests as the determinant of intelligence, they are subjective and unreliable for a number of reasons. Firstly, IQ testing is not a clear-cut measurement of intelligence, but of intelligence compared to the rest of a population and so is not individualised per se.[185] IQ test scores merely approximate a person's intelligence and may not adequately measure the person's reasoning and practical undertaking of daily tasks.[186] They merely show how good or bad a person is at solving psychometric tests measured up to the general population.[187] This lack of statistical clarity is perhaps the reason why measuring the exact extent to which the intellectual functioning of a child with intellectual disability is affected remains challenging.[188] Secondly, there is cultural bias in IQ testing and in understanding of the tests. Most IQ tests appear to measure the knowledge or intelligence of a person based on Western construct of knowledge. They were constructed by white male psychologists and validated on white populations, accounting for bias for people from ethnic minorities who have a history of being identified as being intellectually disabled.[189] In Nigeria, for instance, there are about three hundred ethnic groups with diverse cultural beliefs, languages and practices which could affect the outcome of IQ tests.[190] In fact, some psychologists in Nigeria have acknowledged that a major problem with IQ tests is the difficulty in translating them to the local language of the person being tested as there is currently no local version of any IQ test in Nigeria that is of wide application.[191] They also acknowledged that the IQ tests were designed for Western societies and so some of the questions in the tests are difficult to translate to the local Nigerian context. For instance, one of the tasks in the Wechsler Intelligence Scale tests is the identification of the pomegranate fruit which is not common to Nigeria. Consequently, a child or person that cannot identify the fruit or other questions would score low on the test and may be diagnosed as being

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[184] Reynolds et al (n 182 above).

[185] Altermark (n 162 above) 72.

[186] American Psychiatric Association (n 81 above) 37; Altermark (n 162 above) 72.

[187] Altermark (n 162 above) 72.

[188] RE Udonwa 'Mentally retarded children and deficits in daily living skills: Case study of Calabar Municipality Local Government Area, Cross River State, Nigeria' (2015) 5 *Journal of Research & Method in Education* 21.

[189] Colman (n 178 above) 358; AT Cianciolo & RJ Sternberg *Intelligence: A Brief History* (2004) 54.

[190] MO Bakare et al 'Agreement between clinicians' and care givers' assessment of intelligence in Nigerian children with intellectual disability: Ratio IQ as a viable option in the absence of standardized 'deviance IQ' tests in sub-Saharan Africa' (2009) 5 *Behavioral and Brain Functions* 39, 40.

[191] This was garnered from interviews and discussions with psychologists during the empirical component of this research.

intellectually disabled. The psychologists also acknowledged that some parts of the tests are pictorial and may give rise to bias in the tests as persons from some cultures and locales may have more experience with pictures than others. For instance, children in urban communities in Nigeria are more likely to have been exposed to pictures than those from rural communities. Also, assessing the intelligence of persons with certain disabilities such as persons with visual impairments on pictorial aspects of the tests is likely to produce bias against them. The tests also presuppose that educational social, economic, and cultural backgrounds are the same for all persons and fails to take into cognisance that factors such as poverty, lack of education, quality of education and locality could influence the results of IQ tests.[192] In addition, what is intellectual disability is socially and culturally contingent but the categories in diagnostic manuals of professional associations are based on Western culture.[193] When applied to people from non-Western cultures, there is a risk of causing category fallacy.[194] Thirdly, IQ tests have limited accuracy in testing the intellectual functioning of persons with intellectual disabilities because they are not reliable for testing intellectual disability in the lower ranges.[195] This is known as floor effects and it occurs when a test is too complex for a particular population because they are not adequately represented in the normative sample.[196] Similarly, the Flynn effect which refers to excessively high scores because of out-dated test norms also affects the validity of IQ tests.[197] Fourthly, just as the definitions of intelligence are varied, so also do the scores obtained vary depending on the type of IQ test used. In other words, the type of test administered determines a person's intelligence quotient as different tests could yield different results for the same person.[198] This illustrates the inconsistency of IQ tests and that intelligence cannot be accurately measured. Fifthly, sensory, speech, communicative and fine motor skills are usually required to undertake most IQ tests. However, a lot of persons with intellectual disabilities, especially those who require extensive and pervasive support, have physical, sensory, speech, receptive

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[192] Colman (n 178 above) 360; Colmar et al (n 176 above) 181.

[193] YA Aderibigbe & AK Pandurangi 'The neglect of culture in psychiatric nosology: The case of culture-bound syndromes' (1995) 41 *The International Journal of Social Psychiatry* 235.

[194] Aderibigbe & Pandurangi (n 193 above) 236.

[195] Colmar et al (n 176 above) 181; D Hessl et al 'A solution to limitations of cognitive testing in children with intellectual disabilities: The case of fragile X syndrome' (2009) 1 *Journal of Neurodevelopmental Disorders* 33, 34; S Banks 'Floor effect' in JS Kreutzer et al (eds) *Encyclopaedia of clinical neuropsychology* (2011) 1057; H Hurst 'Floor effect' in FR Volkmar (ed) *Encyclopaedia of autism spectrum disorders* (2013) 1300.

[196] Hessl (n 195 above) 34; Sansone et al 'Improving IQ measurement in intellectual disabilities using true deviation from population norms' (2014) 6 *Journal of Neurodevelopmental Disorders* 16, 17.

[197] American Psychiatric Association (n 81 above) 37.

[198] C Keller-Allen 'The disproportionality of students designated limited English proficient in high incidence disability categories' unpublished PhD thesis, Washington University, 2008, 56.

and/or communicative limitations, which affect their ability to test properly.[199] Lastly, psychologists and educators make decisions about the IQ test to administer based on their training, personal beliefs, policies in their locality or institutions and resources. So the viewpoint of psychologists on the measurability and reliability of an IQ test could also influence their interpretations of the test results.[200] Research has shown that clinicians occasionally make "educated guesses" and estimate test results which reduces the reliability of the test and also the reliance of the resultant diagnosis.[201]

The second component in psychological testing is adaptive functioning or behaviour. Adaptive functioning or behaviour denotes the "conceptual, social, and practical skills" and reasoning that people develop to function in their daily lives.[202] It refers to the aptitude to "achieve expected age and cultural standards in personal independence and social responsibility."[203] It is assessed with the use of clinical evaluation and standardised tests of adaptive functioning.[204] The tests are usually complemented with information from the person to be tested to the extent possible and from parents, family members, teachers and caregivers.[205] Examples of tests used to determine adaptive functioning are Woodcock-Johnson Scales of Independent Behaviour which measures independent behaviour in children; the Vineland Adaptive Behaviour Scale (VABS) which measures the social skills of people from birth to 19 years and the AAIDD Diagnostic Adaptive Behaviour Scale (2013) which measures adaptive functioning skills.[206] Indeed, Colmar suggests that the information obtained from standardised adaptive tests have greater validity than IQ tests because they provide information about a person's ability to accomplish certain daily activities.[207]

There is however no consensus as to what constitutes adaptive functioning because its construction depends on the construer.[208] There is also disagreement about the skills that determine the presence or absence of adaptive functioning.[209] For instance, while the AAIDD

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[199] World Health Organisation 'ICD-10 guide for mental retardation' (1996) 1-2 http://www.who.int/mental_health/media/en/69.pdf (accessed 4 February 2015); Colmar et al (n 176 above) 181-182.

[200] Keller-Allen (n 198 above) 56.

[201] S Boon 'The social construction of profound mental retardation' 4 http://www.crds.org/docs/faculty-resources/marlett/socialconstructionpaper.pdf (accessed 4 February 2015).

[202] The American Association on Intellectual and Developmental Disabilities (n 165 above); American Psychiatric Association (n 81 above) 37.

[203] Colmar et al (n 176 above) 183.

[204] Colmar et al (n 176 above) 178.

[205] American Psychiatric Association (n 81 above) 37; Reynolds et al (n 182 above).

[206] Reynolds et al (n 182 above).

[207] Colmar et al (n 176 above) 184.

[208] Colmar et al (n 176 above) 183.

[209] Colmar et al (n 176 above) 184; Altermark (n 162 above) 5.

and APA agree that the absence of conceptual, social and practical skills indicate lack of adaptive functioning, their notions of what constitute these skills are different. For the AAIDD, conceptual skills include “receptive and expressive language, reading and writing, money concepts and self-directions.” On the other hand, for the American Psychiatric Association, it includes “competence in memory, language, reading, writing, math reasoning, acquisition of practical knowledge, problem solving and judgement in novel situations.” Social skills for the AAIDD include relational responsibility, self-worth, naïveté, rule following, obedience to the law and avoidance of victimisation while for the American Psychiatric Association it includes awareness of others “thoughts, feelings and experiences, empathy, interpersonal communication skills, friendship abilities and social judgement.” Similarly, practical skills for the AAIDD involve “personal activities of daily living such as eating, dressing, mobility and toileting, instrumental activities of daily living such as preparing meals, taking medication, using the telephone, managing money, using transportation, and doing housekeeping activities.” For the American Psychiatric Association, practical skills include “learning and self-management in life such as personal care, employment, money management, recreation, self-management of behaviour and school/work task management.”[210] Hence the difference in what the skills entail gives rise to the question of what rationale is applied in choosing certain criteria over others.[211]

Psychological tests have and still play a large role in the sterilisation of adolescent girls with intellectual disabilities and in excluding them from decision-making in most aspects of their lives, particularly in medical and contraceptive decision-making. Although APA’s DSM-5 deemphasises the use of IQ tests and emphasises the importance of support in in diagnosing persons with intellectual disabilities, it still relies on IQ tests in diagnosing intellectual functioning.[212] On the other hand, AAIDD’s manual and WHO’s ICD-10 still rely on IQ tests in diagnosing intellectual functioning. It is therefore imperative that reliance on IQ tests are deemphasise as they are flawed and so are not true tests of intelligence.

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[210] The American Association on Intellectual and Developmental Disabilities (n 167 above); American Psychiatric Association (n 81 above) 37.

[211] Altermark (n 162 above) 75.

[212] American Psychiatric Association (n 81 above) 37.

2.4.3. Intellectual disability as a social construction

Social constructionism explores how knowledge is produced and sustained as reality in the society.[213] It underscores the importance of linguistics, beliefs, social relations, politics, history and culture and the manner in which meanings are created, understood and shared by people then replicated in their conduct, outlook and language.[214] Consequently, social constructionists argue that intellectual disability is a social concept whose interpretation is subjective, varying from society to society and so its classifications and definitions are bound to be fluid and mutable.[215] Hence its interpretation is subject to 'manipulation'.[216] They emphasise society's inclination to categorise people into different classes, on a subjective basis, "as a means of social control," resulting in some classes of people being treated positively and others being treated differently.[217] In other words, social constructionism argues that categories are not natural but that they are 'naturalised' through discourse.

Categorisation involves "the subjective classification of people into social groups based on similar characteristics they possess such as nationality, age, occupation and diagnosis."[218] It emphasises that behaviour identified as deviant or antisocial is not predetermined but is structured by society.[219] Although social grouping has the potential of bringing people with the same attributes together as equal members, it also has the tendency of separating those that do not share the same attributes and marking them as different.[220] Those identified as different are usually excluded and despised inducing an array of

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[213] National disability Authority (NDA) 'Literature review on attitudes towards disability' 25 http://www.ucd.ie/issda/static/documentation/nda/nda-literature-review.pdf (accessed 03 July 2017).

[214] S Danforth & WC Rhodes 'Deconstructing disability: A philosophy for inclusion' (1997) 18 *Remedial and special education* 357, 359; BS Turner 'Disability and the sociology of the body' in GL Albrecht et al (eds) *Handbook of disability studies* (2001) 256; National Disability Authority (n 213 above) 25; D Wasserman et al 'Disability: Definitions, models, experience' *The Stanford encyclopaedia of philosophy* https://plato.stanford.edu/entries/disability/ (accessed 03 July 2017).

[215] MI Manion & HA Bersani 'Mental retardation as a western sociological construct: A cross-cultural analysis' (1987) *2 Disability, Handicap & Society* 236, 238.

[216] K Nunkoosing 'Constructing learning disability- consequences for men and women with learning disabilities' (2000) 4 *Journal of Learning Disabilities* 49, 54.

[217] IM Young *Justice and the politics of difference* (1990) 47; A Knippenberg & A Dijksterhuis 'Social categorization and stereotyping: A functional perspective' (2000) 11 *European Review of Social Psychology* 105, 107; Conrad & Barker (n 186 above) S67; GV Bodenhausen et al 'Social categorization and the perception of social group' in DW Fiske & DC Adkins (eds) *The sage handbook of social cognition* (2012) 319; HE Keith & KD Keith *Intellectual disability: Ethics, dehumanization, and a new moral community'* (2013) 4; M Rhodes 'The cultural origins of social categorization' http://psych.nyu.edu/cdsc/publications/Rhodes_Leslie_Bianchi_Chalik_under_review.pdf (accessed 22 February 2016); L Thomas 'Examples of ways for categorizing disabilities' https://www.uua.org/sites/live-new.uua.org/files/examples_of_ways_for_categorizing_disabilities.pdf (accessed 22 February 2016).

[218] Knippenberg & Dijksterhuis (n 217 above) 107; Rhodes (n 217 above); Young (n 217 above) 47; Bodenhausen et al (n 217 above) 311.

[219] Conrad & Barker (n 186 above) S67.

[220] Keith & Keith (n 217 above) 4; Bodenhausen et al (n 217 above) 319.

stereotypes which results in their oppression as social categorisation and stereotyping go hand in hand.[221] The oppression refers to 'systemic constraints' on groups, which is structural and tends to restrain or reduce a subjugated group, projecting them as the 'other' in the society and ultimately inferior, resulting in cultural imperialism.[222]

Young defines 'cultural imperialism' as the "universalization and establishment of a dominant group's experience and culture as the norm."[223] According to her, the dominant group emphasises its superiority over the subjugated group by subjecting it to its own rules and reconstructing the difference of the subjugated group as deviant.[224] The dominant group constructs the differences exhibited by the group deficiency and negation treating the subjugated group as the 'other'.[225] As a consequence, intellectual disability becomes objectified as deviance and inferiority. Accordingly, the definitions and classifications systems for intellectual disability are a means of social control and are constructed to identify, differentiate and subjugate persons with intellectual disabilities in the society.[226] The subjugation emanates from the dominant medical profession that defines them, how they are treated and what they can amount to in society. Incompetence and intelligence have been central to their identification as a social group, which in turn has emphasised their difference and resulted in stereotypical labels such as 'deviant', 'immoral', 'idiot', 'imbecile', 'sub-human' and 'mentally deficient'.

The power exercised by the medical profession over persons with intellectual disabilities is similar to the control exhibited by British colonial masters during the era of colonisation. As highlighted in section 2.2.2, the British imposed their culture and practices on the colonised Nigerians and those who did not conform were reconstructed as lunatics. The knowledge and practices of Nigerians in dealing with persons with intellectual disabilities were regarded as "naive knowledge", "hierarchically inferior knowledge," "knowledge below the required level of erudition or scientificity."[227] As Mudimbe points out, the colonising structure in Africa took three forms: "the domination of physical space, the reformation of natives' minds, and the integration of local economic histories into the

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[221] Young (n 217 above) 47; Knippenberg & Dijksterhuis (n 217 above) 106; Bodenhausen et al (n 217 above) 323.

[222] Young (n 217 above) 42-43.

[223] Young (n 217 above) 47.

[224] Young (n 217 above) 59.

[225] Young (n 217 above) 59.

[226] Conrad & Barker (n 186 above) S67.

[227] Foucault (n 138 above) 7.

Western perspective."[228] This is clearly observable in the discourse of intellectual disability. Being classified as intellectually disabled gave medical professionals control over the bodies, minds and lives of person with intellectual disabilities just like the colonial masters over their colonies.[229] The medical professionals also controlled the discourse about intellectual disability. Such discourse which reified persons with intellectual disabilities as "incapable, incompetent, and sometimes even morally inferior" was integrated into the consciousness of the society.[230] This negative stereotypical imaging of persons with intellectual disabilities as incapable and/or incompetent has been used to justify the institutionalisation and sterilisation of persons with intellectual disabilities.[231] As a consequence, their experiences and interpretations of life find little expression in society as they are subsumed by the stigma attached to various labels ascribed to them.

Nonetheless, intellectual disability is not purely a clinical construct or a social construct. As discussed in section 1.7.2 of this study,[232] although some difficulties encountered by persons with intellectual disabilities in their daily lives are products of society,[233] the pain and difficulties they face are rooted in biology. As such, interpreting intellectual disability as a purely social construct undermines the bodily experiences of persons with intellectual disabilities. In so far as the classifications and diagnostic/assessment criteria persist, it cannot be totally construed as a social construct. Intellectual disability is therefore a socio-medical construct, arising from a combination of social and clinical influences that disable persons with intellectual disabilities in the society. This is reinforced by the fact that perceptions about conduct and normality are addressed from two perspectives-'the clinical system approach' and 'the social system approach.'[234] Consequently, it is this socio-medical construal of intellectual disability that brings about the categorisation, labelling and stigmatisation of persons with intellectual disability.

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[228] VY Mudimbe *The invention of Africa: Gnosis, philosophy, and the order of knowledge* (1988) 3.

[229] M Sherry 'Postcolonising disability' (2007) 4 *Wagudu Journal of Transnational Women and Gender Studies* 10, 13.

[230] Sherry (n 229 above) 3.

[231] Keith & Keith (n 217 above) 22-29.

[232] See Chapter One of the study.

[233] CF Goodey A *history of intelligence and intellectual disability: The shaping of psychology in early modern Europe* (2011) 2.

[234] Manion & Bersani (n 215 above) 236.

2.4.3.1. Labelling of persons with intellectual disabilities

The label given to a person can significantly affect how a person is perceived, people's attitudes towards the person and the relationships the person would form in the society.[235]. Labelling involves ascribing a 'descriptor' to a person based on conduct or bodily attributes.[236] It involves the use of general words or phrases to construct a specific identity about a person, focusing on an attribute of the person, no matter how minute, and the use of that attribute to characterise the person. Once a person has been placed into a social group or category, a label tends to follow such a person, whether positive or negative. The label is regarded as a 'real' characteristic of the person so labelled as well as a 'form of life' and personality.[237] The allotment of a name, term, or label to person or his disability can significantly affect how a person is perceived, people's attitudes towards the person and the relationships the person would form in the society.[238] According to Clapton and Fitzgerald:

> "Bodily difference has for centuries determined social structures by defining certain bodies as the norm, and defining those which fall outside the norm as 'Other'; with the degree of 'Otherness' being defined by the degree of variation from the norm. In doing this, we have created an artificial 'paradigm of humanity' into which some of us fit neatly, and others fit very badly…"[239]

For persons with intellectual disabilities, labelling is usually negative.[240] Their disability becomes the focus and is used to describe them regardless of other attributes they may have.[241] The consequence of such labels is that they usually expose the person so labelled to stigma.[242] In Nigeria, labels such as 'akuri', 'dindirin' and 'ode' which mean 'empty-headed,' 'fool' and 'idiot,' respectively, are negative labels used to represent persons with intellectual disabilities in Yoruba language.[243] Similarly, words such as 'dolo' and

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[235] J Simpson *'What's in a name? The language of intellectual disability' in S Melrose et al (eds)* Supporting individuals with intellectual disabilities and mental Illness *(2015)* 9.

[236] ME Gold & H Richards 'To label or not to label: The special education question for African Americans' (2012) 26 *Educational Foundations* 143, 144.

[237] Rapley (n 132 above) 68.

[238] Simpson (n 235 above) 9.

[239] J Clapton & J Fitzgerald 'The history of disability: A history of otherness- how disable people have been marginalized through the ages and their present struggle for their human rights' http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.693.6138&rep=rep1&type=pdf (accessed 12 January 2018).

[240] T Shakespeare *Disability rights and wrongs* (2006) 71; AE While & LL Clark 'Overcoming ignorance and stigma relating to intellectual disability in healthcare: A potential solution' (2010) 18 *Journal of Nursing Management* 166, 169.

[241] Rapley (n 132 above) 68.

[242] Shakespeare *Disability rights and wrongs revisited* (2014) 95.

[243] 'Intellectual Disability- stepping out from the margins in Nigeria https://r18---sn-aigllns6.googlevideo.com/videoplayback?ratebypass=yes&sparams=dur,ei,expire,id,initcwndbps,ip,ipbits,itag,lmt,mime,mip,mm,mn,ms,mv,pl,ratebypass,requiressl,source&expire=1504544145&ipbits=0&ei=MDGtWaGXOoi1VdzhkMAO&signature=C31109AE42EB17B8BFEE7D352B58CF1B78949B.281B20708A79E7053774176D452B48E508695927&requiressl=yes&mime=video%2Fmp4&source=youtube&key=cms1&ip=2a01%3A4f8

‘wawa’ which mean fool or idiot are negative labels used to describe persons with intellectual disabilities in Hausa language.[244] Also, words such as ‘ọzuaị’ and ‘onye iberibe’ which mean imbecile[245] and words such as ‘ịbẹ’, ‘onye amaghi ihe’ and ‘onye nzuzu’ which mean idiot or fool[246] are negative words for persons with intellectual disabilities in Igbo in the South-South and South-East Nigeria, respectively. These labels function to exclude and subject persons with intellectual disabilities to reduce them in the eyes of members of the society.

Some authors have emphasised that the intellectual disability label has some benefits. For instance, to Keogh it serves “as a focus for advocacy and for ensuring attention to the problem, as a category or mechanism for providing services and as a condition or set of conditions that require scientific study.”[247] Anastasiou and Kauffman also contend that labelling is the consequence of the provision of special services and that the provision of special services goes hand in hand with the identification of difference. In other words, labelling entitles persons so labelled to the special services.[248]

Clearly, labelling is ‘complex and paradoxical’. [249] It is contradictory in the sense that even as people oppose it they need the labels to be able to access services that have been put in place for them because of the labels they are identified with.[250] However, in as much as labelling has its benefits, the negative aspects of it outweigh the positive. Having intellectual disability is generally perceived as having a “stigmatised identity”.[251] As such, a label of intellectual disability ‘simultaneously psychologises and reifies categorical identities’ and ‘self-identities as internal components’ and establishes intellectual disability as a vital characteristic of the person.[252] In other words, the label of intellectual disability reinforces

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%3A150%3A62a7%3A%3A2&lmt=1497627042565493&dur=340.009&pl=19&itag=22&id=o-APXAq9gG84XHCDKiu_VTST_tdnkQSsK4AGY2qs2Mozk&title=Intellectual%20Disability%20Stepping%20Out%20from%20the%20Margins%20in%20Nigeria&cms_redirect=yes&mip=169.159.108.208&mm=31&mn=sn-aigllns6&ms=au&mt=1504522543&mv=m (accessed 12 July 2016); Obiakpor et al (n 13 above) 32.

[244] English Hausa Dictionary http://kamus.com.ng/hausa/dolo.html (accessed 13 June 2015); ‘Wawa’ http://hausadictionary.com/wawa (accessed 30 August 2017)

[245] https://igbo.english-dictionary.help/index.php?q=fool&qb (accessed 12 July 2016).

[246] I Asouzu *The method and principles of complementary reflection in and beyond African philosophy* (2005) 191.

[247] BK Keogh ‘Learning disabilities: In defense of a construct’ (1987) 3 *Learning Disabilities Research* 4-5.

[248] D Anastasiou & JM Kauffman ‘The social model of disability: Dichotomy between impairment and disability’ (2013) 38 *Journal of Medicine and Philosophy* 441, *448.*

[249] Shakespeare (n 240 above) 72.

[250] Shakespeare (n 240 above) 72.

[251] KP Dorozenko et al ‘Imposed identities and limited opportunities: advocacy agency staff perspectives on the construction of their clients with intellectual disabilities’ 1 https://espace.curtin.edu.au/bitstream/handle/20.500.11937/7059/232148_232148.pdf?sequence=2 (accessed December 16 2017)

[252] Rapley (n 132 above) 68.

negative attitudes towards persons with intellectual disabilities and brings about their stigmatisation.

2.4.3.2. Stigma and persons with intellectual disabilities

Stigma is a social reaction which sets apart a particular trait of a person and represents it as disagreeable thereby devaluing the person in the process.[253] It involves the "co-occurrence of labelling, stereotyping, separation, status loss and discrimination."[254] According to Coleman, it is a complex concept that characterises an outlook towards life, individual and societal paradigms as well as "social relations and relationships."[255] Misconceptions about persons with intellectual disabilities often give rise to them being stigmatised and set apart from society. The social construction of disability which creates images of persons with intellectual disabilities as "pathetic figures in need of pity, charity and caretaking" gives rise to stigma.[256] Society often prescribes standards for independence; persons who do not fit in with those standards are assumed inferior and the assumption leads to various discriminatory practices that reduce the quality of life of stigmatised persons.[257] According to Goffman, a stigma-theory is constructed to explain such inferiority and the menace such persons denote.[258]

Stigmatisation stems from social categorisation whereby people are treated "categorically rather than individually" and are consequentially held in low esteem.[259] Thus, the placement of persons in categories such as the categories created by diagnostic manuals together with the terminology associated with intellectual disabilities results in their differentiation and stigmatisation.[260] The treatment of persons with intellectual disabilities in the nineteenth century and pre-colonial Nigeria is evidence of how society can stigmatise people because of negative misconceptions. Indeed, the belief that persons with intellectual disabilities were detrimental to societal stability and development led to their removal to

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[253] A Miles T*he mentally ill in contemporary society* (1981) 70.
[254] BG Link & JC Phelan 'Conceptualizing stigma' (2001) 27 *Annual Review of Sociology* 363.
[255] LM Coleman 'Stigma an enigma demystified in LJ Davis (ed) *The disability studies reader* (2nd ed) (2006) 141.
[256] National disability Authority (n 213 above) 28-29; Nigeria Stability and Reconciliation Programme and Inclusive Friends 'What violence means to us: Women with disabilities speak' 11 http://www.nsrp-nigeria.org/wp-content/uploads/2015/09/What-Violence-Means-to-us-Women-with-Disabilities-Speak.pdf (accessed 4 September 2017).
[257] National disability Authority above) 29.
[258] E Goffman 'Selections from stigma' in LJ Davis (ed) *The disability studies reader* (2nd ed) (2006) 132-133.
[259] Coleman (n 255 above) 147.
[260] Coleman (n 255 above) 145.

institution and sterilisation.[261] The labels and terms used to describe intellectual disability can also result in the ascription of negative stereotypes and categories to a person. It is the stereotyping and categorising that lead to the stigmatisation of the person, especially as previous exposure to persons with disabilities has been negative.[262] Historically, clinical labels such as "moron," "imbecile," "idiot" and "mental retardation" that were used to identify persons with intellectual disabilities were stigmatising as they diminished the person so labelled and suggest that the person is 'not functioning normally'. [263]

The social exclusion of persons from society is a consequence of stigma. The exclusion often restricts social relations for stigmatised persons acting as a type of "social quarantine" that restricts their interactions to other stigmatised persons and family members.[264] So stigma related exclusion becomes a form of social control.[265] Moreover, the social exclusion arising from stigma affects not only the stigmatised person but persons associated with the person such as family, friends, relatives and even persons working with the person. In Nigeria, many parents hide their children at home because of the stigma associated with having a child with disability in Nigeria.[266] Some professionals working with persons with disabilities involved in the empirical component of this study also alluded to being treated differently and called derogatory names because of their association with persons with intellectual disabilities.

2.5. Conclusion

This chapter had a broad objective to conceptualise intellectual disability by deconstructing the various principles attached to and affecting the concept. This objective is very crucial in a discourse of a concept as contested and debated as intellectual disability and would form a basis for other issues to be discussed in the study. The starting point of the chapter was to give a historic account of intellectual disability in Nigeria prior to colonisation, during colonisation and after colonisation. It revealed how culture affects the construction of intellectual disability.

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[261] While & Clark (n 240 above) 167.
[262] While & Clark (n 240 above) 169.
[263] Harris (n 7 above) 4.
[264] Harris (n 7 above) 4.
[265] Harris (n 7 above) 4; Link & Phelan (n 254 above) 363.
[266] Atilola et al (n 67 above) 35.

It was also shown that intellectual disability is not always portrayed negatively as some cultures in Nigeria treat persons with intellectual disability positively. Consequently, how a person is regarded in terms of personhood, and as an equal member of society, depends on how intellectual disability is constructed in that society.

It also examined the definitions and classification schemes for intellectual disability and concludes that they are still inadequate. It argued that most of the definitions and standards in the diagnostic manuals highlight the “deficit perspective” of disability which does not take cognisance of the aptitude of persons with intellectual disability.[267] More so, as will be seen subsequently, the diagnosis and assessment criteria in the manuals, especially the intelligence quotient (IQ) and assessment tests, are flawed. Yet they are continually used in determining the status and ability of persons with intellectual disabilities to function in society.

The chapter also examined the construal of intellectual disability clinically and as a social construct. It argued that although the clinical construction of intellectual disability is functionalist and validates the dominance of professional values, there are also socio-economic and attitudinal barriers which work to exclude persons with intellectual disabilities from the society.

Clearly how intellectual disability is construed affects how persons with intellectual disabilities are treated in relation to others in society in terms of equality and non-discrimination. In the light of this, the next chapter examines what the right to equality entails for persons with intellectual disabilities, in general, and adolescents with intellectual disabilities, in particular.

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[267] Garigiulo (n 6 above) 142.

CHAPTER THREE

EQUALITY AND NON-DISCRIMINATION VIS-À-VIS THE STERILISATION OF ADOLESCENT GIRLS WITH INTELLECTUAL DISABILITIES

> Women and girls with disabilities have historically been denied the freedom to make their own choices in matters relating to their reproduction. In the healthcare sector they experience multiple discriminatory practices. Women and girls with intellectual disabilities are particularly vulnerable to coerced or forced medical interventions.[1]

3.1. Introduction

In this chapter, the principles of equality and non-discrimination and what they entail for persons with disabilities, in general, and adolescent girls with intellectual disabilities, in particular, are examined.

Given that women and girls with intellectual disabilities are subject to multiple and intersectional discrimination, the conceptions and significance of equality and non-discrimination for persons with disabilities are examined. Although there are different types of equality, the chapter focuses on two types of equality as gleaned from national and international human rights instruments- formal and substantive equality. It argues that for inclusive equality is required for persons with disabilities who have traditionally been excluded from society.

The chapter also examines the legal framework for equality and non-discrimination under Nigerian law and international law. It interrogates how equality and non-discrimination are conceptualised and the way in which these laws apply theories of equality with a view to highlighting the inadequacies of the legal framework for persons with disabilities especially with regards to the sterilisation of adolescent girls with intellectual disabilities. It further examines the impact of the involuntary sterilisation of adolescent girls with intellectual disabilities in comparison to their male peers and/or their peers without disabilities.

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[1] CG Ngwena 'Reproductive autonomy of women and girls under the Convention on the Rights of Persons with Disabilities' *(2018*) 140 *International Journal of Gynecology & Obstetrics* 128.

3.2. The import of equality and non-discrimination for persons with intellectual disabilities

The rights to equality and non-discrimination underscore the notion that all persons are equal irrespective of their standing in life and are entitled to the same set of rights.[2] They are enshrined in national and international human rights law instruments as a guarantee in the realisation of other human rights and are especially important to persons belonging to a class of people who have historically been marginalised.[3] In a discourse on equality and non-discrimination, a question that arises is whether the two concepts are the same or whether they differ in some sense. In as much as they are two distinct rights that refer to the notion of equal treatment of all persons, it can be argued that equality embodies an "ideal" while non-discrimination leans on specific types of actions.[4] More so, non-discrimination is an indispensable component of equality considering that "the right to non-discrimination is narrower in content and subsumed in the right to equality."[5] As such, equality and non-discrimination are vital in safeguarding the human rights of adolescent girls with intellectual disabilities as many issues affecting them, including involuntary sterilisation, can be expressed within the context of equality and non-discrimination.[6] Accordingly, this section examines the concepts of equality and non-discrimination and their import for persons with disabilities.

3.2.1. Equality: What does it entail?

Equality is a complex and contested concept with differing views on what it entails and how it can be achieved.[7] There are numerous conceptions of equality with corresponding differing

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[2] R Cera 'Article 5 [Equality and Non-Discrimination]' in VD Fina et al (eds) *The United Nations Convention on the Rights of Persons with Disabilities- A Commentary* (2017) 158.

[3] D Moeckli 'Equality and Non-Discrimination' in D Moeckli et al (eds) *International human rights law* (2014) 157, 160.

[4] J Kumpuvuori & M Scheinin 'Treating the different ones differently- a vehicle for equality for persons with disabilities? Implications of Article 5 of the Convention on the Rights of Persons with Disabilities' in J Kumpuvuori & M Scheinin (eds) *United Nations Convention on the Rights of Persons with Disabilities- Multidisciplinary Perspectives* (2010) 54, 55.

[5] NYU Global Institute for Advanced Study *Article 7: The equality and non-discrimination provision. Appendix E to the report of the Global Citizenship Commission* (2016) 1.

[6] Kumpuvuori & Scheinin (n 4 above) 54.

[7] E Barry 'Non-discrimination and equality' in Children's Rights Alliance & Law Centre for Children and Young People (eds) *Making rights real for children: A children's rights audit of Irish law* 6 https://www.childrensrights.ie/sites/default/files/submissions_reports/files/MakingRightsReal2015.pdf (accessed 7 July 2017); MH Rioux & CA Riddle 'Values in disability policy and law: Equality' in Rioux, MH et al (eds) *Critical Perspectives on Human Rights and Disability Law* (2010) 37, 39; S Gosepath 'Equality' *The Stanford Encyclopedia of Philosophy* (2011) https://plato.stanford.edu/archives/spr2011/entries/equality/ (accessed 15 September 2016).

assumptions about it ranging from recognising difference and unequal treatment to structural and institutional transformations, services, strategies and programmes aimed at realising equality.[8] The difficulty in defining equality arises because it is abstract in nature and subject to different interpretations.[9] Hence philosophers, judges and policy makers have strived to give meaning to the concept based on their political and social narratives.[10]

Aristotle expressed equality in terms of justice as requiring “like cases be treated alike” and “unalike cases be treated unalike” in keeping with their differences.[11] He believed that inequality was inevitable in society as individuals are naturally unequal. To him, society is “made up not only of a number of human beings, but also of human beings differing in kind” with different roles and statuses in society according to their natural aptitude.[12] Aristotle’s conception of equality permits gender, proprietary and class inequalities and does not recognise human difference. Locke understood equality from the perspective of natural law and social contract theory asserting that all human beings have equal natural rights.[13] Locke’s conception of equality is patriarchal and indicative of a deference to monarchical and feudal powers which permit inequality of certain classes of persons such as women, children and slaves.[14] To Rawls, equality is focused on the distribution of social advantages and rights. He contends that “the primary subject of justice is the basic structure of society”, or more exactly, ”the way in which the major social institutions distribute fundamental rights and duties and determine the division of advantages from social cooperation.”[15] Thus, as observed by Rioux and Riddle, “the scope of theories of equality extends from the equalization of material resources to the recognition of non-material human rights that require equal attention.”[16]

Equality is guaranteed by most human rights instruments and many national constitutions including the Nigerian constitution; yet adjudging what it means remains a

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[8] M Gaudron ‘In the Eye of the Law; the Jurisprudence of Equality’ (1990) cited in Rioux & Riddle (n 7 above) 39-40.
[9] *Law v Canada (Minister of Employment and Immigration)* [1999] 1 SCR 497, 507, per Iacobucci J.
[10] Gaudron (n 8 above).
[11] Aristotle ‘Nicomachean Ethics’ in J Barnes (ed) *The complete works of Aristotle* (1984) Vol .3, 1131a10-b15; Aristotle ‘Politics’ in in J Barnes (ed) (1984) *The complete works of Aristotle* book III, 9.1280 a8-15, 12. 1282b18-23.
[12] Aristotle ‘Politics’ (n 11 above) 2.2, 1261a23-25.
[13] CG Ngwena ‘Disabled people’ and the search for equality in the Workplace: An appraisal of equality models from a comparative perspective’ unpublished PhD thesis, University of the Free State, 2010, 306; Gosepath (n 7 above).
[14] Ngwena (n 13 above) 306.
[15] J Rawls *A Theory of Justice* (1971) 7.
[16] Rioux & Riddle (n 7 above) 39.

difficult task. It is for this reason that Chief Justice Beverley McLachlin, Chief Justice of the Supreme of Canada called it "the most difficult right"[17] and Justice Mary Gaudron of the High Court of Australia called it "infuriatingly elusive."[18] Similarly, Dworkin calls it "the endangered species of political ideas."[19] Baer states that it contains "the greatest number of conundrums"[20] and Barry refers to it as a "vague nebulous concept."[21] One difficulty in construing equality stems from the assumption that "equality and inequality are simple and easily defined concepts."[22] Another difficulty is due to the generality of equality language which leaves its meaning open to debate as equality can be interpreted as ranging from minimal protection of democratic rights to full economic equality.[23] Moreover, how equality is construed is usually based on the construer's view of society and what it ought to be.[24] Additionally, the promise of equality never seems to be met because states fail to honour their professed equality commitments.[25]

Persons with disabilities, especially those with intellectual disabilities, are continually excluded from all aspects of life and are often excluded in the conceptions of equality. Notwithstanding international human rights law standards on the right to equality, national laws and policies generally perpetuate discrimination and the exclusion of persons with disabilities because of their perceived differences.[26] In particular, women and girls with intellectual disabilities are denied their legal capacity, are involuntarily sterilised and are subjected to negative stereotypes and preconceptions which prevent them from enjoying their rights on an equal basis in relation to their male counterparts and others in society.[27]

Persons with disabilities are a heterogeneous group with different types of impairments, and disability stems from the interaction between their impairment and socio-

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[17] B McLachlin '*Equality: The Most Difficult Right'* (2001) 14 *Supreme Court Law Review* 17, 20.
[18] Gaudron (n 8 above).
[19] R Dworkin *Sovereign virtue: The theory and practice of equality* (2000) 1.
[20] S Baer 'Equality: The jurisprudence of the German Constitutional Court' (1999) 5 *Columbia Journal of European Law* 249.
[21] Barry (n 7 above) 6.
[22] F Mount 'Five types of inequality' 3 https://equality-ne.co.uk/downloads/337_FivetypesofInequality.pdf (accessed 8 July 2017).
[23] McLachlin (n 17 above) 19.
[24] McLachlin (n 17 above) 20.
[25] McLachlin (n 17 above) 20; Ngwena (n 13 above) 304.
[26] United Nations Human Rights Council 'Equality and non-discrimination under article 5 of the Convention on the Rights of Persons with Disabilities' Report of the Office of the United Nations High Commissioner for Human Rights A/HRC/34/2, para 6 https://documents-dds-ny.un.org/doc/UNDOC/GEN/G16/406/73/PDF/G1640673.pdf?OpenElement (accessed 7 July 2017).
[27] Committee on the Rights of Persons with Disabilities (CRPD Committee) 'Article 6: Women and girls with disabilities' (General Comment No. 3) (2016) CRPD/C/GC/3 para 8 http://undocs.org/CRPD/C/GC/3 (accessed 7 July 2017).

economic structures in society.[28] Thus, equality as a principle must direct social action and legal decision-making so as to protect their human rights and ensure their inclusion and participation in society.[29] It requires an appreciation of the socio-political structures that shape laws and policies, underlying socio-economic influences, familial and communal life, stereotypes and cultural beliefs.[30] Consequently, equality is relative and context specific.

The principle of equality should recognise human difference and diversity. In other words, an understanding of how "difference is recognised, given meaning and valued is imperative in achieving equality."[31] This is because equal treatment may not necessarily result in equality.[32] People differ from one another and persons with disabilities, though not a homogenous group, have attributes as a group of persons which make them to be considered as different from others in the society and which, as highlighted in Chapter Two, render them susceptible to stigma as a group.[33] The supposition that persons with disabilities are on an equal footing with others in society and should be treated in the same way as others gives rise to discrimination and inequality.[34] Thus, in the words of Kumpuvuori and Scheinin, recognising persons with disabilities as a group of persons subject to discrimination "will result in the demands for laws and policies that produce equality."[35] However, the differences to be considered relevant in the pursuit of equality must be assessed on a case by case basis as the grounds for difference are not fixed or universal.[36] This identification of difference along with legal and policy measures in the realisation of equality brings about the distinction between formal equality and substantive equality.[37]

3.2.2. Types of equality and their implication for persons with intellectual disabilities

In law, equality has also been construed in different ways including formal equality, equality of opportunity, equality of outcome and substantive equality. The various interpretations of disability can aid in gaining further insight into contextual difficulties and advantages surrounding the legal employment of such forms of equality. However, equality can be

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[28] Convention on the Rights of Persons with Disabilities (CRPD) (2006) 46 ILM 443, article 1 and preamble e.

[29] MH Rioux et al (eds) *Critical Perspectives on Human Rights and Disability Law* (2010) 241; General Comment No. 3 (n 27 above) para 8.

[30] Rioux et al (n 29 above) 241.

[31] Rioux & Riddle (n 7 above) 39.

[32] Kumpuvuori & Scheinin (n 4 above) 55.

[33] n 4 above 63-64.

[34] n 4 above 63.

[35] n 4 above 65.

[36] D Schiek 'Indirect discrimination' in D Schiek et al (eds) *Cases, materials and text on national supranational and international non-discrimination* (2007) 323, 328.

[37] Kumpuvuori & Scheinin (n 4 above) 55.

subsumed into two broad categories around which the discourse on equality for persons with disabilities is focused. Kumpuvuori and Scheinin succinctly observe that “the recognition of positive measures in achieving equality takes us to the distinction between formal and substantive equality” as the basis for understanding human difference.[38]

3.2.2.1. Formal equality

Formal equality entails treating persons in similar situations in the same manner.[39] It upholds the principle of ‘equality before and under the law.’[40] It maintains that laws and rights be applied to all persons on an equal basis equally applied to all and that a person’s characteristics are immaterial in the determination of their right to a social benefit. [41,42]The formal approach is often traced to Aristotle who construed equality as treating likes alike and those unalike unlike.[43]Aristotle’s idea of equality saw nothing wrong in slavery and patriarchal institutions of domination by males in society.[44]

Formal equality presumes that “neutrality in the application of the law and the absence of different treatment” will always result in equality. However, it is illusionary as it is doubtful whether the law can claim to be truly neutral and truly apply equally to all persons without having unequal impacts.[45] In consequence, formal equality does not recognise human difference and does not take into consideration the differential impact that equal treatment may have on some persons especially those with disabilities. It is only concerned with treating people alike regardless of whether or not ‘they are treated equally badly or equally well.’[46] In this regard, the focus in the attainment of the formal equality is ‘procedural justice’ and a strong emphasis of same treatment at all times and in all conditions.[47] Essentially, formal equality is fallacious in believing that persons could be described as alike as it does

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[38] n 4 above 55.
[39] Kumpuvuori & Scheinin (n 4 above) 55; Cera (n 2 above) 162.
[40] Cera (n 4 above) 162
[41] Rioux & Riddle (n 7 above) 42; Equal Rights Trust ‘The ideas of equality and non-discrimination: Formal and substantive equality’ http://www.equalrightstrust.org/ertdocumentbank/The%20Ideas%20of%20Equality%20and%20Non-discrimination,%20Formal%20and%20Substantive%20Equality.pdf (accessed 15 September 2016).
[42] Equal Rights Trust (n 41 above).
[43] Aristotle ‘Nicomachean Ethics’ (n 11 above) 1131a10-b15.
[44] SWE Goonesekere ‘The concept of substantive equality and gender justice in South Asia’ 8 https://zapdoc.tips/queue/the-concept-of-substantive-equality-and-gender-justice-in-so.html (accessed 10 May 2018).
[45] Equal Rights Trust (n 41 above).
[46] S Fredman ‘Less equal than others- equality and women’s rights’ in Gearty, C & Tomkins, A (eds) *Understanding human rights* (1996) 197, 202.
[47] E Durojaye & Y Owoeye ‘Equally unequal or unequally equal’ (2017) 17 *International Journal of Discrimination and the Law* 70, 73.

not take into cognizance the existing differences in persons and structural differences in society which may cause hardship to some persons in society.[48] It fails to recognise that the application of equal standards to persons with disabilities in relation to others may result in their being further disabled on account of their disabilities and structural differences they encounter in society. As such, formal equality overlooks the fact that in some situations the problem “resides in the structures (built to reflect and accommodate privileged norms) and not in the person who is judged different.”[49]

Treating every person in the same way without taking cognizance of their inherent differences would ultimately result in direct discrimination.[50] So, in as much as formal equality strives at the equal treatment of persons and equal application of rights, it may actually accentuate and embed inequality in society. [51] Goonesekere argues that such equal treatment “legitimised differences in treatment based on ethnicity or sex. Since men and women were biologically different, and racial characteristics were different, different treatment was not deemed an infringement of equality.”[52] It misleadingly suggests that one person’s rights *vis á vis* another’s are identical in all contexts and erroneously suggests that all questions of equality are to be examined under a single standard of justification.

Undoubtedly, the formal approach to equality of equal treatment has historically been a veritable quality model in addressing discrimination. It has played an important role in combating discrimination arising from colonialism, sexism and racism. Hence it is not so much an ineffectual principle of equality but an inadequate principle.[53] At best, it promises a highly tempered and constrained citizenship for persons with disabilities. Formal equality merely attends to discrimination but not to the structural inequality that underpins society.[54] It uses persons without disabilities as the comparator and in so doing is certain to disappoint persons with disabilities because such a comparison is structured around the premise that everyone is ‘able-bodied.’[55] Ngwena succinctly observes that “formal equality is optimally functional when the disabled person possesses, as much as possible, the bodily constitution

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[48] n 47 above 73.
[49] n 47 above 73.
[50] Rioux & Riddle (n 7 above) 42.
[51] Durojaye & Owoeye (n 47 above) 73.
[52] Goonesekere (n 44 above) 8.
[53] Ngwena (n 13 above) 315.
[54] n 13 above 319.
[55] n 13 above 319.

and functional capacities of the enabled person."[56] So, in failing to appreciate human individuality and diversity, formal equality ignores the mental impairments of person with intellectual disabilities and the attitudinal barriers serving to exclude them from society. This gives rise to an equality model that is manifestly non-inclusive.

3.2.2.2. Substantive equality

Substantive equality differs from formal equality in that sense that it is focused on ensuring that laws, policies and practices alleviate the inherent disadvantage that certain persons or groups of persons experience.[57] While formal equality does not recognise human difference, substantive equality recognises human diversity and seeks to adopt a practical approach in accommodating them and achieving equality.[58] Substantive equality therefore seeks to treat people equally by taking into consideration their situations and backgrounds in life.[59] It aims at remedying social norms and power dynamics that contribute to inequality and the discrimination of disadvantaged persons in society.[60]

It has been argued that substantive equality encompasses equality of outcome and equality of opportunity for persons with disabilities.[61] t The CRPD expands on the substantive equality approach which incorporates both equal of opportunity and equality of outcome.[62] A substantive equality approach committed only to equality of opportunity even if individualised ensures that a person with disability is provided with the necessary accommodations for realising a right or social benefit without dealing with the underlying reason why they are disadvantaged.[63] On the other hand, equality of outcome focuses not only on the need for providing accommodations on an individualised basis but also on how to ensure that equal treatment is the resultant effect.[64] It goes beyond equal treatment and requires changes to eliminate discrimination and inequality.[65] Thus, a substantive equality approach should be based on accommodating human diversity, addressing disadvantage in

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[56] Ngwena (n 13 above) 320.

[57] Social Protection & Human Rights 'Equality and non-discrimination' http://socialprotection-humanrights.org/framework/principles/equality-and-non-discrimination/ (accessed 10 March 2017).

[58] n 47 above 74.

[59] Kumpuvuori & Scheinin (n 4 above) 55-56; Durojaye & Owoeye (n 47 above) 74.

[60] Social Protection & Human Rights (n 57 above); Kumpuvuori & Scheinin (n 4 above) 56; Durojaye & Owoeye (n 47 above) 73.

[61] Cera (n 2 above) 161; Durojaye & Owoeye (n 47 above) 73.

[62] Committee on the Rights of Persons with Disabilities 'Article 5: equality and non-discrimination' (2018) CRPD/C/GC/6 (General Comment No. 6) para 11.

[63] AS Kanter 'The Americans with Disabilities Act at 25 years: Lessons to learn from the convention on the rights of people with disabilities' (2015) 63 *Drake Law Review* 819, 842–845.

[64] Cera (n 2 above) 162.

[65] n 2 above 162.

society and boosting human development.[66]According to Albertyn and Fredman, a substantive equality framework should deal with stigma, prejudice and violence; remedy socio-economic disadvantage; enable participation and accommodate difference through societal change.[67] The framework must include definite measures directed at overcoming barriers that hinder persons with disabilities from enjoying the same opportunities as others in society.[68]

One problem with promoting substantive equality is that, even with the consensus about modifying formal equality, there is no uniform conception of substantive equality. While the different concepts of substantive equality all agree on the necessity of deviating from formal equality with a view to achieving inclusive equality, they are of different forms and substance. So like the concept of equality, it defies straightforward definitions.[69] Also, if not properly conceptualised to take into consideration human diversity as well as structural differences, substantive equality may result in indirect discrimination.[70] More so, with regards to disability, the application of substantive equality in addressing structural or systemic discrimination is more complex than in other spheres of human rights. This is because disability is the interaction between a person, his or her impairment and the societal structures, and so, equality in the context of disability must direct "social action and legal decision-making."[71] This is perhaps why the Committee on the Rights of Persons with Disabilities (CRPD Committee) states that the CRPD embraces a new model of inclusive equality.[72] This Inclusive equality model builds on Fredman's view of equality and applies it in the context of disability.

3.2.3. The principle of non-discrimination

The principle of non-discrimination is the essence of human rights in the sense that it requires that persons are not excluded based on some trait or membership of a social group but are treated equally.[73] In other words, discrimination may hinder the fulfilment and enjoyment of

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[66] S Fredman & B Goldblatt *Gender equality and human rights* (2015) 315; Durojaye & Owoeye (n 47 above) 74.

[67] C Albertyn & S Fredman 'Equality beyond dignity: Multi-dimensional equality and Justice Langa's judgments' (2015) 1 *Acta Juridica* 430.

[68] Cera (n 2 above) 162.

[69] Ngwena (n 13 above) 337.

[70] Kumpuvuori & Scheinin (n 4 above) 56.

[71] Rioux et al (n 29 above) 241.

[72] General Comment No. 6 (n 62 above) para 11.

[73] A McBeth et al *The International Law of Human Rights* (2011) 111.

other human rights. There are several definitions of 'discrimination' in human rights law. The Committee on Economic, Social, and Cultural Rights defines it as follows:

> "Discrimination constitutes any distinction, exclusion, restriction or preference or other differential treatment that is directly or indirectly based on the prohibited grounds of discrimination and which has the intention or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of [human] rights. Discrimination also includes incitement to discriminate and harassment."[74]

The United Nations Human Rights Committee defines discrimination as:

> "any distinction, exclusion, restriction or preference which is based on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status, and which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise by all persons, on an equal footing, of all rights and freedoms."[75]

The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) also defines discrimination as:

> "any 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."[76]

Discrimination therefore occurs when a person is subjected to "differential treatment" on the basis of an aforementioned prohibited grounds resulting in his or her marginalisation and deprivation of his/her rights or opportunities.[77] In view of that, the principle of non-discrimination proscribes the application of different human rights standards to persons with disabilities.[78] An example of this is the CRPD's requirement of support in the exercise of legal capacity for persons with disabilities in place of pre-CRPD standard of denying them their right to legal capacity based on mental capacity assessments resulting in discrimination and inequality.[79]

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[74] Committee on Economic, Social and Cultural Rights 'Non-discrimination in economic, social and cultural rights (art. 2, para. 2, of the International Covenant on Economic, Social and Cultural Rights)' General Comment No. 20, para 35 http://www.refworld.org/docid/4a60961f2.html (accessed 08 July 2017).

[75] United Nations Human Rights Committee (HRC) 'General Comment No. 18: Non-discrimination' *http://www.refworld.org/docid/453883fa8.html* (accessed 08 July 2017).

[76] Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) (1979) 19 ILM 33, article 1.

[77] Disability Rights California 'Definitions of stigma and discrimination' https://www.disabilityrightsca.org/system/files/file-attachments/CM0401.pdf (accessed 08 July 2017).

[78] L Steele 'Court authorised sterilisation and human rights: Inequality, discrimination and violence against women and girls with disability' (2016) 39 *UNSW Law Journal* 1002, 1017.

[79] Convention on the Rights of Persons with Disabilities (n 28 above) article 12.

Discrimination may be direct, indirect, by association, structural or systemic and intersectional.

i. Direct discrimination

Discrimination is direct when it involves treating a person less favourably than others in the same situation because of his or her background or personal traits.[80] It occurs when a person is discriminated on one or more grounds prohibited by law such as gender, sex, race, age and disability.[81] The involuntary sterilisation of adolescent girls with intellectual disabilities is an example of direct discrimination as sterilisation is usually carried out on them because of their disability and lack of legal capacity.

ii. Indirect discrimination

Indirect discrimination occurs when laws, policies or practices that appear neutral have an uneven effect on a person or put the person at a disadvantage in comparison to others.[82] For instance, a policy that offers free contraception services to women and girls that fails to provide information in simple and accessible formats for women and girls with intellectual disabilities.

iii. Discrimination by association

Discrimination by association occurs where a person is treated differently because of his or her association with a person with a particular characteristic such as disability. For example, treating teachers of students with intellectual disabilities differently or marginalising them because of their association with persons with intellectual disabilities.[83]

iv. Structural or systemic discrimination

Structural or systemic discrimination are hidden or overt patterns of discriminatory behaviour, cultural beliefs and traditions, social norms and stereotypes inextricably linked to a lack of policies, regulation and service provision specifically for women with disabilities.[84]

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[80] Committee on Economic, Social and Cultural Rights, Social and Cultural Rights (n 74 above) para 10; Committee on the Rights of Persons with Disabilities (n 27 above) para 17.

[81] General Comment No. 6 (n 62 above) para 18; Committee on Economic, Social and Cultural Rights, Social and Cultural Rights (n 74 above) para 30.

[82] n 74 above para 10; General Comment No. 3 (n 27 above) para 17.

[83] General Comment No. 3 (n 27 above) para 17; Equal Opportunities Commission 'What is discrimination?' https://www.eoc.org.uk/what-is-discrimination/ (accessed 13 November 2017).

[84] General Comment No. 3 (n 27 above) para 17.

v. Intersectional discrimination

Intersectional discrimination refers to multidimensional discrimination that cuts across identity, gender, status and life circumstances which interact simultaneously such that they are inextricable.[85] It acknowledges the experiences of disadvantage faced by persons with disabilities due to multiple and intersecting forms of discrimination.[86] Involuntary sterilisation is an expression of intersectional discrimination on the basis of gender, disability, disability stereotyping on the basis of incapacity and eugenic stereotyping. Adolescent girls with intellectual disabilities are particularly vulnerable to involuntary sterilisation on the basis that they are disabled, female and perceived as likely to give birth to disabled children.

Persons with disabilities, especially women and girls with intellectual disabilities, are usually subject to multiple forms of discrimination in their families and in the society. They may be discriminated against directly or indirectly, structurally or systematically or may be subject to intersectional discrimination in many aspects of their lives including healthcare. They are often denied legal capacity and their decisions are usually substituted by third parties. Denying them legal capacity can lead to forced medical interventions such as involuntary sterilisation and forced contraception.[87] They are also discriminated against on the basis of negative gender and disability stereotypes such as incapacity to make decisions or be fit parents. Accordingly, the international and national human rights framework on discrimination which is examined in section 3.3 requires states not only to protect them from discrimination but also to adopt measures to eliminate discrimination. Given that discrimination is an underlying cause of inequality, it needs to be addressed with concrete legal, policy and social measures.[88] "Systemic and root-causes of discrimination" as well as laws, policies, practices, programmes, beliefs and/or stereotypes that cause and engrain discrimination should be addressed.[89] Although the international human rights framework provides a robust jurisprudence in this regard, the Convention on the Rights of Persons with Disabilities is ahead as it contains innovative provisions that are potentially useful in promoting non-discrimination of persons with disabilities.

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[85] n 27 above para 17.
[86] n 27 above para 17.
[87] n 27 above para 44.
[88] Human Rights Watch 'Discrimination, inequality, and poverty- a human rights perspective' https://www.hrw.org/news/2013/01/11/discrimination-inequality-and-poverty-human-rights-perspective#_ednref72 (accessed 13 June 2015).
[89] Human Rights Watch (n 88 above).

3.3. Legal framework for equality and non-discrimination

Equality and non-discrimination are fundamental elements of the international human rights framework. The Universal Declaration of Human Rights (Universal Declaration) provides that “all human beings are born free and equal in dignity and rights.”[90] Article 2 of the Universal Declaration also provides that all persons are entitled to all the rights and freedoms set out in the Declaration “without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.” The Universal Declaration further provides for equal recognition before the law, equality before the law and equal protection of the law against discrimination.[91] Similarly, the International Covenant on Economic, Social and Cultural Rights (CESCR) and the International Covenant on Civil and Political Rights (ICCPR) also prohibit discrimination as to “race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status” and guarantee equal rights for men and women.[92] The International Convention on All Forms of Racial Discrimination (CERD) also prohibits all forms of racial discrimination and guarantees equality before the law to all persons.[93] The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) also prohibits all forms of discrimination against women, which includes girls, by promoting amongst others, equality between men and women in national constitutions or legislation.[94] Although they do not include disability as a ground for discrimination, some monitoring bodies have emphasised the need to adopt specific measures to address the root causes of discrimination so as to achieve equality.[95] These specific measures could include measures aimed at addressing discrimination on the basis of disability.

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[90] Universal Declaration of Human Rights 1948, G.A. Res. 217A (III), U.N. Doc. A/810 at 71, article 1.

[91] n 90 above articles 6 & 7.

[92] International Covenant on Economic, Social and Cultural Rights (CESCR) 1966, 993 UNTS 3, articles 2(2) & 3; International Covenant on Civil and Political Rights 1966, 999 UNTS 171, articles 2(1) & 3.

[93] International Convention on the Elimination of All Forms of Racial Discrimination 1969, 660 UNTS 195, article 5.

[94] Convention on the Elimination of All Forms of Discrimination against Women (n 76 above) articles 2 & 14(2).

[95] For instance, the United Committee on Economic, Social and Cultural Rights observed that so as to “eliminate substantive discrimination, States parties may be, and in some cases are, under an obligation to adopt special measures to attenuate or suppress conditions that perpetuate discrimination.”[95] Similarly, the CEDAW Committee observed that “the position of women will not be improved as long as the underlying causes of discrimination against women, and of their inequality, are not effectively addressed.” See Committee on the Elimination of Discrimination against Women (CEDAW Committee) (2004) ‘General recommendation No. 25, on article 4, paragraph 1, of the Convention on the Elimination of All Forms of Discrimination against Women, on temporary special measures’ para 10.

The Convention on the Rights of the Child (CRC) also contains a general provision on discrimination “irrespective of the child’s or his or her parent’s or legal guardian’s race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.”[96] Interestingly, the CRC, unlike most of the instruments discussed in this section, includes disability as a prohibited ground of discrimination. States parties are also to take “all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinion, or beliefs of the child’s parents, legal guardians, or family members.”[97]

At the regional level, the African Charter on Human and Peoples’ Rights prohibits discrimination based on “race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status”[98] and guarantees equality before the law, equal protection of the law and equality of rights to all persons.[99] It also guarantees the protection of the rights and special measures of protection for women, children, the aged and the disabled according to their needs.”[100] Similarly, the African Charter on the Rights and Welfare of the Child contains a general prohibition of discrimination “irrespective of the child’s or his/her parents’ or legal guardians’ race, ethnic group, colour, sex, language, relation, political or other opinion, national and social origin, fortune, birth or other status.”[101]

Nigeria is a party to all these international human rights instruments and can rely on them in guaranteeing the rights to equality and non-discrimination for persons with intellectual disabilities especially in respect of multiple and intersectional discrimination. Some of the instruments have either been domesticated into Nigerian law or similar provisions to those in the instruments can be found in some Nigerian laws. This section however focuses on the legal framework for equality and non-discrimination in the Convention on the Rights of Persons with Disabilities and under Nigerian law.

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[96] Convention on the Rights of the Child (1989) 28 ILM 1456, article 2(1).

[97] n 96above article 2(2).

[98] African Charter on Human and Peoples' Rights (1982) 21 ILM 58, article 2.

[99] n 98 above, article 3(1) & (2); article 19.

[100] n 98 above, article 18(3) & (4).

[101] African Charter on the Rights and Welfare of the Child (1990) OAU Doc. CAB/LEG/24.9/49, article 3.

3.3.1. Equality and non-discrimination in the CRPD

The Convention on the Rights of Persons with Disabilities (CRPD) is premised on the basis that previous human rights interventions have been unsatisfactory in safeguarding the rights to equality and non-discrimination for persons with disabilities.[102] It lays emphasis on equality and non-discrimination as a right and as general principles of non-discrimination, equality of opportunity and equality between men and women.[103] It also emphasises equality for women and girls with disabilities and acknowledges that they face multiple discriminations which requires positive measures in guaranteeing them full and equal enjoyment of all human rights.[104] In addition, the CRPD guarantees to children with disabilities the full of "all human rights and fundamental freedoms on an equal basis with other children."[105] Accordingly, the CRPD Committee in its General Comment No. 6 acknowledges that "equality and non-discrimination are at the heart of the Convention and evoked consistently throughout its substantive articles with the repeated use of the wording "on an equal basis with others", which links all substantive rights of the Convention to the non-discrimination principle".[106] According to the Committee, the CRPD is based on 'inclusive equality which goes further than any equality ideal previously expressed in a human rights convention. It further states as follows:

> It embraces a substantive model of equality and extends and elaborates on the content of equality in: (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.[107]

Article 5 of the CRPD recognises that all persons are "equal before and under the law" and are "entitled to equal protection and benefit of the law" without discrimination.[108] 'Equality under the law', according to the CRPD Committee is "unique to the Convention" and "refers to the possibility to engage in legal relationships." Whereas 'equality before the

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[102] Council of Europe Commissioner for Human Rights 'Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities' CommDH/IssuePaper (2012) 12 https://rm.coe.int/16806da5c0 (accessed 15 February 2014); Cera (n 2 above) 158.

[103] Convention on the Rights of Persons with Disabilities (n 28 above) article 3(b), (e) & (g).

Convention on the Rights of Persons with Disabilities (n 28 above) article 6.

[105] Convention on the Rights of Persons with Disabilities (n 28 above) preamble r & article 7; Committee on the Rights of Persons with Disabilities (CRPD Committee) 'Article 12: Equal recognition before the law' (General Comment No. 1) (2014) CRPD/C/GC/1 para 36 https://daccess-ods.un.org/TMP/6734848.02246094.html (accessed 8 July 2017).

[106] General Comment No. 6 (n 62 above) para 7.

[107] General Comment No. 6 (n 62 above) para 7.

[108] Convention on the Rights of Persons with Disabilities (n 28 above) article 5(1).

law' is tantamount to the right to protection by the law, 'equality under the law' pertains to the "right to use the law for personal benefit" and an acknowledgement that no laws should permit the "denial, restriction or limitation of the rights of persons with disabilities."[109] The committee also states that 'equal protection of the law' mandates national parliaments to desist from making laws and policies that discriminate against persons with disabilities. On the other hand, "equal benefit of the law" entails eliminating barriers to enable access to all the protections and the benefits of the law to claim rights.[110]

Article 5 prohibits "discrimination on the basis of disability and guarantees to persons with disabilities equal and effective legal protection" against all forms of discrimination.[111] This, according to the CRPD Committee is far-reaching as it includes persons with disabilities and persons associated to them and imposes positive duties of protection on States parties.[112] It also takes into consideration multiple and intersectional disability.[113]

Article 2 defines discrimination on the basis of disability as follows:

> "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." [114]

This definition of discrimination although similar to that of CEDAW goes further than CEDAW by including the denial of reasonable accommodation as a form of discrimination.[115] Article 5 further guarantees that persons with disabilities be provided reasonable accommodation to promote equality and eliminate discrimination against them.[116] Reasonable accommodation is defined as

> "necessary 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."[117]

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[109] General Comment No. 6 (n 62 above) para 15.
[110] General Comment No. 6 (n 62 above) para 16.
[111] n 28 above articles 5(2).
[112] General Comment No. 6 (n 62 above) para 17
[113] General Comment No. 6 (n 62 above) para 21; T Degener 'Disability in a human rights context' (2016) 5 *Laws* 35.
[114] n 28 above article 2.
[115] Degener (n 113 above).
[116] n 28 above articles 5(3).
[117] n 28 above article 2.

The Office of the United Nations High Commissioner for Human Rights opines that ‘the terms ‘disproportionate or undue burden’ should be viewed as “a single concept” or as “synonyms” that establish the threshold for providing reasonable accommodation.“[118] The duty to provide reasonable accommodation requires immediate application to all rights and so is a bridge between immediate and progressive rights.[119] It is an “*ex nunc* duty” which means that it comes into effect to enable a person enjoy his or her rights on an equal basis once the person requests it in a particular circumstance.[120]

Reasonable accommodation differs from the provision of “specific measures” such as affirmative action.[121] While specific measures entail the special treatment of persons with disabilities over others, reasonable accommodation is directed at providing necessary and appropriate adjustment for persons with disabilities in the enjoyment of their rights so as to prevent discrimination.[122] Reasonable accommodation also differs from accessibility as the duty to provide accessibility applies to a group of persons and is broad and standardised while reasonable accommodation is individualised and requires immediate implementation.[123] Similarly, reasonable accommodation differs from the provision of support such as the support to exercise legal capacity which forms the basis of discussion in Chapter Five. The duty to ensure reasonable accommodation is conditional and may be limited by a claim of ‘disproportionate or undue burden’ while the duty to provide support is unconditional and cannot be limited by such a claim.[124] Reasonable accommodation also differs from procedural accommodations in respect of the access to justice in article 13 of the CRPD as procedural accommodations unlike reasonable accommodation are not limited by a claim of “disproportionate or undue burden.”[125]

Article 5 is largely a pronouncement that reasonable accommodation is crucial to ensuring the non-discrimination of persons with disabilities.[126] It applies to physical and

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[118] United Nations Human Rights Council (n 26 above) para 31.

United Nations Human Rights Council (n 26 above) para 36.

[120] General Comment No. 6 (n above) para 24; General Comment No. 3 (n 27 above) para 15; Committee on the Rights of Persons with Disabilities (CRPD Committee) ‘Article 9: Accessibility’ (General Comment No. 2) (2014) CRPD/C/GC/2 paras 25 & 26 https://daccess-ods.un.org/TMP/3247302.4725914.html (accessed 8 July 2017).

[121] United Nations Human Rights Council (n 26 above) para 32.

[122] n 26 above para 32.

[123] General Comment No. 2 (n 120 above) paras 25 & 26.

[124] General Comment No. 1 (n 105 above) para 34.

[125] United Nations Human Rights Council (n 26 above) para 35.

[126] Cera (n 2 above) 167.

structural adjustments as well as to decision-making.[127] It requires state parties to impose reasonable accommodation obligations on private entities and to ensure compliance with such obligations.[128] As Lord and Brown observe, the duty to provide reasonable accommodation in the CRPD is applicable to an array of actors, including States and healthcare providers and requires them to adjust policies that permit the exclusion and non-participation of persons with disabilities.[129] It necessitates the reform and enactment of laws and policies as well as substantial comprehensive action on the part of states to check discrimination by state authorities and institutions or private entities.[130] This is imperative as article 5 goes beyond the provisions on discrimination in many national constitutions including section 42 of the Nigerian constitution by providing for reasonable accommodation. The CRPD therefore goes beyond a formal concept of equality to a conception of equality adapted to the lives and experiences of persons with disabilities ensuring that they prevail over barriers to enjoy the same rights and opportunities as others.[131] According to Cera, the CRPD establishes a deeper perception of equality that detaches it from "a formal proclamation of equality that would render non-discrimination clauses empty and toothless."[132]

3.3.2. The right to equality and non-discrimination under Nigerian Law

The provisions of the Nigerian Constitution, the African Charter on Human and Peoples' Rights and the Nigerians with Disability Act and their implications for persons with disabilities in terms of equality and non-discrimination are examined hereunder.

3.3.2.1. The Nigerian constitution

The Nigerian Constitution provides for the "equality of rights, obligations and opportunities before the law" for every Nigerian citizen.[133] This provision therefore guarantees equal treatment to all Nigerians, including adolescent girls with intellectual disabilities on an equal basis as other adolescents. However, the right to equality is enshrined in Chapter II of the constitution containing the Fundamental Objectives and Directive Principles of State Policy

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[127] Council of Europe Commissioner for Human Rights (n 102 above) 12.

[128] A Lawson *Disability and equality law in Britain*: *The role of reasonable adjustment* (2008) 32.

[129] JE Lord & R Brown 'The role of reasonable accommodation in securing substantive equality for persons with disabilities: the UN Convention on the rights of persons with disabilities' 5 https://ssrn.com/abstract=1618903 (accessed 12 November 2016).

[130] Cera (n 2 above) 166.

[131] Council of Europe Commissioner for Human Rights (n 102 above) 12; Cera (n 2 above) 158.

[132] Cera (n 2 above) 159, 161-162.

[133] Constitution of the Federal Republic of Nigeria of 1999 Cap C.34, L.F.N. 2004, section 17(2) (a).

which are non-justiciable.[134] Despite the fact that the right to equality in section 17 is non-justiciable, when read with section 42 of the Constitution which provides for 'the right to freedom from discrimination', a fundamental human right that is justiciable, it can be argued that the constitution guarantees equality to Nigerian citizens.[135]

Section 42(1) provides as follows:

> A citizen of Nigeria of a particular community, ethnic group, place of origin, sex, religion or political opinion shall not, by reason only that he is such a person:-
>
> (a) be subjected either expressly by, or in the practical application of, any law in force in Nigeria or any executive or administrative action of the government, to disabilities or restrictions to which citizens of Nigeria of other communities, ethnic groups, places of origin, sex, religious or political opinions are not made subject; or
>
> (b) be accorded either expressly by, or in the practical application of, any law in force in Nigeria or any such executive or administrative action, any privilege or advantage that is not accorded to citizens of Nigeria of other communities, ethnic groups, places of origin, sex, religious or political opinions.

Section 42(2) further provides that no Nigerian citizen "shall be subjected to any disability or deprivation merely by reason of the circumstances of his birth."

Clearly, disability is not specified as a prohibited ground of discrimination in section 42(1).[136] Also, section 42(1) is focused at ensuring formal equality, not substantive equality to Nigerian citizens. As Umeh points out, section 42(1) proscribes "direct discrimination, differential treatment and positive or compensatory action."[137] According to her, it "does not directly discriminate by expressly excluding groups" but "indirectly discriminates by requiring the same practice, condition or rule to everyone regardless of difference."[138] Moreover, the courts have adopted a fixed category approach in interpreting the section. In the case of *Uzoukwu v Ezeonu,*[139] the Nigerian Court of Appeal held, amongst other things, that the right to non-discrimination is actionable only if the discrimination complained against is one of the prohibited grounds in the constitution.

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[134] Constitution of the Federal Republic of Nigeria (n 133 above) chapter 2.

[135] A Oyebode 'Equality before the law in Nigeria: Myth or reality?' http://nigeriavillagesquare.com/forum/threads/equality-before-the-law-in-nigeria-myth-or-reality.39069/ (accessed 21 December 2017).

[136] RN Nwabueze 'Euthanasia, assisted suicide and decision-making at the end of life' in IO Iyioha & RN Nwabueze (eds) *Comparative health law and policy: Critical perspectives on Nigerian and global health law* (2016) 179, 190; NC Umeh 'Reading 'disability' into the non-discrimination clause of the Nigerian Constitution' (2016) 4 *ADRY* 53, 66.

[137] Umeh (n 136 above) 66.

[138] Umeh (n 136 above) 66.

[139] (1997) 7 NWLR (part 512) 283.

The courts as well as lawyers litigating cases have however failed to direct their minds to section 42(2) of the Constitution, which prohibits "any disability or deprivation merely by reason of circumstance of birth." Given that disability in most cases is a circumstance of a person's birth, it can be argued that disability-based discrimination violates section 42(2) of the Constitution as it is a 'deprivation' or 'disability' suffered by persons with disabilities. Thus, it can be argued that the involuntary sterilisation of adolescent girls with intellectual disabilities on account of their disability is a breach of section 42.

3.3.2.2. Legislative enactment

The African Charter on Human and Peoples' Rights (Ratification and Enforcement) Act 1983 (The African Charter Act)[140] and the Nigerians with Disability Act 1993[141] contain provisions that guarantee the rights to equality and non-discrimination.

Article 2 of the African Charter Act which guarantees freedom from discrimination provides:

> Every individual shall be entitled to the enjoyment of the rights and freedoms recognised and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status.[142]

Article 3 of the African Charter Act also guarantees equality before the law and equal protection of the law to every Nigerian.[143] Similarly, article 19 of the Act provides that all persons are "equal" and are entitled to the "same respect" and "same rights." Article 18 of the Act further guarantees the "protection of the rights of the woman and the child" provided in international instruments and that "the aged and the disabled shall also have the right to special measures of protection in keeping with their physical or moral needs."[144]

These provisions could be relied upon to ensure equality and non-discrimination for persons with intellectual disabilities, including adolescent girls with intellectual disabilities in terms of protecting them from involuntary sterilisation. Even though article 2 does not specify disability as a ground of discrimination, the inclusion of the expression 'other status'

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[140] Cap A9, Laws of the Federation of Nigeria, 2004.

[141] The Nigerians with Disability Act of 1993. The NWDA was initially a federal decree but by virtue of section 315 of the 1999 Constitution, it became deemed an Act of the National Assembly. It is yet to be repealed by any law and is still in force. It precedes the CRPD and does not reflect contemporary notions and principles on disability rights.

[142] n 140 above, article 2.

[143] n 140 above, article 3(1) & (2).

[144] n 140 above, article 18(3) & (4).

in the article, could be construed to include disability as a ground of discrimination under the African Charter Act. Articles 2, 3 and 19 of the African Charter Act manifestly guarantee formal equality to all Nigerians by requiring the same treatment to all persons. This may not ensure the tangible enjoyment of the rights set out in the articles for vulnerable persons in Nigeria. However, a joint reading of articles 3, 18 and 19 may possibly "be explored in securing the equality aspirations" of vulnerable persons, including persons with intellectual disabilities.[145] Indeed, by providing for the 'protection of the rights' of women and children and 'special measures of protection for the 'aged' and 'disabled' in society, the Act indicates a commitment towards achievement of substantive equality for vulnerable persons such as adolescent girls with intellectual disabilities. This underlines the obligation of states "to accommodate diversity by providing required individualised support and services."[146]

Section 2 (1) of the Nigerians with Disability Act (NWDA) provides that "disabled persons shall be guaranteed treatment as equals to other Nigerians for all purposes in the Federal Republic of Nigeria." Section 2 (2) (b) of the NWDA further provides that "disabled persons shall have equal rights, privileges, obligations and opportunities before the law."

Although the NWDA does not contain provisions prohibiting discrimination, it is useful in guaranteeing equality to persons with disabilities, including adolescents with intellectual disabilities. However, like the Nigerian constitution, it is directed at ensuring formal equality for persons with disabilities. The Act by guaranteeing 'treatment as equals to other Nigerians' does not take into consideration human diversity and difference and so is not aimed at ensuring substantive equality for persons with disabilities.

3.4. Involuntary sterilisation as inequality and discrimination

Involuntary sterilisation is essentially a manifestation of inequality and intersectional discrimination. Throughout time, sterilisation policies have been involuntarily enforced in many countries including Germany, Hungary, Peru, Namibia, Slovakia, the Czech Republic, the United States and South Africa on the basis of eugenics, gender, disability, race and class.[147] These discriminatory bases often stem from the exercise of patriarchal, paternalistic, legal and/or medical power and often intersect to further exclude persons subject to them

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[145] Umeh (n 136 above) 69.

[146] Umeh (n 136 above) 70.

[147] R Sifris 'Involuntary sterilisation of marginalised women' http://rightnow.org.au/opinion-3/involuntary-sterilisation-of-marginalised-women/ (accessed 13 June 2015).

from society.[148] The American case of *Buck v Bell*,[149] is instructive in this regard. The case involved a constitutional challenge of a Virginia sterilisation law by a woman named Carrie Buck. The law authorised the involuntary sterilisation of 'feebleminded' persons who had been institutionalised or confirmed as likely to produce "unfit" children. Carrie Buck was in an institution for the feebleminded like her mother had been and had given birth to a daughter, Vivian, out of wedlock. It was contended that Carrie was promiscuous and that she, her mother, and her daughter were 'feebleminded' and that their disability was hereditary. Justice Oliver Wendel Holmes, in delivering the lead judgement stated as follows:

> …It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. Three generations of imbeciles are enough.[150]

The case illustrates structural inequality as well as multiple and intersectional discrimination involving eugenics, gender and class as the basis for recommending that Carrie should be sterilised, that she was an uneducated, poor, and unmarried young woman who had given birth to a child born out of wedlock. It was not established in court that her pregnancy had resulted from rape and that she actually was a victim. More so, school records which showed that Carrie and her daughter, Vivian, were not feebleminded and were good students while in school were not were brought before the court.[151] So Carrie was a victim who was further victimised and discriminated against because of her status in society.

There is a link between the involuntary sterilisation, disability and discrimination which is "complex and mutually reinforcing" as women and girls with disabilities, especially those with intellectual disabilities, are highly susceptible to involuntary sterilisation.[152] In the context of discrimination, women and girls with disabilities are more likely to be involuntarily sterilised if they have an intellectual disability.[153] As highlighted in Chapter

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[148] R Sifris 'The involuntary sterilisation of marginalised women: Power, discrimination and intersectionality' (2016) 25 *Griffith Law Review* 45, 46-55.
[149] 274 U.S. 200 (1927).
[150] n 149 above at 207.
[151] PA Lombardo 'Three generations, no imbeciles: New light on Buck v. Bell' (1985) 60 *New York University Law Review* 30, 61; M Tartakovsky 'Eugenics & the story of Carrie Buck' https://psychcentral.com/blog/eugenics-the-story-of-carrie-buck/ (accessed 15 September 2016); The Embryo Project Encyclopedia 'Buck v. Bell (1927)' https://embryo.asu.edu/pages/buck-v-bell-1927 (accessed 15 September 2016).
[152] Human Rights Watch 'Sterilization of women and girls with disabilities- a briefing paper http://www.hrw.org/news/2011/11/10/sterilization-women-and-girls-disabilities (accessed 22 March 2014).
[153] Center for Reproductive Rights et al 'Submission to the European Court of Human Rights in Gauer v. France' (2011) para 40 https://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/Gauer%20v%20%20France%20Submission%20ECHR%20FINAL.pdf (accessed 15 September 2016).

One, girls with intellectual disabilities are involuntarily sterilised on grounds such as eugenics, menstrual management, prevention of sexual abuse, prevention of unplanned pregnancy and financial incapacity to which their peers without disability are not subject to.[154] This stems largely from the belief that they lack the capacity to make decisions for themselves and so decision-making about sterilisation is made on their behalf.

In Nigeria, evidence from clinical practice indicates that adolescent girls with intellectual disabilities were subjected to involuntary sterilisation at the instance of family members on the basis of their disability and the belief of their incapacity for parenthood.[155] Similarly, a report by Nigeria Stability and Reconciliation Programme and Inclusive Friends stated that women and girls with intellectual disabilities were vulnerable to involuntarily sterilisation.[156] More so, 38.8% of the respondents involved in the empirical component of this study acknowledged that they were aware of instances where adolescent girls with intellectual disabilities had been sterilised.[157] Many of the respondents were also of the view that sterilisation was justified if carried out to prevent pregnancy, especially in situations where the girl has gotten pregnant a few times, and in situations of financial incapability.

Undoubtedly, sterilisation places adolescent girls with intellectual disabilities in a position of inequality and discrimination thereby contravening the provisions of the laws examined in section 3.3. This is because sterilisation is usually not carried out on their peers without disabilities to prevent pregnancy or because of financial incapability or the inability to be a fit parent. Hence sterilisation is usually performed on them on the basis of their

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[154] L Dowse 'Moving forward or losing ground? The sterilisation of women and girls with disabilities in Australia' http://wwda.org.au/issues/sterilise/sterilise2001/steril3/ (accessed 8 October 2016); Women with Disabilities Australia (WWDA) 'WWDA policy & position paper: The development of legislation to authorise procedures for the sterilisation of children with intellectual disabilities' (2007) http://www.wwda.org.au/polpapster07.htm (accessed 28 May 2018); C Frohmader 'Dehumanised: The forced sterilisation of women and girls with disabilities in Australia' WWDA Submission to the Senate Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia (2013) 36 http://wwda.org.au/wp-content/uploads/2013/12/WWDA_Sterilisation_Sub_Summary_and_Recs.pdf (accessed 10 February 2015); C Frohmader 'Moving forward and gaining ground: The sterilisation of women and girls with disabilities in Australia' (2012) 6 http://wwda.org.au/wp-content/uploads/2013/12/Moving_Forward_Gaining_Ground.pdf (accessed 22 March 2014); G Llewellyn 'The involuntary or coerced sterilisation of people with disabilities in Australia' 3-5 https://sydney.edu.au/health-sciences/cdrp/Sterilisation_Submission%2021.pdf (accessed 8 October 2016); L Elliott 'Victims of violence: The forced sterilisation of women and girls with disabilities in Australia' (2017) 6 *Laws*, 8; doi:10.3390/laws6030008; AI Ofuani 'Protecting adolescent girls with intellectual disabilities from involuntary sterilisation in Nigeria: Lessons from the Convention on the Rights of Persons with Disabilities' (2017) 17 *African Human Rights Law Journal* 550, 551.
[155] A Animashaun 'Indications for the sterilisation of the handicapped adolescent' (1978) 8 *Nigerian Medical Journal 253*-254.
[156] Nigeria Stability and Reconciliation Programme and Inclusive Friends 'What violence means to us: Women with disabilities speak' 19 http://www.nsrp-nigeria.org/wp-content/uploads/2015/09/What-Violence-Means-to-us-Women-with-Disabilities-Speak.pdf (accessed 4 September 2017).
[157] See Chapter Seven of the study.

disability resulting in their unequal treatment in relation to their male peers or their peers without disabilities. Measures to address the involuntary sterilisation of women and girls with intellectual disabilities are necessary as inequality and discrimination are aggravated when states fail to act.[158] One of such measures discussed in Chapter Six is to provide support to them in decision-making particularly in respect of healthcare.

3.5. Conclusion

The promotion and protection of the right to equality and non-discrimination is very important in enabling the rights of adolescent girls with intellectual disabilities and protecting them from involuntary sterilisation. This chapter examined the implications of equality and non-discrimination for adolescent girls with disabilities. It was established that women and adolescent girls with intellectual disabilities were subject to multiple and intersectional discrimination and that substantive equality was important in addressing such discriminations. It also examined the national and international legal frameworks on equality and non-discrimination. It was shown that including the denial of reasonable accommodation as a ground for discrimination in article 5 of the CRPD indicates a move from formal equality to ensure substantive equality for persons with disabilities so that they can enjoy the equal opportunities as others in the society. The chapter also highlighted the shortcomings of the Nigerian constitution and legislation in effectively guaranteeing the rights to equality and non-discrimination for persons with disabilities with reference to involuntary sterilisation. The link between discrimination, involuntary sterilisation and disability was established as it was shown that women and girls with intellectual disabilities were more likely to be sterilised because of their disability.

In view of the fact that the denial of legal capacity results in inequality and discrimination, the next chapter examines what legal capacity entails and its implications for adolescent girls with intellectual disability.

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[158] Center for Reproductive Rights et al (n 153 above) para 45.

CHAPTER FOUR

THE RIGHT TO LEGAL CAPACITY AND ITS IMPLICATIONS FOR ADOLESCENTS WITH INTELLECTUAL DISABILITIES

> …legal capacity is the epiphenomenon. It provides the legal shell through which to advance personhood in the life world… it enables persons to sculpt their own legal universe – a web of mutual rights and obligations voluntarily entered into with others.[1]

4.1. Introduction

This chapter examines how legal capacity has developed over the years. It discusses the meaning and the effect of the legal capacity prior to the Convention on the Rights of Persons with Disabilities (CRPD).

Historically, persons with intellectual disabilities have been denied legal capacity because of perceived misconceptions about their abilities. This chapter interrogates how personhood has been framed for persons with intellectual disabilities and its effect on them in terms of inequality and discrimination. It also highlights and critiques the traditional approaches (status, outcome and functional) in determining legal capacity of persons. It also examines the CRPD's conception of the right to legal capacity and the Committee on the Rights of Persons with Disabilities' interpretation of legal capacity in its General Comment No. 1.

The chapter demonstrates that the conception of legal capacity in Nigeria is based on the traditional approaches and how these have resulted in inequality and discrimination for adolescent girls with intellectual disabilities in terms of contraceptive decision-making. It reiterates that because the girls are deemed incapable of making decisions, they are restricted from making decisions about contraception on the same basis as their counterparts without disabilities. This has resulted in the perpetuation of forced contraception and involuntary sterilisation in Nigeria. It further posits that although article 12 of the CRPD's conception of legal capacity has the potential for transforming the lives of persons with disabilities and changing the discourse on legal capacity, it is not without challenges. The strategies and measures to be developed in effectuating must be transmuted in the vernacular and

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[1] G Quinn 'Personhood and legal capacity: Perspectives on the paradigm shift of article 12 CRPD' presented at Harvard Law School Project on Disability (HPOD) Conference on Disability and Legal Capacity under the CRPD, Harvard Law School, 20 February 2010, 16 http://www.nuigalway.ie/cdlp/documents/publications/harvard%20Legal%20Capacity%20gq%20draft%202.doc (accessed 12 February 2014).

represented in local contexts understandable to lay people. It concludes by emphasising that for article 12 to be effective in terms of contraceptive decision-making for adolescent girls with intellectual disabilities, strategies for supporting decision-making must be developed.

4.2. The notion of legal capacity

The meaning of the term 'capacity' varies according to the context it is used.[2] In the legal context, it is a characteristic or a presumption of law, the absence of which, excludes a person from being an actor under the law and entering into legal relations.[3] It underpins the rights of persons to make autonomous decisions in relation to their personal undertakings.[4] Capacity is therefore vital to the participation of persons, including adolescents, in most legal systems. It encompasses issues germane to power, medical ethics, autonomy, and choice, and interrogates the aptitude of persons to make decisions about healthcare and treatment.

A variety of assessment criteria such as status, age, and cognition are applied in the different branches of the law depending on the perspective from which capacity or incapacity is considered.[5] Besides, like the tests for assessing intellectual disability discussed in Chapter Two, the standards for assessing capacity are not definitive because they are influenced by the normative judgments of the assessors.[6] Thus, as Weller observes "capacity and incapacity operate as mutually constitutive dialogues of normality, in which determinations of incapacity disqualify individuals with mental disabilities from mainstream social discourse and from recognition before the law."[7] This has serious implications on how capacity is conceived for persons with intellectual disabilities, who have been and are continually restricted from entering into legal relations based on these assessments.

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[2] T Carney 'Guardianship, citizenship and theorizing substitute-decision-making law' Sydney Law School Legal Studies Research Paper No. 12 (2012) 4 http://ssrn.com/abstract=2041103 (accessed 15 February 2016).

[3] A Dhanda 'Advocacy note on legal capacity' https://s3.amazonaws.com/academia.edu.documents/50224254/LEGAL_CAPACITY_NOTE_AHC2.doc?AWSAccessKeyId=AKIAIWOWYYGZ2Y53UL3A&Expires=1530013005&Signature=WbAWrrU5gdo5JDbvAbFRhw7bWxs%3D&response-content-disposition=attachment%3B%20filename%3DAdvocacy_note_on_legal_capacity.doc (accessed 02 June 2018); Office of the Public Advocate 'Supported decision-making- background and discussion paper' (2009) 5 http://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/supported-decision-making/58-supported-decision-making-background-and-discussion-paper/file; Victorian Law Reform Commission 'Guardianship: Final report 24' (2012) 99 http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf (accessed 08 July 2017).

[4] P Darzins et al *Who can decide? The six step capacity assessment process* (2000) 1.

[5] The Victorian Law Reform Commission (n 3 above) 101.

[6] TL Beauchamp & JF Childress *Principles of biomedical ethics* (2009) 115.

[7] P Weller 'Reconsidering legal capacity: Radical critiques, governmentality and dividing practice' (2014) 23 *Griffith Law Review* 498.

Prior to the CRPD, persons with intellectual disabilities were negatively subjected to different treatment in the society and held as lacking in legal capacity. This 'legally enforced difference' was society's paternalistic way of protecting them and has only recently been questioned as unacceptable.[8] Historically, perceived lack of decision-making, intelligence and intelligence quotient (IQ) scores, rationality, consciousness and reasonableness of decision-making were central to the denial of personhood and legal capacity to persons with intellectual disabilities.[9] This denial resulted in forced medical interventions, such as involuntary sterilisation. In the present-day, although the right to equality is recognised in many national laws, persons with intellectual disabilities are subjected to different standards which have resulted in their being deprived of legal capacity and therefore their personhood.[10] However, these conceptions of legal capacity, as will be illustrated in this chapter, not only exclude persons with intellectual disabilities, but are also fallacious and lacking in empirical certainty.[11] They do not take into consideration that decision-making is both contextual and complex and that personal experience, contacts, social, economic and cultural backgrounds inform how a person makes decisions and choices in life.[12] They only serve as tools of exclusion and discrimination which enable society to deprive persons labelled as different from making personal choices and partaking in social and legal arrangements.[13] Consequently, the CRPD articulates a conceptual shift in how legal capacity is construed and determined. Article 12 of the CRPD has conceptualised personhood and legal capacity as an inherent human attribute and emphasises that persons with disabilities be supported in exercising their right to legal capacity. It is therefore imperative that the meaning and significance of legal capacity are closely examined in this chapter.

4.2.1. Meaning and effect of legal capacity

Legal capacity is a socio-legal construct that has been subject to various interpretations, and knowledge construction processes, all of which reflect how societies have perceived it over time.[14] Black's Law Dictionary describes it as a person's ability to acquire or transfer rights

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[8] SJ Schwartz 'Legal responses to different treatment of persons with disabilities- Review of Martha Minow's *Making all the difference*' (1991) 15 *Mental & Physical Disability Law Reporter* 196.
[9] R Sevo *Basics about disabilities and science and engineering education* (2011)158.
[10] n 9 above 158.
[11] Council of Europe Commissioner for Human Rights 'Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities' (2012) 19 https://rm.coe.int/16806da5c0 (accessed 15 February 2016).
[12] Council of Europe Commissioner for Human Rights (n 11 above) 19.
[13] n 11 above 19.
[14] Dhanda (n 3 above).

or to undertake certain duties, without any interference arising from his or her legal status or circumstance.[15] It involves the recognition of a person's capacity to have rights (the capacity to be a person before the law), that is, 'legal standing' and the person's capacity to act, that is 'legal agency.'[16]

The 'capacity to have rights' or 'be a person before the law' entails that a person is a bearer of rights and obligations, while 'capacity to act' entails that he or she has the ability to exercise rights and obligations.[17] The capacity to have rights and the capacity to act as a legal person are correlated and 'mutually conditioned.'[18] The capacity to have rights or be a person before the law is usually interpreted as an attribute inherent to all human beings from birth up until death.[19] The capacity to have rights is the foundation upon which the capacity to act is built and is a prerequisite for the capacity to act, but can exist independently of the legal capacity to act.[20] In other words, a person can be a person with rights before the law but may legally lack the ability to exercise the rights.[21] On the other hand, the capacity to act is the means through which the capacity to have rights is asserted.[22] For a person to enjoy the capacity to act, he or she must meet certain requirements such as minimum age, absence of disability, the outcome of his or her decision and the person's ability to understand the nature and effect of his or her rights.[23] It is therefore the lack of capacity to act that gives rise to the restriction or denial of a person's legal capacity.

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[15] HC Black's Law Dictionary, 2nd ed 1910; Office of the United Nations High Commissioner for Human Rights (OHCHR) 'Legal capacity' Background conference document for the sixth session of the ad hoc committee on a comprehensive and integral international convention on protection and promotion of the rights and dignity of persons with disabilities on 1- 12 August 2005, 13 http://www2.ohchr.org/SPdocs/CRPD/DGD21102009/OHCHR_BP_Legal_Capacity.doc (accessed 15 February 2015).

[16] T Minkowitz 'The paradigm of supported decision making' https://www.academia.edu/8770379/The_Paradigm_of_Supported_Decision-Making (accessed 15 February 2014); B McSherry 'Decision-making, legal capacity and neuroscience: Implications for mental health laws' (2015) 4 *Laws* 125, 127; Office of the United Nations High Commissioner for Human Rights (n 15 above) 13.

[17] Minkowitz (n 16 above).

[18] Bulgarian Center for Not-for-Profit Law (BCNL) 'New formula for capacity to act - opportunity for everyone to exercise their rights- statement on the paradigm shift of article 12 of CRPD' 7 http://www.bcnl.org/uploadfiles/documents/osi%20researches/statementdraftupdatedeng.pdf (accessed 15 February 2014).

[19] Office of the United Nations High Commissioner for Human Rights (n 15 above) 20.

[20] Bulgarian Center for Not-for-Profit Law (n 18 above) 7.

[21] n 18 above 7.

[22] n 18 above 9.

[23] Bulgarian Center for Not-for-Profit Law (n 18 above) 9; 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) 2 http://irisinstitute.ca/wp-content/uploads/sites/2/2016/07/The-right-to-legal-capacity-under-the-un-convention_cr.pdf (accessed 15 February 2014).

Traditionally, the restrictions on the capacity to act were developed to protect persons who were perceived as unable to act for themselves.[24] This protection operated at three levels. First, it served to protect the persons from themselves by restricting or denying them capacity to act in respect of actions whose effects they do not understand owing to lack of 'legal maturity'.[25] Secondly, it was deemed to protect the interests of third parties who enter into legal relations with the person. Lastly, such a protection was perceived to be in interest of the public.[26] The consequence of this protection was the weakening of the person's legal status, the deprivation of his or her rights and autonomy and the sanctioning of others to act on his or her behalf which is in effect amounts to 'inequality before the law'.[27]

More so, legal capacity is a creation of the law and is a constituent part of the construction of law which underpins modern western legal systems.[28] So law also plays an overt role in objectifying and creating different categories of people. It plays a role in validating 'ableism' through the designation of legal categories and concepts which prevents persons with disabilities from escaping normalising practices.[29] As a result, in many parts of the world, including Nigeria, persons with intellectual disabilities are usually restricted by law from exercising their legal capacity in relation to their basic rights on the basis of protectionism. They are subjected to a legal regime which imputes lack of abilities as who they inherently are. For adolescent girls with intellectual disabilities, it is used to justify their being treated differently from other adolescents, especially in health care settings, where they are subjected to medical interventions such as involuntary sterilisation. However, the CRPD, as this chapter seeks to highlight, guarantees legal capacity to all persons with disabilities, including adolescents with intellectual disabilities and demands that they should be supported in the exercise of their legal capacity.[30] It provides an avenue to challenge the laws, practices, established forms of knowledge and power relations that have delimited legal capacity for persons with intellectual disabilities.

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[24] Bulgarian Center for Not-for-Profit Law (n 18 above) 8.
[25] n 18 above 8.
[26] n 18 above) 8.
[27] n 18 above 8-9.
[28] E Badan-Melnic & C Lachi 'Civil legal capacity- determining factor in establishing and making legal relations' (2014) 6 *Contemporary Legal Institutions* 186, 188; VAJ Kurki, 'Revisiting legal personhood' presented at the Spanish-Finnish Seminar in Legal Theory, Joensuu, June-July 2016 http://www.uef.fi/documents/300201/0/Kurki+-+Revisiting+legal+personhood.pdf/56e99525-ba38-4c05-8034-3505d52d84a0 (accessed 17 November 2016).
[29] FK Campbell 'Legislating disability: Negative ontologies and the government of legal identities' in SL Tremain (ed) *Foucault and the government of disability'* (2009) 126.
[30] Convention on the Rights of Persons with Disabilities (CRPD) (2006) 46 ILM 443, article 12.

4.2.2. Significance of legal capacity

Historically, legal capacity conferred on a person respect under the law. A person's decisions is respected by law if the person had legal capacity while the decisions of a person deemed lacking in legal capacity is not respected.[31] However, the CRPD has done away with this by providing that all persons with disabilities have legal capacity and this means that their decisions should be respected by the law.

Legal capacity is of the essence because it is does not only consist of decision-making but goes to the crux of what being a 'person' entails.[32] Without it, the freedom to make choices which is a great part of being human is greatly diminished.[33] Yet for persons with intellectual disabilities, legal capacity is usually conjoined with mental capacity and tied to discursively constructed norms and criteria about mental capacity. The traditional assumption is that persons with intellectual disabilities lack decision-making capacity, and on that assumption, they are denied legal capacity. This assumption underestimates the capabilities of persons with intellectual disabilities, usually without much empirical evidence and overlooks the fact that capabilities are shaped by personal, social, cultural and economic factors.[34] The assumption ultimately results in the discrimination, stereotyping, objectification and marginalisation of people with intellectual disabilities.[35] This in turn has an adverse effect on their sense of self, propagates helplessness, contributes to their susceptibility to abuse and deprives them of the ability to be 'self-determining and self-actualizing' persons.[36] Legal capacity is therefore important to the promotion of the self-worth of persons with intellectual disabilities and in overturning narratives of social exclusion, discrimination and marginalisation about them.

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[31] E Flynn & A Arstein-Kerslake 'Equal recognition before the law: Exploring a support model of legal capacity' 5 A paper presented at the Kent Critical Law Society Conference on 10 March 2012 at the University of Kent, Canterbury http://www.nuigalway.ie/disability-rights/downloads/kent_presentation.docx (accessed 15 February 2015).

[32] Quinn (n 1 above).

[33] The Kenya National Commission on Human Rights and the Open Society Initiative for Eastern Africa 'How to implement article 12 of convention on the rights of persons with disabilities regarding legal capacity in Kenya: A briefing paper' 15 http://www.knchr.org/Portals/0/GroupRightsReports/Briefing%20Paper%20on%20Legal%20Capacity-Disability%20Rights.pdf (accessed 7 March 2016).

[34] M Bach 'What does article 12 of the CRPD require? Theoretical starting points and questions/implications for law and policy' https://www.inclusionireland.ie/sites/default/files/documents/prof-m-bach-shared/bach-legalcapacity-aug09-inclusionireland.ppt (accessed 27 November 2017); M Bach & L kerzner 'A new paradigm for protecting autonomy and the right to legal capacity' (2010) 7 www.lco-cdo.org/disabilities/bach-kerzner.pdf (accessed 15 February 2014).

[35] Bach (n 34 above).

[36] BJ Winick 'The side effects of incompetency labelling and the implications for mental health' (1995) 1 *Psychology, Public Policy and Law* 6, 16-17 & 25.

Legal capacity also influences how other persons in society, including family members, members of the community and service providers, recognise persons with disabilities.[37] This is because the denial of legal capacity for many persons with intellectual disabilities is a socio-cultural issue rather than a formal issue.[38] That is not to say that the law on legal capacity does not shape how people perceive persons with disabilities. Indeed, the law is implicated in the truth, knowledge, rationales and practices through which disability is rendered known and knowable.[39] Socio-cultural perceptions often inform how the law is shaped. Thus, if persons with intellectual disabilities are perceived as incapable of making certain decisions or taking actions in their own lives, undesirable stereotypes about disability are reinforced, giving rise to discrimination, inequality and social exclusion.[40]

4.3. Intellectual disability, personhood and legal capacity

Intellectual disability strikes at the very heart of conceptions of personhood and what it takes to be regarded as person both socially and legally.[41] The issue of the personhood of persons with intellectual disabilities is a contentious issue that has occupied philosophical, political, legal, psychological, sociological, anthropological, scientific and religious discourses. The construction of their personhood has affected and continues to affect how they are treated by society and before the law.[42] It also affects the role that third parties, including parents and siblings, play in medical decision-making for their intellectually disabled relations particularly those requiring extensive and pervasive support.[43]

In philosophical discourses, personhood is usually linked to the moral status of persons as a critical task in moral philosophy is to distinguish 'persons' from 'non-persons'.[44] Intrinsically, there are competing discourses on the personhood/moral status of persons with

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[37] The Kenya National Commission on Human Rights and the Open Society Initiative for Eastern Africa (n 33 above) 15.

[38] Bach (n 34 above) 7.

[39] Weller (n 7 above) 498.

[40] The Kenya National Commission on Human Rights and the Open Society Initiative for Eastern Africa (n 33 above) 15.

[41] Sevo (n 2 above) 158.

[42] G Wolbring 'Person' http://eugenicsarchive.ca/discover/connections/535eed4e7095aa0000000247 (accessed 31 May 2018).

[43] NL Cantor *Making medical decisions for the profoundly mentally disabled* (2005) 14-16.

[44] MA Warren *Moral status: Obligations to persons and other living things* (1997); Cantor (n 43 above) 13; S Vehmas 'The who or what of Steve: Severe intellectual impairment and its implications' in Häyry, M et al (eds) *Arguments and analysis in bioethics* (2010) 263, 266; D Wasserman et al 'Disability: Definitions, models, experience' *The Stanford encyclopaedia of philosophy* (2017) https://plato.stanford.edu/entries/disability/ (accessed 22 December 2017).

intellectual disabilities, especially those require extensive and pervasive support.[45] Authors such as Locke and Descartes maintain that the essential characteristics of personhood are "rationality and consciousness," and that persons with intellectual disabilities do not reach the same level of personhood as persons of "higher" intellect.[46] Similarly, Crookshank and Boyd and Fletcher state that persons with Down syndrome are non-persons.[47] On the other hand, authors, such as Kittay, Carlson and Nussbaum are of the view that every human being is a 'person' regardless of their intellectual capacity.[48] In line with this, Quinn contends that, in line with the CRPD, personhood for persons with disabilities should be based on the maximum respect for the person.[49] According to him, article 12 of the CRPD "leaves no room for equivocation or doubt about the moral status of persons with intellectual disabilities."[50] At the very extreme, there are also authors such as Singer and McMahan who hold the view that some animals possess a higher intellectual capacity than children who require extensive or pervasive support.[51]

Evidently, personhood is narrowly or expansively construed. Some philosophers base personhood on some narrow criteria such as intellectual functioning and capacity;[52] rationality (that is, the aptitude to reflect and reason);[53] moral responsibility;[54] and self-

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[45] Warren (n 44 above) 91; Cantor (n 43 above) 17, Vehmas (n 44 above) 266; D Wasserman et al (n 44 above).

[46] J Locke *An essay concerning human understanding* (1975) Book II, chapter. 27, sec 9; HE Keith & KD Keith *Intellectual disability: Ethics, dehumanization, and a new moral community* (2013) 82; TR Parmenter 'Beyond introspection and navel gazing: Challenges for the study of intellectual disability' (2013) 9 being the Keynote paper presented at the 48th Annual ASID Conference on 6-8 November at Sydney https://asid.asn.au/files/batch1415579637_beyond_introspection_paper.pdf (accessed 7 March 2016).

[47] Parmenter (n 46 above) 9.

[48] E Kittay 'At the margins of personhood' (2005) 116 *Ethics* 110–113; M Nussbaum 'The capabilities of people with cognitive disabilities' (2009) 40 *Metaphilosophy* 331-351; L Carlson & EF Kittay 'Introduction: Rethinking philosophical presumptions in light of cognitive disability' in L Carlson & EF Kittay (eds) *Cognitive disability and its challenge to moral philosophy (2010)* 1-21; EF Kittay 'The personal is philosophical is political: A philosopher and mother of a cognitively disabled person sends notes from the battlefield' in L Carlson & EF Kittay (eds) *Cognitive disability and its challenge to moral philosophy* (2010) 405, 406; Parmenter (n 46 above) 10.

[49] G Quinn 'Rethinking personhood: New directions in legal capacity law & policy' (2011) 10-11 https://www.inclusionireland.ie/sites/default/files/attach/basic-page/846/rethinkingpersonhood-newdirectionsinlegalcapacitylawandpolicy-gerardquinn-april2011.docx (accessed 14 February 2014).

[50] Quinn (n 49 above) 11.

[51] P Singer *Writings on an ethical life* (2000) 212; H Kuhse & P Singer *Should the baby live? The problem of handicapped infants* (1985) 172; J McMahan *The ethics of killing* (2002) 230. Kushe, Singer and McMahan are in support of the killing of children with severe and profound intellectual disabilities because they perceive them as lacking in intellectual capacity.

[52] Cantor (n 43 above) 17.

[53] J Locke *An essay concerning human understanding* (1975) Book II, chapter 27, sec 9; M Freeden *Rights* (1991) 58–59; Warren (n 44 above) 95; Vehmas (n 44 above) 266-267; Cantor (n 43 above) 17.

[54] Warren (n 44 above) 90; TL Beauchamp 'The failure of theories of personhood' 9 *Kennedy Institute* of *Ethics Journal* 309, 314 (1999).

consciousness (that is, the ability to value one's own existence over time).[55] Constructing personhood on the basis of these criteria would exclude many persons with intellectual disabilities that require extensive and pervasive support as many of them are regarded as having low intellectual functioning and lacking in capacity.[56] Other philosophers construct personhood expansively on the basis of genetic humanity claiming that only human beings are persons;[57] sentience, that is, the ability to experience pain or pleasure;[58] the inherent significance of human life and the capability to interact with others on any level.[59] These expansive criteria include persons with intellectual disabilities that require extensive and pervasive support because they are human beings who experience pain or pleasure and can interact with other people in their own unique ways.

Central to understanding the meaning of legal capacity is the concept of legal personhood. Legal personhood justifies a person's participation in legal relationships and social life.[60] It is the law's recognition of a person as a subject with rights and duties while legal capacity is the instrument through which the rights and duties are accorded or denied to the person.[61] Legal capacity is therefore the basis for conferring legal personhood. If a person is recognised as having legal capacity, he or she is recognised as a "full legal person with rights and duties" the same as others in the society.[62] However, if the person is deemed lacking in legal capacity, he or she is not regarded as a full legal person and is not eligible to the rights and obligations enjoyed by other persons in society.[63] Thus, the prevailing discourse on legal personhood for persons with intellectual disabilities attaches much importance to cognition and rationality, in which legal persons are fully independent and self-

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[55] M Tooley *Abortion and infanticide* (1983) 44; DO Linder 'The other right-to-life debate: When does fourteenth amendment life end?' (1995) 37 *Arizona Law Review* 1182, 1198–1199; JW Walters What *is a person? An ethical exploration* (1997) 26; Cantor (n 43 above) 18.

[56] H Allen & E Fuller 'Beyond the Feeble Mind: Foregrounding the Personhood of Inmates with Significant Intellectual Disabilities in the Era of Institutionalization (2016) 36 *Disability Studies Quarterly* http://dsq-sds.org/article/view/5227/4301; D Wasserman et al 'Cognitive Disability and Moral Status' *The Stanford encyclopaedia of philosophy* (2017) Wasserman, D, Asch, A, Blustein, J & Putnam, D 'Cognitive Disability and Moral Status' *The Stanford encyclopaedia of philosophy* (2017) https://plato.stanford.edu/entries/cognitive-disability/ (accessed 3 July 2017).

[57] Warren (n 44 above) 92.

[58] Warren (n 44 above) 94; Cantor (n 43 above) 19; Vehmas (n 44 above) 267.

[59] Cantor (n 43 above) 19.

[60] A Arstein-Kerslake & E Flynn 'The general comment on article 12 of the Convention on the Rights of Persons with Disabilities: A roadmap for equality before the law' (2016) 20 *International Journal of Human Rights* 471, 474; Bulgarian Center for Not-for-Profit Law (n 18 above) 6.

[61] A Arstein-Kerslake et al 'Future directions in supported decision-making' (2017) 37 *Disability Studies Quarterly* http://dsq-sds.org/article/view/5070/4549 (accessed 08 July 2017).

[62] Arstein-Kerslake & Flynn (n 60 above) 474; Bulgarian Center for Not-for-Profit Law (n 18 above) 6.

[63] Arstein-Kerslake & Flynn (n 60 above) 474.

determining individuals.[64] In liberal-democratic societies, rationality, cognitive capacity and autonomy are used to justify personhood and the duty to accord persons with respect and dignity.[65] In other words, personhood is grounded on capacity to process information, make choices, to comprehend the consequences of those choices and to evaluate the choices in order to arrive at a rational outcome.[66] In essence, persons with intellectual disabilities are particularly vulnerable to denial of their legal capacity and non-recognition of their personhood because they are deemed lacking in cognition and rationality.[67] This perception of personhood has roots in conventional moral philosophy in which 'full legal persons' are persons who are able to make decisions for and by themselves.[68] Only 'rational' persons, who on account of their ability to "reason could assume moral and legal responsibility" for their actions and enter into legal relations, are regarded as having legal personhood.[69]

Thus, as discussed in Chapter Two, persons deemed lacking in personhood are more inclined to be controlled within disciplinary regimes and organisations because of the assumption that they are incapable of autonomy.[70] They are usually categorised as different and stripped of their rights because the 'dominant forms of knowledge-making' objectify them.[71] This objectification is what Foucault calls 'dividing practices.'[72] According to him, the person is "either divided inside himself or divided from others", a process which objectifies him or her by separating him or her from others.[73] The dividing practices manipulate the person through the "mediation of a science and the practice of exclusion" in a social sense.[74] Intrinsically, the person assumes a social and personal identity through this

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[64] Bach (n 34 above); E Flynn & A Arstein-Kerslake 'Legislating personhood: Realising the right to support in exercising legal capacity' (2014) 10 *International Journal of Law in Context* 81-82.

[65] L Davy 'Philosophical inclusive design: Intellectual disability and the limits of individual autonomy in moral and political theory' (2015) 30 *Hypatia* 132, 135-138.

[66] Quinn (n 49 above) 7; 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 *ALTER, European Journal of Disability* 249, 253.

[67] M Lock *Twice dead: Organ transplants and the reinvention of death* (2002) 95.

[68] M Bach 'Supported decision-making under Article 12 of the UN Convention on the Rights of Persons with Disabilities: Questions and challenges' 8 presented at the Conference on legal capacity and supported decision making at Athlone, Ireland on 3 November 2007 http://www.inclusionireland.ie/sites/default/files/documents/prof-m-bach-shared/bach-supporteddecisionmaking-inclusionirelandnov07.doc (accessed 14 February 2014).

[69] Bach (n 68 above); NM Naffine *Law's meaning of life: Philosophy, religion, Darwin and the legal person* (2008) 23.

[70] Weller (n 7 above) 509.

[71] M Bach 'Legal capacity, personhood and supported decision making' http://www.un.org/esa/socdev/enable/rights/ahc7docs/ahc7ii3.ppt (accessed 19 July 2016); M Nowak *UN Covenant on Civil and Political Rights: CCPR Commentary* (2nd ed) (2005) 369.

[72] M Foucault 'The Subject and Power' (1982) 8 *Critical Inquiry* 777.

[73] Foucault (n 73 above) 777.

[74] P Rainbow (ed) *The Foucault Reader* (1984) 8.

process of objectification and categorisation.[75] Furthermore, the assessments of capacity operate as dividing and "distributive practices" that indicate whether or not the individual will be subject to disciplinary regimes.[76] The dividing practices are also interconnected to a web of 'power relations', dominant discourses and knowledge, applicable to dominated persons who are given an identity through the dividing practices.[77]

The conception of legal capacity and indeed legal personhood, with cognition and rationality as the basis of all legal actions, is a foundational assumption of liberal-democratic societies, where persons are typified as free of socio-cultural influences.[78] It overlooks the fact that rationality is often shaped by human inclinations and that people are usually shaped by their cultural backgrounds.[79] It is also essentialist in nature because it assumes that all persons should fit into a specific regulatory and behavioural mould and fails take into cognizance human diversity. As observed by Campbell, 'the political identity of disability within law not only contributes to an "essentialised" and "exteriorised" ontology which normalises and delimits disability in order to make it regulative.'[80] It therefore operates as a means of subordination, while striving for visibility and recognition.[81] It ignores the other relational facets of personhood.[82] This has informed the 'paternalistic' and 'protectionist' attitudes towards persons with intellectual disabilities, who are considered different and do not conform to the idea of subjects who are independent and have full legal personhood. [83] It also discriminates based on disability because the assessment criteria would almost always work against persons with intellectual disabilities. It totally does not make allowances for the fact that for some persons, autonomy is relational, and that with support, many persons with intellectual disabilities can exercise legal capacity.

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[75] Rainbow (n 73 above) 8.
[76] Weller (n 7 above) 509.
[77] Weller (n 7 above) 509.
[78] Quinn (n 1 above) 7.
[79] n 1 above 7.
[80] Campbell (n 29 above) 115.
[81] W Brown *States of inquiry: Power and freedom in late* modernity (1955) 66.
[82] A Pylkkänen 'Construction of gendered legal personhood in the history of Finnish law' 4 http://www.kb.dk/export/sites/kb_dk/da/nb/publikationer/fundogforskning-online/pdf/A21_Pylkkanen.pdf (accessed 19 July 2016).
[83] Pylkkänen (n 82 above) 4.

4.4. Traditional approaches to legal capacity

In most jurisdictions, legal capacity is conceptualised in one or all of three ways- the status of the person, the functioning of the person and the outcome of the person's decisions. These approaches to legal capacity and their differences are discussed below.

4.4.1. Status approach to legal capacity

The status approach entails a person being denied legal capacity usually by operation of law because the person has a disability.[84] The mere presence of impairment suffices to deprive a person of legal capacity in all or some areas of life, irrespective of the person's actual capability.[85] In other words, the existence or non-existence of impairment is the determining factor in adjudging if a person has legal capacity in certain areas of his or her life.[86] For example, in Nigeria, many laws deny persons with intellectual disabilities (referred to as persons of 'unsound mind' or 'mental defectives') legal capacity in most areas of their lives because of their disability.[87] Thus, for an adolescent girl with intellectual disability, the mere fact she has intellectual disability, would exclude her from accessing contraceptives like her counterparts without disabilities.

The status approach is based on the medical model of disability. It relies on prevailing social or medical standards to assess standards without regard to the differences in behavioural and decision-making capacity amongst persons with intellectual disability.[88] In many cases, the denial of legal capacity is dependent on the diagnosis of disability through 'specialist knowledge' and expert opinions of medical professionals with the aid of diagnostic tests.[89] This is particularly trite for persons with intellectual disabilities whose lives are governed by medical professionals and whose abilities are determined by diagnostic tests. Such diagnosis usually presupposes that because of their disability persons with intellectual

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[84] A Dhanda 'Legal capacity in the disability rights convention: Stranglehold of the past or lodestar for the future?' (2006-2007) 34 *Syracuse Journal of International Law & Commerce* 429, 431; Flynn & Arstein-Kerslake (n 31 above) 2; D Gibson 'Conceptual and ethical problems in the mental capacity act 2005: An interrogation of the assessment process' (2015) 4 *Laws* 229, 231; Quinn (n 1 above); Council of Europe Commissioner for Human Rights (n 11 above) 13.

[85] Council of Europe Commissioner for Human Rights (n 11 above) 13.

[86] Quinn (n 1 above) 12; Centre for Disability Law & Policy NUI Galway 'Submission on legal capacity to the Oireachtas Committee on justice, defence & equality' (2011) 10 https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/archive/Submission-on-Legal-Capacity-to-the-Oireachtas-Committee-on-Justice,-Defence-&-Equality-(August,-2011).pdf (accessed 02 June 2018); Dhanda (n 84 above) 433.

[87] A discussion of legal capacity in Nigeria is examined in section 4.6 of this chapter.

[88] B Collier et al *Mental capacity: Powers of attorney and advance health directives* (2005) 62 -63.

[89] Flynn & Arstein-Kerslake (n 31 above) 15; Dhanda (n 84 above) 433.

disabilities lack mental capacity and in turn lack legal capacity. It establishes a relationship between the existence of disability, decision-making ability and legal capacity.[90] This clearly illustrates the medicalisation process described by Illich, as discussed in Chapter Two.[91] It also illustrates Foucault's discussion on the dominance of 'medical discourse' in all aspects of the lives of persons with intellectual disabilities.[92]

One flaw of the status approach is that it commits the fallacy of generalisation because it adopts a "one size fits all approach" to persons with disabilities and assumes that the mere presence of disability signifies an inability to exercise legal capacity.[93] As Quinn points out, the status approach takes a 'binary view of capacity' whereby a person either has or lacks capacity.[94] Another flaw is that it is founded on stereotypes about disability which fail to recognise that in most cases, capacity is not disability related but context specific.[95] In that sense, a person may have the capacity to make decisions in some circumstances but not in others.[96] Moreover, a person with intellectual disability's experiences, socio-economic and cultural backgrounds shape the person's abilities including decision-making aptitude and how they exercise legal capacity. An additional flaw is that it gives rise to labelling, stigmatisation, infringement of rights and can become a 'self-fulfilling prophecy' in the lives of persons with intellectual disabilities.[97] Lastly, it could be used to justify substituted decision-making for persons with disabilities in keeping with paternalistic standards.[98] Furthermore, it does not recognise that legal capacity can be enhanced through support systems, as articulated in the CRPD.[99]

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[90] Dhanda (n 84 above) 431.

[91] I Illich *Limits to medicine- medical nemesis: The expropriation of health* (1976) 39. See also section 2.4.1 of this study.

[92] M Foucault *The birth of the clinic* (2003) xix. See also section 2.4.1of this study.

[93] M Keys 'Capacity- whose decision is it anyway?' Law and Mental Health Conference, Law Faculty, NUI Galway, 17 November 2007, 7 https://www.inclusionireland.ie/sites/default/files/attach/basic-page/846/capacitypaperbymarykeys.doc (accessed 12 February 2014).

[94] Quinn (n 1 above) 12; Centre for Disability Law & Policy NUI Galway (n 86 above) 10.

[95] C Harrison 'Treatment decisions regarding infants, children and adolescents' (2004) 9 *Paediatric Child Health* 99.

[96] Office of the Public Advocate (n 11 above) 4.

[97] K Purser *Capacity assessment and the law: Problems and solutions* (2017) 67.

[98] Quinn (n 1 above) 13.

[99] n 1 above 13.

4.4.2. Functional approach to legal capacity

The functional approach assesses legal capacity based on the quality of a person's decision-making ability, that is, his or her cognitive abilities.[100] Accordingly, legal capacity is determined by whether or not a person understands the nature of a decision, comprehends the consequences of the decision and can convey the decision to others.[101]

In the functional approach, mental capacity is central to the determination of legal capacity because a person's decision-making skill, or lack of thereof, is a legitimate ground for granting or denying a person legal capacity and personhood before the law.[102] Persons with intellectual disabilities, especially those with extensive and pervasive support needs, are most likely to have their legal capacity restricted by an application of the functional approach.[103] This is because capacity is construed as "inherently cognitive" and incapacity is regarded as ineptitude in understanding a decision and the "potential consequences of making or not making that decision."[104]

The functional approach seems to be favoured by some courts, authors and by the Committee on the Rights of Persons with Disabilities (CRPD Committee) in relation to children.[105] For instance, Gibson opines that it is advantageous because it applies 'a complex threshold' before finding that a person lacks capacity.[106] Likewise, Keys suggests that it is consistent with human rights standards and is individual oriented.[107] As will be discussed subsequently, the CRPD Committee and Committee on the Rights of the Child (CRC Committee) also have a purchase in the functional approach but only in respect of children.[108]

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[100] O Lewis 'Legal capacity' http://www.eracomm.eu/UNCRPD/kiosk/speakers_contributions/413DV91/Lewis_Pres.pdf (accessed 12 February 2014); M Stauch et al *Text, cases and materials on medical law and ethics* (4th ed) 100; Flynn & Arstein-Kerslake (n 31 above) 3.

[101] Lewis (n 100 above); Dhanda (n 84 above) 433; Keys (n 92 above) 7-8; Flynn & Arstein-Kerslake (n 31 above) 3.

[102] Dhanda (n 84 above) 433; E Flynn & A Arstein-Kerslake 'The Support model of legal capacity: Fact, fiction, or fantasy?' (2014) 32 *Berkeley Journal of International Law* 124, 129; Gibson (n 83 above) 232.

[103] Flynn & Arstein-Kerslake (n 102 above) 129.

[104] KB Glen 'Changing paradigms: Mental capacity, legal capacity, guardianship, and beyond' 44 *Columbia Human Rights Law Review* 93, 94.

[105] *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] 1 AC 112; *Secretary, Department of Health and Community Services v. J.W.B. and S.M.B.* (Marion's Case) [1992] HCA 15; (1992) 175 CLR 218; Keys (n 93 above) 7-8; Gibson (n 84 above) 232.

[106] Gibson (n 84 above) 232.

[107] Keys (n 93 above) 7-8.

[108] See section 4.5 of this study.

To the casual observer, it does not appear to discriminate based on disability, but in effect it does, albeit less perceptibly than the status approach.[109] Disability is employed as a threshold in that a person could be denied legal capacity if by reason of the disability, he or she is unable to understand the nature and effect of a decision.[110] Also, it essentially disregards the dignity of persons with disabilities even more than the status approach, as it not only infers that they lack legal capacity but also asks for evidence to the contrary.[111] It is also doubtful whether, in fact, the same test is being used if the emphasis is on autonomous cognitive competence. Lastly, the functional approach is based on the medical model of disability because it relies on assessments which are usually carried out by medical practitioners to the effect that failure to pass the assessments results in the denial of legal capacity. These assessments are generally premised on the fallacious assumption that 'the inner-workings of the human mind' can be accurately assessed.[112]

4.4.3. Outcome approach to legal capacity

The outcome approach focuses on the consequence of the decision made by an individual to the effect that if the decision is found wanting, legal capacity is denied.[113] In other words, legal capacity is denied because a person's decision is perceived to be poor or would result in negative consequences or does not abide by traditional societal standards.[114] Like the status approach, the mere establishment that the decision made is poor or resulted in negative consequences is grounds for denial or restriction of legal capacity.[115]

In the outcome approach, capacity is assessed based on the standards and ideologies of the assessor.[116] It aims to guarantee that competent decisions conform to a particular standard.[117] Hence, if a girl with intellectual disability makes a decision that is adjudged by others to be a poor decision, she would be deemed incompetent and lacking in legal capacity in relation to that decision and even in other areas of her life. The label of incapacity or

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[109] Flynn & Arstein-Kerslake (n 31 above) 4.
[110] Dhanda (n 84 above) 431; Council of Europe Commissioner for Human (n 11 above) 13; Flynn & Arstein-Kerslake (n 31 above) 4.
[111] Flynn & Arstein-Kerslake (n 31 above) 4
[112] Dhanda (n 84 above) 431.
[113] Keys (n 93 above) 7.
[114] Dhanda (n 84 above) 432; Committee on the Rights of Persons with Disabilities (CRPD Committee) 'Article 12: Equal recognition before the law' General Comment No. 1 (2014) CRPD/C/GC/1 https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement (accessed 12 February 2014).
[115] Dhanda (n 84 above) 432.
[116] Purser (n 97 above) 68.
[117] Collier et al (n 88 above) 62-63.

incompetence is therefore constructed on the basis of the assessment of the decision by a person or persons other than the person with intellectual disability.[118]

The outcome approach is greatly flawed. It is contradictory and unfairly sets a higher bar for persons with disabilities in comparison to persons without disabilities.[119] It applies double standards as no equivalent test exists for persons without disabilities whereby their legal capacity is deprived because their decision-making is perceived to be below par.[120] Even amongst persons with disabilities, it is more likely to affect persons with intellectual disabilities because they are more likely to be perceived to make poor or unusual decisions. Moreover, the outcome approach does not recognise that learning from poor decisions helps define who we are as human beings, as making mistakes is a human condition, and one from which we learn from.[121] Another flaw with the approach is that it is based on the "reasonableness of the decision" reached by a person which is by no means an objective test.[122] It is dependent on assessments of appropriateness or acceptability of a decision, which is subjective, and hinges on what others think of the decision.[123] As pointed out by the Law Commission of England and Wales, "any decision which is inconsistent with conventional values, or with which the assessor disagrees" may result in the denial or restriction of the decision maker's capacity.[124] This suppresses individuality and mandates conformism to the detriment of personal autonomy.[125]

All of the three above-mentioned approaches are objectionable and have significant impacts on how legal capacity is conceived for persons with intellectual disabilities in general and adolescent girls with intellectual disabilities. Firstly, they are overly inclusive and are founded on the presumption that all persons with intellectual disabilities lack legal capacity.[126] A clear illustration of this is that adolescent girls with intellectual disabilities are automatically assumed to lack the capacity to make decisions about contraception for themselves. As a result, they are subjected to forced medical interventions such as involuntary sterilisation, to which their counterparts without disabilities are not subjected,

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[118] Dhanda (n 84 above) 431.
[119] Centre for Disability Law & Policy NUI Galway (n 86 above) 10.
[120] QM Keys 'Article 12 [equal recognition before the law]' in VD Fina et al (eds) *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (2017) 263, 268.
[121] Centre for Disability Law & Policy NUI Galway (n 86 above) 10.
[122] Council of Europe Commissioner for Human Rights (n 11 above) 13.
[123] Gibson (n 84 above) 232.
[124] Law Commission of England and Wales 'Report No 231: Mental incapacity' (1995) para 3.4. http://www.bailii.org/ew/other/EWLC/1995/231.html (accessed 12 February 2014).
[125] n 124 above para 3.4.
[126] n 124 above para 3.4.

thereby infringing on their right to retain their fertility and dignity. Secondly, they all rest on stereotypes that presume incapacity and disregard the abilities of persons with intellectual disabilities. They tell what Adichie has termed a ‘single story’[127] in the sense that they approach legal capacity from a single point of view- disability/inability. They fail to take into consideration other narratives in a person’s life, such as socio-cultural background, economic situation, support system which influence how a person makes decisions and exercises legal capacity. This single story stems from stereotypical beliefs about intellectual disability which are often fallacious and it serves to perpetuate discrimination, whether directly or indirectly. Moreover, they overlook the importance of support and support networks in the exercise of legal capacity. Hence, “decision-making and legal capacity should not be denied a person because human beings, disabled or non-disabled, are essentially relational and rely on the input of their families and friends in decision-making.”[128] Next, they hold persons with intellectual disabilities to standards not applicable to their counterparts without disabilities. This is because many persons without disabilities do not fully comprehend all the implications and intricacies involved in medical treatments or financial transactions.[129] Lastly, they are medicalised as they are based on assessment and diagnosis typically carried out by medical professionals. These assessments, according to Carney, place too much emphasis on cognitive capacity with no thought for an alternative threshold which may enable persons with disabilities exercise legal capacity in their lives.[130] In consequence, adopting these approaches in determining legal capacity for persons with intellectual disabilities is likely to result in discrimination and exclusion in most aspects of their lives. The CRPD provides an alternative to the approaches to legal capacity to a large extent for adults with disabilities and to some extent for adolescents with disabilities.

4.4.4 Legal Capacity in international treaties prior to the CRPD

The first part in this section examines the concept of legal capacity in international law before the CRPD was adopted. It examines the provisions of the International Covenant on Civil and

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[127] CN Adiche ‘The danger of a single story’ TED Talks https://www.ted.com/talks/chimamanda_adichie_the_danger_of_a_single_story (accessed 08 July 2017).

[128] AI Ofuani ‘Protecting adolescent girls with intellectual disabilities from involuntary sterilisation in Nigeria: Lessons from the Convention on the Rights of Persons with Disabilities’ (2017) 17 *African Human Rights Law Journal* 550, 562; AL Pearl ‘Article 12 of the United Nations Convention on the Rights of Persons with Disabilities and the legal capacity of disabled people: The way forward?’ (2013) 1 *Leeds Journal of Law & Criminology* 18.

[129] Bach (n 71 above).

[130] T Carney ‘Supported decision-making for people with cognitive impairments: An Australian perspective? (2015) 4 *Laws* 37, 47.

Political Rights and the Convention on the Elimination of All Forms of Discrimination against Women, which were prototypes for article 12 of the CRPD. It also examines the African Charter on Human and Peoples' Rights and its protocol on the Rights of Persons with Disabilities in Africa which was adopted on 29 January 2018.

Article 16 of the International Convention on Civil and Political Rights (ICCPR) provides that "everyone shall have the right to recognition everywhere as a person before the law."[131] This right has been articulated by Volio as an 'individual's personhood' in society.[132]

A careful examination of article 16 shows it merely confers on persons' capacity to be a person before the law, that is, "to be recognised as a potential bearer of legal rights and obligations."[133] It merely grants passive legal capacity and not active legal capacity as it does not seem to include the capacity to act which is a driver for undertaking legal actions and establishing legal relationships.[134] Besides, the Third Committee of the General Assembly noted that article 16 was aimed at ensuring that every person is a "subject" and not an "object" of the law; but it was not directed at ensuring a person's legal capacity to act.[135] Nonetheless, article 16 of the ICCPR was not drafted with persons with disabilities in mind. Although its wording suggests that it applies to every person, irrespective of sex, age, race, disability, it stopped short of enabling legal capacity for persons with disabilities. As Dudley et al argue, although article 16 seems to include people with disabilities, the treaty-monitoring body did not interrogate its implication for the deprivation of their legal capacity.[136] Article 16 of the ICCPR is merely a shield and not a sword, because while it guarantees the "capacity to be a person before the law", it does not guarantee the "capacity to act" which is necessary for personhood before the law.

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[131] International Covenant on Civil and Political Rights (1966) 6 ILM 368.

[132] F Volio, 'Legal personality, privacy and the family' in L Henkin (ed) *The international bill of rights: The Covenant on Civil and Political Rights* (1981) 186.

[133] Office of the United Nations High Commissioner for Human Rights (n 15 above) 4.

[134] MJ Bossuyt *Guide to the Travaux Préparatoires of the International Covenant on Civil and Political* Rights (1987) 335; Office of the United Nations High Commissioner for Human Rights (n 15 above) 6; 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 *Loyola of Los Angeles International and Comparative Law Review* 143.

[135] U.N. GAOR C.3, 15th Session UN DOC A/4625 (1960) para. 25.

[136] M Dudley et al (eds) *Mental health and human rights: Vision, praxis, and courage* (2012) 179; Keys (n 120 above) 267.

The Convention on the Elimination of Discrimination against Women (CEDAW) was the first international instrument to explicitly provide for the right to legal capacity.[137] Article 15(1) of the CEDAW guarantees women equality with men before the law and men. This is similar to the provisions of article 16 of the ICCPR and article 12 (1) of the CRPD.[138] It could be interpreted as an acknowledgement of the right of women and girls with disabilities' as 'persons' before the law on the same basis with men and boys with or without disabilities.[139] Article 15(2) of the CEDAW guarantees women and girls with disabilities with legal capacity "identical to that of men" in civil matters and grants them "equal opportunities to exercise their capacity."

An examination of the provisions of section 15 of the CEDAW shows that it encompasses both the capacity to be a person before the law and the capacity to act. It goes further than the ICCPR by guaranteeing women and girls with disabilities the means to act upon or exercise their rights. According to the Office of the United Nations High Commissioner for Human Rights, by making reference to the words 'civil matters', 'same opportunities' and 'exercise' in section 15(2), it includes the capacity to act.[140]

At the regional level, the right to legal capacity is provided in article 3 of the African Charter on Human and Peoples' Rights (ACHPR).[141] It guarantees "equality before the law and equal protection of the law" for every person. As in the case of the ICCPR, the ACHPR clearly includes the capacity to be a person before the law but is unclear whether it includes the capacity to act. The ACHPR goes beyond the ICCPR provision, by providing for equal protection before the law but it does not unequivocally provide for the right to legal capacity like CEDAW does. It cannot therefore be argued that it amounts to a right to legal capacity. Moreover, it clearly was not adopted to address the difficulties persons with disabilities face

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[137] Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) (1979) 19 ILM 33.

[138] Article 15 of the CEDAW provides:

> 1. States Parties shall accord to women equality with men before the law.
> 2. States Parties shall accord to women, in civil matters, a legal capacity identical to that of men and the same opportunities to exercise that capacity. In particular, they shall give women equal rights to conclude contracts and to administer property and shall treat them equally in all stages of procedure in courts and tribunals.
> 3. States Parties agree that all contracts and all other private instruments of any kind with a legal effect which is directed at restricting the legal capacity of women shall be deemed null and void.

[139] CEDAW applies to both women and girls and by implication applies to women and girls with disabilities.

[140] Office of the United Nations High Commissioner for Human Rights (n 15 above) 11-12.

[141] African Charter on Human and Peoples' Rights (1982) 21 ILM 58. This is similar to article 3 of the American Convention on Human Rights which provides that "every person has the right to recognition as a person before the law". See the American Convention on Human Rights (1969) 9 ILM 99.

as a result of the deprivation of their rights. As a result, the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (the African Disability Rights Protocol) was adopted by the African Commission on Human and Peoples' Rights in February 2016.[142] The African Disability Rights Protocol was subsequently also adopted at the African Union summit of heads of state in January 2018 and is currently awaiting the required ratification by 15 countries to come into effect.[143]

Article 6[144] of the African Disability Rights Protocol on equal recognition before the law bears some semblance with article 12 of the CRPD. It provides for the right to legal capacity for persons with disabilities on an equal basis with others in all aspects of life, which is not to be violated by state, non-state actors and other individuals.[145] It also provides that persons with disabilities are provided with the "legal protection" and support in the exercise of their right to legal capacity in keeping with "their rights, will and specific needs."[146] The Protocol further calls for the establishment of mechanisms to safeguard persons with disabilities from abuses resulting from measures pertaining to the enjoyment of their legal capacity as well as the review of laws that limit or restrict their legal capacity.[147]

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[142] Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (The African Disability Rights Protocol) http://blindsa.org.za/wp-content/uploads/2018/02/English-Protocol-on-the-Rights-of-Persons-with-Disabilities-.pdf (accessed 31 May 2018).

[143] Blind SA 'Protocol to the African Charter on Human and People's Rights on the Rights of Persons with Disabilities in Africa' https://blindsa.org.za/2018/02/13/protocol-african-charter-human-peoples-rights-rights-persons-disabilities-africa/ (accessed 31 May 2018).

[144] Article 6 provides:

> 1. 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.
> 2. States Parties shall take all appropriate and effective measures to ensure that:
> a) Persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life;
> b) Non-State actors and other individuals do not violate the right to exercise legal capacity by persons with disabilities;
> c) Persons with disabilities are provided with effective legal protection and support they may require in enjoying their legal capacity consistent with their rights, will and specific needs;
> d) Appropriate and effective safeguards are put in place to protect persons with disabilities from abuses that may result from measures that relate to the enjoyment of their legal capacity;
> e) Policies and laws which have the purpose or effect of limiting or restricting the enjoyment of legal capacity by persons with disabilities are reviewed or repealed;
> f) Persons with disabilities have the equal right to hold documents of identity and other documents that may enable them to exercise their right to legal capacity;
> g) Persons with disabilities have the equal right to own or inherit property and are not arbitrarily dispossessed of their property;
> h) Persons with disabilities have equal rights to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit.

[145] Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (n 142 above) article 6(1), (2)(a) & (b).

[146] n 142 above article 6(2)(c).

[147] n 142 above article 6(2)(d) & (e).

The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa undoubtedly grants both capacity to be a person before the law and the capacity to act to persons with disabilities. It goes further than the CEDAW by guaranteeing legal protection and support to persons with disabilities in the exercise of their right to legal capacity as well as the review of laws that restrict their legal capacity.

4.5. The CRPD and its conception of legal capacity

The CRPD is the first international human rights treaty to specifically recognise the right to legal capacity for persons with disabilities, including those with intellectual disabilities. Article 12 of CRPD provides for "universal legal capacity" while guaranteeing persons with disabilities the right to exercise legal capacity through support.[148] The concept of legal capacity was highly contested during the negotiations and drafting of the CRPD.[149]

Article 12(1) provides that "persons with disabilities have the right to recognition everywhere as persons before the law." It restates and elaborates on the provisions of the ICCPR, CEDAW and ACHPR discussed above.[150] Article 12(2), which will subsequently be discussed in section 4.5.1, provides that persons with disabilities "enjoy legal capacity on an equal basis with others in all aspects of life."

Article 12(3) requires State Parties to "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."[151] This is in line with the CRPD preamble which provides that the human rights of persons with disabilities, including those that need intensive support 'be promoted and protected.'[152] It is historic because it recognises that persons with intellectual disabilities have a right to legal capacity, irrespective of their disability, and at the same time recognises that they may require support in the exercise their legal capacity.[153] It goes beyond the notion of the 'rational

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[148] C O'Mahony 'Impact of human rights approach in member states' legislation: Legal capacity in Ireland' http://ec.europa.eu/social/BlobServlet?docId=15773&langId=en (accessed 08 July 2017).

[149] CJ Sundram 'A discussion of legal capacity in the draft convention on disability' (2006) 11 http://www.mdri.org/mdri-web-007/pdf/A%20discussion%20of%20Capacity.pdf (accessed 08 July 2017); Dhanda (n 84 above) 429; RD Dinerstein 'Implementing legal capacity under article 12 of the UN Convention on the Rights of Persons with Disabilities: The difficult road from guardianship to supported decision-making' (2012) 19 *Human Rights Brief* 8.

[150] Committee on the Rights of Persons with Disabilities (n 114 above) para 11; Keys (n 120 above) 267.

[151] Carney (n 130 above) 43.

[152] Convention on the Rights of Persons with Disabilities (n 30 above) preamble j; Dinerstein (n 149 above) 9.

[153] Flynn & Arstein-Kerslake (n 64 above) 84.

person' to embrace the notion of inclusion.[154] It recognises that human beings are relational, and depend on the familial and communal support, of their social networks in decision-making.[155] In guaranteeing that support is provided to persons with disabilities, it goes a long in advancing their self-determination and equality rights, especially for those with intellectual disabilities.[156] It also ties together civil, political and socio-economic rights.[157] One support mechanism envisaged by article 12 (3) is supported decision-making which is discussed in Chapter Five.

Article 12(4) requires State Parties "to 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." It puts power back in the hands of the persons with disabilities doing away with longstanding 'best interests' standard and providing that their rights, will and preferences be respected. [158] This is a welcome development because in the best interest standard, another person makes judgement in the interest of the disabled person. On the other hand, the objective of the will and preference standard is to aid persons with disabilities express their desires. This is a crucial element in respecting the right to legal capacity.[159] In other words, it guarantees that persons that require assistance in decision-making receive such assistance, are regarded as persons before the law, and that their will and preferences are recognised on the same basis as others.[160]

Article 12(5) guarantees the equal right of persons 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 they are not "arbitrarily deprived of their property."

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[154] The Department of Economic and Social Affairs (UN-DESA), the Office of the United Nations High Commissioner for Human Rights (OHCHR), and the Inter-Parliamentary Union (IPU) 'From exclusion to equality: Realizing the rights of persons with disabilities' Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and Its Optional Protocol (2007) http://www.ipu.org/PDF/publications/disabilities-e.pdf (accessed 15 February 2014); European Disability Forum (EDF) 'Equal recognition before the law and equal capacity to act: Understanding and implementing article 12 of the UN Convention on the Rights of Persons with Disabilities (2009) 4 http://cms.horus.be/files/99909/MediaArchive/library/EDF_positon_on_equal_recognition_before_the_law_under_Article12_UNCRPD.doc (accessed 15 February 2014); Council of Europe Commissioner for Human Rights (n 11 above) 19.

[155] Pearl (n 128 above) 18.

[156] Bach (n 34 above).

[157] S Fredman *Human rights transformed: Positive rights and positive duties* (2008) 66-70.

[158] Centre for Disability Law & Policy NUI Galway (n 86 above) 9.

[159] Centre for Disability Law & Policy NUI Galway (n 86 above) 9.

[160] Centre for Disability Law & Policy NUI Galway (n 86 above) 9.

The implication of article 12(2) of the CRPD for persons with intellectual disabilities is discussed in the next section.

4.5.1. The right to 'universal' legal capacity in article 12

Article 12(2) of the CRPD confers full legal capacity on persons with disabilities.[161] This, according to the CRPD Committee in its General Comment No. 1, includes the capacity to hold rights along with the capacity to exercise the rights.[162] It entitles persons with disabilities to full protection of their rights by the legal system and recognises their power to enter into, modify or terminate legal relationships.[163] In other words, it recognises that their right to legal capacity, in all aspects of their lives, is incontrovertible. Legal capacity, according to the CRPD Committee, is a 'universal' trait, innate in all persons, which must be safeguarded for persons with disabilities on the same basis as others.[164] The Committee emphasises that the right to legal capacity is vital to the fulfilment of other rights in the CRPD and that the denial of legal capacity to persons with disabilities results in the deprivation of their fundamental rights including their reproductive rights.[165] It therefore proscribes the denial of their legal capacity on the basis of their disability and calls for the abolishment of practices that infringe on article 12 to guarantee full legal capacity to persons with disabilities on an equal basis with others.[166] This is in line with its concluding observations on country reports. For instance, in its concluding observations to Australia, Austria and Hungary, the committee recommended that they adopt measures that fully conform to article 12 of the CRPD with respect to a person's right to give or withdraw informed consent for medical treatment, to access justice, to vote, to marry and to work in his or her own capacity.[167] It further recommended that training on recognition of the legal capacity of persons with disabilities in consultation and cooperation with persons with disabilities and their representative organisations, at the national, regional and local levels for all actors, including civil servants,

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[161] Committee on the Rights of Persons with Disabilities (n 114 above) para 8.

[162] Council of Europe Commissioner for Human Rights (n 11 above) 7.

[163] Committee on the Rights of Persons with Disabilities (n 114 above) para 12.

[164] n 114 above para 8.

[165] n 114 above para 8.

[166] n 114 above para 9.

[167] Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Australia, adopted by the Committee at its tenth session (2-13 September 2013) CRPD/C/AUS/CO/1 para 25; Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Austria, adopted by the Committee at its tenth session (2–13 September 2013) CRPD/C/AUT/CO/1 para 28; Committee on the Rights of Persons with Disabilities, Concluding observations on the initial periodic report of Hungary, adopted by the Committee at its eighth session (17-28 September 2012) CRPD/C/HUN/CO/1 para 26

judges and social workers.[168] Similarly, it urged Paraguay to repeal the legal provisions of its Civil Code governing the procedure for declaring legal incapacity on grounds of disability and to set up an independent review mechanism with the aim of fully restoring the rights of those who have been declared legally incapable.[169] Clearly, the CRPD Committee recommendations are to enhance the legal capacity of persons with disabilities so as ensure that the enjoyment of the rights enshrined in the CRPD. The Committee's recognition of universal legal capacity is therefore laudable as it challenges the presumption inherent in most legal systems that legal capacity is rebuttable. As Dhanda points out, it has the potential to bring about growth and development for persons with disabilities if they are given the right opportunities and if the opportunities are fitted to the needs of each person.[170]

The right to legal capacity in article 12 (2) could be conceived as an 'affirmation of human agency' not on the basis of rationalisation but on the basis of the will, preferences or rights of the person.[171] It has the potential for opening up opportunities for free interaction and protecting them against unnecessary interferences by third parties.[172] On the other hand, it could be construed negatively as the phrase 'on an equal basis with others' could be used to 'characterise the difference of disability' and "to rationalise the non-enjoyment of legal capacity as not only justified under equality thinking but actually justified by it."[173]

The Committee also distinguished between legal capacity and mental capacity. It defined legal capacity as "the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency)."[174] Conversely, mental capacity was defined as "the decision-making skills of a person" which varies from person to person depending on environmental and social influences.[175] It stated that "perceived or actual deficits in mental capacity" as well as discriminatory labels such as clear 'unsoundness of mind' are not justification for the denial of legal capacity.[176] It also stated that mental capacity and legal capacity are often 'conflated' to the effect that if a person is deemed "to have impaired

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[168] Concluding observations on the initial report of Australia (n 167 above) para 26; Concluding observations on the initial report of Austria (n 167 above) para 28.
[169] Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Paraguay, adopted by the Committee at its ninth session, 15–19 April 2013 CRPD/C/PRY/CO/1 para 29.
[170] Dhanda (n 84 above) 458.
[171] Carney (n 130 above) 43.
[172] Quinn (n 1 above) 19
[173] n 1 above 19.
[174] Committee on the Rights of Persons with Disabilities (n 114 above) para 13.
[175] n 114 above para 13.
[176] n 114 above para 13.

decision-making skills" their legal capacity is restricted.[177] However, one issue the CRPD Committee fails to adequately clarify is whether or not mental capacity can completely be delinked from decisions regarding to the exercise of legal capacity. As Dawson points out that it may be implausible for the Committee to suggest that under no circumstances can mental incapacity "constitute a relevant difference upon which a legal distinction" can be constructed.[178] According to him, mental incapacity may sometimes be necessary in considering certain decisions by persons with intellectual disabilities.[179]

The Committee further stated that the traditional standards of assessing legal capacity (status, outcome and functional) are not permitted but that support in the exercise of legal capacity is the standard in article 12.[180] This is very significant for persons with intellectual disabilities because the Committee's interpretation of article 12 (2) acts as a check on the social and historical construction of capacity which was used to exclude them in participating in their own affairs. It identifies them as 'subjects' entitled to the respect and enjoyment of their rights and not as 'objects' whose affairs are to be handled by others.[181] However, as is discussed in section 4.5.2 and in Chapter Five, the CRPD Committee adopts a functional approach in interpreting the right to legal capacity for adolescents with disabilities.

Indeed, article 12 is historic for persons with intellectual disabilities. First, it introduces a new discourse on legal capacity. It shifts the discourse from the traditional approaches (to legal capacity to the CRPD conceptualisation of legal capacity especially for persons with intellectual disabilities who have been disenfranchised by those approaches. Secondly, it establishes a new paradigm 'support in exercise of legal capacity.' In doing this, it recognises the interdependency of human beings by reinforcing that individuals are constituted by networks of relationships and usually rely on others and on the networks which they are part of. [182] This enhances the ability of persons with intellectual disabilities to participate in decisions affecting them and places them at the front of the decision-making process. It also recognises that decision-making is contextual and can be learned, enhanced or suppressed. This is crucial as it ensures an inclusive society that guarantees equal rights for

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[177] n 114 above para 15.

[178] J Dawson 'A realistic approach to assessing mental health laws' compliance with the UNCRPD' (2015) 40 *International Journal of Law and Psychiatry* 70, 73.

[179] n 174 above 73.

[180] Committee on the Rights of Persons with Disabilities (n 114 above) para 15.

[181] Quinn (n 1 above) 4.

[182] Pearl (n 128 above) 18; Minkowitz (n 16 above).

them.[183] Thirdly, the recognition of a person's will and preference is the vital to "accessing meaningful participation" in society.[184] It helps others to realise that persons with intellectual disabilities are persons with interests and aims in life, capable of achieving those aims and interests. Fourthly, it is attendant to the realisation of other rights in the CRPD including reproductive health rights such as the right to found a family and retain fertility, informed consent in health, non-discrimination, freedom from violence and sexploitation etc. Without legal capacity, the rights in the CRPD will be pointless for persons with intellectual disabilities.[185] Lastly, it addresses the discrimination experienced by people with intellectual disabilities who are often excluded from participating in affairs concerning them.[186] It does not categorise persons with intellectual disabilities.[187] So, it empowers persons with disabilities by recognising their autonomy and dignity.

Hence there is a need for a multidisciplinary approach and a mix of strategies for the effective realisation of article 12 and universal legal capacity for persons with intellectual disabilities. The usual strategy adopted by states in realising the right to equality for persons with disabilities is the enactment of antidiscrimination laws or disability laws. However, as highlighted by Jones and Basser-Marks, law plays a little role in guaranteeing equality for persons with disabilities.[188] That is not to say that the enactment and/or reform of laws relating to legal capacity is not important but there is also need for meaningful cultural and attitudinal change to guarantee equality and legal capacity for persons with intellectual disabilities. In order to effect cultural and attitudinal change in the ways legal capacity is construed for persons with intellectual disabilities, there is need for awareness-raising and advocacy to acquaint society with the CRPD conception of equality and legal capacity. One way of doing this is to translate it into the local dialects and contexts.[189] As succinctly stated by Merry, one reason international human rights violations occur despite numerous laws, policies and programmes, is that they do not easily translate from the global setting where the

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[183] Minkowitz (n 16 above).

[184] Flynn & Arstein-Kerslake (n 102 above) 127; L Series 'Letter to the United Nations Committee on the Rights of Persons with Disabilities- Re: comments on draft general comment on article 12 - the right to equal recognition before the law' http://www.ohchr.org/Documents/HRBodies/CRPD/GC/LucySeriesArt12.doc (accessed 08 July 2017).

[185] Pearl (n 128 above) 12.

[186] Weller (n 7 above) 499, 504.

[187] T Minkowitz 'The United Nations Convention on the Rights of Persons with Disabilities and the right to be free from non-consensual psychiatric interventions' (2006-2007) 34 *Syracuse Journal of International Law and Commerce* 405, 408.

[188] M Jones & LA Basser-Marks 'Law and the social construction of disability' in M Jones & LA Basser-Marks (eds) *Disability, divers-ability and legal change* 4.

[189] SE Merry Human *rights and gender violence- translating international law into local justice* (2006) 2.

laws are developed to the community and state levels where they are implemented.[190] For human rights to have an impact, it must be brought into the local 'consciousness' of people around the globe and vernacularised.[191] It is not enough to develop laws, policies and awareness programs on article 12, the laws and programmes must be transmuted into the local contexts, understandings and languages of the people.

4.5.2. The CRPD and legal capacity for adolescents with intellectual disabilities

There is recognition of the need to regard adolescents as active rights-holders'[192] but implicit in this recognition is that lack of capacity may inhibit the adolescent from exercising his or her rights.[193] In most legal systems, there is a general presumption of legal incapacity for children/adolescents and the age for attainment of legal capacity is usually fixed at 18 years of age.[194] The presumption is greater for children/adolescents with intellectual disabilities, who because of their disability are assumed to be incapable of making decisions compared to other children.[195] This gives rise to familial and societal protectionism thereby restricting their potential for development and independence.[196] This is mostly manifested in health care settings where parents make decisions for their children especially in terms of contraception and involuntary sterilisation. The tension between protecting adolescents and recognizing their autonomy pertains to determining the point at which the law should recognise adolescents with intellectual disabilities, particularly those with intermittent and limited support needs, as capable of making decisions. However, research has established that because an adolescent has intellectual disability does not necessarily mean he or she cannot consent to treatment.[197] Indeed, it has been established that adolescents with intellectual disabilities who require intermittent and limited support are capable of consenting to routine medical treatment and that with support and education, they can make complex treatment

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[190] n 189 above 2-3.

[191] n 189 above 3.

[192] Committee on the Rights of the Child (CRC Committee) 'Adolescent health and development in the context of the Convention on the Rights of the Child' (General Comment No. 4) (2003) CRC/GC/2003/4.

[193] C Breen *Age discrimination and children's rights: Ensuring equality and acknowledging difference* (2006) 1.

[194] UNICEF 'Using the human rights framework to promote the rights of children with disabilities: Discussion paper- an analysis of the synergies between CRC, CRPD and CEDAW' https://www.unicef.org/disabilities/files/Synergies_paper_V6_Web_REVISED(1).pdf (accessed 08 July 2017).

[195] L Ganzini et al 'Ten myths about decision making capacity' 5 *Journal of American Medical Directors Association* (2004) 263-267.

[196] A Broderick 'Article 7 [children with disabilities]' in VD Fina et al (eds) The United Nations Convention on the Rights of Persons with Disabilities- a commentary (2017) 209.

[197] South Australia Committee on Rights of Persons with Handicaps *The law and persons with handicaps, vol 2: Intellectual handicaps* (1981) 125; Marion's Case (n 105 above) para 24 per Mason CJ, Dawson JJ, Toohey JJ and Gaudron JJ.

decisions.[198] The capacity of an adolescent "to give informed consent to medical treatment depends on the rate of development of each individual."[199]

As highlighted in Chapter One, the CRPD Committee, in interpreting the implications of article 12 for children with disabilities links it to Article 7 of the CRPD. It states that although article 12 applies to them, consideration should be given to their 'developing capacities' in line with article 7 of the CRPD.[200] This is in line with the principle of the 'evolving capacities' of children with disabilities provided for in article 3 of the CRPD.[201] The Committee also states the best interests standard should guide all actions affecting them and that "their views be given due weight" in keeping with their "age and maturity."[202] It further states that to conform to article 12 requires state parties to ensure that the "will and preferences of children with disabilities are respected" on equal terms with other children.[203]

The implication of the CRPD Committee's linking of article 12 with article 7 is that it can be taken to positively signify that adolescents with intellectual disabilities have the same rights as their counterparts without disabilities. Broderick argues along this line that article 7 is remarkable because it does not allow participation to be weighted according to degree of disability.[204] Indeed, providing adolescents with disabilities with age-appropriate support to exercise their right to express their views is practical in enabling them to make decisions for themselves. It is potentially useful in ensuring that adolescent girls with intellectual disabilities are allowed to make decisions in matters affecting them, including contraception. This is pertinent because with age-appropriate assistance and information, adolescents with intellectual disabilities with intermittent and limited support needs are usually capable of giving informed consent to medical treatment, including invasive treatment.[205] The presence of disability should not reduce the weight attached to the adolescents with intellectual disabilities' views because they have valid insights into their well-being in line with their

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[198] KA Shogren et al 'Promoting self-determination in health and medical care: A critical component of addressing health disparities in people with intellectual disabilities' (*2006*) 3 *Journal of Policy and Practice in Intellectual Disabilities* 105, 108.

[199] Marion's Case (n 105 above) para 24 per Mason CJ, Dawson JJ, Toohey JJ and Gaudron JJ.

[200] Committee on the Rights of Persons with Disabilities (n 114 above) para 36.

[201] n 114 above article 3 (h).

[202] n 114 above para 36.

[203] n 114 above para 36.

[204] Broderick (n 196 above) 208.

[205] JM Rey & B Birmaher *Treating child and adolescent depression* (2007) 314.

evolving capacities.[206] This is in line with UNICEF's recommendation that adolescent with disabilities should be allowed to be involved in decisions affecting them.[207] It guarantees that adolescent girls with intellectual disabilities are accorded legal capacity, supported in the exercise of their legal capacity in terms of making decisions about contraceptives and are not subjected to contraception against their will or without their knowledge. Nevertheless, the CRPD Committee, in linking the best interests' standard to the will and preference of children/adolescents with disabilities, embraces a functional approach which it denounces for adults with disabilities because it goes against the tenets of article 12.[208] The Committee offers little or no guidance on what the best interest standard essentially entails for children with disabilities.[209] This leaves room for abuse as best interest is contextual and usually represents the interest of other parties such as parents. In Nigeria, where there is little oversight in private and family affairs, the best interests of parents and other relatives could be imputed as best interests of the adolescent. For instance, the involuntary sterilisation of an adolescent girl could be justified based on the ground that it is in her best interest. More so, when adolescents with an intellectual disability attain the age of 18 years, they become adults, which has implications for the application of the best interests' standard to them, in the sense that different standards are applied at childhood and adulthood, yet the disability remains the same.

It is clear that much has yet to be answered in respect of application of legal capacity to children. A clash of values is at play– protectionism versus recognition of autonomy. The evolving capacities approach does not provide an adequate answer as it reproduces a functional test which favours adolescents without intellectual disabilities. As such, it is crucial that laws, policies and professional practice provide a balance between protecting adolescents with intellectual disabilities and recognising their autonomy as this would enable them to participate in matters affecting them. Recourse could be had to the Committee on the Rights of the Child (CRC Committee) recommendation in this regard. In seeking to provide a balance between respect for the evolving capacities and the protection of adolescents, the

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[206] J Boyden & D Levison 'Children as economic and social actors in the development process' Working Paper No. 1, Expert Group on Development Issues, Stockholm, 2000, cited in G Lansdown *The evolving capacities of the child* (2005) 23.

[207] UNICEF 'The state of the world's children 2013: Children with disabilities' Executive Summary, key recommendations, para 8 http://www.unicef.org/publications/files/SOWC2013_Exec_Summary_ENG_Lo_Res_24_Apr_2013.pdf (08 October 2016).

[208] Committee on the Rights of Persons with Disabilities (n 114 above) paras 36 and 15.

[209] M Freeman 'Article 3: The best interests of the child' in A Alen et al (eds) A Commentary on the United Nations Convention on the Rights of the Child (2007) 27.

Committee suggests that a variety of factors should be considered. These factors include the level of the risk concerned; the likelihood for exploitation; adolescent development; an appreciation that competence and understanding do not develop evenly across all fields at the same pace; and the recognition of personal experiences and abilities.[210]

4.6. Legal capacity for adolescents with intellectual disabilities in the Nigerian context

Legal capacity in Nigeria is contextual and varies from one sphere of law to another.[211] In many cases, capacity is determined by age. However, for persons with disabilities upon attainment of the prescribed age, they may be disqualified from exercising their capacity to act because of their disability status. For instance, although the age of capacity to form a company is 18 years,[212] a person may be disqualified from joining in the formation of a company if he or she is of 'unsound mind'.[213] In other words, a person may be disqualified from forming a company because of his or her status as a person with disability. Similarly, in *Medical and Dental Practitioners Disciplinary Tribunal* (*MDPDT) v Okonkwo*[214] in which one of the issues for determination was whether a patient could refuse life-saving medical treatment, the Supreme Court held that a patient may refuse treatment so long as the patient is an adult and is 'competent'. [215] On the other hand, by the Evidence Act, all persons can testify as witnesses in court except they are incapable of "understanding the questions put to them, or from giving rational answers to the questions."[216] The Act further provides that "a person of unsound mind is not incompetent to testify unless he is prevented by his mental infirmity from understanding the questions put to him and giving rational answers to them."[217]

The age of capacity for medical treatment in Nigeria is 18 years. This is demonstrated by the National Health Act 2014, which places the "age of consent to medical treatment" at the attainment of the age of majority.[218] Although the Act does not define what age of majority is, the Child's Right Act 2003 defines 'age of majority' as 18 years.[219] This age

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[210] CRC Committee General Comment No. 4 (n 192 above) para 20.

[211] FAR Adeleke 'Age relevance in determining legal capacity: An overview' in OW Egbewole (ed) *Readings in jurisprudence and international law* (2004) 141, 151.

[212] Companies and Allied Matters Act, cap C.20 LFN 2004, section 20(1) (a).

[213] n 212 above section 20(1) (b).

[214] *MDPDT v Okonkwo* [2001] 7 NWLR (part 711) 206.

[215] n 214 above 244, paras A-G, per Ayoola, JSC.

[216] Evidence Act 2011, section 175(1) www.nassnig.org/document/download/5945 (accessed 08 July 2017).

[217] n 216 above section 175(2).

[218] National Health Act 2014, section 64.

[219] Child's Right Act 2003, Act No. 26 of 2003, section 277.

prescription reinforces the misconception that children/adolescents below the age of 18 years lack decision-making capacity. It fails to appreciate that whilst adolescents may lack legal capacity by reason of age, they may have the capacity to consent to medical treatment if they understand the nature of the treatment and can give informed consent. It must however be noted that this over-reach in age prescription applies in all cases, irrespective of disability.

In jurisdictions such as South Africa and the United Kingdom, laws grant adolescents below the age of 18 years the capacity to consent to medical treatment. For instance, in South Africa, a child of 12 may consent to medical treatment, and/or contraceptives, if he or she has "sufficient maturity" and "can understand the benefits, risks and social implications of the treatment or operation."[220] With regards to surgical operations which includes sterilisation, a child may consent to the operation if he or she is of "sufficient maturity", understands "the benefits, risks and social implications" of the treatment or operation and is duly assisted by his/ her parent or guardian.[221]

In the United Kingdom, a child of 16 can consent to surgical, medical and dental treatment.[222] Similarly, in the English case of *Gillick* v *West Norfolk and Wisbech Area Health Authority*,[223] it was held that a child below the age of 16 years can give consent for contraception if he or she demonstrates "sufficient understanding and intelligence to fully understand the proposed treatment."

Remarkably, medical practice in Nigeria seems to be evolving along contemporary legislative trends as adolescents from the age of 16 years and above are allowed to make contraceptive decisions.[224] In the same vein, the Supreme Court of Nigeria in the case of *Okekearu v Tanko*[225] expressed the view that a child of 14 years could make medical decisions if the child demonstrates the aptitude to comprehend the nature of the treatment and gives rational answers. In that case, the plaintiff, a boy of 14 years, instituted an action against the defendant, through his next friend, claiming general damages for battery ensuing from the amputation of his left centre finger without his consent. In his defence, the defendant claimed that he sought and obtained the consent from the plaintiff's aunty before

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[220] Children's Act No. 38 of 2005, sections 129(2) and 134.

[221] n 220 above, section 129 (3).

[222] Section 8 of the Family Law Reform Act 1969.

[223] [1986] 1 AC 112.

[224] Interviews with doctors during the empirical component of this study discussed in Chapter Five of the study.

[225] [2002] 15 NWLR (part 791) 657.

amputating the plaintiff's finger. The Court held the doctor liable for battery. In the words of Tobi JSC:

> It is clear from the above that Tanko's consent was not sought. Did Tanko lack the legal capacity to give his consent? Was Tanko in a state of coma that he was not in a position to give his consent? Why was consent, not directly procured from Tanko? …Tanko was fourteen years when his finger was amputated. In the absence of any medical evidence that Tanko lacked the capacity to give his consent to the amputation of his finger, I cannot see the justification of ignoring him to obtain the consent of PW2, his aunt… the point I am struggling to make is that there is no evidence on the record why effort was not made to obtain the consent of Tanko, a rational human being of fourteen years.[226]

Notwithstanding these developments in medical and judicial practice, adolescent girls with intellectual disabilities in Nigeria are presumed to be incapable of consenting to medical treatment or making medical decisions.[227] Unlike their non-disabled counterparts, they are denied legal capacity with regards to contraceptive decisions because they are perceived as lacking mental capacity. They are rarely consulted on decisions affecting their bodies and decision-making with regards to medical procedures often emanate from their parents, or guardians without any input from them. Despite evidence to show that many adolescents with intellectual disability with intermittent and limited support needs can make decisions, they are not afforded the opportunity to make decisions for themselves.[228] The empirical component of this study also showed that respondents believed that adolescent girls with intellectual disability who require intermittent and limited support are capable of making medical decisions on their own.[229] Even though some medical professionals are of the view that adolescent girls with intellectual disabilities who require intermittent and limited support can make contraceptive decisions, unlike their counterparts without disabilities, they still give primacy to parental consent to avoid legal liability. This is because the legislation in Nigeria is yet to catch up with medical practice.

Disability is a residual matter under the Nigerian Constitution and is within the legislative competence of States. However, only a few states like Lagos state have enacted

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[226] n 225 above 670-671, paras. F-H, per Tobi JSC.

[227] Medical and Dental Council of Nigeria, *Codes of Medical Ethics in Nigeria*, Rule 19, part A; E Chianu 'The horse and ass yoked- legal principles to aid the weak in a World of unequals' presented at the 91st Inaugural Lecture Series at the Akin Deko Auditorium, University of Benin, Nigeria on 20th September 2007; ER Ezeome & PA Marshall 'Informed consent practices in Nigeria' (2009) 9 *Developing World* Bioethics 138, 139; Lawal et al 'The doctrine of informed consent in surgical practice' (2011) 10 *Annals of African Medicine* 1, 2.

[228] South Australia Committee on Rights of Persons with Handicaps (n 197 above) 125; Marion's Case (n 105 above) para 24 per Mason CJ, Dawson JJ, Toohey JJ and Gaudron JJ; Shogren et al (n 198 above) 108.

[229] See Chapter Seven of this study.

disability laws. Section 31(5) of the Special People's Law of Lagos State guarantees equal rights to children with disabilities same as other children.[230] This is similar to the provisions of section 15(5) of the recently passed People with Disabilities Law of Kwara State.[231] It is also similar to the provisions of article 7 of the CRPD and is significant for adolescent girls with intellectual disabilities because it guarantees that they are treated on the same basis as other girls in terms of medical treatment. It could serve to protect them because, as discussed in Chapter Three, sterilising would amount to inequality.

The Ekiti State Rights of Persons with Disability bill of 2016[232] also contains elaborate provisions on the rights to legal capacity and seems to have drawn on the provisions of article 12 of the CRPD and the interpretation by the CRPD Committee. Section 6 (1) of the bill provides that persons with disabilities have legal capacity on an equal basis with others. It also provides that they have the right to equal recognition as persons before the law. Section 6 (2) prohibits deprivation of legal capacity on the grounds of disability in any "legislation, rule, notification, order, bye-law, regulation, custom or practice." Section 6 (4) provides for access to arrangements and support in exercising legal capacity in accordance with the will and preferences of persons with disabilities. Section 6 (5) provides that the intensity of support required to support a person with disability to exercise legal capacity is not a ground for questioning the person's legal capacity. It also prohibits undue influence and conflict by the supporter or support network and also recommends that the support provided must respect the autonomy, dignity and privacy of persons with disabilities. Interestingly, section 8 of the bill also provides that it is the government's duty to ensure the creation of community and support networks to provide support in exercise of legal capacity.[233] With regards to children with disabilities, the bill provides that the state government and local governments should "ensure that children with disabilities enjoy human rights on an equal basis with other children."[234] It also provides that they ensure that children with disabilities can

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[230] Special People Law of Lagos State, section 31(5). https://www.lagoshouseofassembly.gov.ng/download/special-peoples-law-vol-5/?wpdmdl=1232 (accessed 22 October 2016).

[231] Kwara State People with Disabilities Law 2016, section 15(5) http://kwha.gov.ng/Content/Images/pdfFiles/people-with-disabilities-bill-2016.pdf (accessed 08 July 2017).

[232] Ekiti State Rights of Persons with Disability Bill 2013 http://moj.ekitistate.gov.ng/legislation/ekiti-state-rights-of-persons-with-disability-bill/ (accessed 08 July 2017).

[233] n 232 above section 8 (1).

[234] n 232 above section 5 (1).

"freely express their views on all matters affecting them", on the same basis as other children, and that they are provided with age and disability appropriate support.[235]

The Ekiti state bill is more explicit than the article 12 and has enormous potential for transforming the right to legal capacity for persons with intellectual disabilities, including girls with intellectual disabilities. It not only provides for a universal legal capacity and support in exercise of will and preference of persons with disabilities but also prohibits the restriction of legal capacity on the ground that a person requires high intensity support. It also enables disabled children to exercise their rights on an equal basis with other children. Unfortunately, the bill was passed into law by the Ekiti State House of Assembly but is yet to receive the assent of the Governor.[236]

4.7. Conclusion

The importance of legal capacity in empowering persons with disabilities should not be trivialised. The determination of legal capacity and legal personhood based on cognition and rationality as determinants for legal capacity leads to the discrimination and exclusion of persons with intellectual disabilities. It is therefore important that the traditional modes of constructing legal capacity must be dismantled to ensure that such persons are integrated into the society. Article 12 challenges the traditional notions of legal capacity by guaranteeing the right to legal capacity for persons with disabilities on an equal basis with others. However, achieving the mandates of article 12 is not an easy task as there are challenges inherent in its effective implementation especially for persons with intellectual disabilities. It requires overturning the existing regimes on legal capacity and necessitates its principles being translated to local languages and brought into the consciousness of ordinary people around the world.

An examination into the regime of legal capacity in Nigeria showed that much is still needed to be done to guarantee the legal capacity of adolescent girls with intellectual disabilities on an equal basis with other girls. The best interests' standard and the functional approach adopted by the CRPD Committee in interpreting the implication of article 12 for adolescents with disabilities leaves room for abuse as the standards for determining them are

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[235] n 232 above section 5 (2).

[236] 'Law to protect disabled persons soon in Ekiti' http://www.nigerianbestforum.com/index.php?PHPSESSID=78f864659ec5dd7570e8ec28c9588ba3&topic=304363.0;nowap (accessed 08 July 2017).

indefinite. In spite this, with age-appropriate and disability appropriate support, adolescent girls with intellectual disabilities can be supported in the exercising their right to legal capacity in the medical context. Accordingly, the next chapter discusses what the right to support in the exercise of legal capacity and its attendant right to supported decision-making entails generally for persons with intellectual disabilities and particularly for adolescent girls with intellectual disabilities.

CHAPTER FIVE

SUPPORTED DECISION-MAKING FOR ADOLESCENT GIRLS WITH INTELLECTUAL DISABILITIES

> Children and adolescents with disabilities belong at the centre of efforts to build inclusive societies- not just as beneficiaries, but as agents of change…The right to be heard applies to all children, regardless of type or degree of disability, and even children with profound disabilities can be supported to express their choices and desires… It does mean, however, that children's rights, perspectives and choices must be respected…[1]

5.1. Introduction

In Chapter Four, the concept of legal capacity was examined. It was emphasised that article 12 of the Convention on the Rights of Persons with Disabilities (CRPD)[2] provides a fresh approach to how legal capacity is conceived by stipulating that persons with disabilities be provided access to support in exercising their legal capacity. Against this background, this chapter interrogates what supported decision-making entails for adolescent girls with intellectual disabilities and whether it is practical as a paradigm for protecting them from involuntary sterilisation or not.

The concept of supported decision-making is emerging as a decision-making model that enables persons with disabilities, especially those with intellectual disabilities, to exercise their legal capacity. Accordingly, the questions which underlie this chapter are:

a. What does the supported decision-making paradigm envisaged by the Committee on the Rights of Persons with Disabilities (CRPD Committee) entail?
b. Does it apply to adolescent girls with intellectual disabilities?
c. Is it potentially useful in protecting adolescent girls with intellectual disabilities from involuntary sterilisation?
d. In the light of the socio-economic realities of Nigeria, is it a practicable modality for militating against the involuntary sterilisation of adolescent girls with intellectual disabilities?
e. What models of supported decision-making, if applicable, can be developed to enhance the legal capacity of adolescent girls with intellectual disabilities?

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[1] United Nations Children's Fund (UNICEF) The state of the world's children 2013: Children with disabilities (2013) 84.

[2] Convention on the Rights of Persons with Disabilities (CRPD) (2006) 46 ILM 443, article 12(3).

This chapter begins by examining the import of support in the exercise of legal capacity in article 12(3) and (4) of the CRPD. It argues that it is implicit from the CRPD Committee's interpretation of article 12 that supported decision-making applies to adolescents with disabilities, including those with intellectual disabilities. The practicality of supported decision-making for adolescent girls with intellectual disabilities in the Nigerian context is also examined. It is posited that the complexities in applying supported decision-making for adolescent girls with intellectual disabilities, which are examined in this chapter, may in some cases give rise to substituted decision-making for them. Accordingly, developing effective supported decision-making systems in Nigeria would be challenging. That is not to say that developing supported decision-making systems in Nigeria is an exercise in futility, but to emphasise its difficulty in the light of the Nigerian realities. The chapter concludes by examining informal supported decision-making mechanisms with the aim of drawing lessons from the operation of informal supported decision-making systems in Australia and Canada. It examines three of such systems namely: circles of support, peer support and micro-boards. It argues that these models may be better suited to enhancing the legal capacity of adolescent girls with intellectual disability in terms of contraceptive decision-making thereby mitigating their being involuntarily sterilised.

5.2. Unpacking the supported decision-making model of legal capacity

The historic evolution of supported decision-making as a concept has been examined by some scholars.[3] Support in decision-making is innate in human relations and interactions as people offer support to others and receive support from other people to make decisions daily.[4] However, in most legal systems, persons with intellectual disabilities have been legally deprived the opportunity to make decisions affecting their lives.

Supported decision-making was developed in Canada in the 1970s as a as a concept for realising equal legal rights for persons with disabilities with regards to decision-making.[5] The tenets of supported decision-making were first espoused by the Canadian Association for

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[3] M Bach 'Securing self-determination: Building the agenda in Canada' (1998) http://www.communitylivingbc.ca/what_we_do/innovation/pdf/Securing_the_Agenda_for_Self-Determination.pdf (accessed 12 February 2014); M Browning et al 'Supported decision making: Understanding how its conceptual link to legal capacity is influencing the development of practice' (2014) 1 *Research and Practice in Intellectual and Developmental Disabilities* 34, 35; A Arstein-Kerslake et al 'Future directions in supported decision-making' (2017) 37 *Disability Studies Quarterly* http://dsq-sds.org/article/view/5070/4549 (accessed 08 July 2017).

[4] Arstein-Kerslake (n 3 above).

[5] Bach (n 3 above); T Stainton 'Supported decision-making in Canada: Principles, policy, and practice' (2015) *Research and Practice in Intellectual and Developmental Disabilities* 1.

Community Living (CACL) Taskforce in 1992.[6] The CACL proposed supported decision-making as a framework for decision-making and a mechanism for recognising the autonomy of persons with disabilities. The principles proposed by CACL included the right to self-determination and decision-making; recognition of the need for support relationships; and the recognition of persons' wills and abilities to make choices and non-discrimination on the basis of mental incapability.[7] The CACL's principles of supported decision-making were subsequently improved upon and incorporated into legislation in some provinces in Canada.[8]

The support paradigm attained international awareness during the negotiations and drafting of the provisions of article 12 of the CRPD to challenge existing legal systems which incapacitate persons with disabilities.[9] It is set out in article 12(3) to provide persons with disabilities with support in the exercise of their rights to legal capacity on an equal basis with others. Even though the term 'supported decision-making' is not specifically mentioned in the CRPD, the CRPD Committee in its General Comment No. 1, has interpreted the right to support in the exercise of legal capacity in article 12 (3) in terms of supported decision-making.[10]

5.2.1. The support paradigm in article 12 CRPD

Article 12 (3) requires persons with disabilities to be provided access to 'support' in the exercise of their legal capacity and is considered as the "locus situ" of state parties' duty to provide supported decision-making to persons with disabilities.[11] According to the CRPD Committee, 'support in the exercise of legal capacity' entails providing support to persons with disabilities to enable them make decisions that are of legal effect.[12] Quinn, Flynn and

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[6] Canadian Association for Community Living (CACL) 'Taskforce report of the CACL Task force on alternatives to guardianship' (1992) 2; Browning et al (n 3 above) 35; Arstein-Kerslake et al (n 3 above).

[7] Canadian Association for Community Living (n 6 above) 6-7; Browning et al (n 3 above) 35-36; Arstein-Kerslake (n 3 above).

[8] Examples of such legislation are the Vulnerable Persons Living with a Mental Disability Act (1993) in Manitoba, the Representation Agreement Act (1996) in British Columbia, and the Decision Making, Support and Protection to Adults Act, 2003 in Yukon. See Browning et al (n 3 above) 36; Arstein-Kerslake (n 3 above).

[9] Browning et al (n 3 above) 36; Arstein-Kerslake (n 3 above).

[10] Committee on the Rights of Persons with Disabilities (CRPD Committee) 'Article 12: Equal recognition before the law' (General Comment No. 1) (2014) CRPD/C/GC/1 https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement (accessed 12 February 2014).

[11] G Quinn 'Personhood and legal capacity perspectives on the paradigm shift of article 12 CRPD' presented at Harvard Law School Project on Disability (HPOD) Conference on Disability and Legal Capacity under the CRPD, Harvard Law School, 20 February 2010, 16 http://www.nuigalway.ie/cdlp/documents/publications/harvard%20Legal%20Capacity%20gq%20draft%202.doc (accessed 12 February 2014); P Gooding, 'Navigating the flashing amber lights of the right to legal capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to major concerns' (2015) 15 *Human Rights Law Review* 49, 50.

[12] Committee on the Rights of Persons with Disabilities (n 10 above) para 16.

Arstein-Kerslake are of the view that it involves a wide range of measures for providing assistance to persons with disabilities in accordance with their wishes.[13] The Committee also emphasises that support in the exercise of legal capacity must ultimately respect the "rights, will and preferences" of persons with disabilities and never result in substitute decision-making.[14]

However, the CRPD Committee provides little guidance on how to determine the 'will and preference' in situations where it is difficult to do so. This issue is brought into focus in situations where a person has requires extensive and pervasive support or cannot communicate his intentions conventionally and/or has no support network that can claim to know his or her will and preferences. The Committee's solution to this issue is that where after "significant effort" has been made and it is impracticable to ascertain a person's will and preferences, the "best interpretation of the person's will and preferences" should be the determinant.[15] Still, the Committee provides no guidance on how to determine the "best interpretation of a person's will and preferences." Quinn suggests that it should always be assumed that the will and preferences can be ascertained.[16] He argues that additional steps should be taken to determine such persons' will and preferences and that recent advancement in medical technology would be useful in making such determinations. He also advises against giving up on the possibility of detecting the wills and preference of such persons.[17] Quinn's interpretation raises even more questions and issues. One of such questions is- how can the will and preference be assumed where it was impracticable to ascertain it in the first instance? More so, in developing countries like Nigeria, such medical technologies alluded to by Quinn are unavailable and the cost of buying them and training personnel to use them to read the will and preferences of disabled persons are extremely high.[18] It seems that in such situations substituted decision-making may be inevitable.

Similarly, Flynn and Arstein-Kerslake suggest that the "starting point should always be will and preferences and only where this fails to be conclusive should other considerations

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[13] Quinn (n 11 above) 14; E Flynn & A Arstein-Kerslake 'The support model of legal capacity: Fact, fiction, or fantasy?'(2014) 132 *Berkeley Journal of International Law* 124; Gooding (n 11 above) 50.
[14] Committee on the Rights of Persons with Disabilities (n 10 above) para 17.
[15] Committee on the Rights of Persons with Disabilities (n 10 above) para 21.
[16] Quinn (n 11 above) 16.
[17] Quinn (n 11 above) 16.
[18] T Carney 'Supported decision-making for people with cognitive impairments: An Australian perspective? (2015) 4 *Laws* 37, 43.

be taken into account."[19] Such considerations involve the supporter assisting the person in exercising his or her legal capacity by learning the person's means of communication, examining previous communications and finding alternative ways to determine the person's wishes. Where determining the person's wishes proves impossible, they suggest that the supporter makes a decision based on what he or she considers to be the wishes of the individual and not what he or she perceives as being in the person's best interests.[20] They suggest that the supporter should look for signs of the person's wishes by speaking to persons close to him or her and considering his or her beliefs and previous expressions made, even where communication is minimal or difficult to understand.[21] However, their argument lacks substance in that it begins by conceding that the 'will and preference' may be 'impossible' to determine but then asks the supporter to determine it anyway. Substantively, this would amount to substituted decision-making. Semantics is not sufficient to replace substituted decision-making with some undefined and undefinable standard. More so, in situations where the supporter is unable to ascertain the person's wishes from those close to him or her, or from previous beliefs and expressions, their argument would prove ineffective. Besides, how does one make a decision he/she believes to be the wishes of the supported person where determining the person's wishes is already impossible?

The afore-mentioned determinants of the 'will and preference' are merely academic as any purported decision-making done would amount to substituted decision-making. Moreover, the terms 'significant effort' and 'best interpretation of will and preferences' are ambiguous and difficult to determine. The determination of 'significant effort' or 'best interpretation of will and preference' is subjective as it may differ from person to person rendering it subject to different interpretations. This could inevitably result in third parties making decisions on behalf of persons with disabilities, a situation which the CRPD and CRPD Committee seek to prevent.

The duty to provide safeguards to ensure that support measures respect the "rights, will and preferences" of persons with disabilities, are devoid of undue influence, and are suited to their needs, was also reiterated by the Committee as vital in protecting them from

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[19] E Flynn & A Arstein-Kerslake 'Legislating personhood: Realising the right to support in exercising legal capacity' (2014) 10 *International Journal of Law in Context* 81, 98.
[20] Flynn & Arstein-Kerslake (n 13 above) 131.
[21] n 13 above 131.

abuse of their rights.[22] Yet it is unclear what the provision of safeguards that are devoid of undue influence and are suited to their needs of persons with disabilities to prevent abuse of their rights entails. How do we provide a balance between too much oversight and too little oversight in the provision of safeguards?[23] The Committee further stated that the 'best interests' standard currently being applied to adults with disabilities must be replaced by the respect for their 'will and preferences'.[24] This, in Kong's opinion, "signals a strict interpretation" that the validation of decision-making on behalf of persons with disabilities based on the 'best interests' standard is disallowed.[25] According to her, the personal preferences of the individual must always supersede all altruistic factors or third-party interventions.[26]

Additionally, what the 'support' envisaged in article 12 entails is not distinctly stated in the CRPD. The CRPD Committee, however, interprets it broadly as wide-ranging and including various types of informal and formal assistive measures such as peer supportuniversal design and accessibility, communication aids and linguistic aids.[27] McSherry and Butler are of the view that 'support' should be interpreted widely to include the provision of adequate services and anti-discriminatory social attitudes.[28] Support, in this context, therefore includes legislative and/or administrative measures used to develop the capacity of persons with disabilities and assist them to make decisions in line with their wishes to enable them achieve more independence and participate in society.[29] As regards mitigating the involuntary sterilisation of girls with intellectual disabilities, it includes measures that ensure that they are supported in decision-making about contraception and treated on an equal basis with their peers in health-care. Such support measures include providing age-appropriate and

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[22] Convention on the Rights of Persons with Disabilities (n 2 above) article 12(4); Committee on the Rights of Persons with Disabilities (n 10 above) paras 20 and 22.
[23] KB Glen 'Beyond guardianship: Supported decision-making by individuals with intellectual disabilities' 22 http://supporteddecisions.org/wp-content/uploads/2015/09/Glen.Beyond-Guardianship.Briefing-Paper.pdf (accessed 15 February 2014).
[24] Committee on the Rights of Persons with Disabilities (n 10 above) para 21.
[25] C Kong 'The convention for the rights of persons with disabilities and article 12: Prospective feminist lessons against the will and preferences paradigm' (2015) 4 *Laws* 709, 712.
[26] Kong (n 25 above) 712.
[27] Committee on the Rights of Persons with Disabilities (n 10 above) para 17.
[28] B McSherry & A Butler 'Support for the exercise of legal capacity: The role of the law' (2015) 22 *Journal of Law and* Medicine 739, 740.
[29] DD Unger 'Workplace supports: A view from employers who have hired supported employees' (1999) 14 *Focus on Autism and Other Developmental Disabilities* 172; M Beirne-Smith et al *Mental retardation* (6th ed) (2002) 287; R Luckasson et al *Mental retardation: Definition, classification, and systems of supports* (10th ed.) (2002) 15; RL Schalock & MAV Alonso *Handbook on quality of life for human service practitioners* (2002) 320; A Arstein-Kerslake *Restoring voice to people with cognitive disabilities: Realizing the right to equal recognition before the law* (2017) 24.

accessible information about contraception and sexual education, ensuring that they are provided access to contraception, and assisting them with decision-making on what contraceptives to take.[30] The provision of such support would aid them in becoming self-determining.[31] The support could be provided by family members, friends, teachers and/or health professionals.[32] As such, support measures must be personalised, socially validated, dependable, age-appropriate, flexible, and consistent with the supported person's personal wishes.[33] Such support must be proffered and not forced.[34] The Committee also states that the form and degree of support to be offered will be different for each person on account of human diversity.[35] This is in keeping with article 3(d) which provides for "respect for difference and acceptance of persons with disabilities as part of human diversity and humanity." However, a problematic outcome of the CRPD's Committee's wide interpretation of 'support' is the potential for every type of strategy and measure to be construed as support, without much impact on the status and rights of persons with disabilities.

The support paradigm in article 12 therefore gives rise to obligations which could be used in challenging law and practice on legal capacity for persons with intellectual disabilities, including adolescent girls with intellectual disabilities. Arstein-Kerslake contends that it is a tool for social change with the potential for challenging law and practice on legal capacity and decision-making for persons with disabilities.[36] By recognising that persons with intellectual disabilities have wills and preferences, it invalidates traditional approaches that deny them legal capacity and allow the decisions made by others to be substituted for theirs. In line with this, the CRPD Committee enjoins state parties to make provisions against abuse within the support system and to replace existing substituted decision-making systems with supported decision-making systems.[37]

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[30] World Health Organization S*elected practice recommendations for contraceptive use* (3rd ed) (2016) 23-24.

[31] Committee on the Rights of Persons with Disabilities (n 10 above) para 24.

[32] 'Frequently asked questions on intellectual disability and the AAIDD definition' 3 https://aaidd.org/docs/default-source/sis-docs/aaiddfaqonid_template.pdf?sfvrsn=2 (accessed 22 November 2016); M Scholten & J Gathe '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' (2017) *Journal of Medical Ethics* 1, 3.

[33] NJ Dalrymple 'Environmental supports to develop flexibility and independence' in KA Quill (ed) *Teaching children with autism: Strategies to enhance communication and socialization* (1995) 243-264; Thompson et al *Support intensity scale: Users' manual* (2004) 6.

[34] Flynn & Arstein-Kerslake (n 13 above) 129.

[35] Committee on the Rights of Persons with Disabilities (n 10 above) para 18.

[36] Arstein-Kerslake (n 29 above) 37.

[37] Consideration of reports submitted by States parties under article 35 of the Convention: Concluding observations, Tunisia, Committee on the Rights of Persons with Disabilities (CRPD), 5th Sess., at 4, U.N. Doc. CRPD/C/TUN/CO/1 (April 11-15 2011); Consideration of reports submitted by States parties under article 35 of

5.2.2. Supported decision-making: Challenging old standards for persons with intellectual disabilities?

Supported decision-making has been developed as a mechanism for tackling substituted decision-making regimes. Substituted decision-making involves a person being designated to make decisions that have legal effects on behalf of another person.[38] The CRPD Committee defines a substituted decision-making system as one where a person is denied legal capacity; an external decision-maker is appointed against the person's will; and the decision-maker makes decisions in the person's 'best interests' without regard to the person's will and preference.[39] Guardianship and other systems that deprive persons with intellectual disabilities power to make decisions that have legal effect, including contraceptive decisions, are examples of substituted decision-making.[40] Hence, substituted decision-making regimes allow legal capacity to be denied, removed or restricted from a person and conferred on a third party, who makes decisions on his or her behalf.[41] They are the result of the paternalism generally expressed towards persons with intellectual disabilities. Consequently, the CRPD Committee in its concluding observations on state reports recommended that Australia "take immediate steps to replace substitute decision-making with supported decision-making" and provide a wide range of measures which respect a person's autonomy, will and preferences.[42] Similarly, it recommended that Austria, Hungary, Spain, China, Tunisia and Argentina take steps to replace substituted decision-making with supported decision-making for persons with disabilities, and ensure that persons with disabilities have access to supported decision-making and are not subjected to guardianship and trusteeship.[43] It further recommended that

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the Convention: Concluding observations, Spain, Committee on the Rights of Persons with Disabilities (CRPD), 6th Sess., at 5, U.N. Doc. CRPD/C/ESP/CO/1 (September 19-23, 2011); Consideration of reports submitted by States parties under article 35 of the Convention: concluding observations, Peru, Committee on the Rights of Persons with Disabilities (CRPD), 7th Sess., at 25, UN Doc CRPD/C/PER/CO/1 (April 16-20, 2012); Committee on the Rights of Persons with Disabilities (n 10 above) paras 26 & 28.

[38] T Minkowitz 'Submission to the committee on the rights of persons with disabilities day of general discussion on CRPD article 12' http://www.ohchr.org/Documents/HRBodies/CRPD/GC/WNUSP.doc (accessed 14 February 2016); P Gooding 'Supported decision-making: A rights-based disability concept and its implications for mental health law' (2013) 20 *Psychiatry, Psychology and Law* 431, 442.

[39] Committee on the Rights of Persons with Disabilities (n 10 above) para 27.

[40] Minkowitz (n 38 above).

[41] Flynn & Arstein-Kerslake (n 13 above) 125.

[42] Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Australia, adopted by the Committee at its tenth session (2-13 September 2013) CRPD/C/AUS/CO/1, Para 25

[43] Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Austria, adopted by the Committee at its tenth session (2–13 September 2013) CRPD/C/AUT/CO/1 para 28; Committee on the Rights of Persons with Disabilities, Concluding observations on the initial periodic report of Hungary, adopted by the Committee at its eighth session (17-28 September 2012) CRPD/C/HUN/CO/1, para 26; Committee on the Rights of Persons with Disabilities, Concluding observations of the Committee on the Rights of Persons with Disabilities Spain CRPD/C/ESP/CO/1, para 34; Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of China, adopted by the Committee at its eighth

supported decision-making measures respect the person's autonomy, will and preferences, and be in full conformity with article 12 of the Convention.[44] The Committee also urged Paraguay to develop a model for support in the decision-making that takes into consideration the individual's autonomy, free will and preferences and rights.[45]

Supported decision-making involves providing assistance to persons with disabilities in the exercise of legal capacity, in a manner that grants them legal recognition as ultimate decision-makers and ensures that their wishes are central to the decision reached.[46] In a

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session (17–28 September 2012) CRPD/C/CHN/CO/1, para 21; Committee on the Rights of Persons with Disabilities, Concluding observations of the Committee on the Rights of Persons with Disabilities Tunisia CRPD/C/TUN/CO/1, paras 22 and 23; Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Argentina as approved by the Committee at its eighth session (17–28 September 2012) CRPD/C/ARG/CO/1, para 20.

[44] Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Austria, adopted by the Committee at its tenth session (2–13 September 2013) CRPD/C/AUT/CO/1 para 28; Committee on the Rights of Persons with Disabilities, Concluding observations on the initial periodic report of Hungary, adopted by the Committee at its eighth session (17-28 September 2012) CRPD/C/HUN/CO/1, para 26; Committee on the Rights of Persons with Disabilities, Concluding observations of the Committee on the Rights of Persons with Disabilities Spain CRPD/C/ESP/CO/1, para 34; Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of China, adopted by the Committee at its eighth session (17–28 September 2012) CRPD/C/CHN/CO/1, para 21; Committee on the Rights of Persons with Disabilities, Concluding observations of the Committee on the Rights of Persons with Disabilities Tunisia CRPD/C/TUN/CO/1, paras 22 and 23; Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Argentina as approved by the Committee at its eighth session (17–28 September 2012) CRPD/C/ARG/CO/1, para 20.

[45] Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Paraguay, adopted by the Committee at its ninth session, 15–19 April 2013 CRPD/C/PRY/CO/1, para 30.

[46] T Minkowitz 'The paradigm of supported decision making' https://www.academia.edu/8770379/The_Paradigm_of_Supported_Decision-Making (accessed 15 February 2014); EW Maina 'The right to equal recognition before the law, access to justice and supported decision making' presented at the CRPD Conference of Parties on 2-4 September 2009 in New York http://www.un.org/disabilities/documents/COP/Edah%20Presentation%20COSP.doc (accessed 15 February 2014); UN General Assembly 'Thematic study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities' A/HRC/10/48 26 (2009) para. 45 http://www2.ohchr.org/english/bodies/hrcouncil/docs/10session/A.HRC.10.48.pdf (accessed 15 February 2014); B Carter 'Supported decision-making background and discussion paper' (2009) 8 http://www.publicadvocate.vic.gov.au/our-services/publications-forms/58-supported-decision-making-background-and-discussion-paper?path (accessed 15 February 2014); L Kerzner 'Paving the way to full realization of the CRPD's rights to legal capacity and supported decision-making: A Canadian perspective' presented at the Legal Capacity Symposium From the Margins: New Foundations for Personhood and Legal Capacity in the 21st Century at the University of British Colombia, Ontario, Canada on April 2011, 13 https://cic.arts.ubc.ca/files/2014/07/In__From_The_Margins_Paper-Lana_Kerzner-FINAL-April_22__2011__2_.pdf (accessed 15 February 2014); Gooding (n 38 above) 434; RD Dinerstein 'Implementing legal capacity under article 12 of the UN Convention on the Rights of Persons with Disabilities: The difficult road from guardianship to supported decision-making' (2012) 19 *Human Rights Brief* 8, 10; Minkowitz (n 38 above); NA Kohn et al 'Supported decision-making: A viable alternative to guardianship?' (2013) 117 *Penn State Law Review* 1111, 1120; Browning et al (n 3 above) 35; Carney (n 18 above) 38; The Bulgarian Center for Not-for-Profit Law (BCNL) 'New formula for capacity to act- opportunity for everyone to exercise their rights-statement on the paradigm shift of article 12 of CRPD' (2015) 3 www.bcnl.org/uploadfiles/documents/osi%20researches/statementdraftupdatedeng.pdf (accessed 08 July 2017); AS Kanter 'Expert opinion submitted to the Ontario Law Commission on its interim report on legal capacity, decision making and guardianship' (2016) 17 http://www.cacl.ca/sites/default/files/uploads/Expert%20Opinon%20ASKanter%20-%20FINAL%20COPYRIGHT.pdf (accessed 12 October 2017).

supported decision-making system, the person being supported is at the centre of the decision-making process and the support person is not permitted to make decisions on his or her behalf but merely interprets the will and preferences of the person being supported. Supported decision-making requires third parties to assist persons with disabilities to make decisions in line with their will and preferences. The support may include the provision of information to aid in decision-making and aid in communicating the decisions made. The means of support will depend on the requirements of the disabled person.[47] In the words of the CRPD Committee, "a supported decision-making regime comprises various support ."[48] Such a regime should include different support prospects which give priority to the person's will and preferences; remain consistent with human rights standards and do not control the person's life.[49]

In addition, whilst acknowledging that supported decision-making regimes comprise a variety of measures, the CRPD Committee specifies some requirements that supported decision-making regimes should have.[50] First, supported decision-making must be available to all irrespective of their support needs; must be based on the person's will and preference not on his or her perceived best interests.[51] This means that it must be available to all persons with disabilities, including adolescents with intellectual disabilities, regardless of the degree of their disabilities and the degree of support they require. Next, the lack of communication or the use of non-conventional modes of communication should not hinder a person from obtaining support. Thirdly, all types of support in the exercise of legal capacity must be anchored on the will and preference of the person and not on his or her best interests as perceived by others. Fourthly, states are obliged to ensure that support persons are legally recognised, facilitate the provision of support particularly to persons who are isolated and to put in place mechanisms that ensure the accountability of support persons. Fifthly, states must ensure that support is accessible at little or no charge to persons with disabilities and the lack of finances should not bar access to support in the exercise of legal capacity. Sixthly, support in decision-making must not be used to justify the denial or restriction of other fundamental rights of persons with disabilities, including reproductive rights and the right to consent to medical treatment. This requirement is especially significant for adolescent girls with intellectual disabilities as it guarantees that their right to retain their fertility is not

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[47] Carney (n 18 above) 38.
[48] Committee on the Rights of Persons with Disabilities (n 10 above) para 29.
[49] n 10 above, para 26.
[50] n 10 above, para 29.
[51] n 10 above, para 29.

infringed and that they are not subjected to involuntary sterilisation. Another requirement is that the person being supported must be able to refuse, end or adjust the support relationship at any time. The eighth requirement is that the safeguards relating to legal capacity and support in the exercise of legal capacity must be in place to ensure that the person's will and preferences are respected. Lastly, support to exercise legal capacity should be based on non-discriminatory indicators and not on mental capacity."[52] So supported decision-making can therefore be informal or formal.

Although the right to support in the exercise of legal capacity, which includes supported decision-making and the right to reasonable accommodation in article 5(3) of the CRPD are interrelated, doctrinally they are essentially not the same. As discussed in Chapter Three, article 5(3) of the CRPD enjoins states to take all appropriate measures to ensure that reasonable accommodation is afforded to persons with disabilities so as to promote equality and eliminate discrimination. Reasonable accommodation refers to adjustments and modifications to be made to ensure that persons with disabilities enjoy their human rights on the same basis as others.[53] Such modifications and adjustments include access to buildings such as courts, banks, and voting sites; accessible information about legal decisions; and personal assistance.[54] On the other hand, supported decision-making is about making structures that preserve persons with disabilities' role in the decision-making processes enabling them to determine their own lives available.[55] Also, the duty to ensure reasonable accommodation may be limited by a State's claim of disproportionate or undue burden while supported decision-making is not limited by such a claim because States have an unconditional duty to provide support in the exercise of legal capacity.[56] Thus, both rights complement each other and rest on the view that existing structures and processes for exercising legal capacity are not accessible to persons with disabilities and ought to be adjusted to meet the tenets of equality.[57] However, supported decision-making goes beyond

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[52] Committee on the Rights of Persons with Disabilities (n 10 above) para

[53] Convention on the Rights of Persons with Disabilities (n 2 above) article 2.

[54] Committee on the Rights of Persons with Disabilities (n 10 above) para 34.

[55] Browning et al (n 3 above) 42.

[56] Committee on the Rights of Persons with Disabilities (n 10 above) para 34.

[57] Council of Europe Commissioner for Human Rights 'Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities' (2012) 14 https://rm.coe.int/16806da5c0 (accessed 15 February 2016).

reasonable accommodation by exploring how legal mechanisms should be employed to ensure that persons with disabilities are supported in the exercise of their legal capacity.[58]

The key concepts of supported decision-making are empowerment, choice and control.[59] Some authors have highlighted the benefits of supported decision-making both to persons with disabilities and their families as well as to society. Chartres and Brayley suggest that it guarantees independence and control to persons with disabilities in their lives; it provides a positive structure for them and their families in terms of decision-making and planning and the recognition and advancement of their legal capacity.[60] The benefits of supported decision-making to society have been said to include promoting an improved and broader appreciation of the need to respect the rights of all persons; providing a more comprehensive approach to disability and enabling better decision-making.[61] According to Kohn et al:

> …supported decision-making is therefore appealing from multiple perspectives. From a civil rights perspective, it recognizes the personhood of persons with cognitive and intellectual disabilities and avoids stripping them of their fundamental freedoms. It is also consistent with the CRPD's call for states to provide access to the support that persons with disabilities "may require in exercising their legal capacity." From a disability rights perspective, the supported decision-making model is consistent with the social model of disability that sees disability as socially constructed and seeks to avoid the use of disabling labels such as "incompetent." Adoption of supported decision-making has been described as presenting "an opportunity to re-imagine the disabled legal subject" and may thus have political and symbolic value in and of itself. From a public health perspective, supported decision-making has the potential to improve the overall physical and psychological well-being of persons with cognitive and intellectual disabilities by creating a sense of empowerment, which in turn has been linked to positive health outcomes.[62]

Governments are accountable for "developing, promoting and offering support services to persons with disabilities, and for establishing safeguards that ensure a high quality of support", which recognises the "rights, will, and preferences of person", is free of conflict of interest and undue influence, and is tailored to their personal circumstances.[63] It is also the government's responsibility to overturn the prevailing systems of substituted decision-making for supported decision-making.

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[58] Browning et al (n 3 above) 42.

[59] Carter (n 46 above) 9.

[60] D Chartres & J Brayley 'Office of the Public Advocate South Australia: Submission to the Productivity Commission Inquiry into disability care and support' (2010) 32 https://www.pc.gov.au/inquiries/completed/disability-support/submissions/sub0325.pdf (accessed 6 June 2018).

[61] 'Supported decision making- experiences, approaches and preference' 3 http://www.niassembly.gov.uk/globalassets/documents/raise/knowledge_exchange/briefing_papers/series7/davidson070218.pdf (accessed 6 June 2018).

[62] Kohn et al (n 46 above) 1127.

[63] International Disability Alliance (IDA) 'Legal Opinion on Article 12 of the CRPD, (2008)' www.un.org/disabilities/documents/COP/Article%2012%20Principles%20Final.doc (accessed 14 February 2016).

At face value, supported decision-making seems to empower persons with intellectual disabilities by recognising their autonomy and inherent dignity.[64] It is attendant to the realisation of other rights in the CRPD, including the right to retain fertility, informed consent in health and non-discrimination which are important in guaranteeing that girls with intellectual disabilities are not involuntarily sterilised.[65] It recognises that decision-making is contextual and can be learned, enhanced or suppressed. It empowers persons with intellectual disabilities, and in particular adolescent girls with intellectual disabilities, to make decisions in all aspects of their lives, especially in terms of contraceptive decision-making on an equal basis with their peers. Nonetheless, it is a complex and highly nuanced concept rife with tensions and debates. One area of tension and debate is how to theorise supported decision-making for persons with intellectual disabilities that require extensive and pervasive support Although persons with intellectual disabilities who require intermittent support can be supported in decision-making, for some who require extensive or pervasive support or persons who have multiple disabilities, whose impairments are very limiting, no amount of support may enable them to make decisions.[66] The CRPD's presumption of legal capacity may result in those persons being supported to make decisions with little or no knowledge of the consequences of their decisions, making them more susceptible to being manipulated, coerced, or abused. The CRPD Committee in guaranteeing supported decision-making for all should acknowledge that for some persons it may not be feasible and set out standards to ensure that rights of such persons are respected. Acknowledging that some persons with intellectual disabilities may lack the aptitude to make decisions should not be perceived as validating the rights of third parties to make decisions for all persons with disabilities or as "endorsing a negative image of disability".[67] Indeed, Browning et al are of the view that "if it is accepted that substituted decision-making will sometimes be necessary, it is important to explore how these two concepts, substituted and supported decision-making, can coexist on the continuum."[68] The Victorian Law Reform Commission (VLRC) also suggests that in such

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[64] M Bach 'What does article 12 of the CRPD require? Theoretical starting points and questions/implications for law and policy' https://www.inclusionireland.ie/sites/default/files/documents/prof-m-bach-shared/bach-legalcapacity-aug09-inclusionireland.ppt (accessed 27 November 2017).

[65] Committee on the Rights of Persons with Disabilities (n 10 above) para 31.

[66] The Cambridge Intellectual & Developmental Disabilities Research Group 'Submission to the Committee on the Rights of Persons with Disabilities in response to the call for papers on the practical and theoretical measures for the implementation of article 12 of the united nations convention on the rights of persons with disabilities' (2011) 2 http://www.psychiatry.cam.ac.uk/ciddrg/files/2014/02/Article-12-CRPD-12-07-11.pdf (accessed 15 February 2014).

[67] The Cambridge Intellectual & Developmental Disabilities Research Group (n 66 above) 3.

[68] Browning et al (n 3 above) 40-41.

cases the goal should be amongst others to promote “the personal and social wellbeing” of the supported person.[69]

There is also ambiguity and little or no accord on the scope, models and principles of supported decision-making.[70] As observed by Carney and Beaupert, it has been taken to include a variety of legal and social interventions including assistance with daily familial and social interactions.[71] There is also little evidence on the impact of supported decision-making and whether or not it actually empowers persons with intellectual disabilities.[72] Consequently, it has been referred to by commentators as ‘ill-defined’,[73] ‘indefinite’, subject to different interpretations and covering a wide variety of models and powers.[74] For instance, Bach and Kerzner suggest a three prong model of decision-making namely: ‘autonomous decision-making’, ‘supported decision-making’ and ‘facilitated decision-making’.[75] They define ‘facilitated decision-making’ as a “status in which others facilitate” required decisions for persons with disabilities.[76] Similarly, the Office of the Public Advocate in South Australia (OPA) has integrated various decision-making options into a model called the ‘steeped model’ comprising a variety of supported decision-making mechanisms such as “representation agreements”, “co-decision-making” and “substitute decision-making arrangements”.[77] It also includes “autonomous decision-making”, “assisted decision-making”, “supported decision-making agreement” and appointment of private and public guardians.[78] However, the facilitated decision-making status of the Bach and Kerzner model and guardianship in OPA’s steeped model give rise to substituted decision-making.

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[69] Victorian Law Reform Commission ‘Guardianship: Final report 24’ (2012) at 388-398 http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf (accessed 08 July 2017).

[70] T Carney ‘Clarifying, operationalizing and evaluating supported decision making models’ 1 *Research and Practice in Intellectual and Developmental Disabilities* (2014) 46–50.

[71] T Carney & F Beaupert ‘Public and private bricolage- challenges balancing law, services and civil society in advancing CPRD supported decision-making’ (2013) 36 *University of New South Wales Law Journal* 175, 178.

[72] Kohn et al (n 46 above) 1114.

[73] Carney & Beaupert (n 71 above) 178.

[74] RM Gordon ‘The emergence of assisted (supported) decision-making in the Canadian law of adult guardianship and substitute decision making’ (2000) 23 *International Journal of Law and Psychiatry* 61, 63; Carney & Beaupert (n 71 above) 178; Kohn et al (n 46 above) 1120-1121; S Then ‘Evolution and innovation in guardianship laws: Assisted decision-making’ (2013) 35 *Sydney Law Review* 133, 155.

[75] M Bach & L kerzner ‘A new paradigm for protecting autonomy and the right to legal capacity’ (2010) 7 www.lco-cdo.org/disabilities/bach-kerzner.pdf (accessed 15 February 2014) 83-94.

[76] n 75 above 93.

[77] Office of the Public Advocate (South Australia) ‘Annual report’ (2012) 55-56 http://www.opa.sa.gov.au/files/64_annual_report_2011-2012.pdf (accessed 19 July 2016); Office of the Public Advocate (South Australia) ‘A journey towards autonomy? Supported decision-making in theory and practice- a review of literature’ (2014) 11 http://www.justice.qld.gov.au/__data/assets/pdf_file/0005/249404/Decision-making-support-for-Queenslanders-with-impaired-capacity-A-review-of-literature-March-2014.pdf (accessed 19 July 2016).

[78] Office of the Public Advocate ‘A journey towards autonomy?’ (n 77 above) 12.

The models allow decisions to be made for persons with disabilities[79] demonstrating that those who are trying to be innovative and come up with standards for supported decision-making have been unable to totally rule out substituted decision-making for persons with intellectual disabilities.

So the CRPD Committee's concept of supported decision-making appears to be out of tune with empirical evidence on the issue. There are little or no comprehensive perspectives about supported decision-making as considerations of its "legal and social measures tend to be abstracted from their social or operational context."[80] This is further buttressed by the fact that there is little guidance from the CRPD Committee on the extent of its applicability to children and adolescents with intellectual disabilities. Hence as Oliver and Campbell observe that in taking a "purist" approach to issues such as substituted decision-making, the Committee has left itself "somewhat adrift from the complex realities on the ground" which may in turn hamper law reform.[81]

5.3. Supported decision-making for adolescent girls with intellectual disabilities

The CRPD Committee, in considering the applicability of article 12 to children (adolescents) with disabilities, stated:

> While article 12 of the Convention protects equality before the law for all persons, regardless of age, article 7 of the Convention recognizes the developing capacities of children and requires that 'in all actions concerning children with disabilities, the best interests of the child…be a primary consideration' (para. 2) and that 'their views [be] given due weight in accordance with their age and maturity' (para. 3). To comply with article 12, States parties must examine their laws to ensure that the will and preferences of children with disabilities are respected on an equal basis with other children.[82]

The CRPD Committee in its interpretation of article 12 seems to recognise that children with disabilities, which include adolescents with disabilities, have a right to equality before the law, but seems to restrict them from exercising that right by linking it to article 7. As highlighted in Chapter One, the Committee seems to adopt the functional approach to legal capacity and in doing so seems to approve of the assessment of decision making capacity

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[79] N Devi 'Supported decision-making and personal autonomy for persons with intellectual disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities' (2013) 41 *Journal of Law, Medicine & Ethics* 792, 802.

[80] Carney & Beaupert (n 66 above) 178.

[81] O Lewis & A Campbell "Violence and abuse against people with disabilities: A comparison of the approaches of the European Court of Human Rights and the United Nations Committee on the Rights of Persons with Disabilities" *International Journal of Law and Psychiatry* (2017) 56.

[82] Committee on the Rights of Persons with Disabilities (n 10 above) para 36.

which it condemns for adults with disabilities.[83] Having proscribed the use of mental assessment tests and best interests' standard for adults,[84] the Committee appears to have no problem in applying them to children with disabilities seemingly validating substituted decision-making for them. Thus, in applying the 'will and preference' standard along with the functional assessments for children with disabilities which usually places them at a disadvantage, the CRPD Committee seems to have "conflated the old paradigm with the new", "constructing children with disabilities as a moment of difference in personhood" but protected by article 12.[85] What then is the relevance of the duty to ensure that 'the will and preference of children' is respected on an equal basis with other children if the test is reduced to a functionality test? Would the same position not be reached by substituted decision-making? More so, in applying the functional test to children with disabilities, the Committee fails to take into consideration situations where a person is 30 years but is judged to have a mental age of five according to a functionality test or where a girl of 16 is judged to be 12 years. In such situations, which test is applicable to whom? Is the 30 years old person a child for the purpose of the CRPD? The Committee also fails to consider that by its interpretation of article 12, it could be implied that a different standard is applied to a child with intellectual disability, and another when the child attains the age of 18 years, even though the intellectual disability remains the same. Moreover, the assessment of 'due weight' is subjective because it is left to the judgement of the person assessing the legal capacity of a child in a particular context.[86]

Article 7 of the CRPD guarantees children with disabilities the "full enjoyment" of all rights and fundamental freedoms "on an equal basis with other children" and that "in all actions concerning children with disabilities, the best interests of the child shall be a primary consideration."[87] This is related to article 3 of the Convention on the Rights of the Child (CRC) which provides that "in all actions concerning children whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration."[88] Article 7(3) goes further by providing that "children with disabilities have the right to express their views

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[83] n 10 above para 15.
[84] n 10 above para 21.
[85] R Sandland 'A clash of conventions? Participation, power and the rights of disabled children' social inclusion (2017) 5 *Social Inclusion* 93, 99.
[86] A Broderick 'Article 7 [children with disabilities]' in VD Fina et al (eds) *The United Nations Convention on the Rights of Persons with Disabilities- a commentary* (2017) 195, 209.
[87] Convention on the Rights of Persons with Disabilities (n 2 above) article 7(1) and (2).
[88] Convention on the Rights of the Child (1989) 28 ILM 1456, article 3(1).

freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children". It also provides that they be provided with "disability and age-appropriate assistance" to fulfil the right.[89] This is similar to the provisions of article 12 of the CRC which guarantees "to the child capable of forming his or her own views the right to express those views freely in all matters" affecting him or her whilst taking into cognizance the age and maturity of the child.[90] In addition, the CRPD Committee recognises the developing (evolving) capacities of children with disabilities which is one of the general principles guiding the implementation of the CRPD.[91] This is analogous with the provisions of article 5 of the CRC which provides that while parents, extended family, the community or legal guardians have a duty to provide "direction and guidance" to children, they must exercise their duty "in a manner consistent with the evolving capacities of the child." However, in spite of the CRC Committee's scholarship on the evolving capacities of children,[92] it problematises it by linking it to the best interest standard which is subjective and compatible with substituted decision making.

However, article 7(3) of the CRPD goes beyond article 12 of the CRC in three areas. One, unlike article 12, article 7(3) makes reference to equality between children with disabilities and other children.[93] Two, article 7(3) does not make reference to the child who is capable in article 12 CRC. It can therefore be argued that this is indicative of the CRPD's aversion towards 'capacity' tests.[94] Last, unlike Article 12(1) CRC, article 7(3) CRPD requires children with disabilities to be provided with "disability and age-appropriate assistance". It could be therefore argued that the best reading of article 7(3) is that it rejects the applicability of capacity tests and applies an approach consistent with supported decision-making to the participation rights of children with disabilities.[95] In view of this, the CRPD Committee's linkage of articles 12 and 7 for children with disabilities does not preclude the application of supported decision-making to children with disabilities.[96] The Committee, by

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[89] Convention on the Rights of Persons with Disabilities (n 2 above) article 7(3).
[90] Convention on the Rights of the Child (n 88 above) article 12.
[91] Committee on the Rights of Persons with Disabilities (n 10 above) para 36; Convention on the Rights of Persons with Disabilities (n 2 above) article 3(h).
[92] Committee on the Rights of the Child, General Comment No. 4, 2003, CRC/GC/2003/4, paras. 1 and 7; Committee on the Rights of the Child, General Comment No. 7, 2005, CRC/C/GC/7/ Rev.1, paras 15, 16 and 19.
[93] Sandland (n 85 above) 99.
[94] n 85 above 99.
[95] n 85 above 99.
[96] n 85 above 101.

referring 'the will and preferences' of children with disabilities in its interpretation of article 12 suggests that the support paradigm applies to them on an equal basis with other children.[97]

Furthermore, recourse to treaty interpretation indicates that article 12 of the CRPD and its attendant right to supported decision-making can be broadly interpreted as applying to children with disabilities. In fact, the Vienna Convention on the Law of Treaties, which is an accepted authority in treaty interpretation, does not give room for the narrow interpretation of treaties.[98] The Vienna Convention provides that "a treaty shall be interpreted in good faith in accordance with the ordinary meaning to be given to the terms of the treaty in their context and in the light of its object and purpose."[99] The conventional meaning of the terms of a treaty can be determined by reference to a dictionary as well as the common usage of the term.[100] The 'context' of a treaty comprises the entirety of the treaty text, including the preamble, purpose and annexes, as well as certain other agreements, instruments, and practices made by parties in relation to the treaty.[101]

The purpose of the CRPD, which underlies all the articles of the CRPD "is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities."[102] The preamble to the CRPD also recognises "that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children."[103] It can therefore be inferred from these provisions that article 12 applies to children with disabilities. Moreover, the articulation of the 'will and preference' in General Comment No. 1 suggests that article 12 of the CRPD applies to children with disabilities with respect to other children. The implication of this is in the context of this study is that adolescent girls with intellectual disabilities have a right to be supported in decision-making about contraception on an equal basis with their peers. Such support must be age and disability appropriate. Enabling their right to support in decision making would in turn mitigate their being sterilised as having being supported in contraception; sterilising them becomes a moot point. Consequently, the legal regime for supporting them in the exercise of their capacity will differ from that of the adult with intellectual disabilities. This is in line with the Partnership to Ensure Reform of Supports in

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[97] n 85 above 101.
[98] The Vienna Convention on the Law of Treaties (1969) 1155 UNTS 331.
[99] n 98 above article 31(1).
[100] Arstein-Kerslake (n 29 above) 17.
[101] Arstein-Kerslake (n 29 above) 17.
[102] Convention on the Rights of Persons with Disabilities (n 2 above) article 1.
[103] n 2 above preamble (r).

Other Nations (PERSON)'s argument that while legal capacity is applies to all persons, some adaptation of the concept is required in the context of children.[104] Similarly, Minkowitz opines that there is a need for advancing an approach to legal capacity and support for children.[105]

In Nigeria, socio-cultural beliefs and attitudes about the causes of intellectual disabilities and the capabilities of adolescent girls with intellectual disabilities, and restrictive legal structures, have resulted in their discrimination.[106] Negative stereotypes and beliefs that intellectual disability has religious connotations, is hereditary, and that girls with intellectual disabilities are "child-like", "asexual", "hyper-sexual", "dependent", "incompetent", helpless and incapable of parenthood are widely believed.[107] These beliefs are used to justify denying them legal capacity on equal basis with other adolescents without disabilities in the context of health care, and their being sterilised involuntarily. This is further compounded by the fact they are perceived by their parents and society at large as helpless disabled children incapable of doing anything for and by themselves. Even so, while adolescent girls with intellectual disabilities with intermittent and limited support needs may be capable of making decisions for themselves with support,[108] those that require extensive and pervasive support may not be able to. The assumption that their will and preferences would be determinable at all times could result in substituted decision-making in situations where they have no support network or cannot communicate their wishes especially where assistive and communicative devices and technologies are lacking..[109] It is therefore imperative that in developing supported decision-making systems or models, mechanisms that address negative social, cultural change and legislative beliefs and practices are also developed.

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[104] Partnership to Ensure Reform of Supports in Other Nations (PERSON) 'Principles for legal capacity reform' preamble http://www.eu-person.com/publication/person-principles-english/wppa_open/ (accessed 08 October 2016).

[105] T Minkowitz 'CRPD article 12 and the alternative to functional capacity: Preliminary thoughts towards transformation' http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2371939 (accessed 08 October 2016).

[106] Olubukola 'Intellectually retarded education in Nigeria: Past, present, and future' (2007) 22 *Essays in Education* 75; MBI Omoniyi 'Parental attitude towards disability and gender in the Nigerian context: Implications for counselling' (2014) 5 *Mediterranean Journal of Social Sciences 2255;* HO Ishola-Esan 'Impact of the remnants of African worldviews on perception of pastors towards ministering to persons with disabilities in Nigeria' 20 (2016) *Journal of Disability and Religion* 103, 108.

[107] TJ Aderemi 'Teachers' Perspectives on Sexuality and Sexuality Education of Learners with Intellectual Disabilities in Nigeria' (2013) *32 Sexuality and Disability 247, 256;* Inclusive Friends & Nigeria Stability and Reconciliation Programme (NSRP) 'What violence means to us: women with disabilities speak' (2015) 12 http://www.nsrp-nigeria.org/wp-content/uploads/2015/09/What-Violence-Means-to-us-Women-with-Disabilities-Speak.pdf (accessed 05 July 2016); PN Sango 'Country profile: Intellectual and developmental disability in Nigeria' (2017) 22 *Tizard Learning Disability Review* 87.

[108] JM Rey & B Birmaher *Treating child and adolescent depression* (2007) 314.

[109] OF Akinpelu et al 'Perspectives from the drafting of the UN Convention on the Rights of Persons with Disabilities' Discussion Paper for Side Event at UN Open-ended Working Group on Ageing 3-4.

In as much as the article 12 breaks new ground for children and adolescents with disabilities, especially those with intellectual disabilities, implementing it is not without challenges. One challenge in implementing it is due to the tension between the protectionist and autonomy perspectives of children's rights. The tension, according to Nakata, is "informed by different conceptions of childhood" and empirical claims about who children are.[110] The protectionist perspective regards children as "weak, vulnerable, innocent" and requiring protection from being exploited as well as from their childishness.[111] It emphasises welfare and protection rights with little or no room for children to seek redress for harm done to them without adults to advocate for them.[112] On the other hand, the autonomy perspective, which stems from the jurisprudence by child liberationists, calls for greater autonomy for children to better safeguard their rights. This claim for autonomy strongly accentuates "children's equal moral status" as grounds for equal rights.[113] Each perspective is not without problems. The protectionist perspective is problematic as it gives no consideration to the importance of children's views and the notion of empowerment.[114] The emphasis on equality by proponents of the autonomy perspective is equally problematic as it dismisses the distinction between childhood and adulthood, dispelling the claim of rights on the basis that children are different and "should be included in political communities" based on that difference.[115] The tension between the two perspectives on children rights is also reflected in the CRC. Articles 5 and 12, which provide for the 'evolving capacity of the child' and 'respect for the views of the child' respectively, are based on the autonomy perspective of children's rights while article 3 which provides for 'best interests of the child' is protectionist in nature. Nevertheless, when it comes to adolescents, including those with intellectual disabilities who require intermittent and limited support, consideration should be given to both protection and autonomy. As Freeman succinctly states:

> It is not a question of whether child-savers or liberationists are right – for they are both correct in emphasising part of what needs to be recognised, and both wrong in failing to address the claims of the other side. To take children's rights seriously requires us to take seriously both welfare and self-determination.[116]

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[110] S Nakata *Childhood citizenship, governance and policy: The politics of becoming adult* (2015) 25.

[111] Nakata (n 103 above) 24; I Derluyn et al 'Victims and/or perpetrators? Towards an interdisciplinary dialogue on child' soldiers' (2015) 15 *BMC International Health and Human Rights* DOI 10.1186/s12914-015-0068-5 3; H Kosher et al *Children's rights and social work* (2016) 12.

[112] n 110 above 24.

[113] n 110 above 27.

[114] M Freeman 'Whither children: Protection, participation, autonomy' (1994) 22 *Manitoba Law Journal* 307, 312.

[115] Nakata (n 110 above) 27.

[116] Freeman (n 114 above) 327.

Whereas for adolescents with intellectual disabilities that require extensive and pervasive support, protectionism becomes important especially where it is difficult to ascertain their will and preferences so as not to stretch interpretations and constructions of article 12 to absurdity.

Another factor affecting the effective implementation of supported decision-making for adolescent girls with intellectual disabilities is the manipulation or undue control by the persons supposed to support them, especially in medical decision-making. The likelihood of them giving way to their supporter is exigent as it could result in their will not been reflected in ensuing decisions, thereby defeating the purpose of article 12.[117] Although article 12 provides that measures pertaining to the exercise of legal capacity should be 'free of conflict of interest', little guidance is provided on how this should be achieved. This makes determining whether or not a purported supported decision is a substituted decision difficult, especially for persons with intellectual disabilities that require extensive and pervasive support, who are susceptible to being manipulated by others.[118] As Kohn et al contend, the manipulation may arise from intentional or unintentional influence of supporters, but also from the adolescent girl with intellectual disability deliberately deferring to the support person(s).[119] So the complexity is on how to establish supported decision-making structures that are voluntary; reflect the wishes of adolescent girls with intellectual disabilities; and reduce their risk of being manipulated and/or coerced.

The lack of knowledge about the CRPD and supported decision-making is another factor that could affect the implementation of supported decision-making for adolescent girls with intellectual disabilities. Supported decision-making is generally not known to the general public, policymakers, the judiciary, teachers and lawyers. Even as the importance of promoting the rights of persons with disabilities is emerging in Nigeria, there is little awareness on the CRPD or supported decision-making even among professionals such as teachers and doctors.[120] Where professionals like teachers and doctors who constantly deal with adolescents do not understand the concept, how then can they effectively provide support to them? People cannot utilise what they do not understand and so part of addressing the challenge is to ensure that supported decision is made known and understood. Where

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[117] Gooding (n 11 above), 58-60.

[118] The Cambridge Intellectual & Developmental Disabilities Research Group (n 66 above) 2.

[119] Kohn et al (n 46 above) 1123.

[120] See section 7.2.3.1 and 7.3.3.1 of this study.

professionals like teachers and doctors who constantly deal with adolescents do not understand the concept, how then can they effectively provide support to them?

Economic dependence and lack of social welfare and support services also affect the realisation of article 12 of the CRPD. In terms of contraception, for instance, the financial burden to provide both contraception and support in contraception is usually on the parent such that where the girl and her parents do not agree on an option she would be forced to do her parents' bidding because they are paying for the contraception. So balancing the adolescent's right to contraceptives with parental responsibility may be difficult especially as there are no support services for them. As such, it is unrealistic to expect parents who may be against contraception, or who may want to sterilise their child because of financial burden or poverty, to provide support to their child or pay for contraception.

Clearly, the implementation of the supported decision-making is not likely to be easy or quick. This is aggravated by the paternalism, which is often more pronounced for children (adolescents) with intellectual disabilities than for other children (adolescents) because they are usually subject to over-protectiveness and unwillingness by parents or caregivers to respect their wishers or accept their capabilities.[121] While policy and legislative reforms are necessary, it is vital that socio-cultural beliefs and practices are dismantled so that the concept of supported decision-making could live up to its promises. This is because merely reforming the legal system and legal structures to include supported decision-making without addressing existent cultural beliefs and perceptions would likely be ineffective.[122] It requires strategic and cooperative effort to bring all these indicators into play.[123] Research and advocacy suggest that programmes "to address attitudinal barriers and build a community and familial environment that recognises the value of supported decision-making will be integral" to implementing supported decision-making laws.[124] Given that the traditions around protection of children are strong, creating significant change will require a consistent and coordinated effort.[125] It would require significant political will at both the national and

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[121] M Sabatello 'Children with disabilities: A critical appraisal' (2013) 21 *International Journal of Children's Rights* 464, 484; Carney (n 18 above) 43.

[122] Browning et al (n 3 above) 40-41.

[123] Advocacy for Inclusion 'Supported decision making, legal capacity and guardianship- implementing article 12 of the Convention on the Rights of Persons with Disabilities in the Australian capital territory' http://www.advocacyforinclusion.org/publications/supported_decision_making_legal_capacity_and_guardianship2012final.pdf (accessed 16 October 2016).

[124] Burton Blatt Institute 'Supported decision making: An agenda for action (2014) 10 http://bbi.syr.edu/news_events/news/2014/02/Supported%20Decision%20Making-2014.pdf (08 October 2016).

[125] n 124 above 10.

international levels, and any changes that would occur in the appreciation and the implementation of the rights of children (adolescents) with intellectual disabilities would likely be little and incremental.[126]

Additional studies on the perspectives of adolescents with disabilities about their rights, how they want them to be implemented, and the barriers they experience, are crucial to developing an adolescent centred approach to the implementation of the CRPD.[127] This is necessary because there is a gap not only about how to apply supported decision-making to adolescent girls with intellectual disabilities who require extensive and pervasive support but also a gap in the jurisprudence on supported decision-making for children in general. Even General Comment No. 1 is deficient in this regard as it does not give much thought to the applicability of article 12 to children (adolescents) with disabilities. Clearly, this is a complex issue that should be examined by the CRC Committee and the CRPD Committee. However, this should not be taken to mean that the concept of supported decision-making should be abandoned but that there is need for constant discourse and development of strategies on how to implement it. One of such strategies emerging from the discourse on supported decision-making is the development of informal support mechanisms which will be discussed in the next section.

5.4. Informal supported decision mechanisms for adolescent with intellectual disabilities

Informal support mechanisms are mechanisms that are not formalised but are provided by persons close to a person with a disability. This study postulates that given the socio-cultural milieu of Nigeria where family and community structures are still strong, informal support mechanisms may be best suited for the needs of adolescent girls with intellectual disabilities. Informal support mechanisms may not have adequate legal safeguards for protecting the rights, wishes of persons using the support; but they are beneficial in the sense that the supporters are more likely to know the person being supported and to have been in the

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[126] Sabatello (n 121 above) 484.
[127] Sabatello (n 121 above) 484.

person's life for some time.[128] Carney also notes that supported decision-making possibly may not necessitate engaging with the law whatsoever. According to him:

> Circles of support, micro-boards, or friendship networks, may better be cultivated purely within civil society, overseen simply by the advocacy, service protocols, health and welfare professional standards and other processes of the myriad of informal community, self-help, non-government and government human services agencies.[129]

Similarly, Gooding points out that in practice, supported decision-making "can reasonably span beyond narrow legislative reform, to include policy, programming and other forms of extra-legal regulation, such as professional ethics guidelines".[130] The central feature of these arrangements is an emphasis on the will and preferences of the individual concerned.[131] Three informal support mechanisms, peer support, circles of support and micro-board are examined below.

5.4.1 Peer support

Peer support refers to initiatives where persons meet on equal terms to support one other on a mutual basis. It involves the exchange of information, experiences as well as the provision of social, emotional, or hands-on assistance to each other.[132] Peer support can be informal whereby peers meet to support each other or formal involving qualified and remunerated peer support workers; and can involve two or more people.[133] It includes peer mentoring, peer counselling and peer education which could be provided on a personal basis or in a group setting.[134]

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[128] A Arstein-Kerslake & E Flynn 'The general comment on article 12 of the convention on the rights of persons with disabilities: A roadmap for equality before the law' (2016) 20 *International Journal of Human Rights* 471, 477.

[129] Carney (n 18 above) 53.

[130] Gooding (n 38 above) 442.

[131] Flynn & Arstein-Kerslake (n 13 above) 124.

[132] The Kenya National Commission on Human Rights and the Open Society Initiative for Eastern Africa 'How to implement article 12 of convention on the rights of persons with disabilities regarding legal capacity in Kenya: A briefing paper' 36 http://www.knchr.org/Portals/0/GroupRightsReports/Briefing%20Paper%20on%20Legal%20Capacity-Disability%20Rights.pdf (accessed 7 March 2016).

[133] Disability Services 'Peer support- a guide to how people with a disability and carers can help each other to make the most of their disability supports' https://www.google.com.ng/search?ei=48LIWuLHBMK0gQa476vgCQ&q=Disability+Services+Peer+Support+A+guide+to+how+people+with+a+disability++and+carers+can+help+each+other+to+make++the+most+of+their+disability+supports&oq=Disability+Services+Peer+Support+A+guide+to+how+people+with+a+disability++and+carers+can+help+each+other+to+make++the+most+of+their+disability+supports&gs_l=psy-ab.12...3077123.3077123.0.3078534.1.1.0.0.0.0.0.0..0.0....0...1c.2.64.psy-ab..1.0.0....0.2z9iaqvMg8g (accessed 12 January 2018).

[134] P Block & T Nelis 'Peer support' in G Albrecht et al (eds) *Encyclopedia of disability* vol 1 (2006) 1229, 1231.

Peer support is a constructive support mechanism as it is a practical way of enabling a persons with intellectual disabilities to reach a decision that reflects their wishes.[135] It is not advocacy but is about sharing experiences between peers. Its benefits include the reduction of dependency on formal structures; build-up of confidence, self-esteem and ultimately autonomy; self-determination and empowerment. Peer support helps not only to persons with intellectual disabilities but also their family members to deal with difficulties inherent in caring for their disabled relatives.[136]

A recent project on peer support for children and young persons with intellectual disabilities and their families conducted in Victoria, Canada, by Social Action Partners highlighted the advantages of peer support.[137] Some of the advantages included experience sharing, mentoring and role modelling, development of autonomy and confidence as well as sustaining relationships.[138] Similarly, in one of the schools used for the empirical research, peer support was evident. There was a system of mentoring by older students in place. Every student was placed in a group comprising hearing impaired students and students with intellectual disabilities. They read together, went to school together and went to their boarding facilities together. There was a system of support in place for members of the group by members of the group. Communication did not seem to be a barrier as most of the students in the school, hearing impaired or not, could communicate in sign language. Accordingly, peer support would be beneficial in enabling support for adolescent girls with intellectual disabilities where the girls learn from each other about their rights, share their difficulties and help each other become independent over time. It is therefore recommended that schools and government facilities encourage peer support systems for adolescent girls with intellectual disabilities.

5.4.2. Circles of support

Circles of support consist of a small group of people, usually relatives and friends, who provide support to a person with disability to enable him or her make decisions about his or

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[135] The Kenya National Commission on Human Rights and the Open Society Initiative for Eastern (n 132 above) 36.

[136] Centre of Excellence in Peer Support 'What is Peer Support' https://www.peersupportvic.org/index.php/2014-12-15-22-41-58/2014-12-15-22-59-27 (accessed 7 July 2017).

[137] Social Action Partners 'Peer support for children and young people with intellectual disability and their families in Victoria' https://www.sprc.unsw.edu.au/media/SPRCFile/Social_Action_Partners__Final_Report.pdf (accessed 3 February 2018).

[138] Social Action Partners (n 137 above) above 31-32.

her life.[139] It is person-centred and is based on the principles of inclusion.[140] Circles of support provide persons with disabilities with an improved sense of well-being, social inclusion and a greater aptitude for planning for the future.[141]

Circles of support vary in form, but a common element is that people collaborate in assisting a person with disability in decision-making.[142] A circle is centred on the person with disability- the focus person but a facilitator is usually selected from within the circle to ensure that the circle runs effectively.[143] The members of the circle are usually not paid any remuneration because their involvement in the circle is on account that they care about helping the focus person to overcome difficulties in life and become more control self-determined.[144]

Organisations in Australia and the United Kingdom such as Civil Society Australia,[145] Circles Network UK[146] and Inclusive Solutions[147] have been successful in providing training and support in the setting up circles of support for children/adolescents with disabilities especially in education. Lessons could be drawn from them as regards providing support to adolescents with intellectual disabilities in health care in Nigeria. Indeed, studies have shown that circles of support are beneficial not only for children and adolescents with intellectual disabilities but also for members of the circle. Newton et al show that circles of support

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[139] Kerzner (n 46 above) 16; Kohn et al (n 46 above) 1123; Foundation for People with Learning Disabilities 'Circles of support and circles of friends' (2014) https://www.mentalhealth.org.uk/ learning-disabilities/a-to-z/c/circles-support-and-circles-friends (accessed 02 June 2018); ILSI manual chapter 7 'Circles of support' https://www.adhc.nsw.gov.au/__data/assets/file/0005/275576/ILSI_Manual_Chapter_7_Circles_of_Support.pdf (accessed 02 June 2018); Martina Rynne Brothers of Charity Services Clare 'Circles of support' http://www.fedvol.ie/_fileupload/Research/Master%20Class%20Series/MasterClass%205/Family%20leadership%20Martina%20Rynne-what%20why%20how.pdf (accessed 02 June 2018); H Sanderson '9 reasons why I am excited about the potential of community circles to make a difference' http://www.community-circles.co.uk/blog/9-reasons-why-i-am-excited-about-the-potential-of-community-circles-to-make-a-difference/ (accessed 02 June 2018).
[140] G Wistow et al 'UK circles of support and personalization: Exploring the economic case' (2016) 20 *Journal of Intellectual Disabilities* 194, 195.
[141] ILSI manual chapter 7 (n 139 above) 5.
[142] Kerzner (n 46 above) 16; Office of the Public Advocate 'A journey towards autonomy?' 12 (n 77 above).
[143] Mental Disability Advocacy Centre (MDAC) 'Supported decision-making: An alternative to guardianship' 14 http://mdac.info/sites/mdac.info/files/English_Supported_Decision-making_An_Alternative_to_Guardianship.pdf (8 January 2016).
[144] Mental Disability Advocacy Centre (n 143 above) 14.
[145] Civil Society Australia 'Circles of Support' http://www.civilsociety.org.au/Circles.htm (accessed 31 May 2018).
[146] Circles Network 'Supporting children, young people and families' http://www.circlesnetwork.org.uk/index.asp?slevel=0z128&parent_id=128 (accessed 31 May 2018).
[147] Inclusive Solutions 'Children helping children' https://inclusive-solutions.com/circles/circle-of-friends/children-helping-children/ (accessed 31 May 2018).

enhance problem-solving skills of the focus child/adolescent.[148] Similarly, Whitaker et al show that circles of support enhance self-esteem as well as foster social integration and inclusion of the focus child/adolescent.[149] Eddas and Schlieder et al also show that circles of support have helped to enhance peer acceptance and build the confidence of the focus child/adolescent.[150] The studies further show that circles of support positively shift the perspective of circle members about persons with disabilities and their understanding of disability.[151] A properly facilitated circle is therefore empowering to all persons involved and does not reinforce dependence. [152] Thus, circles of support are potentially useful in supporting adolescent girls with intellectual disabilities in contraceptive decision-making and mitigating their being involuntarily sterilised.

5.4.3. Micro-board

A micro-board is similar to a circle of support in some respects as it comprises a group of people whose aim is to assist a person realise his or her wishes.[153] However, a micro-board is a non-profit organisation developed to provide support to persons a person with disabilities and in some cases, act as a service provider for them.[154] Micro-boards differ from other personal networks in the sense that they not only provide support to individuals but also provide them with individualised funding provided by government agencies.[155] The combination of both personal and functional services provides a deep-seated foundation for continued engagement. [156]

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[148] C Newton et al ‘Circles of friends- an Inclusive approach to meeting emotional and behavioural difficulties’ (1998) 11 *Educational Psychology in Practice: Theory, Research and Practice in Educational Psychology* 41, 45.

[149] P Whitaker et al ‘Children with autism and peer group support: Using circles of friends*’* (1998) 25 *British Journal of Special Education* 60, 62.

[150] M Eddas (2002) ‘Circles of friends: A qualitative study of this technique with a ten-year-old child with an autistic spectrum disorder’ (2002) 3 Good Autism Practice 31-36 cited in National Autistic Society Autism Helpline ‘Circle of friends information sheet’ https://www.tes.com/teaching-resource/circle-of-friends-6035339 (accessed 31 May 2018); M Schlieder et al ‘An investigation of circle of friends peer-mediated intervention for students with autism’ (2014) 6 *Journal of Social Change* 27, 31-32.

[151] Newton et al (n 148 above) 45; Whitaker et al (n 149 above) 62; Schlieder et al (n 150 above) 32.

[152] Mental Disability Advocacy Centre (n 143 above) 14.

[153] Networks for Training and Development Incorporated *The all our own project- a Fieldbook for developing microboards* (2nd ed) (2006) 9; Kohn et al (n 46 above) 1123; The Pennsylvania Health Law Project Introduction to microboards https://www.med.upenn.edu/pan/documents/IntroductiontoMicroboards.pdf (accessed 31 May 2018); Virginia Microboard Association ‘What is a Microboard?’ http://virginiamicroboards.org/ (accessed 10 March 2017); Microboards Australia ‘What is a microboard?’ http://microboard.org.au/what-is-a-microboard/ (accessed 10 March 2017); Vela Canada ‘About microboards’ https://www.velacanada.org/vela-microboards (accessed 10 March 2017).

[154] Kohn et al (n 46 above) 1123.

[155] Stainton (n 5 above) 8.

[156] Stainton (n 5 above) 8.

Every micro-board is unique to the person it is intended for and centres on determining the person's wishes and providing support to the person For instance, members of a micro-board must develop and sustain a personal relationship with the person for whom the board is created.[157] Also, every person is assumed to have the capacity for self-determination which must be acknowledged and respected by all members and in all the dealings of the board.[158] Similarly, all planning and choices made by a micro-board must respect the supported person's dignity and enable the supported person to participate in community activities.[159] Hence, micro-boards are obligated to arrange, preserve, control, and administer support measures to meet the wishes of the person being supported.[160] There is also no age limit for creating micro-boards and so micro-boards can be established for children and adolescents with intellectual disabilities. Thus, micro-boards are beneficial to adolescent girls with intellectual disabilities in institutions who do not have close family ties as the caregivers and teachers in the institutions can form part of their micro-board.

Research shows that micro-boards provide an effectual means of implementing the support paradigm in article 12 of the CRPD. According to Micro-boards Australia, research shows that micro-boards could enable persons with intellectual disabilities to be included in society and control their lives.[161] It must however be noted that circles of support and micro-boards can be effective mechanisms for implementing supported decision-making. However, where members of a micro-board or circle of support make decisions for the person being supported, such support does not promote supported decision-making.[162]

5.5. Conclusion

This chapter examined the support paradigm in article 12 of the CRPD. Article 12 (3) of the CRPD guarantees support in the exercise of legal capacity and that the will and preferences of persons with disabilities be respected on an equal basis with others. This guarantee places an obligation on states to develop measures required to make the right meaningful. The right though empowering, is rife with tensions, complexities and debates regarding its applicability. For adolescents with intellectual disabilities, including the functional and best

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[157] Vela Canada 'Principles and functions for microboards' https://www.velacanada.org/principles-for-microboards http://virginiamicroboards.org/ (accessed 10 March 2017); Stainton (n 5 above) 8.

[158] Vela Canada (n 157 above).

[159] Vela Canada (n 157 above).

[160] Virginia Microboard Association (n 153 above); Networks for Training and Development Incorporated (n 153 above) 9.

[161] Microboards Australia (n 153 above).

[162] Kohn et al (n 46 above) 1123.

standard tests along with the right, creates ambiguities as to the extent of its applicability. If supported decision-making is to yield positive results for adolescent girls with intellectual disabilities, it must be thought through carefully. Accordingly, if a more substantial model of supported decision-making is to be developed, there is need for research and evaluation of the concept. Nonetheless, supported decision-making has the potential for transforming the reproductive health rights of adolescent girls with intellectual disabilities, especially those with intellectual disabilities who require intermittent and limited support. This is because where they are empowered and supported to make decisions about contraception on an equal basis with their peers, involuntary sterilisation may be a thing of the past.

CHAPTER SIX

EMPRICAL RESEARCH: METHODOLOGY

6.1. Introduction

This chapter discusses the empirical research strategies and procedures employed in the empirical component of this study. It explains the research design, research site, the population, the population sample and sampling techniques, the instruments, and the methods of data collection and analysis used in the research. It also discusses the strategies used to ensure the trustworthiness of the research.

The focus of this study is the viability of supported decision-making as it relates to the legal capacity of adolescent girls with intellectual disabilities as a means of curbing involuntary sterilisation.

The purpose of the empirical research was not to test the efficacy of supported decision-making mechanisms in Nigeria but to assess the respondents' opinions on its viability for adolescent girls with intellectual disabilities especially in the context of medical and contraceptive decision-making. This in turn informs the recommendations made in Chapter Eight about implementing supported decision-making mechanisms in the context of decision-making for adolescents with intellectual disabilities to mitigate their being sterilised. The empirical research was also carried out to buttress the study by examining respondents' outlook on the involuntary sterilisation for adolescent girls with intellectual disabilities and legal capacity for adolescent girls with intellectual disabilities.

In line with the socio-legal approach of the study, a mixed methods research approach involving the use of questionnaires and semi-structured interviews was adopted.[1] Mixed methods research involves the use of "quantitative methods[2] and qualitative methods[3] in the design, data collection and data analysis" in a study.[4]

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[1] A Bryman & RG Burgess *Qualitative research* (1999) 45; R Banakar & M Travers 'Introduction' in R Banakar & M Travers (eds) *Theory and method in socio-legal research* (2005) xi; E Adler & R Clark *How it's done: An invitation to social research* (3rd ed) (2007) 121; D Ary et al *Introduction to research in education* (8th ed) (2010) 119; DM Mertens *Research and evaluation in education and psychology: Integrating diversity with quantitative, qualitative, and mixed methods* (3rd ed) (2010) 293.

[2] Quantitative research involves the gathering, measurement and interpretation of data in numerical values to test knowledge claims. See G King et al *Designing social inquiry: Scientific inference in qualitative research* (1994) 3; JW Creswell Research design qualitative, quantitative and mixed methods approaches (2003) 153; B

6.2. Design of the study

A research design is the logical order through which a study's empirical information is linked to its research questions and eventually to its conclusions.[5] It shows how the aims of the research would be achieved, how the research questions would be answered and how the research would be carried out.[6] The research design employed for this empirical research is the survey research design. A survey involves the methodical garnering of data from respondents with the aim of understanding a subject matter of interest.[7] A survey is very suitable for collecting significant facts about people, their beliefs, opinions, attitudes, motivation and behaviour and to describe "what exists, in what amount, and in what context."[8]

The survey research design employed in this study involves the use of questionnaires and semi-structured interviews that were descriptive, exploratory and contextual. A questionnaire is a document comprising of a series of questions requiring written answers, which are used for garnering information from respondents about their viewpoints and understanding of an issue or range of issues.[9] Questionnaires can be administered in person, by mail, as hand-outs or electronically.[10] On the other hand, an interview is a method of collecting data from respondents, involving the interviewer(s) meeting up with respondents personally, to solicit answers on an issue or issues from them.[11] An interview can be done

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Johnson & L Christensen *Educational research: Quantitative, qualitative and mixed approaches* (4th ed) (2012) 33-34.

[3] Qualitative research involves the interpretation of people's understanding of certain phenomena in non-mathematical values. See C Glesne & A Peshkin *Becoming qualitative researchers: An introduction* (1992) 1; NK Denzin & YS Lincoln *Handbook of qualitative research* (1994) 2; MQ Patton & M Cochran *A Guide to using qualitative research methodology* (2002) 2; Johnson & Christensen (n 2 above) 33-34.

[4] Brysman and Burgess (n 1 above) 45; Mertens (n 1 above) 293.

[5] J Mouton *Understanding social research* (1996) 175; RK Yin *Case study research design and methods* (4th ed) (2009) 26.

[6] Mouton (n 5 above) 175; Yin (n 5 above) 26; B Van Wyk 'Research design and methods Part' https://www.uwc.ac.za/students/postgraduate/documents/research_and_design_i.pdf (accessed 16 March 2016); DR Cooper & PS Schindler *Business research methods* (2014) 82.

[7] DS Tull & GS Albaum *Survey research: A Decisional Approach* (1973) 3; S Guyette *Community-based research: A handbook for Native Americans* (1983) 48; BG Nworgu *Educational research: Basic issues and methodology* (1991) cited in KO Omorogiuwa *Research and Applied statistics for the behavioural sciences* (2006) 38; S Isaac & WB Michael *Handbook in research and evaluation: A collection of principles, methods and strategies useful in the planning, design and evaluation of studies in education and the behavioral sciences* (1997) 136.

[8] Nworgu (n 7 above) 38.

[9] DF Polit and BP Hungler *Essentials of nursing research: Methods, appraisal and utilisation* (1997) 466; DF Polit & CT Beck *Essentials of nursing research: Appraising evidence for nursing practice* (7th ed) (2010) 466, 565.

[10] 'Data collection methods for program evaluation: Questionnaires' https://www.cdc.gov/healthyyouth/evaluation/pdf/brief14.pdf (accessed 11 September 2016).

[11] Polit & Beck (n 9 above) 295.

face-to-face, by telephone, or over the internet.[12] Interviews can be structured, semi-structured, unstructured.[13] Semi-structured interviews are used to address wide-ranging questions in an interview while allowing the respondents/participants to talk freely about all the topics on the guide.[14] In semi-structured interviews, the interview is at the interviewer's discretion, who decides the order and wording of the questions, the questions to be asked, when to ask for explanation, or clarification.[15]

6.3. Location of the study

The research was conducted in the southern part of Nigeria. The southern part of Nigeria is made up of three geopolitical zones namely south-east, south-south and south-west geopolitical zones comprising of 17 states. The south-east geo-political zone comprises of five states - Abia, Anambra, Ebonyi, Enugu and Imo States. The south-south geo-political zone comprises of six states - Akwa Ibom, Bayelsa, Delta, Edo, Cross Rivers and River States. The south-west geo-political zone consists of six states - Ekiti, Lagos, Ogun, Ondo, Osun and Oyo States. A total number of six states were randomly selected from the three geopolitical zones; two states from each zone amounting to about one-third of the states in southern Nigeria. The states selected for the research were Anambra State, Edo State, Ekiti State, Imo State, Lagos State and Rivers State (see figure 6.1 below).

Southern Nigeria was selected as the research site because of the availability of private and public schools for children with intellectual disabilities in the area. Secondly, there is relative political stability in the region which allowed for ease of access to the localities used in the research as well as access to respondents and information. Northern Nigeria was left out of the research because at the time of obtaining the relevant approvals from the relevant authorities and informed consent from respondents, there was instability and insecurity in the region as a result of the activities of the insurgent group, Boko haram.[16] Thirdly, the research area covered three out of six geo-political zones in Nigeria cutting

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[12] Polit & Beck (n 9 above) 557.

[13] P Corbetta *Social research theory, methods and techniques* (2003) 269.

[14] Polit & Beck (n 9 above) 341.

[15] Corbetta (n 13 above) 270.

[16] 'Nigeria's boko haram crisis: Zaria bomb 'kills 25' BBC News 7 July 2015; M Fick 'Boko haram bombing kills 32 in Northern Nigeria' Financial Times 18 November 2015; S Isuwa & D Searcey 'Boko haram burns villages in north-eastern Nigeria' The New York Times 31 January 2016; 'Boko haram: Children among villagers burned to death in Nigeria attack' The Guardian 1 February 2016; F Karimi 'Boko haram: A bloody insurgency, a growing challenge' CNN 1 February 2016; Human Rights Watch 'Nigeria: Northeast children robbed of education-boko haram's devastating toll on students, teachers, schools' https://www.hrw.org/news/2016/04/11/nigeria-northeast-children-robbed-education (accessed 10 November 2016) ; 'Boko haram shoot dead 18 women at funeral in northern Nigeria' Reuters 17 June 2016.

across rural and urban locales with people from diverse ethnic, cultural, social and economic backgrounds.

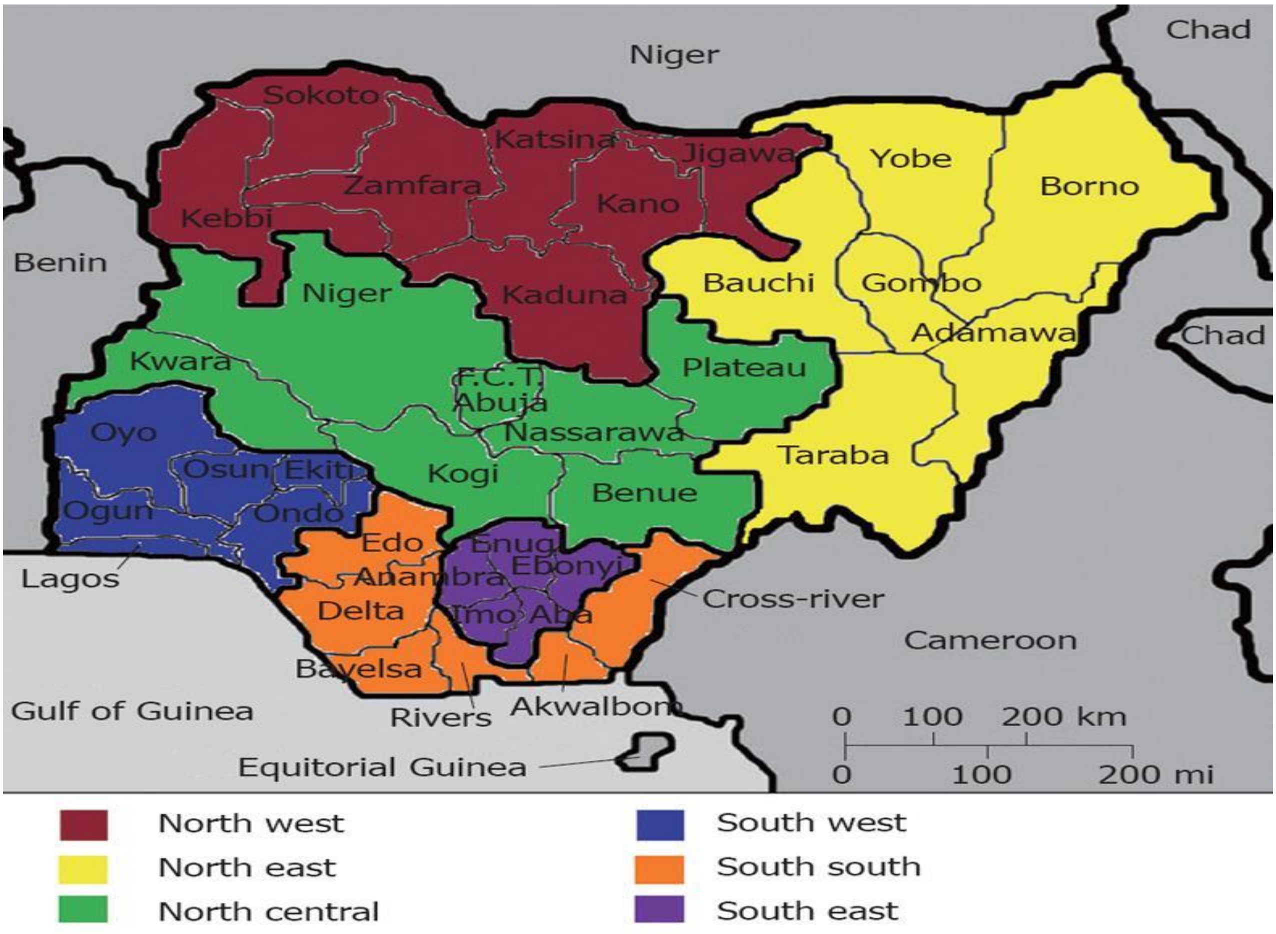

Figure 6.1: Map of Nigeria displaying the geo-political zones and the states of Nigeria[17]

6.4. Population of the study

The population of an empirical study refers to the entirety or collective number of persons in an area that conform to certain criteria to be involved in a study.[18] In this research, the population consisted of all the professionals working with adolescent girls with intellectual disabilities aged 13-18 years in primary schools for students with intellectual disabilities in southern Nigeria and the parents of the girls in the schools. It also consists of all paediatrics doctors, gynaecologists, psychologists and psychiatrists in Teaching Hospitals in southern Nigeria.

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[17] The map is adapted from OS Ogah et al 'Blood pressure, prevalence of hypertension and hypertension related complications in Nigerian Africans: A review' (2012) 4(12) *World Journal of Cardiology* 327, 332.

[18] Mouton (n 5 above) 134 and N Burns & SK Grove *Understanding nursing research* (3rd ed) (2003) 43.

6.5. Sample and sampling techniques

A sample of a study refers to a designated subgroup of a population selected for the purpose of studying certain characteristics of the parent population while sampling refers to the mode of selecting that subgroup to be studied as an estimation of the parent population.[19] A sample is generally used instead of the total population in an empirical research to minimise limitations in time and money which usually occur in gathering information from the total population.[20] For instance, in this research, rather than using the entirety of the professionals working with adolescent girls with intellectual disabilities in primary schools for students with intellectual disabilities in Southern Nigeria, parents of the students in the schools' and the doctors in all the teaching hospitals, a sample was used. The sample in this research comprised 238 respondents whose perspectives and opinions informed the recommendations proffered in the study.

In sampling the respondents, the multistage sampling technique was used.[21] The first stage involved stratifying the states of Nigeria into geo-political zones using the stratified random sampling.[22] Secondly, from each of the geo-political zones in Southern Nigeria (south-east, south-south and south-west), two states were randomly selected through simple random sampling.[23] This amounted to a total number of six states. Thirdly, primary schools for students with intellectual disabilities in the selected states were purposively selected to provide respondents for the research.[24] Seventeen primary schools consisting of 115

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[19] A Fink *How to sample in surveys* (2nd ed) (2003) 1; Burns & Grove (n 18 above) 31; BS Everitt & A Skrondal *The Cambridge dictionary of statistics* (4th ed) (2010) 376-377; E Babbie *The practice of social research* (13th ed) (2013) 124.

[20] Fink (n 19 above) 1; Burns & Grove (n 18 above) 31; Everitt & Skrondal (n 19 above) 376-377; Babbie (n 19 above) 124.

[21] Multi-stage sampling involves an amalgam of sampling methods involving the selection of a sample from a population by dividing the sample into smaller groups at different stages stage using different methods. See Fink (n 19 above) 11; Mertens (n 1 above) 319; H Liew 'Multistage sampling' https://sites.google.com/site/drhuiliew/ sampling-and-weighting/multistage-sampling (accessed 26 May 2017).

[22] Stratified random sampling involves dividing a population into subgroups, or strata and selecting a random sample is then selected from each subgroup or strata. See FW Mugo 'Sampling in research' (2002) http://indiana.edu/~educy520/sec5982/week_2/mugo02sampling.pdf (accessed 26 May 2017); Fink (n 19 above) 11; Everitt & Skrondal (n 19 above) 415; Johnson & Christensen (n 2 above) 226.

[23] Simple random sampling involves dividing a target population into a group of subsets and selecting a sample from the subset in such a way that each subset has equal chance of selection. The most common way of selecting a simple random sample is by assigning random numbers to a group of potential participants and selecting a number or numbers. See Mugo (n 22 above); Fink (n 19 above) 9 10-11; Ary et al (n 1 above) 150; and K Chaturvedi 'Sampling methods' http://www.pitt.edu/~super7/43011-44001/43911.ppt (accessed 26 May 2017).

[24] Purposive sampling (judgemental sampling) involves researchers deliberately soliciting people that they believe will facilitate their research to partake in the research. See K Gerrish & A Lacey *The research process in nursing* (2010) 149; Adler & Clark (n 1 above) 121; Ary et al (n 1 above) 156; Polit & Beck (n 9 above) 312; Johnson & Christensen (n 2 above) 231

adolescent girls with intellectual disabilities aged 13-18 years, who were registered in the schools for the 2016 academic session, were selected.[25] The schools included nine public schools and eight private schools. Thereafter, professionals working with the girls in the selected schools and parents of the girls, who were inclined to participating in the research, were selected as the respondents. The respondents were determined by the number of adolescent girls with intellectual disabilities aged 13-18 years in the selected schools (see table 6.1 below). Homes and rehabilitation centres, including those providing primary educational services, were not included in the research. One hundred and fifty-eight professionals participated in the study and questionnaires were administered to 144 of the professionals.

Eighty-three professionals in the selected schools participated in the research (see table 6.1 above). Professionals in the selected schools that were unwilling or unavailable, at the time of the research, were excluded. Ninety questionnaires were distributed to the professionals and 83 were returned to the researcher. Eighty parents also participated in the research (see table 1 below). Parents that did not have daughters aged 13-18 years in the selected schools, or who were unable or unwilling to participate, were not included in the research. A total of 115 questionnaires were distributed to the parents in the selected schools and eighty of the questionnaires were returned to the researcher.

Similarly, three teaching hospitals were initially purposively selected from each of the three geo-political zones in Southern Nigeria. Unfortunately, one of the hospitals was not used in the research because the hospital was engaged in a strike action during data collection. Seventy-four doctors and one social worker formed part of the research (see table 6.2 below). Doctors in the teaching hospitals were selected because many doctors in teaching hospitals also own their own clinics or work in private hospitals or clinics. As such, they provided perspectives from both the public and private purview of medical practice.

To ensure the anonymity of the respondents and to protect the confidentiality of the information obtained, the names of the institutions and respondents engaged in the research were not used in analysing the data obtained. In view of this, numbers were randomly assigned to them during analysis, where necessary.

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[25] Some of the schools used in the research had included in their records students who had registered for previous academic sessions but were not registered in the 2016 session but only students registered in the 2016 session were considered.

REGION	STATE	SCHOOLS	TYPE OF SCHOOL	NO OF GIRLS AGED 13-18	NO OF PARENTS	NO OF PROFESSIONALS
REGION 1	STATE 1	School 1	Public school for students with disabilities	2	2	2
		School 2	Missionary school for children with developmental disabilities	9	7	11
	STATE 2	School 1	Private school for children with disabilities	2	2	4
		School 2	Public school for students with intellectual disabilities	8	6	6
		School 3	Private school for children with cognitive and developmental disabilities	5	5	3
REGION 2	STATE 3	School 1	Public school for students with hearing impairment and intellectual disabilities	9	7	4
		School 2	Public school for students with hearing impairment and intellectual disabilities	6	-	3
	STATE 4	School 1	Private school for students with intellectual disabilities	4	3	4
		School 2	Missionary school for students with hearing impairment and intellectual disabilities	4	2	2
		School 3	Public school for students with hearing impairment and intellectual disabilities	8	6	7
		School 4	Missionary school for students with hearing impairment and intellectual disabilities	5	3	5
		School 5	Public school for students with hearing impairment and intellectual disabilities	6	-	3
REGION 3	STATE 5	School 1	Public school for students with disabilities	21	17	13
		School 2	Public school for students with physical and intellectual disabilities	9	7	6
		School 3	Private school for students with down syndrome	4	3	4
		School 4	Private school for children with developmental disabilities	2	2	2
	STATE 6	School 1	Public school for students with disabilities	11	8	4
TOTAL			***17***	***115***	***80***	***83***

Table 6.1- Distribution of parents and teachers in the research

S/N	DOCTORS (By Specialization)	HOSPITAL 1	HOSPITAL 2
1.	Paediatricians	22	16
2.	Obstetricians and Gynaecologists	8	12
3.	Clinical Psychologists	3	4
4.	Psychiatrists (Mental Health)	3	6
5.	Social Worker (Mental Health)	-	1
TOTAL		***36***	***39***
GRAND TOTAL		**75**	

Table 6.2 - Distribution of doctors in the research

6.6. Ethical considerations

Conducting research involving persons with intellectual disabilities, especially children or adolescents with intellectual disabilities, raises many intricate ethical issues such as informed consent, risk and benefit of the research and prevention of coercion or manipulation.[26]

Adolescent girls with intellectual disabilities in the schools sampled for the research were not enlisted in the research for several reasons. First, the researcher lacked the requisite expertise required to conduct research on adolescents with intellectual disabilities. This is because intellectual disability is heterogeneous and adolescent girls with intellectual disabilities in the selected schools have different degrees of intellectual disabilities. As such, conducting a survey, especially on girls with intellectual disabilities who require extensive and pervasive support would have been very challenging as many of them could not communicate verbally or in writing. This may have required engaging the services of an expert to aid in soliciting information from the girls which would have been expensive. Next, obtaining written informed consent, especially from girls that could not communicate verbally or in writing, would have been problematic as the researcher lacked the expertise to secure such consent. Thirdly, adolescents with intellectual disabilities have different ways of communication, reading, writing and processing information; so, determining the survey method best suited for them was challenging. It may have been also difficult to minimise interference from teachers and care givers and thereby avoid coercion or manipulation of the girls because the research would likely have been carried out in the schools. More so, the girls may have little or no knowledge of some of the issues sought to be answered such as involuntary sterilisation. So, the parents of the girls in the sampled schools as well as

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[26] L Carlson 'Research ethics and intellectual disability: Broadening the debates' (2013) 86 Y*ale Journal of Biology and Medicine* 303.

professionals in the sampled schools and hospitals who work with the girls were enlisted as respondents. They were enlisted on the belief that they could provide information on issues sought to be ascertained by the research.

The rights of respondents and the principles of empirical research were taken into consideration while conducting this research. To achieve this, approval was obtained from the Ethics Committee of the Faculty of Law, University of Pretoria, to conduct this research.[27] Letters requesting permission for the researcher to carry out the research in the selected schools and hospitals were also submitted to the relevant state ministries of education or school management boards and the ethics committees of the selected hospitals.[28] The researcher was granted approval in writing by the relevant authorities to carry out the research in the selected schools and hospitals.[29]

After approvals were granted by the relevant authorities to undertake the research, letters of introduction explaining the nature and purpose of the research were submitted to the heads of the schools and relevant heads of department in the hospitals.[30] Attached to the letters were the head of institutions' informed consent forms.[31] The consent forms were duly filled and returned to the researcher. Thereafter, the heads of the schools granted the researcher access to the school to enlist respondents and helped identify classes for students with intellectual disabilities.

Potential respondents in the selected schools were approached during morning meetings and assembly or in their classes. The researcher introduced herself to potential respondents and informed them orally about the nature of the research. They were also given participant information leaflets containing the nature, purpose and duration of the research as well as the contact details of the researcher.[32] Attached to the given participant information leaflets were informed consent forms.[33] Similarly, the researcher approached potential respondents in the selected hospitals during their morning review meetings or clinic days. The researcher introduced herself to them and informed them about the nature and purpose of the research. Participant information leaflets explaining the nature and purpose of the

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[27] See appendix 1.
[28] See appendix 2 and 3.
[29] See appendices 4-11.
[30] See appendix 12.
[31] See appendix 13.
[32] See appendix 14.
[33] See appendix 15.

research containing informed consent forms were also given to them to ensure their willing participation in the research.[34] In the schools and hospitals, potential respondents were given 24 hours to peruse the information leaflets and decide whether to participate in the research or not. Those who were willing to participate in the research filled and returned the informed consent forms to the researcher.

With regards to parents of girls with intellectual disabilities in the selected schools, the heads of schools informed the researcher of dates when parent-teacher meetings or school open days would occur. At such meetings and open days, the researcher addressed potential respondents on the nature and purpose of the research. Participant information leaflets explaining the nature and purpose of the research, along with informed consent forms, were also distributed to potential respondents. They were given 24 hours to read the information leaflets and decide whether to participate in the research or not. Those who were willing to participate in the research filled and returned the informed consent forms to the researcher.

The right of respondents to refuse participation in the research was also respected. They were informed of this right before their consent was obtained as well as during the administration of questionnaires and the conduct of interviews. Accordingly, it was reiterated that participation in the research was voluntary and that they reserved the right to withdraw from the research at any stage before its completion. The participant information leaflet also contained a statement that participation is voluntary and that respondents can withdraw from the research at any time. In addition, during the interviews, respondents were informed of their rights to refuse to be audio recorded. Those who were willing to be recorded were given consent forms authorizing the researcher to record them[35] while notes were taken by hand for those who refused to be recorded.

The anonymity of the respondents and confidentiality of the information provided was also protected. Respondents were assured that the information obtained from them would only be used for research purposes. All documents that could link respondents to the information provided or documents containing the names and addresses of respondents and institutions, used in the research were securely locked away in a file cabinet only the researcher had access to. Such documents were eventually submitted to the Centre for Human Rights, University of Pretoria, to be securely stored. Completed questionnaires were locked

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[34] See appendix14 and 15.

[35] See appendix 16.

up in a file cabinet that only the researcher had access to and were eventually submitted to the Centre for Human Rights, University of Pretoria to be securely stored. Codes were assigned to the audio recordings of the interview and transcribed interview notes which were stored electronically in encrypted files. Pseudo names and numbers were also used in data analysis to protect the anonymity of the respondents and institutions used in the research as well as the confidentiality of the information obtained. The respondents were also informed that the researcher may also refer to the data obtained from the research in the future for further research purposes.

6.7. Instruments of the study

The instruments used in this research were questionnaires and an interview schedule.[36] The instruments were developed after an examination of the existing literature and in keeping with the research objectives of the research.

Two questionnaires were used to collect data from the respondents. A questionnaire titled 'Questionnaire for Professionals Working with Adolescent Girls with Intellectual Disabilities' was used to elicit information from professionals in the selected schools and hospitals.[37] A second questionnaire titled 'Questionnaire for Parents of Adolescent Girls with Intellectual Disabilities' was used to solicit information from parents of adolescent girls with intellectual disabilities in the selected schools.[38]

The questionnaire for teachers, professionals and doctors contained 20 items and was divided into four sections. The first section contained six items and solicited demographic data from the respondents. The second section contained four items pertaining to intellectual disability and non-therapeutic sterilisation including questions about the respondents' training on intellectual disability, the cause(s) of intellectual disability and their knowledge and beliefs about non-therapeutic sterilisation. The third section contained four items relating to the respondents' knowledge about CRPD and its concept of supported decision-making. The last section contained six items relating to legal capacity and supported decision-making. The questions solicited respondents' opinions on the right to legal capacity and supported

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[36] An interview schedule is an instrument that contains all the questions a researcher intends to ask respondents in a survey. See Polit & Beck (n 9 above) 557-558.

[37] See appendix 17.

[38] See appendix 18.

decision-making of adolescent girls with intellectual disabilities in terms of medical and contraceptive decision-making.

The questionnaire for parents contained 17 items and was divided into four sections. The first section contained 6 items and solicited demographic data from the respondents. The second section contained four items about intellectual disability and non-therapeutic sterilisation. It included questions about their descriptions of their child's intellectual disability, the cause(s) of their children's intellectual disability and their knowledge and beliefs about non-therapeutic sterilisation. The third section contained four items relating to the respondents' knowledge about CRPD and its concept of supported decision-making. The last section contained six items pertaining to legal capacity and supported decision-making. It contained three questions framed to solicit their opinions on the legal capacity of their children to make medical and contraceptive decisions as well as their children's rights to support in decision-making in terms of contraceptive decision-making and sterilisation.

An interview schedule[39] was also used to conduct face to face semi-structured interviews aimed at getting in-depth information from the 17 head teachers in schools and 13 consultant doctors in the hospitals used in the research. It contained questions on the personal information of respondents excluding their names. It also contained questions aimed at eliciting the opinions of the respondents on the causes of intellectual disability, their knowledge and beliefs in involuntary sterilisation and their knowledge of the CRPD and supported decision-making. The interview schedule also contained questions aimed at determining their personal and professional opinions on the right to legal capacity and supported decision-making of adolescent girls with intellectual disabilities in terms of medical and contraceptive decision-making.

The semi-structured interview format was chosen because it gave room for the researcher to drive the direction of the interview depending on the responses given by the respondents. It was used to provide practical insights about the practicability of supported decision-making as a paradigm in protecting the legal capacity of adolescent girls with intellectual disabilities with regards to decision-making about sterilisation in Nigeria. In addition, the findings clarified the appropriateness or inappropriateness of the existing structures in terms of Nigeria's socio-cultural, economic and political realities. More importantly, the interviews engaged participants in a discourse on involuntary sterilisation,

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[39] See appendix 19.

legal capacity and supported decision-making. The interviews were recorded where permitted by the respondents, and subsequently coded and analysed.

6.8. Validity of the instrument

The validity of an instrument refers to the extent to which the instrument is capable of achieving the aim for which it was set or if it measures what it purports to measure.[40] Two experts in the Department of Educational Evaluation and Counselling Psychology, University of Benin, were also consulted to ensure the content and face validity of the instruments.[41] The corrections made by these experts were taken into cognizance in the final drafts of the instruments.

6.9. Reliability of the instrument

Reliability refers to the degree of consistency or stability of the measures obtained from the instruments of a study.[42] To ensure the reliability of the instruments, the questionnaires were pre-tested prior to the collection of data.[43] Accordingly, the questionnaires were administered to thirty people with similar characteristics to the research sample, who were not involved in the research, to determine if the items are comprehensible.

The questionnaire for professionals was administered to ten teachers in a school that has students with intellectual disabilities not used in the research and ten doctors in a teaching hospital not used in the research. The questionnaire for parents was administered to ten parents of adolescent girls with intellectual disabilities in the same school the ten teachers worked.

The major problem identified from the pre-test was that some terms such as 'sterilisation' and 'legal capacity' were very technical, particularly for parents. The problem was resolved by explaining the terms in a leaflet attached to the questionnaire and orally before the administration of the questionnaires.

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[40] See CSL Delport 'Quantitative data-collection methods' in AS de vos et al (eds) *Research at grass roots for the social sciences and human service professionals* (3rd ed) (2005) 160. See also Babbie (n 19 above) 191.

[41] Content validity deals with how representative and adequate an instrument is, while face validity deals with the 'superficial appearance' or 'face value' of the instrument. See Delport (n 40 above) 160-161and Babbie (n 19 above) 191-192.

[42] See Polit & Hungler (n 9 above) 296; Delport (n 40 above) 162-163 and Babbie (n 19 above) 191-192.

[43] Pre-testing involves determining the workability of an instrument by conducting a small-scale trial whereby the instrument is administered to a sample of respondents for the purpose of detecting and resolving problems with the instrument. See CM Varkevisser *Designing and conducting health systems research: Volume 1-proposal development and fieldwork* (1993) 264; TJ Singh and SK Sahu Research methodology (2016) 64.

Similarly, four of the doctors and four of the teachers on whom the questionnaires for professionals were pre-tested were also interviewed to ascertain their willingness to answer certain questions and gain some insight on how to relate with the respondents.

After pre-testing the instruments, they were revised in preparation for the administration of questionnaires and conducting of interviews on the actual respondents used in the research. The scores from the administration of the questionnaires were subjected to Cronbach Alpha and an internal consistency reliability coefficient of 0.79 and 0.80 was obtained for the questionnaires. This means that the questionnaires used in the research were reliable.

6.10. Method of data collection

The data for this research was collected by the researcher with the aid of two research assistants.[44] The data collection process took place from July 2016 to October 2016. The interrogation/communication method was employed to solicit responses from respondents.[45] The research assistants were certified sign language interpreters and were extremely helpful in a few of the selected schools where hearing impaired teachers taught students with intellectual disabilities.

Questionnaires were the primary data collection instruments for the empirical research and semi-structured interviews were secondarily used to garner more information from consultant doctors and headmasters/headmistresses/head-teachers.

The approval and informed consent process took place from October 2015 to July 2016. Only respondents that filled and signed the informed consent forms and expressed willingness to participate in the research were administered questionnaires or interviewed.

The questionnaires were administered to the professionals in the selected schools and hospitals at their workplaces, during work hours and on designated days, by the researcher and research assistants. With regards to parents, the questionnaires were distributed at parent-teacher meetings, school open days or specially arranged meetings. The questionnaires were

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[44] Data collection refers to the detailed and methodical gathering of information germane to a research. See N Burns & SK Grove *The practice of nursing research: Conduct, critique and utilization* (1993) 766.

[45] The interrogation/communication method involves questioning and collection of responses from respondents ‘by personal or impersonal means’ through interviews or questionnaires. See Cooper & Schindler (n 6 above) 135.

administered by states and a date was arranged for collection of the questionnaires by the researcher or research assistants.

Similarly, the interviews were held at the convenience of the respondents and were determined by the states where the respondents were located. They were personally conducted by the researcher at the respondents' work places or at locations chosen by the respondents and at times convenient for the respondents. Before the interviews were conducted, the respondents were informed that their participation was voluntary and that they had the right to withdraw from the interview at any time or to refrain from answering any question. They were also assured that their names and/or the names of their institutions would not be used in the data analysis.

During the interviews, the respondents were questioned about their personal and professional opinions, and their experiences on issues pertaining to the rights of adolescent girls with intellectual disabilities to legal capacity and supported decision-making.

Thirty-one interviews were conducted involving the head teachers/masters/mistresses of the seventeen selected schools and fourteen consultant doctors (six gynaecologists, four paediatricians, two clinical psychologists and two psychiatrists) in the selected hospitals. Although questionnaires had been previously administered to the heads of schools, they were interviewed to get an in-depth perspective from them especially as they dealt with the adolescent girls daily. On the other hand, the doctors that were interviewed had not previously been administered questionnaires because the interviews were more convenient for them. The interviews were conducted in English language and each interview was conducted within 30 to 45 minutes. Audio recorders were primarily used to record the interviews but hand written notes were used to document the interviews of respondents who opted out of being recorded. All but five of the interviews were audio-recorded. The interviews were transcribed and the audio-recordings, notes and transcripts were stored electronically in encrypted files and later submitted to the Centre for Human Rights, University of Pretoria, for secure storage.

6.11. Method of data analysis

The data analysis of the questionnaire was conducted by a statistician at the Department of Educational Evaluation and Counselling Psychology at the University of Benin. Teachers and doctors were termed 'professionals' in the data analysis and the information obtained from them were jointly analysed since they were administered the questionnaire for professionals. On the other hand, the information obtained from parents was analysed separately.

Descriptive statistics such as frequencies and percentages were used to analyse the data obtained from respondents. A summary of the responses as represented in the tables were discussed. Data from the interviews and responses to open-ended questions in the questionnaires were coded and saved electronically. The data were categorised by themes and discussed as participant vignettes to complement the data from the questionnaires. However, for anonymity of the respondents and to protect the confidentiality of the information obtained, the names of the respondents and institutions involved in the research were not used in the analysis of the data obtained. Numbers and pseudonyms were used. Chapter Seven presents a comprehensive discussion on the data analysis.

6.12. Time dimension

Empirical research is either cross-sectional or longitudinal in terms of the time involved in conducting the research. A longitudinal research approach involves the collection of data about a phenomenon repetitively over a period while a cross-sectional research involves the collection of data at a certain point in time.[46] This research was cross-sectional as it involved the collection of data by means of questionnaires and interviews at one time.

6.13. Methodological limitations

Some limitations were experienced by the researcher during the empirical component of this study. One of such limitations was the difficulty in assessing data on the population of respondents (total number of parents, doctors, teachers and other professionals working with adolescents with intellectual disabilities) in southern Nigeria. As this was required to determine the total population of the research, an estimated number obtained mostly from the field was used.

Another limitation was that the empirical study focused on schools and hospitals in southern Nigeria. So, the respondents involved in the research were only from southern Nigeria. Hence, the results obtained from the research cannot be generalised to represent the views of teachers, doctors and parents of adolescent girls with intellectual disabilities in all parts of Nigeria.

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[46] M Struwig & GB Stead *Planning, reporting and designing research* (2001) 40; Babbie (n 19 above) 105; Cooper & Schindler (n 6 above) 136.

Furthermore, only seventeen schools/special education centres providing primary education for students with intellectual disabilities in southern Nigeria were used in the research. The empirical component of the research did not include homes used for solely residential purposes, secondary schools for students with intellectual disabilities or rehabilitation centres. Similarly, only two teaching hospitals were utilised in the research. Hence, the professionals that participated in the empirical research were drawn from only such schools/centres and hospitals. Hence, the results obtained from the empirical research cannot be purported to represent all the perspectives of all professionals in all schools/special education centres for students with intellectual disabilities and all doctors in all hospitals in Nigeria.

Obtaining approvals from the relevant authorities in charge of the public schools visited was also a limitation. Getting approvals took as long as three to four months because of bureaucracy in the relevant ministries and agencies in charge. Strike actions by the teaching hospitals and ministries in the states used in this research also constituted a challenge. During the time of obtaining approvals from the relevant authorities and informed consent from participants for the research, the teaching hospitals in many states in Nigeria were on strike which resulted in delays. Eventually, only two teaching hospitals were used out of the eight teaching hospitals in the states selected.

In conclusion, the respondents were predominantly female (70.0% of the parents and 65.3% of the professionals) and perhaps may not be truly representative of the views of male parents and professionals in southern Nigeria.

6.14. Conclusion

This chapter dealt with the methodology of the empirical component of the research which was exploratory, descriptive and contextual involving a combination of quantitative and qualitative approaches. Questionnaires and semi-structured interviews were utilised as instruments of data collection. The research design, location, population, sample and sampling process, research procedure, instruments, method of data collection, the research instrument were discussed in detail. Consideration was given to ensuring the validity and reliability in the research and steps were taken to ensure that the ethical rights of the respondents were guaranteed. The method of data analysis was also briefly discussed because the results and findings of the research are discussed in Chapter Seven.

CHAPTER SEVEN

DATA ANALYSIS

7.1. Introduction

This chapter analyses the data collected during the empirical component of the study. As stated in Chapter Six, a combination of quantitative and qualitative methods involving the use of questionnaires and semi-structured interviews was used in the study.

Data was primarily collected using two questionnaires titled ‘Questionnaire for Professionals Working with Adolescent Girls with Intellectual Disabilities’[1] and ‘Questionnaire for Parents of Adolescent Girls with Intellectual Disabilities,’ respectively.[2] The first questionnaire was distributed to professionals comprising teachers and other professionals in the selected schools as well as doctors in the selected teaching hospitals. The second questionnaire was distributed to parents of adolescent girls with intellectual disabilities, aged 13-18 years, in the selected schools. The respondents completed the questionnaires and returned them to the researcher or to the research assistants. Descriptive statistics, including frequency tables, bar charts and pie charts, was used to analyse the data obtained from the questionnaires. The analysed data is presented in frequency distribution tables.

Data was also collected through semi-structured interviews of 31 professionals comprising 17 head teachers in the selected schools and 14 consultant doctors in the selected hospitals. The interviews were conducted to get more detailed information on the viewpoints of the respondents who had also been administered questionnaires. Some of the views of respondents garnered from the interviews are presented with pseudonyms in section 7.4.

7.2. The Questionnaire for Professionals

This section discusses the questionnaire titled ‘Questionnaire for Professionals Working with Adolescent Girls with Intellectual Disabilities.’[3] The questionnaire was distributed to respondents in the sample schools and teaching hospitals used in the study. One hundred and sixty-five questionnaires were distributed to the professionals and 144 were returned back to

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[1] See appendix 17.
[2] See appendix 18.
[3] See appendix 17.

researcher indicating a response rate of about 87%, which can be rated as good.[4] The questionnaire contained 20 items and was divided into four sections. It contained questions on personal information, intellectual disability and involuntary sterilisation, the Convention on the Rights of Persons with Disabilities (CRPD), legal capacity and supported decision-making. The meaning of the terms such as 'involuntary sterilisation' and 'legal capacity' were explained to the respondents before the administration of the questionnaires. In total, 144 respondents comprising doctors in the selected hospitals and professionals in the selected schools completed the questionnaires.

The respondents were selected from six states in southern Nigeria namely- Anambra State, Edo State, Ekiti State, Imo State, Lagos State and Rivers State. Twenty (13.9%) respondents were from Anambra State, 44 (30.6%) from Edo State, 35 (24.3%) from Ekiti State, 7 (4.9%) respondents from Imo State, 25 (13.9 %) from Lagos State and 13 (9.0%) from Rivers State. This is illustrated in table 7.1 below.

STATES	**FREQUENCY**	**PERCENTAGE**	**VALID PERCENTAGE**	**CUMULATIVE PERCENTAGE**
Anambra State	20	13.9	13.9	13.9
Edo State	44	30.6	30.6	44.5
Ekiti State	35	24.3	24.3	68.8
Lagos State	25	17.4	17.4	86.2
Imo State	7	4.9	4.9	91.1
Rivers State	13	9.0	9.0	100
Total	144	100	100	

Table 7.1: Distribution of professionals according to states

7.2.1. Section A: Personal information

Section A of the questionnaire gathered the biographical data of the respondents such as their gender, marital status, age range, educational qualifications, occupation and employment.

7.2.1.1. Question 1: Gender

Fifty (34.7%) of the respondents were male and 94 (65.3%) of the respondents were female. This is illustrated in table 7.2 below.

7.2.1.2. Question 2: Marital status

Forty-eight (33.3%) respondents were single, 95 (66.0%) were married and one (0.7%) was widowed. This is illustrated in table 7.2 below.

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[4] GK Huysamen *Methodology for the social and behavioural sciences* (1994) 149-150; 'Response rates' https://facultyinnovate.utexas.edu>files (accessed 15 October 2016).

PERSONAL INFORMATION	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Gender				
Male	50	34.7	34.7	34.7
Female	94	65.3	65.3	100.0
Total	144	100.0	100.0	
Marital Status				
Single	48	33.3	33.3	33.3
Married	95	66.0	66.0	99.3
Widowed	1	0.7	0.7	100.0
Total	144	100.0	100.0	
Age Range				
18-25	8	5.6	5.6	5.6
26-25	58	40.3	40.3	45.9
36-35	52	36.1	36.1	82.1
46-45	21	14.6	14.6	96.6
56-64	5	3.5	3.5	100
Total	144	100	100	
Educational Qualification				
SSCE	5	3.5	3.5	3.5
OND	1	0.7	0.7	4.2
HND	2	2.1	2.1	6.3
NCE	34	23.6	23.6	29.9
NRN	2	1.4	1.4	31.3
First degree	91	61.8	61.8	93.1
Masters	10	6.9	6.9	100.0
Total	144	100	100	
Occupation				
Teaching	71	49.3	49.3	49.3
Vocational Training	5	3.5	3.5	52.8
Speech Therapy	2	1.4	1.4	54.2
Nursing	2	1.4	1.4	55.6
Occupational Therapy	1	0.7	0.7	56.3
Physiotherapy	1	0.7	0.7	57
Physiatrist	1	0.7	0.7	57.7
Paediatrics	34	23.6	23.6	81.3
Gynaecology	14	9.7	9.7	91
Clinical Psychology	8	5.6	5.6	96.6
Psychiatry	4	2.7	2.7	99.3
Social Works	1	0.7	0.7	100
Total	144	100	100	
Employment				
Private employment	34	23.6	23.6	23.6
Civil Servant	110	76.4	76.4	100.0
Total	144	100.0	100.0	

Table 7.2: Distribution of professionals according to their socio-demographic background

7.2.1.3. Question 3: Age range

Eight (5.6%) respondents were within the ages of 18-25; 58 (40.3%) within the ages of 26-35; 52 (36.1%) within the ages of 36-45; 21 (14.6%) within ages of 46-55 and five (3.5%) were within the ages of 56-64. This is illustrated in table 7.2 above.

7.2.1.4. Question 4: Educational qualification

Five (3.5%) respondents had the Senior Secondary Certificate (SSCE), one (0.7%) respondent had an Ordinary National Diploma (OND) and three (2.1%) had the Higher National Diploma (HND). Also, 34 (23.6%) respondents had the National Certificate of Education (NCE); two (1.4%) had the Nigerian Registered Nurse Certificate (NRN); 65 (45.1%) had a first degree and ten (6.9%) had Masters Degrees. This is illustrated in table 7.2 above.

7.2.1.5. Question 5: Occupation

Seventy-one (49.3%) respondents were teachers; five (3.5%) were vocational trainers; two (1.4%) were speech therapists; two (1.4%) were nurses, one (0.7%) was an occupational therapist, one (0.7%) was a physiotherapist and one (0.7%) was a physiatrist in the schools. Also, 34 (23.6%) were paediatricians, 14 (9.7%) were gynaecologists, eight (5.6%) were clinical psychologists, four (2.7%) were psychiatrists and one (0.7%) was a social worker in the selected hospitals. This is illustrated in table 7.2 above.

7.2.1.6. Question 6: Employment

Thirty-four (23.6%) respondents were employed by private employers while 110 (76.4%) were civil servants under the employment of the government as illustrated in table 7.2 above.

7.2.2. Section B: Intellectual disability and involuntary sterilisation

This section contained questions on respondents’ formal training as well as their outlook on the causes of intellectual disability and involuntary sterilisation.

7.2.2.1 Question 7: Formal training

FORMAL TRAINING	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
None	54	37.5	37.5	37.5
Medical training	44	30.6	30.6	68.1
Special education	34	23.6	23.6	91.7
Seminars/Short courses	6	4.2	4.2	95.9
Psychological training	4	2.8	2.8	98.6
Counselling	2	1.4	1.4	100
Total	144	100	100	

Table 7.3: Distribution of professionals according to formal training on intellectual disability

Fifty-four (37.5%) respondents had not received any formal training on intellectual disability. Forty-four (30.6%) had medical training, 34 (23.6%) had training in special education, six

(4.2%) had training from seminars or short courses, four (2.1%) had psychological training and two (1.4%) had training in counselling. This is illustrated in table 7.3 above.

7.2.2.2. Question 8: Causes of intellectual disability

CAUSES OF INTELLECTUAL DISABILITY	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Biological Causes				
Valid	97	67.4	100.0	100.0
Missing system	47	32.6		
Total	144	100.0		
Medical Negligence				
Valid	36	25.0	100.0	100.0
Missing system	108	75.0		
Total	144	100.0		
Parental Negligence				
Valid	31	21.5	100.0	100.0
Missing system	113	78.5		
Total	144	100.0		
Illness during Pregnancy				
Valid	54	37.5	100.0	100.0
Missing system	90	62.5		
Total	144	100.0		
Witchcraft				
Valid	11	7.6		
Missing system	133	92.4	100.0	100.0
Total	144	100.0		
Demon Possession				
Valid	3	2.1	100.0	100.0
Missing system	141	97.9		
Total	144	100.0		
Anger of the gods				
Valid	1	0.7	100.0	100.0
Missing system	143	99.3		
Total	144	100.0		
Accident				
Valid	34	23.6	100.0	100.0
Missing system	110	76.4		
Total	144	100.0		
Disease				
Valid	32	22.2	100.0	100.0
Missing system	112	77.8		
Total	144	100.0		
Other Causes				
Drugs during pregnancy	5	3.5	38.5	38.5
Prolonged labour	4	2.8	30.8	69.2
Juju/spiritual causes	3	2.1	23.1	92.3
Food poisoning	1	0.7	7.7	100
Total	13	9.0	100	
Missing system	131	91.0		
Overall Total	**144**	**100**		

Table 7.4: Distribution of professionals according to views on the causes of intellectual disability

Multiple responses were permitted for this question. Respondents were also given the option of indicating other causes that were not listed in the questionnaire. Ninety-seven (67.4%)

respondents attributed the cause of intellectual disability to biological factors, 36 (25.0%) to medical negligence, 31 (21.5%) to parental negligence and 54 (37.5%) to illness during pregnancy. Also, 11(7.6%) respondents attributed the cause of intellectual disability to witchcraft; three (2.1%) to demon possession; one (0.7%) to anger of gods; 34 (23.6%) to accident and 32 (22.2%) to disease. Additionally, five (3.5%) respondents attributed the cause of intellectual disability to the use of drugs during pregnancy; four (2.8%) to prolonged labour during child birth; three (2.1%) to juju[5] or spiritual influences and one (0.7%) to food poisoning. This is illustrated in table 7.4 above.

7.2.2.3. Question 9: Awareness of situations of involuntary sterilisation

Eighty-five (59.0%) respondents indicated that they did not know or had not heard of situations where girls with intellectual disabilities were or had been involuntarily sterilised. On the other hand, 58 (40.3%) respondents affirmed that they knew or had heard of such situations. One person (0.7%) did not select any option. This is illustrated in table7.5 below.

AWARENESS OF STERILISATION	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
No	85	59.0	59.4	59.4
Yes	58	40.3	40.6	100.0
Total	143	99.3	100.0	
Missing System	1	0.7		
Total	144	100.0		

Table 7.5: Distribution of professionals according to awareness of situations of involuntary sterilisation

7.2.2.4. Question 10: Attitude towards involuntary sterilisation

Multiple responses were allowed for this question. The respondents' perception on the question is examined below and illustrated in table 7.6.

Prevention of the birth to children with intellectual disability

One hundred and twenty-five (86.8%) respondents believed that the prevention of adolescent girls with intellectual disabilities giving birth to children with intellectual disability was not a reason to sterilise them while 19 (13.2%) respondents believed that it was reason enough.

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[5] Juju refers to magical power, magical enchantment, spells, charms or objects infused with magical power or enchantment, spells and charms which may be used for positive purposes as well as for evil purposes. See I Cbanga 'Juju magic' *Encyclopaedia Britannica* (2017) https://www.britannica.com/topic/juju-magic (accessed 22 August 2017); P Iroegbu 'Juju medicine: Reality and meaning in Igbo and Nigerian political culture' http://chatafrik.com/articles/nigerian-affairs/juju-medicine-reality-and-meaning-in-igbo-and-nigerian-political-culture#.WfWdcPlSzIX (accessed 22 August 2017); 'What is juju' http://msongo.blogspot.com.ng/2013/06/what-is-juju.html (accessed 22 August 2017).

Financial incapability of the parents

One hundred and sixteen (80.6%) respondents believed that the financial incapability of parents is no reason to sterilise girls with intellectual disabilities while 28 (19.4%) respondents believed that it is enough reason.

If the girl gets pregnant once

One hundred and nineteen (82.6%) respondents believed that adolescent girls with intellectual disabilities should not be sterilised even if they have got pregnant once while 25 (17.4%) respondents believed that they should be sterilised for that reason.

If the girl gets pregnant twice

One hundred and four (72.2%) respondents believed that adolescent girls with intellectual disabilities should not be sterilised even if they have got pregnant twice before while 40 (27.8%) respondents believed that they should be sterilised after they have got pregnant twice.

If the girl gets pregnant three times and above

Eighty-eight (61.1%) respondents believed that adolescent girls with intellectual disabilities should not be sterilised even if they have got pregnant three times or more. On the other hand, 56 (38.9%) respondents believed that they should be sterilised.

Prevention of sexual abuse

One hundred and thirty-six (94.4%) respondents believed that prevention of sexual abuse is not justification for sterilising adolescent girls with intellectual disabilities while eight (5.6%) believed that it is reason enough.

Prevention of un-cleanliness during menstruation

One hundred and forty-one (97.9%) respondents opined that adolescent girls with intellectual disabilities should not be sterilised to prevent un-cleanliness during menstruation. In contrast, three (2.1%) respondents believed that they should be sterilised to prevent uncleanliness during menstruation.

Avoidance of fears about menstruation/blood

One hundred and forty-one (97.9%) respondents believed that adolescent girls with intellectual disabilities should not be sterilised to avoid their phobias about menstruation or blood. Conversely, three (2.1%) respondents believed that they should be sterilised.

ATTITUDE TOWARDS INVOLUNTARY STERILISATION	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Birth of Children with intellectual disability				
No	125	86.8	86.8	86.8
Yes	19	13.2	13.2	100.0
Total	144	100.0		
Financial incapability			80.6	80.6
No	116	80.6	19.4	100.0
Yes	28	19.4	100.0	
Total	144	100.0		
If the girl gets pregnant once				
No	119	82.6	82.6	82.6
Yes	25	17.4	17.4	100.0
Total	144	100.0	100.0	
If the girl gets pregnant twice				
No	104	72.2	72.2	72.2
Yes	40	27.8	27.8	100.0
Total	144	100.0	100.0	
If the girl gets pregnant thrice or more				
No	88	61.1	61.1	61.1
Yes	56	38.9	38.9	100.0
Total	144	100.0	100.0	
Prevention of sexual abuse				
No	136	94.4	94.4	94.4
Yes	8	5.6	5.6	100.0
Total	144	100.0	100.0	
Uncleanliness during menstruation				
No	141	97.9	97.9	97.9
Yes	3	2.1	2.1	100.0
Total	144	100.0	100.0	
Fears about menstruation/blood				
No	141	97.9	97.9	97.9
Yes	3	2.1	2.1	100.0
Total	144	100.0	100.0	

Table 7.6: Distribution of professionals according to their attitudes towards involuntary sterilisation

7.2.3. Section C: Convention on the Rights of Persons with Disabilities (CRPD)

Section C of the questionnaire contained questions on the Convention on the Rights of Persons with Disabilities (CRPD) and the concept of supported decision-making.

7.2.3.1. Question 11: Awareness of the CRPD

Eighty-one (56.3%) respondents had not heard about the CRPD while 63 (43.8%) had heard about the CRPD. This is illustrated in table 7.12 below.

AWARENESS OF THE CRPD	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
No	81	56.2	56.2	56.2
Yes	63	43.8	43.8	100.0
Total	144	100.0	100.0	

Table 7.7: Distribution of professionals according to their awareness of the CRPD

7.2.3.2. Question 12: Attainment of the information about the CRPD

Twenty-two (15.3%) respondents heard about the CRPD through the media; 20 (13.9%) through the internet; 18 (12.5%) at work and one respondent from friends. Eighty-three (57.6%) respondents did not answer the question as illustrated in table 7.8 below.

INFORMATION ABOUT THE CRPD	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Media	22	15.3	36.1	36.1
Internet	20	13.9	32.8	68.9
Work	18	12.5	29.5	98.4
Friends	1	0.7	1.6	100.0
Total	61	42.4	100.0	
Missing System	83	57.6		
Overall Total	**144**	**100.0**	**100.0**	

Table 7.8: Distribution of professionals according to attainment of information about CRPD

7.2.3.3. Question 13: Awareness of the concept of 'supported decision-making'

One hundred and nineteen (82.6%) respondents had not heard about supported decision-making (SDM) while 25 (17.4%) respondents had heard about it as illustrated in table 7.9.

AWARENESS OF SDM	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
No	119	82.6	82.6	82.6
Yes	25	17.4	17.4	100.0
Total	144	100.0	100.0	

Table 7.9: Distribution of professionals according to their awareness of the concept of SDM

7.2.3.4. Question 14: Understanding of the concept of supported decision-making

The question required respondents to show their knowledge of the concept of supported decision-making by explaining it. Ten respondents (12.5%) had understood the concept while 70 (87.5%) did not. This is illustrated in table 7.10 below.

UNDERSTANDING OF SDM	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Correct	10	12.5	12.5	12.5
Incorrect	70	87.5	87.5	100.0
Total	80	100.0	100.0	

Table 7.10: Distribution of professionals according to their understanding of SDM

7.2.4. Section D: Legal capacity and supported decision-making

Section D contained questions pertaining to legal capacity and supported decision-making of sterilisation of girls with intellectual disabilities. The responses to the questions are examined below.

7.2.4.1. Question 15: Right to make medical decisions

One hundred and twenty-five (86.8%) respondents were of the professional opinion that adolescent girls with intellectual disabilities are not entitled to make medical decisions. In contrast, 19 (13.2%) respondents believed that adolescent girls with intellectual disabilities are entitled to make medical decisions. This is illustrated in table 7.11 below.

RIGHT TO MAKE MEDICAL DECISIONS	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
No	125	86.8	86.8	86.8
Yes	19	13.2	13.2	100.0
Total	144	100.0	100.0	

Table 7.11: Distribution of professionals according to their opinions on the right of adolescent girls with intellectual disabilities to make medical decisions

7.2.4.2. Question 16: Decision maker for adolescent girls with intellectual disabilities

Multiple responses were allowed for this question. One hundred and twenty (83.3%) respondents believed that parents make medical decisions for adolescent girls with intellectual disabilities. Also, 33 (22.9%) respondents believed that guardians make the decisions for them; 4 (2.8%) believed that siblings make medical decisions for them; 9 (6.2%) believed that doctors make medical decisions for them and 13 (9.0%) believed that teachers make medical decisions for them. This is illustrated in table 7.12 below.

MEDICAL DECISION-MAKER	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Parents	120	83.3	100.0	100.0
Missing System	24	16.7		
Total	144	100.0		
Guardians	33	22.9	100.0	100.0
Missing System	111	77.1		
Total	144	100.0		
Siblings	4	2.8	100.0	100.0
Missing System	140	97.2		
Total	144	100.0		
Doctors	9	6.2	100.0	100.0
Missing System	135	93.8		
Total	144	100.0		
Teachers	13	9.0	100.0	100.0
Missing System	131	91.0		
Total	144	100.0		

Table 7.12: Distribution of professionals according to their opinions on who makes medical decisions for adolescent girls with intellectual disabilities

7.2.4.3. Question 17: Legal capacity

In response to this question, respondents were instructed to tick an option indicating that they strongly agree (SA); agree (A); strongly disagree (SD) or disagree (D).

17 (a): Adolescent girls with intellectual disabilities have a right to give birth

Forty-seven (32.6%) respondents strongly agreed that adolescent girls with intellectual disabilities have a right to give birth to children; 78 (54.2%) agreed; six (4.2%) strongly disagreed and 13 (9.0%) disagreed. This is illustrated in table 7.13.1 below.

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	47	32.6	32.6	32.6
A	78	54.2	54.2	86.8
SD	6	4.2	4.2	91.0
D	13	9.0	9.0	100.0
Total	144	100.0	100.0	

Table 7.13.1: Distribution of professionals according to their opinions on whether adolescent girls with intellectual disabilities have a right to give birth

17 (b): Parents should make medical decisions for their daughters

Twenty-one (14.6%) respondents strongly agreed that parents should make medical decisions for their daughters with intellectual disabilities; 78 (54.2%) agreed; ten (6.9%) strongly disagreed; 35 (9.0%) disagreed. This is illustrated in table 7.13.2 below.

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	21	14.6	14.6	14.6
A	78	54.2	54.2	68.8
SD	10	6.9	6.9	75.7
D	35	24.3	24.3	100.0
Total	144	100.0	100.0	

Table 7.13.2: Distribution of professionals according to their opinions on whether parents should make medical decisions for their daughters with intellectual disabilities

17 (c): Parents should make decisions about contraception for their daughters with intellectual disabilities

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	13	9.0	9.0	9.0
A	88	61.1	61.1	70.1
SD	11	7.6	7.6	77.7
D	32	22.2	22.2	100.0
Total	144	100.0	100.0	

Table 7.13.3: Distribution of professionals according to their opinion on whether parents should make decisions about contraception for their daughters with intellectual disabilities

Thirteen (9.0%) respondents strongly agreed that parents should make decisions about contraception for their daughters with intellectual disabilities; 88 (61.1%) agreed; 11 (7.6%) strongly disagreed; and 32 (22.2%) disagreed. This is illustrated in table 7.13.3 above.

17 (d): Parents should make decisions about sterilisation for their daughters with intellectual disabilities

Eleven (7.6%) respondents strongly agreed that parents should make decisions about sterilisation for their daughters with intellectual disabilities; 56 (38.9%) agreed; 37 (25.7%) strongly disagreed and 40 (27.8%) disagreed. This is illustrated in table 7.13.4 below.

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	11	7.6	7.6	7.6
A	56	38.9	38.9	46.5
SD	37	25.7	25.7	72.2
D	40	27.8	27.8	100.0
Total	144	100.0	100.0	

Table 7.13.4: Distribution of professionals according to their opinion on whether parents should make decisions about sterilisation for their daughters with intellectual disabilities

17 (e): Parents should involve, inform and consult their adolescent daughters with intellectual disabilities when making medical decisions for them

Twenty-eight (19.4%) respondents strongly agreed that parents should involve, inform and consult their daughters in medical decision-making; 78 (54.2%) agreed; one (0.7%) strongly disagreed and 37 (25.7%) disagreed. This is illustrated in table 7.13.5 below.

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	28	19.4	19.4	19.4
A	78	54.2	54.2	73.6
SD	1	0.7	0.7	74.3
D	37	25.7	25.7	100.0
Total	144	100.0	100.0	

Table 7.13.5: Distribution of professionals according to their opinion on parents including their adolescent daughters with intellectual disabilities in medical decision-making

17 (f): *Parents should involve, inform and consult their adolescent daughters with intellectual disabilities when making decisions about contraception for them*

Twenty-seven (18.8%) respondents strongly agreed that parents should involve, inform and consult their adolescent daughters with intellectual disabilities in contraceptive decision-making; 88 (56.9%) agreed; three (2.1%) strongly disagreed; and 32 (22.2%) disagreed. This is illustrated in table 7.13.6 below.

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	27	18.8	18.8	18.8
A	82	56.9	56.9	75.7
SD	3	2.1	2.1	77.8
D	32	22.2	22.2	100.0
Total	144	100.0	100.0	

Table 7.13.6: Distribution of professionals according to their opinion on parents including their adolescent daughters with intellectual disabilities in contraceptive decision-making

17 (g): Parents should involve, inform and consult their adolescent daughters with intellectual disabilities when making decisions about sterilisation for them

Twenty-one (14.6%) respondents strongly agreed that parents should involve, inform and consult their daughters with intellectual disabilities in decision-making about sterilisation for them; 79 (54.9%) agreed; 12 (8.3%) strongly disagreed; and 32 (22.2%) disagreed. This is illustrated in table 7.13.7 below.

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	21	14.6	14.6	14.6
A	79	54.9	54.9	69.5
SD	12	8.3	8.3	77.8
D	32	22.2	22.2	100.0
Total	144	100.0	100.0	

Table 7.13.7: Distribution of professionals according to their opinion on parents including their adolescent daughters with intellectual disabilities in decision-making about sterilisation

7.2.4.4. Question 18: Intellectual disability, legal capacity and supported decision-making

Multiple responses were allowed for this question. Respondents' opinions on the question are examined below.

18 (a): Adolescent girls with intellectual disabilities should be given the opportunity to give birth to children

One hundred and fourteen (79.2%) respondents believed that adolescent girls with intellectual disabilities who require intermittent support should be accorded the opportunity to give birth to children. Fifteen (10.5%) respondents believed that those with intellectual disabilities with limited support needs should be given the opportunity. Two (1.4%) respondents believed that those with intellectual disabilities with extensive support needs should be given the opportunity and one respondent (0.7%) believed that those with intellectual disabilities with pervasive support needs should be given the opportunity. However, 12 (8.3%) respondents believed that no adolescent girls with intellectual disability should be given the opportunity to give birth to children. This is illustrated in table 7.14.1 below.

LEVEL OF SEVERITY	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Mild	114	79.2	79.2	79.2
Moderate	15	10.4	10.4	89.6
Severe	2	1.4	1.4	91.0
Profound	1	0.7	0.7	91.7
Not at all	12	8.3	8.3	100.0
Total	144	100.0	100.0	

Table 7.14.1: Distribution of professionals according to their beliefs on whether the level of disability should affect adolescent girls with intellectual disabilities opportunity to give birth to children

18 (b): Adolescent girls with intellectual disabilities have the capacity to make medical decisions on their own

Ninety-one (63.2%) respondents believed that adolescent girls with intellectual disabilities who require intermittent support possess the capacity to make medical decisions on their own while seven (4.9%) believed that those with intellectual disabilities with limited support needs have the capacity to do so. Forty six (31.9%) respondents believed that no adolescent girl with intellectual disability can make medical decisions on their own while none of the respondents believed that those who require extensive and pervasive support can do so. This is illustrated in table 7.14.2 above.

LEVEL OF SEVERITY	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Mild	91	63.2	63.2	63.2
Moderate	7	4.9	4.9	68.1
Not at all	46	31.9	31.9	100.0
Total	144	100.0	100.0	

Table 7.14.2: Distribution of professionals according to their beliefs on whether the level of disability affects adolescent girls with intellectual disabilities capacity to make medical decisions on their own

18 (c): Adolescent girls with intellectual disabilities have the capacity to make medical decisions if they are given appropriate support

Ninety-nine (68.8%) respondents believed that adolescent girls with intellectual disabilities who require intermittent support have the aptitude to make medical decisions with appropriate support while 20 (13.9%) believed that those with limited support needs have the capacity. One (0.7%) respondent believed that adolescent girls with intellectual disabilities who require extensive support have the capacity to make medical decisions with appropriate support. Conversely, 24 (16.7%) respondents believed that no adolescent girl with intellectual disability can make medical decisions even with appropriate support. No respondent believed that adolescent girls with intellectual disabilities who require pervasive support can make medical decisions even if they are given appropriate support. This is illustrated in table 7.14.3 below.

LEVEL OF SEVERITY	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Mild	99	68.8	68.8	68.8
Moderate	20	13.9	13.9	82.6
Severe	1	.7	.7	83.3
Not at all	24	16.7	16.7	100.0
Total	144	100.0	100.0	

Table 7.14.3: Distribution of professionals according to their beliefs on whether the level of disability affects adolescent girls with intellectual disabilities can make medical decisions with support

18 (d): Adolescent girls with intellectual disabilities are capable of taking care of their children if they are given appropriate support

One hundred and seventeen (81.3%) respondents believed that adolescent girls with intellectual disabilities who require intermittent support are capable of taking care of their children with appropriate support. Eighteen (12.5%) believed that with appropriate support adolescent girls with intellectual disabilities with limited support needs can take care of their children. Nonetheless, nine (6.3%) respondents believed that adolescent girls with intellectual disabilities, regardless of the degree of their disability, are generally incapable of taking care of children, even with appropriate support. None of the respondents believed that adolescent girls with intellectual disabilities that require extensive and pervasive support have the capability to take care of their children even with appropriate support. This is illustrated in table 7.14.4 above.

LEVEL OF SEVERITY	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Mild	117	81.3	81.3	81.3
Moderate	18	12.5	12.5	93.8
Not at all	9	6.3	6.3	100.0
Total	144	100.0	100.0	

Table 7.14.4: Distribution of professionals according to their beliefs on whether the level of disability affects capability of adolescent girls with intellectual disabilities to take care of their children

18 (e): Adolescent girls with intellectual disabilities can make decisions about contraception if they are given appropriate support

One hundred and five (72.9%) respondents believed that adolescent girls with intellectual disabilities who require intermittent support can make decisions about contraception with appropriate support while 13 (9.0%) believed that those with limited support needs can. One (0.7%) respondent believed that adolescent girls with intellectual disabilities with extensive support needs can make decisions about contraception with appropriate support. In contrast, 25 (17.4%) respondents believed that adolescent girls with intellectual disabilities cannot make decisions about contraception even with appropriate support. No respondent believed that adolescent girls with intellectual disabilities who require pervasive support can make decisions about contraception even with appropriate support. This is illustrated in table 7.14.5 below.

LEVEL OF SEVERITY	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Mild	105	72.9	72.9	72.9
Moderate	13	9.0	9.0	81.9
Severe	1	0.7	0.7	82.6
Not at all	25	17.4	17.4	100.0
Total	144	100.0	100.0	

Table 7.14.5: Distribution of professionals according to their beliefs on whether the level of disability affects the contraceptive decision making of adolescent girls with intellectual disabilities

18 (f): Adolescent girls with intellectual disabilities can make decisions to undergo sterilisation if they are appropriate given support

Fifty-two (72.9%) respondents believed that adolescent girls with intellectual disabilities with intermittent support needs can make decisions about undergoing sterilisation with appropriate support, while six (4.2%) believed that those with intermittent and limited support needs can. Four (2.8%) respondents believed that adolescent girls with intellectual disabilities who require pervasive support can make such decisions with appropriate support. However, 82 (56.9%) respondents believed that adolescent girls with intellectual disabilities are incapable of making decisions about sterilisation, even with appropriate support. No respondent believed that adolescent girls with intellectual disabilities who require extensive support can make decisions about undergoing sterilisation even with appropriate support. This is illustrated in table 7.14.6 below.

LEVEL OF SEVERITY	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Mild	52	36.1	36.1	36.1
Moderate	6	4.2	4.2	40.3
Profound	4	2.8	2.8	43.1
Not at all	82	56.9	56.9	100.0
Total	144	100.0	100.0	

Table 7.14.6: Distribution of professionals according to their beliefs on the capability of adolescent girls with intellectual disabilities to make decisions about sterilisation with appropriate support

18 (g): Sterilisation is a suitable contraceptive option for adolescent girls with intellectual disabilities

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Mild	1	0.7	0.7	0.7
Severe	7	4.9	4.9	5.6
Profound	12	8.3	8.3	13.9
Not at all	124	86.1	86.1	100.0
Total	144	100.0	100.0	

Table 7.14.7: Distribution of professionals according to their beliefs that sterilisation is a suitable contraceptive option for adolescent girls with intellectual disabilities

One respondent (0.7%) believed sterilisation is suitable for girls with intellectual disabilities with intermittent support needs; seven (4.9%) believed it is suitable for girls with intellectual disabilities who require extensive support and 12 (8.3%) believed it is suitable those with pervasive support needs. However, 124 (86.1%) respondents believed that sterilisation is not suitable for adolescent girls with intellectual disabilities, regardless of the level of disability. No respondent believed that sterilisation is a suitable contraceptive option for adolescent girls with intellectual disabilities that require limited support. This is illustrated in table 7.14.7 above.

7.2.4.5. *Question 19: Attitude towards support in contraceptive decision-making for adolescent girls with intellectual disabilities*

Thirty-eight (26.4%) respondents believed that even with age-appropriate support, adolescent girls with intellectual disabilities are incapable of making decisions about contraception, while 106 (73.6%) respondents believed they can. This is illustrated in table 7.15 below.

CONTRACEPTIVE DECISION MAKING	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
No	38	26.4	26.4	26.4
Yes	106	73.6	73.6	100.0
Total	144	100.0	100.0	

Table 7.15: Distribution of professionals according to their beliefs on support in contraceptive decision-making for adolescent girls with intellectual disabilities

7.3. The Questionnaire for Parents

This section discusses the questionnaire titled ‘Questionnaire for Parents of Adolescent Girls with Intellectual Disabilities.’ One hundred and fifteen questionnaires were distributed to parents of adolescent girls with intellectual disabilities attending the selected schools and 80 questionnaires were returned to the researcher. This indicates a response rate of about 70%, which can be regarded as acceptable.[6] They were selected from six states in southern Nigeria namely- Anambra State, Edo State, Ekiti State, Imo State, Lagos State and Rivers State. Eleven (13.8%) respondents were from Anambra State; 13 (16.3%) from Edo State; eight (10.1%) from Ekiti State; seven (8.8%) from Imo State; 32 (40.0%) from Lagos State and nine (11.3%) from Rivers State. The distribution of respondents according to states is illustrated in table 7.16 below.

STATES	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Anambra State	11	13.8	13.8	13.8
Edo State	13	16.3	16.3	30.1
Ekiti State	8	10.0	10.0	40.1
Imo State	7	8.8	8.8	48.9
Lagos State	32	40.0	40.0	88.9
Rivers State	9	11.3	11.3	100
Total	80	100	100	

Table 7.16: Distribution of parents according to states

7.3.1. Section A: Personal Information

Section A of the questionnaire garnered the biographical data of the respondents such as their gender, marital status, age range, educational qualification and occupation. Their responses are illustrated in table 7.17 below.

7.3.1.1. Question 1: Gender

Twenty-four (30.0%) respondents were male while 56 (70.0%) respondents were female.

7.3.1.2. Question 2: Marital Status

Five (6.3%) respondents were single, 64 (80.0%) were married, two (2.5%) were widowed and nine (11.3%) were divorced.

7.3.1.3. Question 3: Age range

One (1.3%) respondent was within ages 18-25; eleven (13.8%) were within ages 26-35; 20 (25.0%) were within ages 36-45; 32 (40.0%) within ages 46-55; 12 (15.0%) were within ages 56-64; and four (5.0%) were 65 years and above.

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[6] A Fink *How to sample in surveys* (2nd ed) (2003) 54; DM Mertens *Research and evaluation in education and psychology- integrating diversity with quantitative, qualitative and mixed methods* (3rd ed) (2009) 182.

PERSONAL INFORMATION	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Gender				
Male	24	30	30	30
Female	56	70	70	100.0
Total	80	100.0	100.0	
Marital Status				
Single	5	6.3	6.3	6.3
Married	64	80.0	80.0	86.3
Widowed	2	2.5	2.5	88.8
Divorced	9	11.3	11.3	100.0
Total	80	100.0	100.0	
Age Range				
18-25	1	1.3	1.3	1.3
26-25	11	13.8	13.8	15.0
36-35	20	25.0	25.0	40.0
46-45	32	40.0	40.0	80.0
56-64	12	15.0	15.0	95.0
65 and above	5	5.0	5.0	100
Total	80	100	100	100.0
Educational Qualification				
No formal education	4	5.0	5.0	5.0
SSCE	23	28.8	28.8	33.8
OND	4	5.0	5.0	38.8
HND	6	7.5	7.5	46.3
NCE	2	2.5	2.5	48.8
NRN	5	6.3	6.3	55.1
First degree	29	36.3	36.3	91.4
Masters	7	8.8	8.8	100
Total	80	100	100	
Occupation				
Unemployed	6	7.5	7.5	7.5
Business	21	26.3	26.3	33.8
Artisans	8	10.0	10.0	43.8
Civil service	31	38.8	38.8	73.8
Public service	11	13.8	13.8	82.6
Farming	2	2.5	2.5	98.8
Clergy	1	1.3	1.3	100
Total	80	100	100	
Age of Child				
13 years old	19	23.8	23.8	23.8
14 years old	11	13.8	13.8	37.6
15 years old	19	23.8	23.8	61.4
16 years old	11	13.8	13.8	75.1
17 years old	11	13.8	13.8	88.9
18 years old	9	11.3	11.3	100
Total	80	100	100	

Table 7.17: Distribution of professionals according to their socio-demographic background

7.3.1.4. **Question 4: Educational Qualification**

Four (5.0%) respondents had no formal education; twenty-three (28.8%) had the senior secondary certificate (SSCE); four (5.0%) had the Ordinary National Diploma (OND) and six (7.5%) had the Higher National Diploma (HND). Also, two (2.5%) respondents had the National Certificate of Education (NCE); five (6.3%) had the Nigerian Registered Nurse

Certificate (NRN); twenty-nine (36.3%) had a first degree and seven (8.8%) had a Masters' Degree.

7.3.1.5. Question 5: Occupation

Six (7.5%) respondents were unemployed; 21 (26.3%) were business persons; eight (10.0%) were artisans; 31(38.8%) were civil servants; eleven (13.8%) were public servants; two (2.5%) were farmers and one (1.3%) was a clergy man.

7.3.*1.6.* *Question 6: Age of child*

Nineteen (23.8%) respondents' daughters were 13 years old and 11 (13.8%) respondents' daughters were 14 years old. Nineteen (23.8%) respondents' daughters were 15 years old; 11 (13.8%) respondents' daughters were 16 years old; 11 (13.8%) respondents' daughters were 17 years old and nine (11.3%) respondents' daughters were 18 years old.

7.3.2. Section B: Intellectual disability and involuntary sterilisation

Section B of the questionnaire contained questions to elicit respondents' opinions on the level of disability of their daughters, the causes of intellectual disability as well as their outlook on the involuntary sterilisation of adolescent girls with intellectual disabilities.

7.3.2.1 Question 7: Level of disability of Child

Thirty-three (41.3%) respondents opined that their child's disability was minor; 22 (27.5%) believed that their child's disability was not serious; 18 (22.5%) held the view that their child's disability was serious; and seven (8.8%) opined that their child's disability was very serious. This is illustrated in table 7.18 below. As explained to the respondents, minor means the child requires intermittent support; not serious means the child requires intermittent support; serious means the child requires extensive support; and very serious means the child requires pervasive support.

LEVEL OF DISABILITY	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Minor	33	41.3	41.3	41.3
Not serious	22	27.5	27.5	68.8
Serious	18	22.5	22.5	91.3
Very serious	7	8.8	8.8	100.0
Total	80	100.0	100.0	

Table 7.18: Distribution of parents according to their opinion on their child's level of disability

7.3.2.2. Question 8: Causes of intellectual disability

CAUSES OF INTELLECTUAL DISABILITY	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Biological Causes				
Valid	23	28.8	100.0	100.0
Missing system	57	71.3		
Total	80	100.0		
Medical Negligence				
Valid	21	26.3	100.0	100.0
Missing system	59	73.7		
Total	80	100.0		
Parental Negligence				
Valid	7	8.8	100.0	100.0
Missing system	73	91.3		
Total	80	100.0		
Illness during Pregnancy				
Valid	24	30.0	100.0	100.0
Missing system	56	70.0		
Total	80	100.0		
Witchcraft				
Valid	13	16.3	100.0	100.0
Missing system	67	83.8		
Total	80	100.0		
Demon Possession				
Valid	1	1.3	100.0	100.0
Missing system	79	98.8		
Total	80	100.0		
Accident				
Valid	5	6.3	100.0	100.0
Missing system	75	93.8		
Total	80	100.0		
Disease				
Valid	5	6.3	100.0	100.0
Missing system	75	93.8		
Total	80	100.0		
Other Causes				
Juju/spiritual causes	5	6.3	50.0	50.0
Divine design/intervention	3	3.8	30.0	30.0
Food poisoning	1	1.3	10.0	90.00
No Idea	1	1.3	10.0	100.0
Total	10	12.5	100.0	
Missing System	70	87.5		
Overall Total	**80**	**100.0**		

Table 7.19: Distribution of parents according to causes of intellectual disability

Multiple responses were permitted in response to this question. Respondents were also given the option of indicating other causes that were not listed in the questionnaire. Twenty-three (28.8%) respondents attributed the cause of intellectual disability to biological causes; 21 (26.3%) to medical negligence; seven (8.8%) to parental negligence; and 24 (30.0%) to illness during pregnancy. Also, 13 (16.3%) respondents attributed the cause of intellectual disability to witchcraft; one (1.3%) to demon possession; five (6.3%) to accidents; and five (6.3%) to disease. Furthermore, five (6.3%) respondents attributed the cause of intellectual disability to juju[7] or spiritual influences; three (3.8%) to divine design/intervention’ and one (1.3%) to food poisoning. One (1.3%) respondent had no idea about what causes intellectual disability. This is illustrated in table 7.19 above.

7.3.2.3. Question 9: Awareness of situations of involuntary sterilisation

Fifty (62.5%) respondents had not heard of situations where girls with intellectual disabilities had been involuntarily sterilised while 29 (36.3%) knew or had heard of such situations. One respondent (0.7%) did not select any option. This is illustrated in table 7.20 above.

INVOLUNTARY STERILISATION	**FREQUENCY**	**PERCENTAGE**	**VALID PERCENTAGE**	**CUMULATIVE PERCENTAGE**
No	50	62.5	63.3	63.3
Yes	29	36.3	36.7	100
Total	79	98.8	100	
Missing System	1	1.3		
Total	80	100		

Table 7.20: Distribution of parents according to awareness of situations of involuntary sterilisation

7.3.2.4. Question 10: Attitude towards involuntary sterilisation

This question required respondents to select yes or no options from a range of reasons indicative of their beliefs on involuntary sterilisation of girls with intellectual disability. Their responses are illustrated in table 7.21 below.

Prevention of the birth to children with intellectual disability

Sixty-nine (86.3%) respondents believed involuntary sterilisation of adolescent girls to prevent them from giving birth to children with intellectual disability is not justifiable while 11 (13.8%) respondents believed that it is justifiable.

Financial incapability of the parents

Fifty-six (70.0%) respondents believed financial incapability of parents is not a good reason to sterilise adolescent with intellectual disabilities while 24 (30.0%) believed it is a good reason.

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[7] Cbanga (n 5 above); Iroegbu (n 5 above); ‘What is juju’ (n 5 above).

ATTITUDE TOWARDS INVOLUNTARY STERILISATION	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
Birth of Children with intellectual disability				
No	69	86.3	86.3	86.3
Yes	11	13.8	13.8	100.0
Total	80	100.0		
Financial incapability				
No	56	70.0	70.0	70.0
Yes	24	30.0	30.0	100.0
Total	80	100.0	100.0	
If the girl gets pregnant once				
No	65	81.3	81.3	81.3
Yes	15	18.8	18.8	100
Total	80	100.0	100.0	
If the girl gets pregnant twice				
No	62	77.5	77.5	77.5
Yes	18	22.5	22.5	100.0
Total	80	100.0	100.0	
If the girl gets pregnant thrice or more				
No	55	68.8	68.8	68.8
Yes	25	31.3	31.3	100.0
Total	80	100.0	100.0	
Prevention of sexual abuse				
No	70	87.5	87.5	87.5
Yes	10	12.5	12.5	100.0
Total	80	100.0	100.0	
Uncleanliness during menstruation				
No	71	88.8	88.8	88.8
Yes	9	11.3	11.3	100.0
Total	80	100.0	100.0	
Fears about menstruation/blood				
No	73	91.3	91.3	91.3
Yes	7	8.8	8.8	100.0
Total	80	100.0	100.0	

Table 7.21: Distribution of parents according to their attitudes towards involuntary sterilisation

If the girl gets pregnant once

Sixty-five (81.3%) respondents believed that adolescent girls should not be sterilised to prevent them from giving birth to children after they have got pregnant once while 15 (18.8%) believed that that they should be sterilised after they have got pregnant once.

If the girl gets pregnant twice

Sixty-two (77.5%) respondents believed that adolescent girls with intellectual disabilities should not be sterilised even if they have got pregnant twice while 18 (22.5%) respondents believed that they should be sterilised.

If the girl gets pregnant three times and above

Fifty-five (68.8%) respondents believed that adolescent girls should not be sterilised to prevent them from giving birth to children after they have got pregnant three times or more. Twenty-five (31.3%) respondents believed that they should be sterilised after they have got pregnant three times or more.

Prevention of sexual abuse

Seventy (87.5%) respondents believed that prevention of sexual abuse is no reason to sterilise adolescent girls with intellectual disabilities while ten (12.5%) believed that it is reason enough.

Prevention of un-cleanliness during menstruation

Seventy-one (88.8%) of the respondents believed that un-cleanliness during menstruation is not a good reason to sterilise adolescent girls with intellectual disabilities while nine (2.1%) respondents believed that it is reason enough.

Avoidance of fears about menstruation/blood

Seventy-three (91.3%) respondents believed that adolescent girls with intellectual disabilities should not be sterilised to avoid their fears about menstruation or blood while seven (8.8%) respondents believed that they should be sterilised.

7.3.3. Section C: Convention on the Rights of Persons with Disabilities (CRPD)

Section C of the questionnaire contained questions on the Convention on the Rights of Persons with Disabilities (CRPD) and the concept of supported decision-making.

7.3.3.1. Question 11: Awareness of the CRPD

Seventy (87.5%) of the respondents had not heard about the CRPD while ten (12.5%) of the respondents had heard about the CRPD. This is illustrated in table 7.22 below.

AWARENESS OF THE CRPD	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
No	70	87.5	87.5	87.5
Yes	10	12.5	12.5	100.0
Total	80	100.0	100.0	

Table 7.22: Distribution of parents according to awareness of the CRPD

7.3.3.2. Question 12: Attainment of the information about the CRPD

Nine (11.3%) respondents heard about the CRPD through the media while one (1.3%) heard about it from the internet. Seventy (87.5%) respondents did not answer the question. This is illustrated in table 7.23 below.

INFORMATION ABOUT THE CRPD	**FREQUENCY**	**PERCENTAGE**	**VALID PERCENTAGE**	**CUMULATIVE PERCENTAGE**
Media	9	11.3	90.0	90.0
Internet	1	1.3	10.0	100.0
Total	10	12.5	100.0	
Missing System	70	87.5		
Overall Total	**80**	**100.0**		

Table 7.23: Distribution of parents according to attainment of information about CRPD

7.3.3.3. Question 13: Awareness of the concept of 'supported decision-making'

Seventy-seven (96.3%) respondents had not heard about supported decision-making (SDM) while three (3.8%) respondents had heard about it. This is illustrated in table 7.24 below.

AWARENESS OF SDM	**FREQUENCY**	**PERCENTAGE**	**VALID PERCENTAGE**	**CUMULATIVE PERCENTAGE**
No	77	96.3	96.3	96.3
Yes	3	3.8	3.8	100.0
Total	80	100.0	100.0	

Table 7.24: Distribution of parents according to awareness of the concept of SDM

7.3.3.4. Question 14: Understanding of the concept of supported decision-making

Two (2.5%) respondents had knowledge of the concept of supported decision-making while 68(97.5%) did not. This is illustrated in table 7.25 below.

UNDERSTANDING OF SDM	**FREQUENCY**	**PERCENTAGE**	**VALID PERCENTAGE**	**CUMULATIVE PERCENTAGE**
Correct	2	2.5	2.5	12.5
Incorrect	68	97.5	97.5	100.0
Total	80	100.0	100.0	

Table 7.25: Distribution of parents according to their understanding of SDM

7.3.4. Section D: Legal capacity and supported decision-making

This section contained questions to assess parents' perspective on legal capacity and supported decision-making especially in terms of medical decision-making, contraceptive decision-making and sterilisation of their daughters. The questions are examined below.

7.3.4.1. Question 15: Legal Capacity

In response to this question, respondents were instructed to tick an option indicating that they strongly agree (SA); agree (A); strongly disagree (SD) or disagree (D).

15 (a): My daughter has a right to give birth to children

Forty-two (52.5%) respondents strongly agreed that daughters had a right to give birth to children; 30 (37.5%) agreed; three (3.8%) strongly disagreed; and five (6.3%) disagreed. This is illustrated in table 7.26.1 below.

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	42	52.5	52.5	52.5
A	30	37.5	37.5	90.0
SD	3	3.8	3.8	93.8
D	5	6.3	6.3	100
Total	80	100.0	100.0	

Table 7.26.1: Distribution of parents according to their beliefs on their daughters' right to give birth

15(b): My daughter should be given the opportunity to give birth to children

Thirty-seven (46.3%) respondents strongly agreed that their daughters should be given the opportunity to give birth to children; 24 (30.0%) agreed; four (5.0%) strongly disagreed and 15 (18.8%) disagreed. This is illustrated in table 7.26.2 below.

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	37	46.3	46.3	46.3
A	24	30.0	30.0	76.3
SD	4	5.0	5.0	81.3
D	15	18.8	18.8	100
Total	80	100	100	

Table 7.26.2: Distribution of parents according to their opinions that their daughters should be given the opportunity to give birth

15 (c): My daughter has the capacity to make medical decisions on her own

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	7	8.8	8.8	8.8
A	21	26.3	26.3	35.1
SD	5	6.3	6.3	41.4
D	47	58.8	58.8	100
Total	80	100	100	

Table 7.26.3: Distribution of parents according to their opinions that their daughters can make medical decisions on their own

Seven (8.8%) respondents strongly agreed that their daughters had the capacity to make medical decisions on their own; 21 (26.3%) agreed; five (6.3%) strongly disagreed; and 47 (58.8%) disagreed. This is illustrated in table 7.26.3 above.

15 (d): My daughter has the capacity to make medical decisions if she is given appropriate support

Thirteen (16.3%) respondents strongly agreed that their daughters can make medical decisions with appropriate support; 35 (43.8%) agreed; three (3.8%) strongly disagreed; and 29 (36.3%) disagreed. This is illustrated in table 7.26.4 below.

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	13	16.3	16.3	16.3
A	35	43.8	43.8	43.8
SD	3	3.8	3.8	63.9
D	29	36.3	36.3	100
Total	80	100	100	

Table 7.26.4: Distribution of parents according to their opinions that their daughters can make medical decisions with appropriate support

15 (e): My daughter is capable of taking care of her children if she is given appropriate support

Twelve (15.0%) respondents strongly agreed that their daughters can take care of their children; 39 (48.8%) agreed; four (5.0%) strongly disagreed; and 25 (31.3%) disagreed. This is illustrated in table 7.26.5 below.

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	12	15.0	15.0	15.0
A	39	48.8	48.8	63.8
SD	4	5.0	5.0	68.8
D	25	31.3	31.3	100
Total	4	5.0	5.0	

Table 7.26.5: Distribution of parents according to their opinions on whether their daughters are capable of taking care of their children with appropriate support

15 (f): My daughter can make decisions about contraception if she is given appropriate support

Eleven (13.8%) respondents strongly agreed that their daughters can make decisions about contraception with appropriate support; 32 (40.0%) agreed; three (3.8%) strongly disagreed; and 34 (42.5%) disagreed. This is illustrated in table 7.26.6 below.

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	11	13.8	13.8	13.8
A	32	40.0	40.0	53.8
SD	3	3.8	3.8	57.6
D	34	42.5	42.5	100
Total	80	100	100	

Table 7.26.6: Distribution of parents according to their opinions on whether their daughters can make decisions about contraception with appropriate support

15 (g): I should make medical decisions for my daughter

Sixteen (20.0%) respondents strongly agreed that they should make medical decisions for their daughters; 47 (58.8%) agreed; three (3.8%) strongly disagreed; and 14 (17.5%) disagreed. This is illustrated in table 7.26.7 below.

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	16	20.0	20.0	20.0
A	47	58.8	58.8	78.8
SD	3	3.8	3.8	82.6
D	14	17.5	17.5	100
Total	80	100	100	

Table 7.26.7: Distribution of parents according to their opinions on whether they should make medical decisions for their daughters

15 (h): I should make decisions about contraception for my daughter

Thirteen (30.0%) respondents strongly agreed that make decisions about contraception for their daughters; 44 (55.0%) agreed; 12 (15.0%) strongly disagreed; and 11 (13.8%) disagreed. This is illustrated in table 7.26.8 below.

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	13	16.3	16.3	16.3
A	44	55.0	55.0	71.3
SD	12	15.0	15.0	86.3
D	11	13.8	13.8	100
Total	80	100	100	

Table 7.26.8: Distribution of parents according to their opinions on whether they should make decisions about contraception for their daughters

15 (i): I should make decisions about sterilisation for my daughter

Eleven (13.8%) respondents strongly agreed that they should make decisions about sterilisation for their daughters; 27 (33.8%) agreed; 11 (13.8%) strongly disagreed; and 31 (38.8%) disagreed. This is illustrated in table 7.26.9 below.

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	11	13.8	13.8	13.8
A	27	33.8	33.8	47.6
SD	11	13.8	13.8	61.4
D	31	38.8	38.8	100
Total	80	100	100	

Table 7.26.9: Distribution of parents according to their opinions on whether they should make decisions about sterilisation for their daughters

15 (j): I should involve, inform and consult my daughter when making medical decisions for her

Twelve (15.0%) respondents strongly agreed that they should involve, inform and consult their daughters when making medical decisions for them; 45 (56.3%) agreed; three (3.8%) strongly disagreed; and 20 (25.0%) disagreed. This is illustrated in table 7.26.10 below.

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	12	15.0	15.0	15.0
A	45	56.3	56.3	71.3
SD	3	3.8	3.8	75.1
D	20	25.0	25.0	100
Total	80	100	100	

Table 7.26.10: Distribution of parents according to their opinions on whether they involve, inform and consult their daughters when making medical decisions for them

15 (k): I should involve, inform and consult my daughter when making decisions about contraception for her

Twelve (15.0%) respondents strongly agreed that they should involve, inform and consult their daughters in decision-making about contraception; 40 (50.0%) agreed; four (5.0%) strongly disagreed; and 24 (30.0%) disagreed. This is illustrated in table 7.26.11 below.

	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
SA	12	15.0	15.0	15.0
A	40	50.0	50.0	65.0
SD	4	5.0	5.0	70.0
D	24	30.0	30.0	100.0
Total	80	100.0	100.0	

Table 7.26.11: Distribution of parents according to their opinions on whether they involve, inform and consult their daughters when making decisions about contraception for them

15 (l): I should involve, inform and consult my daughter if I make decisions about sterilisation for her

Thirteen (16.3%) respondents strongly agreed that they should involve and consult their daughters in decision-making about sterilisation; 36 (45.0%) agreed; five (6.3%) strongly disagreed; and 26 (32.5%) disagreed. This is illustrated in table 7.26.12 below.

	FREQUENCY	**PERCENTAGE**	**VALID PERCENTAGE**	**CUMULATIVE PERCENTAGE**
SA	13	16.3	16.3	16.3
A	36	45.0	45.0	61.3
SD	5	6.3	6.3	67.6
D	26	32.5	32.5	100
Total	80	100	100	

Table 7.26.12: Distribution of parents according to their opinions on whether they involve, inform and consult their daughters when making decisions about sterilisation for them

15 (m): Sterilisation is a suitable contraceptive option for my daughter

Five (6.3%) respondents strongly agreed that sterilisation is a suitable contraceptive option for their daughters; eight (10.0%) agreed; thirty-two (40.0%) strongly disagreed; and thirty-five (43.8%) disagreed. This is illustrated in table 7.26.13 below.

	FREQUENCY	**PERCENTAGE**	**VALID PERCENTAGE**	**CUMULATIVE PERCENTAGE**
SA	5	6.3	6.3	6.3
A	8	10.0	10.0	16.3
SD	32	40.0	40.0	56.3
D	35	43.8	43.8	100
Total	80	100	100	

Table 7.26.13: Distribution of parents according to their opinions on whether sterilisation is a suitable contraceptive option for their daughters

7.3.4.2. Question 16: Attitude towards support in contraceptive decision-making for adolescent girls with intellectual disabilities

Forty-eight (60.0%) respondents believed that even with age-appropriate support, adolescent girls with intellectual disabilities are incapable of making decisions about contraception. Conversely, 32 (40.0%) respondents believed that they are capable. This is illustrated in table 7.27 below.

CONTRACEPTIVE DECISION MAKING	FREQUENCY	PERCENTAGE	VALID PERCENTAGE	CUMULATIVE PERCENTAGE
No	48	60.0	60.0	60.0
Yes	32	40.0	40.0	100.0
Total	80	100.0	100.0	

Table 7.27: Distribution of parents according to their beliefs on support in contraceptive decision-making for adolescent girls with intellectual disabilities

7.4. Discussion of findings

The findings discussed below are based on four themes derived from the research questions of the study and the empirical research**.** The themes are causes of intellectual disability; attitude of parents and professionals towards involuntary sterilisation; attitude of parents and professionals towards legal capacity and supported decision-making; and viability of supported decision-making for adolescent girls with intellectual disabilities in contraception.

7.4.1. Causes of intellectual disability

Cultural and social factors underpin how intellectual disability is construed and persons with intellectual disabilities are treated in society. Studies by Abasiubong et al,[8] Atilola et al[9] and Chukwu and Onyeneho[10] show that intellectual disability was largely attributed to cultural and religious beliefs, such as witchcraft, diabolic powers, evil spirits, punishment for violating taboos and curse from gods. In contrast, this study found that most respondents attributed the cause of intellectual disability to medical and biological (natural) factors. Indeed, 65.2% respondents attributed the cause of intellectual disability to medical factors such as illness during pregnancy, medical negligence, disease, use of drugs during pregnancy and prolonged labour.[11] Similarly, 48.1% of the respondents attributed intellectual disability to biological factors.[12] Sixty-seven per cent (67.7%) of the interviewed respondents also attributed the cause of intellectual disability to biological and medical factors. In contrast, 20.1% respondents attributed the cause of intellectual disability to cultural and/or religious factors such as witchcraft, demon possession, juju, divine design/intervention and anger of gods. These findings are like those of Ishola-Esan who found that majority of the respondents in his study attributed the cause of disability, which included intellectual disability, to

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[8] F Abasiubong et al ‘The Opinions and attitudes of mothers to mental retardation in Lagos, Nigeria’ (2008) 6 *Nigerian Journal of Psychiatry* 80.

[9] O Atilola et al ‘Neurological and intellectual disabilities among adolescents within a custodial institution in south-west Nigeria’ (2014) 21 *Journal of Psychiatric and Mental Health Nursing* 31, 35.

[10] NE Chukwu & NG Onyeneho ‘Sociocultural factors associated with abuse of mentally impaired persons in Imo State, Nigeria’ (2015) *International Quarterly of Community Health Education* 35(4) 349, 362.

[11] See tables 7.4 and 7.19.

[12] See tables 7.4 and 7.19.

disease, sickness and infection; accidents; issues at conception; issues at birth; and malnutrition.[13]

The attribution of biological and medical factors to intellectual disability by respondents in this study could be because of trainings, advocacy and educative meetings for parents and teachers which are conducted by schools or even their personal experiences in dealing with persons with intellectual disabilities. In fact, 90 professionals indicated that they had formal training on intellectual disability ranging from medical training, special education to counselling and psychological training.[14] The findings could also imply an inclination towards a positive outlook towards intellectual disability at least by parents and professionals dealing with children with intellectual disabilities. As discussed in Chapter One, this study is partly anchored on the critical theory of Foucault. Foucault was interested in how certain discourses are produced rather than others in a society and according to him, the production of discourse is “controlled” and “reorganised” by certain processes.[15] These findings illustrate how advocacy and institutional (schools and hospitals) discourses have controlled and reorganised the discourse on intellectual disability from the belief in the spiritual causes of intellectual disability to biological and medical factors as the causes of intellectual disability. Foucault also argued that when institutional discourses overlap, new forms of knowledge are created.[16] These findings illustrate this creation of new forms of knowledge about the causes of intellectual disability because of intersection of discourses between parents (familial institution) and professionals (medical and educational institutions).

7.4.2. Attitude of parents and professionals towards involuntary sterilisation

Attitudes are an intricate pool of values and dispositions which reflects people’s thoughts about certain issues.[17] The social model of disability underlines the disabling environments, along with other factors, including attitudinal barriers that disable persons with disabilities.[18]

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[13] HO Ishola-Esan ‘Impact of the remnants of African worldviews on perception of pastors towards ministering to persons with disabilities in Nigeria’ (2016) 20 *Journal of Disability and Religion* 103, 108.
[14] See table 7.3 above.
[15] M Foucault ‘The order of discourse’ in R. Young (ed) *Untying the Text: A post-structuralist reader* (1981) 52.
[16] E McSherry ‘A Foucauldian discourse analysis of intellectual disability in Irish education’ unpublished PhD thesis, University of Limerick, 2013 84.
[17] H Aiden & A McCarthy ‘Current attitudes towards disabled people’ https://www.scope.org.uk/Scope/media/Images/Publication%20Directory/Current-attitudes-towards-disabled-people.pdf?ext=.pdf (accessed 22 June 2017).
[18] Union of the Physically Impaired against Segregation (UPIAS) ‘Aims and policy statement’ http://disability-studies.leeds.ac.uk/files/library/UPIAS-UPIAS.pdf (accessed 29 April 2015); H Hahn ‘Public support for rehabilitation in programs: The analysis of US disability policy’ (1986) 1 *Disability, Handicap and Society* 121,128; J Morris *Pride against prejudice: Transforming attitudes to disability’* (1991) 1-3.

Accordingly, respondents' attitudes towards involuntary sterilisation of adolescent girls with intellectual disabilities were elicited based on grounds drawn from the literature on the issue. Financial incapability and prevention of pregnancy were the most selected reasons. Fifty-two respondents (28 professionals and 24 parents) believed that the sterilisation of adolescent girls with intellectual disabilities was justifiable on grounds of financial incapability.[19] With regards to the prevention of pregnancy, 40 respondents (25 professionals and 15 parents) were of the view that sterilisation is justifiable if a girl with intellectual disability gets pregnant once. Likewise, 58 respondents (40 professionals and 18 parents) believed that sterilisation was justified if a girl gets pregnant twice while 81 (56 professionals and 25 parents) believed that it was justifiable if the girl gets pregnant thrice or more. Additionally, 30 respondents (19 Professionals and 11 parents) believed that sterilising adolescent girls with intellectual disabilities to prevent them from giving birth to children with intellectual disability was also justifiable. These findings are in line with the views of Dowse,[20] Elliot,[21] Frohmader,[22] and Stern[23] highlighted in this study to the effect that sterilisation is often sought amongst other things on grounds of prevention of pregnancy and financial limitations.[24]

The inclusion of the number of pregnancies as a determinant was to ascertain whether the frequency or number of pregnancies would affect respondents' views on the decision to sterilise or not. It can be inferred that the number of times a girl with intellectual disability gets pregnant could affect whether she should be sterilised or not. This is linked to the issue of financial burden of caring for a child with intellectual disability or the child's offspring highlighted in this study and the lack of support services which can result in the decision to sterilise.[25] This buttresses the need for government to provide effective support to children with intellectual disabilities and their families.

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[19] See tables 7.6 and 7.21 above.

[20] L Dowse 'Moving forward or losing ground? The sterilisation of women and girls with disabilities in Australia' http://wwda.org.au/issues/sterilise/sterilise2001/steril3/ (accessed 8 October 2016);

[21] L Elliott 'Victims of violence: The forced sterilisation of women and girls with disabilities in Australia' (2017) 6 *Laws*, 8; doi:10.3390/laws6030008.

[22] C Frohmader 'Dehumanised: the forced sterilisation of women and girls with disabilities in Australia' WWDA Submission to the Senate Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia (2013) 36 http://wwda.org.au/wp-content/uploads/2013/12/WWDA_Sterilisation_Sub_Summary_and_Recs.pdf (accessed 14 February 2014).

[23] AM Stern 'Sterilized in the name of public health race, immigration, and reproductive control in modern California' (2005) 95 *American Journal of Public Health* 1128, 1129.

[24] See Chapter One of this study.

[25] See section 1.1 in Chapter One of this study.

Remarkably, most of the respondents did not believe that sterilisation is justified because of prevention of sexual abuse and prevention of uncleanliness during menstruation and/or menstruation phobias.[26] The views of some interviewees in this regard as follows:

> “Sterilisation does not stop menstruation. Parents should guide them, with time they will learn” (IRT1, a teacher)
>
> “Some are very capable of taking care of themselves. Proper guidance on how to take care of themselves when menstruating is required and they’ll be fine” (IRT2, a teacher)
>
> “Educate them on what to do and they will cope with menstruation” (IRT3, a teacher)
>
> ”Sterilisation does not stop the girl child from menstruating; sterilisation simply means tying the tubes” (IRT4, a doctor)
>
> “Sterilisation does not stop menstruation; tying the tubes. The uterus is still there and the woman (girl) still menstruates” (IRT5, a doctor)
>
> “Sterilisation does not stop sexual abuse” (IRT6, a teacher)
>
> “It is duty of the parents to protect their children with or without disability from sexual abuse not to sterilise” (IRT7, a teacher)
>
> “I don’t understand how sterilisation would stop sexual abuse. People would still abuse them if given the opportunity. It merely prevents the girl from getting pregnant (IRT8, a doctor)”

These findings reflect the outlook of the social model of disability upon which this study is partly anchored on. Respondents’ views that financial incapability justifies involuntary sterilisation illustrate how economic factors disable persons with disabilities. Also, respondents’ views that prevention of pregnancy justifies involuntary sterilisation illustrate how social and economic factors disable persons with disabilities.

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[26] See tables 7.6 and 7.21.

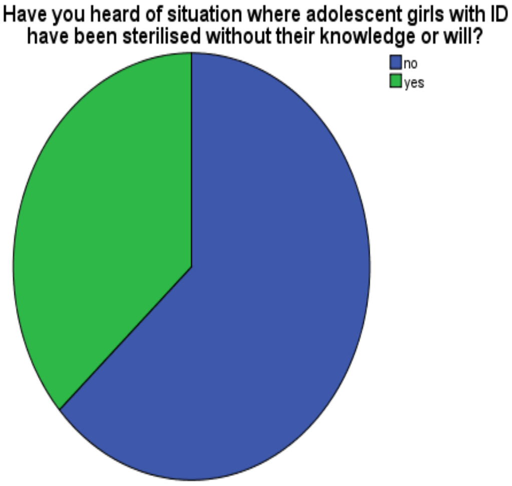

Figure 7.2 Awareness of situations of sterilisation according to professionals

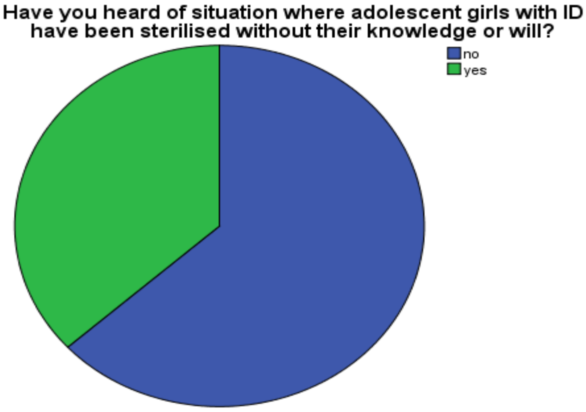

Figure 7.3 Awareness of situations of sterilisation according to parents

7.4.3. Attitude of parents and professionals towards legal capacity and supported decision-making for adolescent girls with intellectual disabilities

Most of the professionals in the study believed that adolescent girls with intellectual disabilities who require intermittent support can make medical and contraceptive decisions with appropriate support while 13.9% believed that those with intellectual disabilities who require limited support are capable. [27]

However, even though 41.3% of the parents were of the view that their child's disability was minor and 27.5% believed that their child's disability was not serious,[28] 65.1%

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[27] See tables 7.14.2, 7.14.3 and 7.14.5.

[28] See table 7.18.

of the parents were of the views that that their daughters lacked the capacity to make medical decisions on their own.[29] Also, 60.1% of the parents believed their daughters could make medical decisions with appropriate support[30] and 53.8% believed that their daughters could make decisions about contraception with appropriate support.[31] This illustrates the protectionist attitude of parents in the study towards medical decision-making by their children highlighted in Chapters Four and Five, whereby parents are reluctant for their children to make decisions even though by their own account their children's disabilities were not such that they required extensive or pervasive support. The findings are also a reflection of the Foucauldian perspective on familial discourse and parental power discussed in Chapter Two. According to him, the family had its own discourse and there is power relations within the family involving the exertion of parental power over children.[32] The findings illustrate parental control over their daughters' bodies and how parental discourse and knowledge on decision-making reifies the incapacity of adolescent girls with intellectual disabilities.

7.4.4. Viability of supported decision-making for adolescent girls with intellectual disabilities in contraception?

This section examines the respondents' views on the viability of supported decision-making for adolescent girls with intellectual disabilities in Nigeria in contraceptive decision-making. In other words, it assesses the respondents' views on whether supported decision-making is practicable for adolescent girls with intellectual disabilities or not.

Viability in this context touches on whether or not supported decision-making works for all levels of intellectual disability. It also entails whether or not, from the respondents' perspectives, supported decision-making excludes substituted decision-making for adolescent girls with intellectual disabilities who require extensive and pervasive support where their will and preferences are not discernable. Viability in the context of this study also involves an assessment of what supported decision-making means for parents, teachers and the heath sector.

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[29] See Table 7.26.3

[30] See table 7.26.4.

[31] See table 7.26.6.

[32] E McSherry 'A Foucauldian discourse analysis of intellectual disability in Irish education' unpublished PhD thesis, University of Limerick, 2013 60.

Although 41.3% of the parents were of the view that their children's disability was minor and 27.5% believed that their children's disability was not serious, only 46.3% of them believed that their daughters can make decisions about contraception with appropriate support.[33] Indeed, 60% of the parents believed that even with age-appropriate support adolescent girls with intellectual disabilities are incapable of making decisions about contraception while 40.0% believed that they could.[34] In response to question 17 of the questionnaire for parents,[35] they emphasised factors like the lack of governmental support, lack of infrastructure, financial incapability as well as social-cultural factors like the fact that they are children and dependent on their parents. The implication of this is that parents may be unwilling to support their daughters with intellectual disabilities in contraceptive decision-making. This means that a large number of the parents that participated in the empirical component of the study do not believe that supported decision-making is generally viable for adolescent girls with intellectual disabilities in terms of contraception. This suggests that substituted decision-making may be inevitable as they would rather make contraceptive decisions for their daughters which could lead to their being subjected to forced contraception or involuntary sterilisation. Nonetheless, 40.0% of the parents believed that with age-appropriate support, their daughters can make decisions about contraception. So it could be inferred that since many of them believed that their daughters' disabilities were minor or not serious, they may consider supported decision-making in contraception practicable for their daughters.

Over 72% of the professionals who were administered questionnaires believed that adolescent girls with intellectual disabilities with intermittent support needs can make decisions about contraception, with appropriate support, while 13.9% believed that those with intellectual disabilities with limited support needs can.[36] Similarly, about 71% of the respondents who were interviewed believed that supported decision-making was viable for girls with intellectual disabilities with intermittent support needs in terms of contraception but that it would take time to implement. In response to question 20 of the questionnaire for professionals[37] and question 5 (4) of the interview schedule,[38] they highlighted factors likely to affect the implementation of supported decision-making in Nigeria. The factors include the

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[33] See table 7.26.6.
[34] See table 7.27.
[35] See appendix 18.
[36] See table 7.14.5.
[37] See appendix 17.
[38] See appendix 19.

need for a legislative framework, the availability of personnel, awareness raising, funding and the provision of facilities. These factors formed the basis for the recommendations made in Chapter Eight of this thesis. The responses of some of the interviewees are as follows:

"No it won't work. We have developmental and other issues to tackle" (IRT8, a doctor)

"I am very optimistic about it because things are taking a new form. There's been advocacy for people disabilities, that they have rights. I think it will work for those with mild intellectual disability but it will take long time to work…parents, society, communities have to be enlightened." (IRT9, a teacher)

"It will not work. This is Africa and our parents take decisions for us. Even those that are normal- parents make decisions for them" (IRT10, a teacher)

"It will work in respect of those that are educable but it will take time because of many factors- no government policies, lack of personnel, lack of equipment, lack of funding" (IRT11, a doctor)

"No it won't work. I think decisions should be made for them since they may not understand the implication of making such decisions" (IRT12, a teacher)

"Supported decision-making will work but it will be difficult with a lot of challenges. With mild intellectual disability it will work because they can speak up for themselves; because they have understanding" (IRT5, a doctor)

"It ought to work because every child should be allowed to make decisions if the child is able to understand the decision" (IRT13, a teacher)

"With time, and if you have people that will stand and fight for it because awareness is on the increase, it will work. Legal framework should be implemented; awareness in the home, communities, schools and hospitals is needed" (IRT14, a teacher)

The responses of the professionals indicate that they believe supported decision-making is practicable for adolescent girls with intellectual disabilities who require intermittent and limited support in contraception. It also indicates that they believe that it is not viable for all levels of intellectual disabilities but only for those requiring intermittent and limited support. This clearly accentuates the argument made in Chapter Five that substituted decision-making may be inevitable for adolescent girls with intellectual disabilities that with extensive and pervasive support needs. It could therefore be implied that if adolescent girls with intellectual disabilities with intermittent and limited support needs are supported in contraceptive decision-making, they would be provided with alternative means of contraception rendering sterilisation unnecessary. It is also an indication of the potential for supported decision-making to be employed by teachers and professionals in health care and for them to involve adolescent girls with intellectual disabilities, especially those who require intermittent and limited support, in decision-making about contraception. Thus, supported decision-making is a potentially useful measure for teachers and health care professionals in protecting adolescent girls with intellectual disabilities from involuntary sterilisation.

Evidently, supported decision-making is a viable mechanism in enhancing the legal capacity of adolescent girls with intellectual disabilities who require intermittent and limited support in decision-making about contraception and protecting them from involuntary sterilisation. It has the potential for transforming how teachers and health care professionals treat them in terms of their legal capacity to make medical decisions. It is therefore imperative that measures are put in place to ensure that the legal capacity of adolescent girls with intellectual disabilities with intermittent and limited support is advanced. Even if substituted decision-making may be inevitable for adolescent girls with intellectual disabilities that require extensive and pervasive support, measures that take into cognisance the relational understanding of decision-making and safeguard their human rights, should also be put in place.

7.5. Conclusion

The results of the quantitative and qualitative research revealed that medical, biological and cultural factors shape the attitudes about intellectual disability and persons with intellectual disabilities in Nigeria. These corroborated the results from other studies in Nigeria that intellectual disability is largely attributed to biological factors, illness during pregnancy, medical negligence, disease, use of drugs during pregnancy and prolonged labour. It was also found that cultural/religious beliefs also shape how intellectual disability is construed as a few of the respondents attributed it to witchcraft, demon possession, juju, and the anger of gods. The study also revealed that most respondents believed that sterilisation to prevent pregnancy and financial incapability was justifiable while sterilisation to prevent sexual abuse or avoid menstrual related issues were not justifiable. The complexities surrounding the supported decision-making paradigm as a concept and for adolescent with intellectual disabilities were highlighted in this study.[39] It was shown that enabling supported decision-making for adolescents, although challenging, would be viable for those with intellectual disabilities intermittent and limited support. The findings revealed that most respondents were more inclined to support for adolescents with disabilities with intermittent support needs and in some cases, those with limited support needs in terms of contraceptive decision-

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[39] See section 5.22 and 5.23 of this study.

making. It was widely believed that even with age-appropriate support, adolescents intellectual disabilities with extensive and pervasive support needs cannot or should not be allowed to make medical and contraceptive decisions. This reflects the discussions on the complexities of implementing supported decision-making for persons with intellectual disabilities who require extensive and pervasive support in Chapter Five of this study. The study also showed that most of the interviewees believed that supported decision-making was viable for adolescent girls with intellectual disabilities with intermittent and limited support needs as regards decision-making about contraception. Arguably, supported decision-making is a viable for enhancing the legal capacity of adolescent girls with intellectual disabilities with intermittent and limited support needs in contraceptive decision-making and protecting them from involuntary sterilisation.

In the next chapter, recommendations are provided based on the findings in this chapter and discussions in previous chapters.

CHAPTER EIGHT

SUMMARY, RECOMMENDATIONS AND FINAL CONCLUSION

8.1. Summary

This study set out to critically assess the viability of the Convention on the Rights of Persons with Disabilities (CRPD)'s concept of supported decision-making in protecting adolescent girls with intellectual disabilities from involuntary sterilisation in Nigeria. It examined the ideologies and constructions underlying the concept of intellectual disability and their effects on persons with disabilities. The study also critically analysed the concepts of legal capacity, support in the exercise of legal capacity and supported decision-making and the challenges inherent in their implementation for adolescent girls with intellectual disabilities. To provide a discursive assessment based on the research questions, the study consisted of eight chapters. A summary of each chapter is presented below.

8.1.1. Chapter One: Summary

Chapter One provided a general introduction to the study. It presented a background to the study and explained the following terms: adolescent, sterilisation, intellectual disability and legal capacity, which are central to the study. It also outlined the problem statement and objectives, the research questions, the methodology, the literature review, the theoretical framework, the significance, the scope and limitations, the ethical considerations and overview of the chapters of the study.

8.1.2. Chapter Two: Summary

Chapter Two conceptualised intellectual disability. It gave a historic account of intellectual disability in Nigeria during the pre-colonial, colonial and post-colonial eras. It was shown that from historical accounts and from the proverbs of the Igbo and Yoruba in Southern Nigeria, attitudes about intellectual disability during the pre-colonial era were rooted in cultural and religious beliefs. The attitudes towards persons with intellectual disabilities in the pre-colonial era were found to be either positive or negative depending on how intellectual disability was constructed in the society. The discussions in the chapter also indicated that during the colonial era, western ideologies influenced how intellectual disability was constructed, resulting in a change in the construction of intellectual disability from the spiritual to the bio-medical. It was also highlighted that intellectual disability was attributed to a variety of causes ranging from the medical to the biological to the spiritual during the post-colonial era. The chapter also examined the definitions and classification schemes for intellectual disability and concluded that they are inadequate. It also argued that the diagnosis and assessment criteria in the manuals, especially the intelligence quotient (IQ) and assessment tests, were flawed thereby rendering intellectual disability a highly contested concept. The chapter also argued that intellectual disability is a socio-medical construct, arising from the interaction between social and clinical factors that result in the categorisation, labelling and stigmatisation of persons with intellectual disabilities.

8.1.3. Chapter Three: Summary

Chapter Three provided a discussion on the rights to equality and non-discrimination and what they entail for persons with intellectual disability. It was posited that although equality is a recognised principle of human rights, its meaning is contested. The different types of equality were also examined. It was argued that substantive equality comprising of equality of opportunities and equality of outcome can address the systemic discrimination and inequality faced by persons with intellectual disabilities. It was argued that although many national and international laws recognise the rights to equality and equality before the law, the denial of legal capacity of persons with intellectual disabilities undermined their realization of the rights and thus resulting in inequality, discrimination, and exclusion. The chapter also argued that involuntary sterilisation of adolescent girls with intellectual disabilities gives rise to discrimination, inequality and unequal treatment before the law. It was argued that an ideological shift was needed to examine the unequal treatment of persons with intellectual disabilities before the law. It was further posited that the CRPD’s provisions on equality, non-discrimination and equal recognition before the law had the potential of providing that ideological shift for persons with intellectual disabilities.

8.1.4. Chapter Four: Summary

In Chapter Four, the concept of legal capacity was examined. It highlighted the different views on personhood for persons with disabilities as well as the link between person hood and legal capacity. It argued that framing personhood on the basis of cognition and rationality has resulted in inequality and discrimination. A discussion of the meaning and significance of legal capacity was also carried out. It was posited that legal capacity is a socio-legal construct subject to different interpretations which reflected its time of usage. The chapter also discussed the traditional approaches - status, outcome and functional approaches - to legal capacity and their shortcomings. It argued that the conception of legal capacity in Nigeria is based on the traditional approaches which have resulted in inequality and discrimination particularly for adolescent girls with intellectual disabilities in terms of contraceptive decision-making. It was argued that because the girls are deemed incapable of making decisions, they are restricted from making decisions about contraception on an equal basis with their counterparts without disabilities, resulting in their being involuntarily sterilised. The chapter also examined the conception of legal capacity in article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) and the Committee on the Rights of Persons with Disabilities (CRPD Committee)'s interpretation of the right. It argued that although the CRPD has the potential of changing the discourse on legal capacity, the CRPD Committee's interpretation of the right is for adolescents with disabilities not without difficulties. One of such difficulties is that the CRPD Committee adopts a functional approach which it proscribes for adults with disabilities by linking the best interests' standard to the will and preference of children/adolescents with disabilities. The Committee also leaves room for abuse as it provides no guidance on what the best interest standard means for children with disabilities.

8.1.5. Chapter Five: Summary

An analysis of support paradigm in article 12 of the CRPD and its attendant supported decision-making was carried out in Chapter five. The chapter examined the meaning and import of the support in the exercise of legal capacity. It found that although the CRPD Committee opined in its General Comment No. 1 that support in the exercise of legal capacity must respect the "rights, will and preferences" of persons with disabilities, it provided little or no guidance on how to determine the 'will and preference' of persons with extensive and pervasive support needs . It also argued that the CRPD Committee's interpretation of article 12 for children and adolescents with disabilities raises questions about its applicability to those with intellectual disabilities. The challenges inherent in implementing supported decision-making for adolescent girls with intellectual disabilities in the Nigerian context were highlighted. It was posited that in view of complexities in applying supported decision-making to adolescents with disabilities, substituted decision-making may be inevitable for adolescent girls with intellectual disabilities that require extensive and pervasive support. In view of that, developing effective supported decision-making systems in Nigeria would be difficult. The chapter also examined informal supported decision-making mechanisms with the aim of drawing lessons from the operation of informal supported decision-making systems in Australia and the United Kingdom. Circles of support, peer support and micro-boards were examined on the ground that they may be suited to enhancing the legal capacity of adolescent girls with intellectual disability in terms of contraceptive decision-making and mitigating against their being involuntarily sterilised.

8.1.6. Chapter Six: Summary

The methodology of the empirical component of the study was discussed in Chapter Six. As discussed, a mixed methods research approach, comprising the use of quantitative and qualitative approaches, was adopted. It was shown that the survey research design was employed to assess respondents' opinions on the viability of supported decision-making for adolescent girls with intellectual disabilities in contraceptive decision-making through questionnaires and semi-structured interviews. The chapter also showed that the empirical research was conducted in Anambra, Edo, Ekiti, Imo, Lagos and Rivers States of southern Nigeria, representing two states from the three geopolitical zones of Southern Nigeria. The multistage sampling technique was shown to be the sampling technique used in the research. It involved the use of stratified random sampling to stratify the states of Nigeria into geo-political zones; simple random sampling to select two states from the three geopolitical zones of Southern Nigeria and purposive sampling to select the respondents for the research. The necessary approvals from relevant authorities, including a letter of ethical clearance from the Ethics Committee of the Faculty of Law, University of Pretoria, were sought and granted to enable the research to be carried out. The chapter also discussed the processes through which the anonymity and confidentiality of the respondents and the information they provided were guaranteed. The content and face validity of the instruments of the research were shown to have been verified by two experts in the Department of Educational Evaluation and Counselling Psychology, University of Benin and a pre-test was conducted prior to the collection of data to ensure the reliability of the instruments. The procedure for data collection and method of data analysis were also discussed.

8.1.7. Chapter Seven: Summary

Chapter Seven presented the findings of the empirical component of the research. The findings of the quantitative and qualitative research showed that most of the respondents of the research attributed the causes of intellectual disability to biological and medical factors such as illness during pregnancy, medical negligence, disease, use of drugs during pregnancy and prolonged labour. It also found that a few of the respondents attributed intellectual disability to cultural/religious factors such as witchcraft, demon possession, juju, and the anger of gods. This showed that attitudes about intellectual disability and about persons with intellectual disabilities in Nigeria are shaped by medical, biological and cultural factors. The study also found that most respondents believed that the sterilisation of adolescent girls with intellectual disabilities was justifiable on grounds of prevention of pregnancy and financial incapability. It was also shown that most respondents believed that supported decision-making was viable for adolescent girls with intermittent and limited support needs as regarding decision making about contraception. The respondents also believed that even with age-appropriate support, adolescents with intellectual disabilities who require extensive and pervasive support cannot or should not be allowed to make medical and contraceptive decisions. The findings of Chapter Seven show that while supported decision-making may be viable in protecting adolescent girls with intellectual disabilities who require intermittent and limited support from involuntary sterilisation, it may not be viable for those with intellectual disabilities requiring extensive and pervasive support. Thus, substituted decision-making may be inevitable for adolescent girls with disabilities with extensive and pervasive support needs.

8.2. Recommendations

In view of the difficulties in implementing article 12 for adolescent girls with intellectual disabilities, this section provides recommendations drawn from the issues discussed and from the findings of the empirical component of this study. The recommendations emphasise the need for legislative enactment and reform, awareness raising and sensitization, the provision of support mechanisms as well as research and training of policy-makers and relevant stakeholders.

8.2.1 The need for legislative enactment and reform

The study has established that involuntary sterilisation of adolescent girls with disabilities is discriminatory and amounts to unequal treatment. Thus, law and policy reform is required to put an end to such sterilisation. It is therefore recommended that disability laws be enacted at both state and federal levels with provisions prohibiting the sterilisation of persons with disabilities. Such laws must also guarantee the rights to equality and support in the exercise of legal capacity for adolescents (children) with intellectual disabilities, on an equal basis with other adolescents especially about contraceptive decision-making.

The laws must also safeguard the right of adolescents with intellectual disabilities to support in the exercise of legal capacity, particularly about decision-making so as to mitigate the involuntary sterilisation of girls with intellectual disabilities.[1]

The Nigerian government must also not permit substitute decision-making as the standard for providing consent to sterilisation of girls with disabilities. Healthcare personnel should disallow that third parties, including family members from making decisions about the sterilisation for the girls.[2] The government must also take steps to put a stop to the infringement of the girls' right to support by non-state actors.[3] In developing a supported decision-making regime, the government must guarantee "that other rights such as the right to autonomy, informed consent, to retain fertility and human dignity are protected" and that "the support provided is not used as a justification for limiting their rights."[4]

The study also recommends that the legislature consults with persons with intellectual disabilities, including adolescents with disabilities, through their representatives or advocacy groups, when enacting and enforcing laws, policies and other decision-making practices that effectuate article 12 of the CRPD.[5] Discriminatory terms and labels used in laws and policies such as 'unsound mind, and 'mental defectives' should be removed as they perpetuate negative stereotypes and attitudes towards persons with intellectual disabilities. Although as Dinerstein points out, law making and law reform will not automatically enable supported decision-making regimes; they are a start.[6]

8.2.2 The need for awareness raising and sensitisation

Socio-cultural beliefs and traditions are deep rooted in the fabric of society and law reform through legislative enactments and judicial pronouncements are not enough to change such beliefs and traditions. The study established that prevailing negative beliefs and stereotypes hinder the rights in article 12 for adolescent girls with intellectual disabilities. The empirical

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[1] AI Ofuani 'Protecting adolescent girls with intellectual disabilities from involuntary sterilisation in Nigeria: Lessons from the Convention on the Rights of Persons with Disabilities' (2017) 17 *African Human Rights Law Journal* 550, 566-567.

[2] Ofuani (n 1 above) 567.

[3] Committee on the Rights of Persons with Disabilities (CRPD Committee) 'Article 12: Equal recognition before the law' (General Comment No. 1) (2014) CRPD/C/GC/1, para 24. https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement (accessed 12 February 2014).

[4] Ofuani (n 1 above) 567; Committee on the Rights of Persons with Disabilities (n 3 above) para 29.

[5] Committee on the Rights of Persons with Disabilities (n 3 above) para 13(c).

[6] RD Dinerstein 'Implementing legal capacity under article 12 of the UN convention on the rights of persons with disabilities: The difficult road from guardianship to supported decision-making' (2012) 19 *Human Rights Brief* 8, 12.

component of this work also found that many respondents have not heard about the CRPD or supported decision-making.[7] One reason for this as highlighted in Chapter Five is lack of societal awareness and education about intellectual disability, the CRPD and supported decision-making. As Jones and Basser-Marks observe, the law alone is not enough to bring about the "social, cultural and political change" needed to achieve justice for persons with disabilities.[8] Thus, law reform is only part of the strategy required to enable the rights in article 12 of the CRPD for persons with disabilities.

Although law reform is necessary to effect change, social and attitudinal change is also required to ensure equality, non-discrimination, respect for the legal capacity and support of persons with intellectual disabilities. As such, there is need for awareness raising and sensitization programmes to educate the public and address negative beliefs and stereotypes. Such programmes should be focus on communities, families, law enforcement agencies, policymakers, and all relevant stakeholders, including adolescents with intellectual disabilities and their advocacy groups. The programmes should also make use of the media, awareness campaign posters, handbills, and other unconventional awareness raising programmes such as walks, road shows, sensitization marches and sporting events to educate the public.[9] They require co-operation between different sectors such as the government and its agencies, the media, non-governmental organisations (NGOs), parents, community leaders, medical professionals, educators, as well as adolescents with intellectual disabilities and their advocacy groups.[10] This would aid in fostering a positive view of persons with intellectual disabilities as part of human diversity.[11]

8.2.3 The need to provide to support measures and services

Support measures and services are lacking in Nigeria for persons with disabilities in general, and adolescent girls with intellectual disabilities, in particular. It is therefore imperative that the government allocates monetary resources to ensure that support

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[7] See sections 7.2.3.1 and 7.3.3.1 of this study.

[8] E Flynn & A Arstein-Kerslake 'Legislating personhood: Realising the right to support in exercising legal capacity' (2014) 10 *International Journal of Law in Context* 81, 102; M Jones & LA Basser-Marks 'The limitations on the use of law to promote rights: An assessment of the Disability Discrimination Act 1992' in M Hauritz et al (eds) *Justice for people with disabilities: Legal and institutional issues* (1998) 60-84.

[9] Ofuani (n 1 above) 568.

[10] I Worm *A human rights-based approach to disability in development entry points for development organisations* (2012) 26; K Scior et al 'Intellectual disabilities: Raising awareness and combating stigma- a global review' (2015) 84 https://www.ucl.ac.uk/ciddr/documents/Global_ID_Stigma_Report_Final_July_15.pdf (08 October 2016).

[11] Ofuani (n 1 above) 568.

mechanisms and services are available to persons with disabilities, especially those who are in remote locales, to advance support networks.[12] Safeguards for such support must be premised on respect for the rights, will and preferences of persons with disabilities.[13] Given that individual needs vary, the government should endeavour to develop a variety of support options rather than adopting a one-size-fits-all approach.[14] Such support must also be accessible to persons with intellectual disabilities, such as providing information in simple language. The support networks also require a legal, institutional and policy framework, establishment of infrastructure and trained personnel.[15]

In as much as supporting adolescent girls with intellectual disabilities, especially those that require extensive and pervasive support, may be difficult, an approach that fosters their human rights, especially their right to retain their fertility, is necessary. According to Bridgeman, such an approach necessitates "an understanding of the child as both an individual and as situated within a web of relationships, such that the insights, knowledge and experiences of parents" and other people that have to do with the child are important.[16] It could also consist of the informal support mechanisms discussed in section 5.4 of this study involving persons that are familiar to them such as family members, friends and teachers. So, even when they are unable to make decisions, people who love and appreciate them can enable decisions on their behalf in a way that promotes their right to support in the exercise of their legal capacity.[17] This relational understanding of legal capacity accentuates the significance of support and promoting the interactions between those that care them and the girls themselves.[18] This would protect the girls from being involuntarily sterilised.

Nevertheless, as highlighted in Chapter Five, there will be some occasions where a support may not be feasible and substituted decision-making may be unavoidable, such as

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[12] L Kerzner 'Paving the way to full realization of the CRPD's rights to legal capacity and supported decision-making: A Canadian perspective' presented at the Legal Capacity Symposium From the Margins: New Foundations for Personhood and Legal Capacity in the 21st Century at the University of British Colombia, Ontario, Canada on April 2011, 71 https://cic.arts.ubc.ca/files/2014/07/In_From_The_Margins_Paper-Lana_Kerzner-FINAL-April_22_2011__2_.pdf (accessed 15 February 2014).

[13] Committee on the Rights of Persons with Disabilities (n 3 above) para 13(b).

[14] Council of Europe Commissioner for Human Rights 'Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities' (2012) 20 https://rm.coe.int/16806da5c0 (accessed 15 February 2016).

[15] M Bach, 'Supported decision making under article 12 UN convention on the right of persons with disabilities: Questions and challenges' presented at the Conference on Legal Capacity and Supported Decision Making at Athlone, on 3 November 2007, 13-14.

[16] J Bridgeman 'Caring for children with severe disabilities: Boundaried and relational rights' in M Freeman (ed) *Children's health and children's rights (*2006) 99,116.

[17] Ofuani (n 1 above) 562.

[18] Bridgeman (n 16 above) 113.

where the girls are in institutions and lack family or social connections.[19] In spite of this, substituted decision-making in terms of sterilisation should never be contemplated as an option for supporting the adolescent.

8.2.4 The need for research

As discussed in Chapters One and Five, there are challenges and tensions underpinning the CRPD Committee's interpretation of the support paradigm in article 12. These challenges include its applicability to children with disabilities, how to postulate it for individuals with intellectual disabilities with extensive and pervasive support needs and what standards should be applied when determination of the will and preference is impossible. More so, there is little jurisprudence on the extent of applicability of article 12 to adolescents with intellectual disabilities. There is therefore need for research by academics, government and non-governmental entities to develop best standards with regards to the right to the legal capacity of adolescents with disabilities and support in the exercise of their legal capacity.[20] Evidence based research on the implementation of supported decision-making is also lacking. As such, the Nigerian government, private entities as well as NGOs should initiate pilot projects and empirical research to explore supported decision-making mechanisms for persons with disabilities, in general, and adolescents with intellectual disabilities, in particular.

8.2.5. The need for training of policy-makers and relevant stakeholders

There is a need to train law and policy makers as well as other relevant stakeholders including governmental officials, communities, health workers, teachers, family members, and adolescent with intellectual disabilities themselves, on the significance of article 12 and supported decision-making. Such training should be practical and based on a robust theoretic and legal framework of equality and non-discrimination.[21] The effective training for medical practitioners will aid in addressing the preconceived notions and stereotypes about persons with intellectual disabilities and mitigate against their being involuntarily sterilised.

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[19] J Tobin & E Luke 'The involuntary, non-therapeutic sterilisation of women and girls with an intellectual disability- can it ever be justified?' (2013) *3 Victoria University Law and Justice Journal* 27, 37.
37; P Gooding 'Navigating the 'flashing amber lights of the right to legal capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to major concerns' (2015) *15 Human Rights Law Review* 45, 58-60.

[20] Committee on the Rights of Persons with Disabilities (n 3 above) para 51.

[21] Dinerstein (n 6 above) 12.

8.2.6. The need for civil society action

Civil societies are fundamental to ensuring compliance with, enforcement and monitoring of human rights, holding governments accountable for infractions, dismantling prevailing discriminatory customs and enabling the application of revolutionary norms and standards.[22] Article 33 of the CRPD enjoins States Parties to establish enforcement and compliance mechanisms at the domestic level, with the involvement of civil societies, including persons with disabilities and their representative organisations.[23] This provision enables civil societies and disabled persons' organisations in Nigeria to monitor the government's compliance with the CRPD and to report areas of non-compliance with the CRPD Committee. Civil societies and disabled persons' organisations could therefore be catalytic in preventing adolescent girls with intellectual disabilities from being subjected to involuntary sterilisation.

8.3. Concluding remarks

This study sought to examine the viability of supported decision-making in protecting adolescent girls with intellectual disabilities from involuntary sterilisation in Nigeria. It was emphasised that how intellectual disability is construed can affect who is labelled as intellectually disabled and ultimately who will be sterilised because of the label. The study also found that implicit in the involuntary sterilisation of adolescent girls with intellectual disabilities is multiple and intersectional discrimination that places them in a position of inequality which is reinforced by legal, social, economic and cultural factors. The complexities inherent in the existing literatures on supported decision-making, including the General Comment No. 1, in interpreting supported decision-making, for persons with disabilities were also highlighted. Measures including law making and reform, raising awareness about intellectual disability and supported decision-making, facilitation of support services, research, training of stakeholders and civil society action were recommended.

Finally, although the scope of the study on the promotion of decision-making for adolescent girls with intellectual disabilities to mitigate involuntary sterilisation is limited to Nigeria, its implications are not limited to Nigeria. Arguably, the broad recommendations made in the study could also apply to the rest of Africa in the least.

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[22] Ofuani (n 1 above);Dinnerstein (n 6 above) 12; 'Civil Society provides the critical foundation for promoting all human rights' https://geneva.usmission.gov/2011/09/15/civil-society-promoting-all-human-rights/(08 October 2016); Kingdom of Morocco National Human Rights Council 'Promotion and protection of human rights: Role of civil society' http://www.cndh.org.ma/an/bulletin-d-information/promotion-and-protection-human-rights-role-civil-society (8 October 2016).

[23] Convention on the Rights of Persons with Disabilities (CRPD) (2006) 46 ILM 443, article 33(1) and (3).

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Child's Right Act 2003, Act No. 26 of 2003

Companies and Allied Matters Act, Cap C.20, Laws of the Federation of Nigeria, 2004

Constitution of the Federal Republic of Nigeria of 1999, Cap C.34, Laws of the Federation of Nigeria, 2004

Discrimination against Persons with Disabilities (Prohibition) Act, 2018

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Evidence Act 2011

Kwara State People with Disabilities Law 2016

Lunacy Act, Cap. 112, Laws of the Federation of Nigeria, 1958

National Health Act 2014

Medical and Dental Council of Nigeria, *Codes of Medical Ethics in Nigeria*

National Adolescent Health Policy 1995

National Policy on Education (4th ed) 2004

National Policy on the Health & Development of Adolescents & Young People in Nigeria 2007

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South Africa

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United Kingdom

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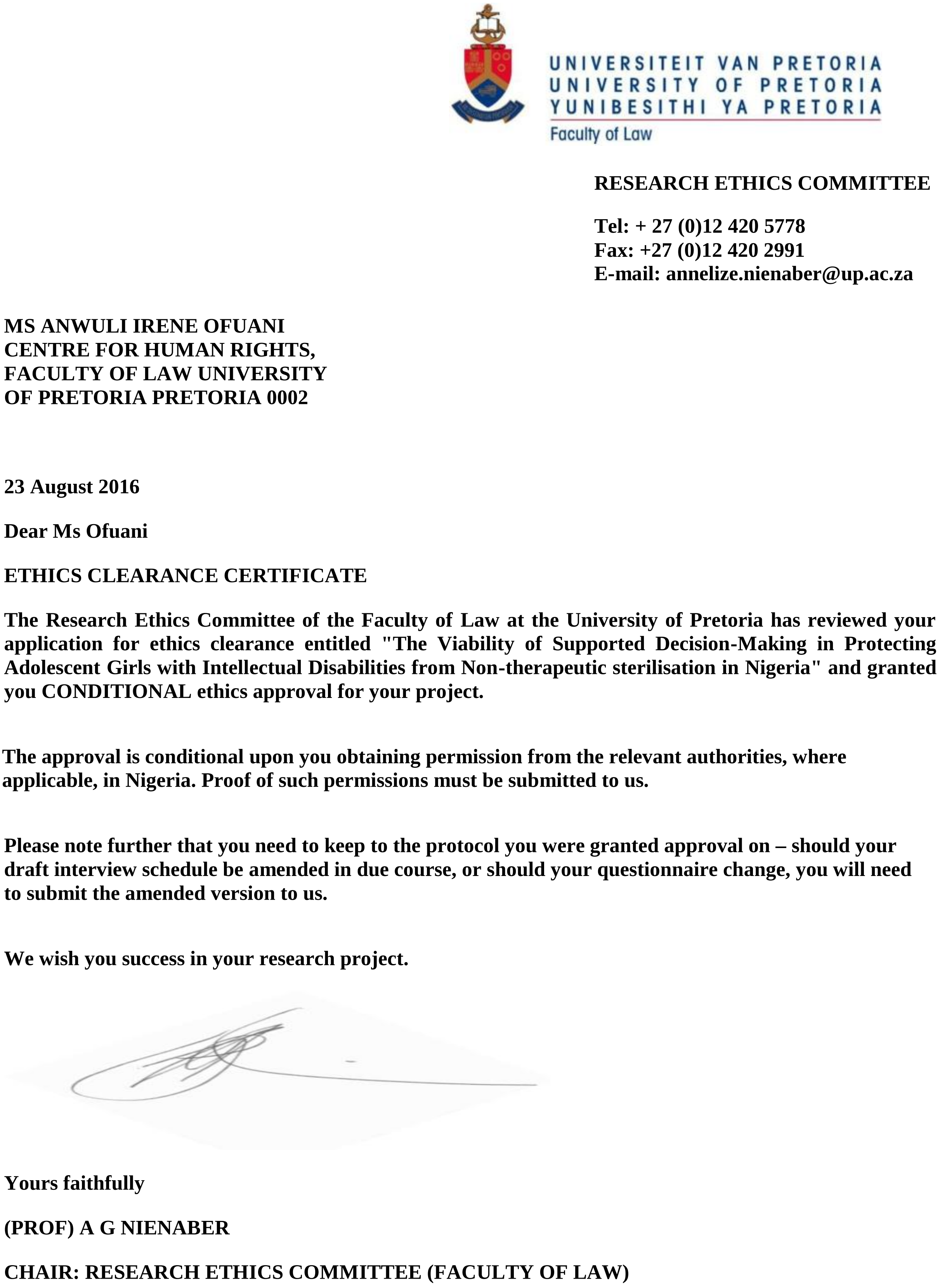
Appendices

Appendix 1: Faculty of Law, University of Pretoria ethical clearance letter



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Law

RESEARCH ETHICS COMMITTEE

Tel: + 27 (0)12 420 5778
Fax: +27 (0)12 420 2991
E-mail: annelize.nienaber@up.ac.za

MS ANWULI IRENE OFUANI
CENTRE FOR HUMAN RIGHTS,
FACULTY OF LAW UNIVERSITY
OF PRETORIA PRETORIA 0002

23 August 2016

Dear Ms Ofuani

ETHICS CLEARANCE CERTIFICATE

The Research Ethics Committee of the Faculty of Law at the University of Pretoria has reviewed your application for ethics clearance entitled "The Viability of Supported Decision-Making in Protecting Adolescent Girls with Intellectual Disabilities from Non-therapeutic sterilisation in Nigeria" and granted you CONDITIONAL ethics approval for your project.

The approval is conditional upon you obtaining permission from the relevant authorities, where applicable, in Nigeria. Proof of such permissions must be submitted to us.

Please note further that you need to keep to the protocol you were granted approval on – should your draft interview schedule be amended in due course, or should your questionnaire change, you will need to submit the amended version to us.

We wish you success in your research project.

Yours faithfully

(PROF) A G NIENABER

CHAIR: RESEARCH ETHICS COMMITTEE (FACULTY OF LAW)

Appendix 2: Letters requesting permission to relevant state ministries to carry out the research in the selected schools

Dear Sir /Madam,

PERMISSION TO UNDERTAKE RESEARCH IN SPECIAL SCHOOLS IN --------- STATE

I wish to request your permission and approval to enable me undertake a PhD research study in Special Primary Schools for Children with Intellectual Disabilities in ------ State.

I am a lecturer at the Faculty of Law, University of Benin, Benin City and I am currently undertaking my PhD programme at the University of the Pretoria, South Africa.

The purpose of my study is to ascertain the viability of the Convention on Persons with Disabilities (CRPD)'s concept of supported decision making for adolescents with intellectual disabilities in Nigeria. Consequently, I wish to administer questionnaires and interview teachers and professionals working with Children in the special schools.

I would appreciate your written approval to enable me undertake my research in the special schools.

Yours faithfully,

Anwuli Irene Ofuani
Student/ Investigator

Appendix 3: Letters requesting permission to carry out the research in the selected hospitals

Dear Sir /Madam,

PERMISSION TO UNDERTAKE RESEARCH IN YOUR HOSPITAL

I wish to request your permission and approval to enable me undertake a PhD research study in your

I am a lecturer at the Faculty of Law, University of Benin, Benin City and I am currently undertaking my PhD programme at the University of the Pretoria, South Africa.

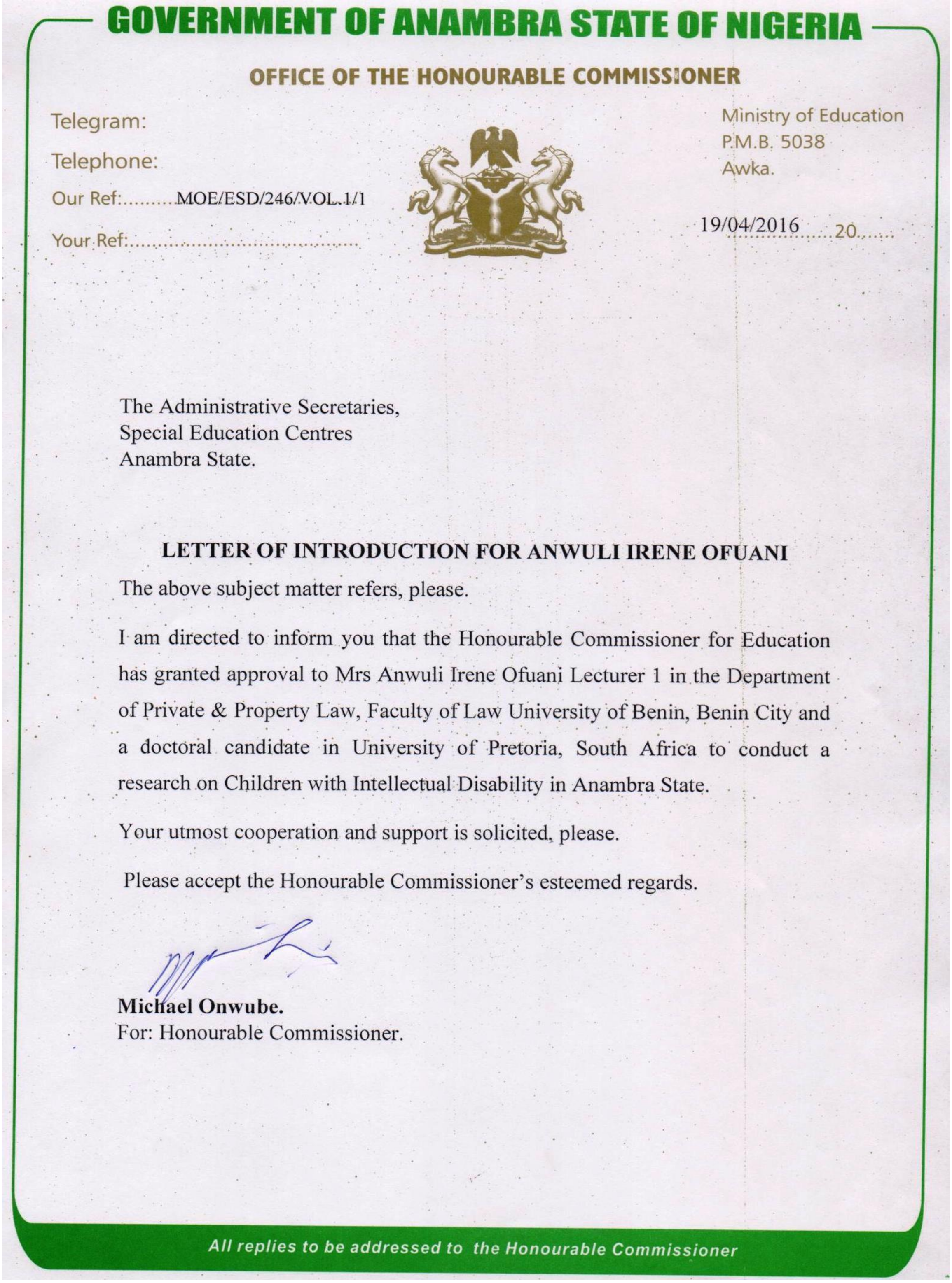
The purpose of my study is to ascertain the viability of the Convention on Persons with Disabilities (CRPD)'s concept of supported decision-making for adolescents with intellectual disabilities in Nigeria. Consequently, I wish to administer questionnaires and interview professionals that deal with adolescents with intellectual disabilities in your hospital.

I would appreciate your written approval to enable me undertake my research in the special schools.

Yours faithfully,

Anwuli Irene Ofuani
Student/ Investigator

Appendix4: Letter of approval to conduct research in Anambra State



GOVERNMENT OF ANAMBRA STATE OF NIGERIA

OFFICE OF THE HONOURABLE COMMISSIONER

Telegram:
Telephone:

Ministry of Education
P.M.B. 5038
Awka.

Our Ref:.........MOE/ESD/246/VOL.1/1

Your Ref:...

19/04/2016 ....20......

The Administrative Secretaries,
Special Education Centres
Anambra State.

LETTER OF INTRODUCTION FOR ANWULI IRENE OFUANI

The above subject matter refers, please.

I am directed to inform you that the Honourable Commissioner for Education has granted approval to Mrs Anwuli Irene Ofuani Lecturer 1 in the Department of Private & Property Law, Faculty of Law University of Benin, Benin City and a doctoral candidate in University of Pretoria, South Africa to conduct a research on Children with Intellectual Disability in Anambra State.

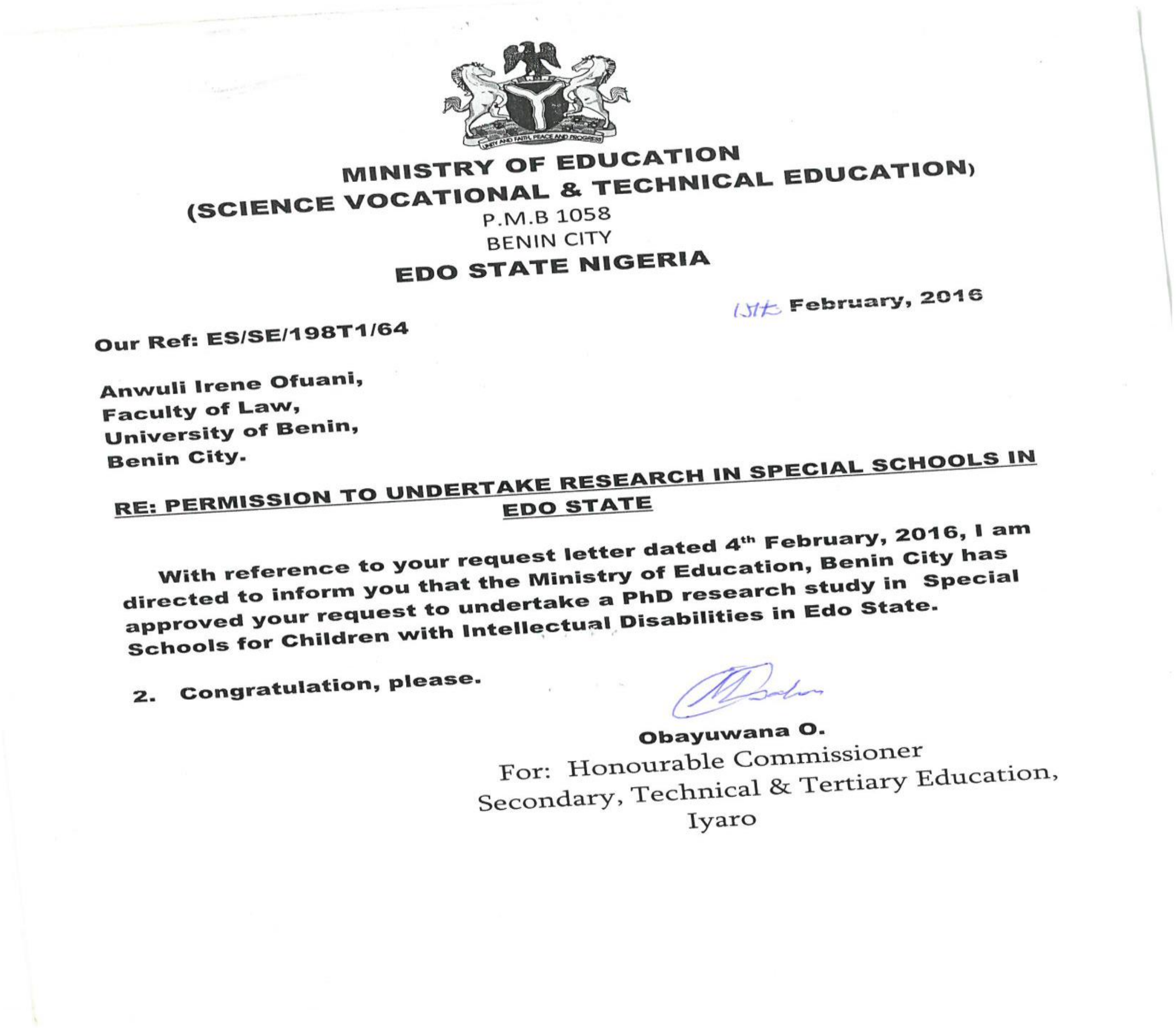
Your utmost cooperation and support is solicited, please.

Please accept the Honourable Commissioner's esteemed regards.

Michael Onwube.
For: Honourable Commissioner.

All replies to be addressed to the Honourable Commissioner

Appendix 5: Letter of approval to conduct research in Edo State



MINISTRY OF EDUCATION
(SCIENCE VOCATIONAL & TECHNICAL EDUCATION)
P.M.B 1058
BENIN CITY
EDO STATE NIGERIA

15th **February, 2016**

Our Ref: ES/SE/198T1/64

Anwuli Irene Ofuani,
Faculty of Law,
University of Benin,
Benin City.

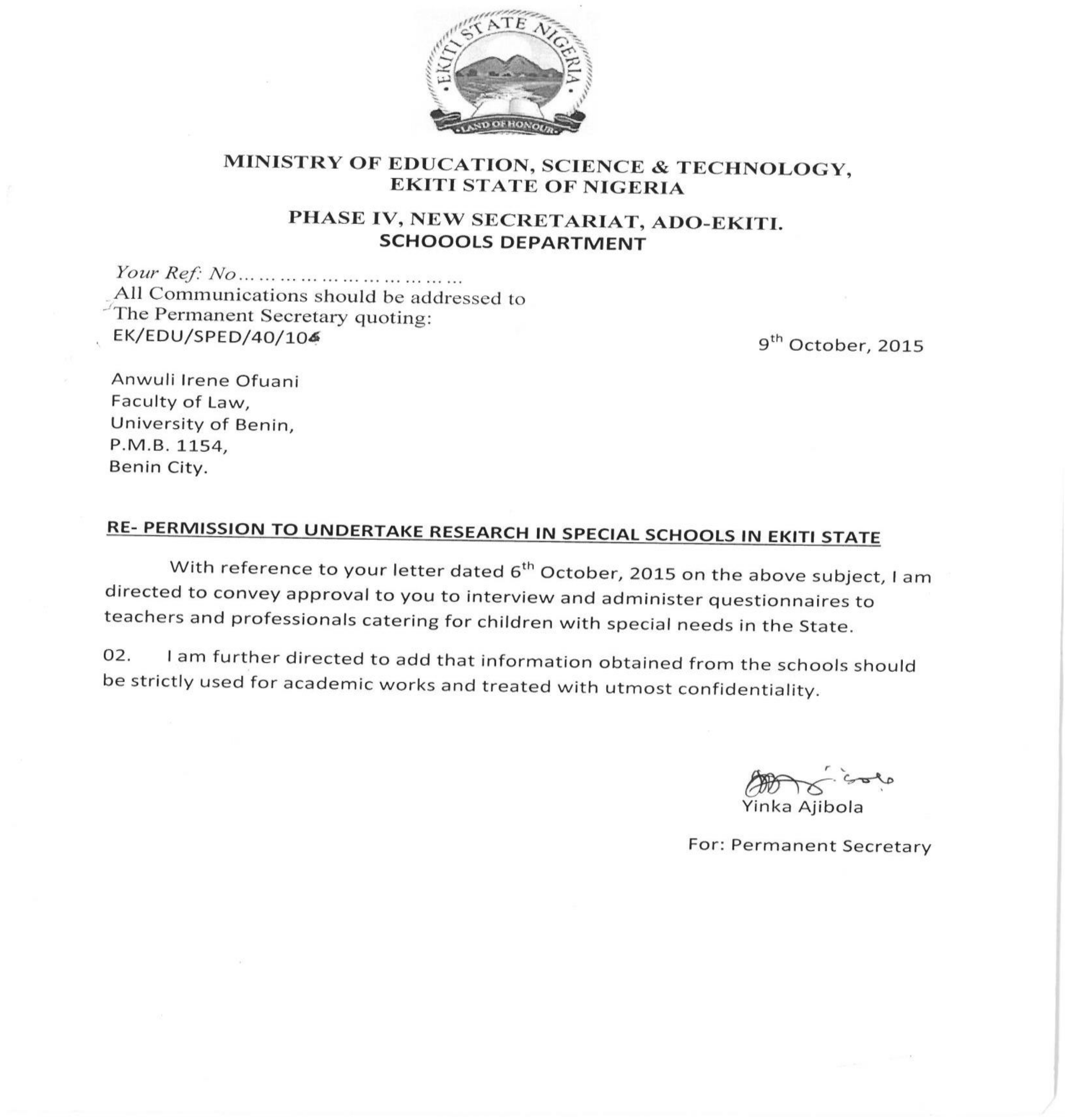
RE: PERMISSION TO UNDERTAKE RESEARCH IN SPECIAL SCHOOLS IN EDO STATE

With reference to your request letter dated 4th February, 2016, I am directed to inform you that the Ministry of Education, Benin City has approved your request to undertake a PhD research study in Special Schools for Children with Intellectual Disabilities in Edo State.

2. Congratulation, please.

Obayuwana O.
For: Honourable Commissioner
Secondary, Technical & Tertiary Education,
Iyaro

Appendix 6: Letter of approval to conduct research in Ekiti State



MINISTRY OF EDUCATION, SCIENCE & TECHNOLOGY,
EKITI STATE OF NIGERIA

PHASE IV, NEW SECRETARIAT, ADO-EKITI.
SCHOOOLS DEPARTMENT

Your Ref: No……………………………
All Communications should be addressed to
The Permanent Secretary quoting:
EK/EDU/SPED/40/106

9th October, 2015

Anwuli Irene Ofuani
Faculty of Law,
University of Benin,
P.M.B. 1154,
Benin City.

RE- PERMISSION TO UNDERTAKE RESEARCH IN SPECIAL SCHOOLS IN EKITI STATE

With reference to your letter dated 6th October, 2015 on the above subject, I am directed to convey approval to you to interview and administer questionnaires to teachers and professionals catering for children with special needs in the State.

02. I am further directed to add that information obtained from the schools should be strictly used for academic works and treated with utmost confidentiality.

Yinka Ajibola

For: Permanent Secretary

Appendix 7: Letter of approval to conduct research in Imo State

GOVERNMENT OF IMO STATE
IMO STATE UNIVERSAL BASIC EDUCATION BOARD *(IMSUBEB)*

Your Ref:
Our Ref:

P.M.B. 1500
Owerri, Imo State
Phone:

(All Replies To Be Addressed To The Executive Chairman)

IM/SUBEB/PER/42/109

4TH MAY, 2016

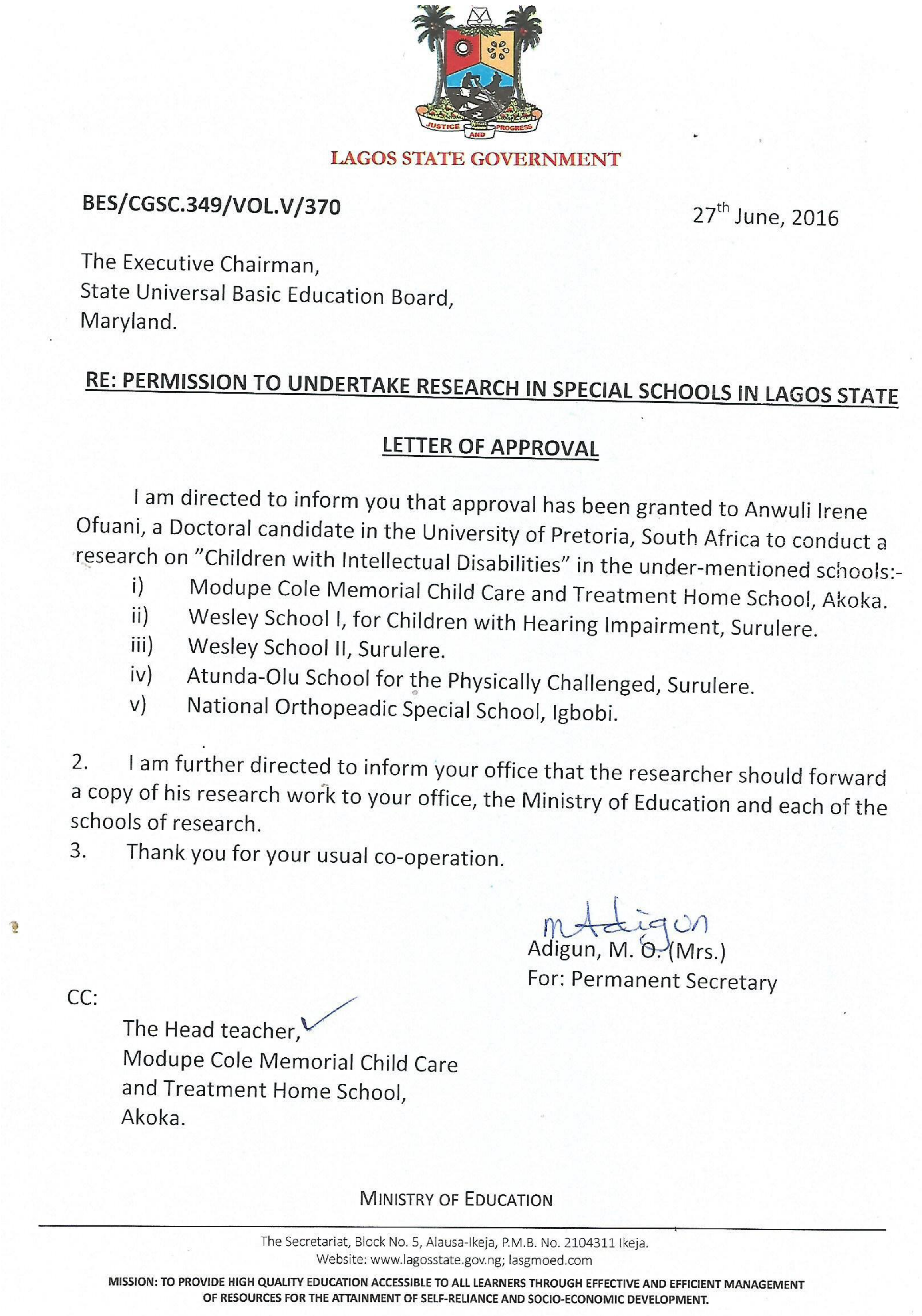
TO WHOM IT MAY CONCERN
RE: PERMISSION TO UNDERTAKE RESEARCH IN SPECIAL SCHOOLS IN IMO STATE

I am directed to refer to the above subject dated 28th April, 2016 and to inform you that the Board has authorized the bearer Anwuli Irene Ofuani to carry out a research in primary schools in your LGEA.

Please accord her with your usual assistance.

UKAGBA, S.I
DAS
FOR: EXECUTIVE CHAIRMAN

Appendix 8: letter of approval to conduct research in Lagos state



LAGOS STATE GOVERNMENT

BES/CGSC.349/VOL.V/370

27th June, 2016

The Executive Chairman,
State Universal Basic Education Board,
Maryland.

RE: PERMISSION TO UNDERTAKE RESEARCH IN SPECIAL SCHOOLS IN LAGOS STATE

LETTER OF APPROVAL

I am directed to inform you that approval has been granted to Anwuli Irene Ofuani, a Doctoral candidate in the University of Pretoria, South Africa to conduct a research on "Children with Intellectual Disabilities" in the under-mentioned schools:-

i) Modupe Cole Memorial Child Care and Treatment Home School, Akoka.
ii) Wesley School I, for Children with Hearing Impairment, Surulere.
iii) Wesley School II, Surulere.
iv) Atunda-Olu School for the Physically Challenged, Surulere.
v) National Orthopeadic Special School, Igbobi.

2. I am further directed to inform your office that the researcher should forward a copy of his research work to your office, the Ministry of Education and each of the schools of research.

3. Thank you for your usual co-operation.

mAdigun
Adigun, M. O. (Mrs.)
For: Permanent Secretary

CC:

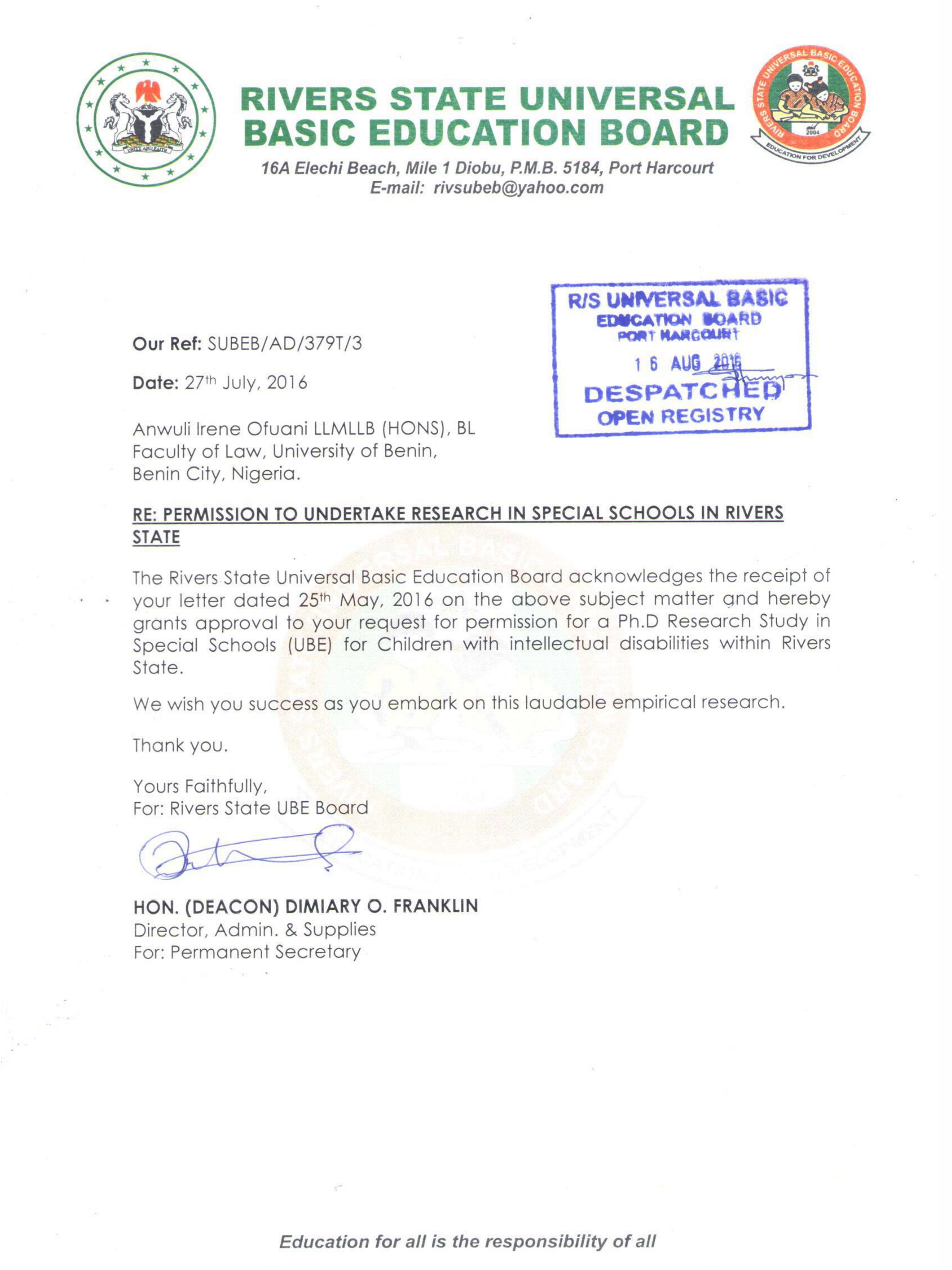
The Head teacher, ✓
Modupe Cole Memorial Child Care
and Treatment Home School,
Akoka.

MINISTRY OF EDUCATION

The Secretariat, Block No. 5, Alausa-Ikeja, P.M.B. No. 2104311 Ikeja.
Website: www.lagosstate.gov.ng; lasgmoed.com

MISSION: TO PROVIDE HIGH QUALITY EDUCATION ACCESSIBLE TO ALL LEARNERS THROUGH EFFECTIVE AND EFFICIENT MANAGEMENT OF RESOURCES FOR THE ATTAINMENT OF SELF-RELIANCE AND SOCIO-ECONOMIC DEVELOPMENT.

Appendix 9: Letter of approval to conduct research in Rivers State



RIVERS STATE UNIVERSAL BASIC EDUCATION BOARD

16A Elechi Beach, Mile 1 Diobu, P.M.B. 5184, Port Harcourt
E-mail: rivsubeb@yahoo.com

R/S UNIVERSAL BASIC
EDUCATION BOARD
PORT HARCOURT
16 AUG 2016
DESPATCHED
OPEN REGISTRY

Our Ref: SUBEB/AD/379T/3

Date: 27th July, 2016

Anwuli Irene Ofuani LLMLLB (HONS), BL
Faculty of Law, University of Benin,
Benin City, Nigeria.

RE: PERMISSION TO UNDERTAKE RESEARCH IN SPECIAL SCHOOLS IN RIVERS STATE

The Rivers State Universal Basic Education Board acknowledges the receipt of your letter dated 25th May, 2016 on the above subject matter and hereby grants approval to your request for permission for a Ph.D Research Study in Special Schools (UBE) for Children with intellectual disabilities within Rivers State.

We wish you success as you embark on this laudable empirical research.

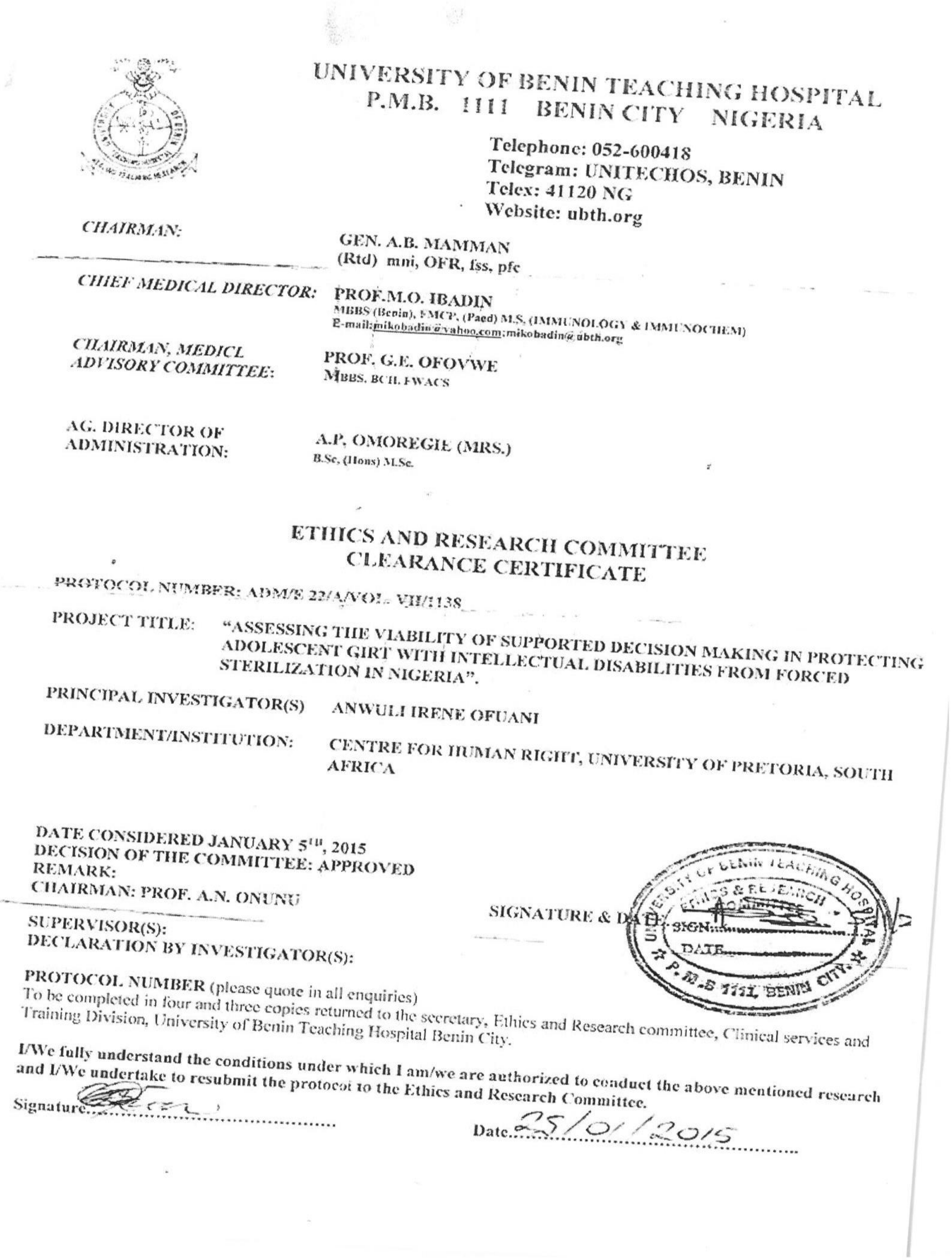
Thank you.

Yours Faithfully,
For: Rivers State UBE Board

HON. (DEACON) DIMIARY O. FRANKLIN
Director, Admin. & Supplies
For: Permanent Secretary

Education for all is the responsibility of all

Appendix 10: Letter of approval to conduct research in University of Benin Teaching Hospital



UNIVERSITY OF BENIN TEACHING HOSPITAL
P.M.B. 1111 BENIN CITY NIGERIA

Telephone: 052-600418
Telegram: UNITECHOS, BENIN
Telex: 41120 NG
Website: ubth.org

CHAIRMAN: GEN. A.B. MAMMAN (Rtd) mni, OFR, fss, pfc

CHIEF MEDICAL DIRECTOR: PROF.M.O. IBADIN
MBBS (Benin), FMCP, (Paed) M.S, (IMMUNOLOGY & IMMUNOCHEM)
E-mail:mikobadin@yahoo.com;mikobadin@ubth.org

CHAIRMAN, MEDICL ADVISORY COMMITTEE: PROF. G.E. OFOVWE
MBBS. BCH. FWACS

AG. DIRECTOR OF ADMINISTRATION: A.P, OMOREGIE (MRS.)
B.Sc, (Hons) M.Sc.

ETHICS AND RESEARCH COMMITTEE CLEARANCE CERTIFICATE

PROTOCOL NUMBER: ADM/E 22/A/VOL. VII/1138

PROJECT TITLE: "ASSESSING THE VIABILITY OF SUPPORTED DECISION MAKING IN PROTECTING ADOLESCENT GIRT WITH INTELLECTUAL DISABILITIES FROM FORCED STERILIZATION IN NIGERIA".

PRINCIPAL INVESTIGATOR(S) ANWULI IRENE OFUANI

DEPARTMENT/INSTITUTION: CENTRE FOR HUMAN RIGHT, UNIVERSITY OF PRETORIA, SOUTH AFRICA

DATE CONSIDERED JANUARY 5TH, 2015
DECISION OF THE COMMITTEE: APPROVED
REMARK:
CHAIRMAN: PROF. A.N. ONUNU

SIGNATURE & DATE:

SUPERVISOR(S):
DECLARATION BY INVESTIGATOR(S):

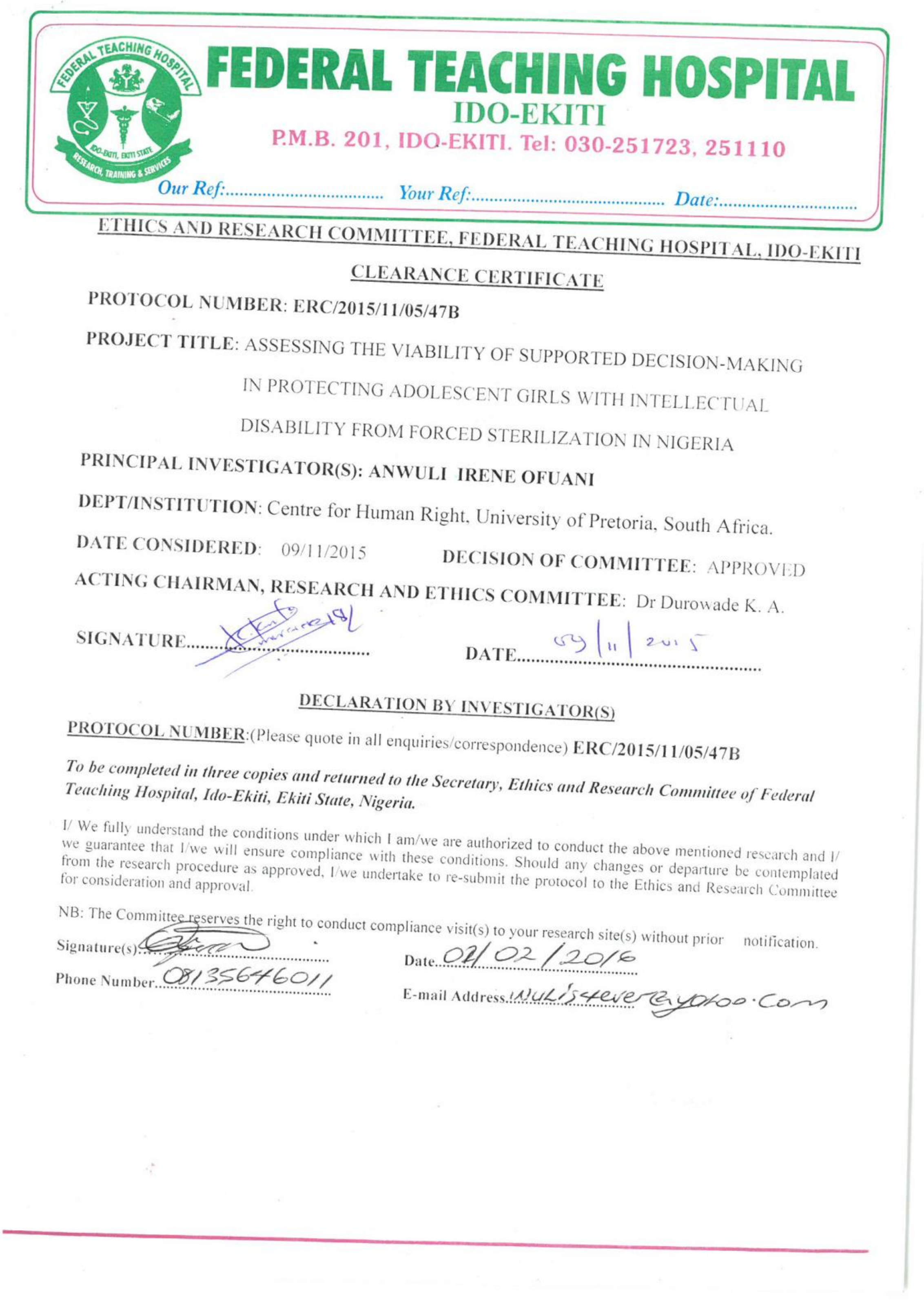
PROTOCOL NUMBER (please quote in all enquiries)
To be completed in four and three copies returned to the secretary, Ethics and Research committee, Clinical services and Training Division, University of Benin Teaching Hospital Benin City.

I/We fully understand the conditions under which I am/we are authorized to conduct the above mentioned research and I/We undertake to resubmit the protocol to the Ethics and Research Committee.

Signature……………………………………

Date 25/01/2015

Appendix 11: Letter of approval to conduct research in Federal Teaching Hospital



FEDERAL TEACHING HOSPITAL

IDO-EKITI

P.M.B. 201, IDO-EKITI. Tel: 030-251723, 251110

Our Ref:.................................. *Your Ref:*.. *Date:*..............................

ETHICS AND RESEARCH COMMITTEE, FEDERAL TEACHING HOSPITAL, IDO-EKITI

CLEARANCE CERTIFICATE

PROTOCOL NUMBER: ERC/2015/11/05/47B

PROJECT TITLE: ASSESSING THE VIABILITY OF SUPPORTED DECISION-MAKING IN PROTECTING ADOLESCENT GIRLS WITH INTELLECTUAL DISABILITY FROM FORCED STERILIZATION IN NIGERIA

PRINCIPAL INVESTIGATOR(S): ANWULI IRENE OFUANI

DEPT/INSTITUTION: Centre for Human Right, University of Pretoria, South Africa.

DATE CONSIDERED: 09/11/2015 **DECISION OF COMMITTEE:** APPROVED

ACTING CHAIRMAN, RESEARCH AND ETHICS COMMITTEE: Dr Durowade K. A.

SIGNATURE.................................... **DATE**..09 | 11 | 2015.............................

DECLARATION BY INVESTIGATOR(S)

PROTOCOL NUMBER:(Please quote in all enquiries/correspondence) **ERC/2015/11/05/47B**

To be completed in three copies and returned to the Secretary, Ethics and Research Committee of Federal Teaching Hospital, Ido-Ekiti, Ekiti State, Nigeria.

I/ We fully understand the conditions under which I am/we are authorized to conduct the above mentioned research and I/ we guarantee that I/we will ensure compliance with these conditions. Should any changes or departure be contemplated from the research procedure as approved, I/we undertake to re-submit the protocol to the Ethics and Research Committee for consideration and approval.

NB: The Committee reserves the right to conduct compliance visit(s) to your research site(s) without prior notification.

Signature(s)....................................

Date..02/ 02 /2016..........

Phone Number..08135646011

E-mail Address..inulis4ever@yahoo.com

Appendix 12: Letter of permission to conduct research within selected institutions

Dear Sir /Madam,

<u>RESEARCH ON SUPPORTED DECISION MAKING FOR ADOLESCENT GIRLS WITH INTELLECTUAL DISABILITIES</u>

I am a lecturer at the University of Benin, Nigeria and a PHD student at the University of the Pretoria, South Africa. I wish to request your permission to conduct my research within your institution. My research explores the perspectives of professionals working with adolescent girls with intellectual disabilities on the Convention on the Rights of Persons with disabilities (CRPD)'s concept of supported decision-making in relation to involuntary sterilisation.

I wish to administer questionnaires and interview teachers and other professionals in your school working with adolescent girls with intellectual disabilities within the age range of 13-18 years.

Attached to this letter is an information leaflet on the nature and purpose of the research and a head of institution consent form. As a confirmation of your permission to use your school/institution for my research, please fill and return the consent form to me.

Thank you.

Yours faithfully,

Anwuli Irene Ofuani

Student/researcher

Appendix 13: Head of institution consent form

I……………………………………………………………………the ………………………...
of ………………………………………………………………………………………………,
do hereby grant Anwuli Irene Ofuani permission to conduct her research in my school/institution.

I hereby confirm that I have been informed by the researcher about the nature, conduct, benefits and risks of the proposed research. I have also received, read and understood the above written information regarding the study.

Head of Institution’s name: ____

Head of Institution’s signature: ____

Witness’s name: ____

Witness’s signature: ____

Date: ____

Appendix 14: Participant information leaflet

Dear Participant

Title of project: The Viability of Supported Decision-Making in Protecting Adolescent Girls with Intellectual Disabilities from Non-therapeutic sterilisation in Nigeria

Introduction

You are invited to volunteer for a research study. This information leaflet is to help you decide if you would like to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the researcher. You should not agree to take part unless you are completely happy about all the procedures involved.

What is the purpose of the study?

The study forms part of a PhD research conducted by the researcher. The purpose of the study is to assess whether the Convention on the Rights of Person with Disabilities CRPD's concept of supported decision-making is viable in protecting adolescent girls with intellectual disabilities in terms of decision-making about sterilisation. In doing this, it would garner participants' opinions about intellectual disability, legal capacity, and the right to retain fertility and involuntary sterilisation of adolescent girls with intellectual disabilities.

The study forms part of a PhD research conducted by the researcher. It involves the administration of questionnaires and interview of doctors, teachers and other professionals working with adolescent girls with intellectual disabilities within the age range of 13-18 years as well as the parents of the girls. The study would be conducted in six states of Nigeria- Anambra, Edo, Ekiti, Imo, Lagos and Rivers states of Nigeria.

How will the study be conducted?

The study would involve the use of questionnaires on professionals working with adolescent girls with intellectual disabilities in selected schools such as teachers, nurses, speech therapists, physiotherapists, vocational teachers etc. as well as doctors in the residency programme in the selected teaching hospitals. Principals, headmistresses, head teachers, and consultant doctors would be interviewed to get their perspectives because of their teaching and medical experience.

What is the duration of the study?

The study would be conducted for a period of three months.

Has the study received ethical approval?

This research protocol was submitted to the Faculty of Law Research Ethics Committee, University of Pretoria, and written approval has been granted by the Committee. The study has been structured in accordance with ethical considerations such as the protection of the identity of all participants.

What are my rights as a research participant in this study?

Your participation in this research is entirely voluntary and you can refuse to participate or stop at any time without stating any reason. The investigator retains the right to withdraw you from the study if considered to be in your best interest.

May any of the research procedures result in any discomfort?

[No]

What are the benefits involved in the study?

The benefits of the study are as follows:

a. It would fill the gap in the literature on legal capacity and supported decision-making for adolescent girls with intellectual disabilities especially from the Nigerian context.
b. It would expand the present body of knowledge on supported decision-making for adolescent girls with intellectual disabilities in respect of medical procedures such as sterilisation.
c. It would promote awareness about the CRPD and its supported decision-making in Nigeria

Are there any restrictions concerning my participation in this study?

There are no restrictions concerning participation in the study.

Source of additional information

The study will be conducted by way of questionnaires and interviews by **Anwuli Irene Ofuani**. Should you have any questions, please do not hesitate to contact her. The telephone number is +2348135646011, through which you can reach her or another authorised person.

Confidentiality

All information obtained during the course of this research is strictly confidential. Data that may be reported in law or scientific journals will not include any information which identifies you as a participant in this study. Data / information will be published anonymously. No information will be disclosed to any third party without your written permission.

Appendix 15: Informed consent form

I hereby confirm that I have been informed by the researcher ______________________________ (state particulars) about the nature, conduct, benefits and risks of the proposed research. I have also received, read and understood the above written information (informed consent) regarding the study.

I am aware that the results of the study, including personal details regarding sex, age, marital status etc (state) of myself will be anonymously processed into the research report. (See in particular the definition of "personal information" in the Promotion of Access to Information Act 2 of 2000.)

I may, at any stage, without prejudice, withdraw my consent and participation in the study. I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

Participant's name: ______________________________

Participant's signature: ______________________________

I, ________________________ herewith confirm that the above participant has been informed fully about the nature and scope of the above study.

Investigator's name: ______________________________

Investigator's signature: ______________________________

Witness's name: ______________________________

Witness's signature: ______________________________

Date: ______________________________

Appendix 16: Consent to be recorded during interview

I hereby grant Anwuli Irene Ofuani permission to record the content of the interview.

I have read and understood the information letter. I understand that recordings and information about the participants will be granted confidentiality to the best of the researcher’s ability and that verbatim quotes might be used in the research findings, without reference to participants’ names.

Participant’s name: ____

Participant’s signature: ____

Investigator’s name: ____

Investigator’s signature: ____

Date: ____

Appendix 17: Questionnaire for professionals working with adolescent girls with intellectual disabilities

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Thank you for taking time to fill this questionnaire. The questionnaire is purely for research purpose. Your anonymous, honest response is highly appreciated. Please be assured that all information supplied will be kept strictly confidential.

SECTION A: PERSONAL INFORMATION

1. Gender: Male [ ] Female [ ]
2. Marital Status: Single [ ] Married [ ] Divorced [ ] Widowed [ ]
3. Age range: 18-25 [ ] 26-35 [ ] 36-45 [ ] 46-55 [ ] 55-64 [ ] 65 and above [ ]
4. Educational Qualification: SSCE[ ] OND [ ] HND [ ] NCE [ ] First Degree [ ] Masters [ ]
   Others [……..………………………………………………………………………………………………………]
5. Occupation: ……………………………………………………………………………………..................................
6. Employment: Private employment [ ] Public servant [ ] Civil servant [ ]

SECTION B: INTELLECTUAL DISABILITY AND INVOLUNTARY STERILISATION

7. Do you have formal training on intellectual disability: None [ ] Medical Training [ ] Special Education [ ]
Others […………………………………………………………………]

8. Which of these do you believe is the cause of intellectual disability? Biological causes [ ] Medical negligence [ ]
Parental negligence [ ] Illness during Pregnancy [ ] Witchcraft [ ] Demonic Possession [ ] Accident [ ]
Anger of the gods [ ] Disease [ ] Others [please specify ...…...……………………………………………………..]

9. Have you heard of situations where adolescent girls with intellectual disabilities have been sterilised without their knowledge or will? Yes [ ] No [ ]

10. Do you believe a girl with intellectual disability should be sterilised for any of the following reasons:
    a) To prevent her from giving birth to children with intellectual disability? Yes [ ] No [ ]
    b) If her parents are financially incapable of taking care of her or her child? Yes [ ] No [ ]
    c) If she gets pregnant once? Yes [ ] No [ ]
    d) If she gets pregnant twice? Yes [ ] No [ ]
    e) If she gets pregnant three times and above? Yes [ ] No [ ]
    f) To prevent her from being sexually abused? Yes [ ] No [ ]
    g) To prevent un-cleanliness during menstruation? Yes [ ] No [ ]
    h) To avoid fears about menstruation/blood? Yes [ ] No [ ]

SECTION C: CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (CRPD)

11. Have you heard about the Convention on the Rights of Persons with Disabilities (CRPD)? Yes [ ] No [ ]

12. If yes, how did you hear about the CRPD? Media[ ] Work[ ] Friends[ ] Internet[ ] Others [ ]

13. Have you heard about CRPD's concept of "supported decision-making"? Yes [ ] No [ ]

14. If your answer to question 13 is yes, what do you understand "supported decision-making" to mean? ....
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SECTION D: LEGAL CAPACITY AND SUPPORTED DECISION-MAKING

15. In your professional opinion, do adolescent girls with intellectual disabilities have the right to make medical decisions in Nigeria? Yes [ ] No [ ]

16. If your answer to question 15 is no, who makes the decisions for them? Parents [ ] Guardians [ ]
Siblings [ ] Doctors [ ] Teachers [ ]

17. Please indicate by ticking the option that applies to you -SA=Strongly agree; A=Agree; SD=Strongly disagree; D=Disagree

S/N		A	SA	D	SD
(a)	Adolescent girls with intellectual disabilities have a right to give birth to children				
(b)	Parents should make medical decisions for their daughters with intellectual disabilities				
(c)	Parents should make decisions about contraception for their daughters with intellectual disabilities				
(d)	Parents should make decisions about sterilisation for their daughters with intellectual disabilities				
(e)	Parents should involve, inform and consult their adolescent daughters with intellectual disabilities when making medical decisions for them				

(f)	Parents should involve, inform and consult their adolescent daughters with intellectual disabilities when making decisions about contraception for them				
(g)	Parents should involve, inform and consult their adolescent daughters with intellectual disabilities when making decisions about sterilisation for them				

18. Please indicate by ticking the option(s) that applies to you.

S/N		If the disability is mild	If the disability is moderate	If the disability is severe	If the disability is profound	Not at all
(a)	Adolescent girls with intellectual disabilities should be given the opportunity to give birth to children					
(b)	Adolescent girls with intellectual disabilities have the capacity to make medical decisions on their own					
(c)	Adolescent girls with intellectual disabilities have the capacity to make medical decisions if they are given appropriate support					
(d)	Adolescent girls with intellectual disabilities are capable of taking care of their children if they are given appropriate support					
(e)	Adolescent girls with intellectual disabilities can make decisions about contraception if they are given appropriate support					
(f)	Adolescent girls with intellectual disabilities can make decisions about undergo sterilisation if they are appropriate given support					
(g)	Sterilisation is a suitable contraceptive option for adolescent girls with intellectual disabilities					

19. Do you believe that with age appropriate support adolescent girls with intellectual disabilities can make decisions about contraception including sterilisation, in Nigeria? Yes [ ] No [ ]

20. Please state the reason for your answer to question 19 above.

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Appendix 18: Questionnaire for parents of adolescent girls with intellectual disabilities

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Thank you for taking time to fill this questionnaire. The questionnaire is purely for research purpose. Your anonymous, honest response is highly appreciated. Please be assured that all information supplied will be kept strictly confidential.

SECTION A: PERSONAL INFORMATION

1. Gender: Male [ ] Female [ ]
2. Marital Status: Single [ ] Married [ ] Divorced [ ] Widowed [ ]
3. Age range: 18-25 [ ] 26-35 [ ] 36-45 [ ] 46-55 [ ] 55-64 [ ] 65 and above [ ]
4. Educational Qualification: SSCE[ ] OND [ ] HND [ ] NCE [ ] First Degree [ ] Masters [ ]
   Others [……..…….………………………………………………………………………………………….]
5. Occupation: …………………………………………………………………………………….....................................
6. How old is your child? 13 [ ] 14 [ ] 15 [ ] 16 [ ] 17 [ ] 18 [ ]

SECTION B: INTELLECTUAL DISABILITY AND INVOLUNTARY STERILISATION

7. How would you describe your child’s disability? Minor [ ] Not too Serious [ ] Serious [ ] Very Serious [ ]
8. Which of these do you believe is the cause of your child’s disability? Biological causes [ ] Medical negligence [ ] Parental negligence [ ] Illness during Pregnancy [ ] Witchcraft [ ] Demonic Possession [ ] Anger of the gods [ ] Accident [ ] Disease [ ] Others [please Specify ...………………………………..…….…….….…….………………………………………………………….]
9. Have you heard of situations where adolescent girls with intellectual disabilities have been sterilised without their knowledge or will? Yes [ ] No [ ]
10. Would you sterilise your daughter for any of the following reasons:
    a) To prevent her from giving birth to children with intellectual disability? Yes [ ] No [ ]
    b) If her parents are financially incapable of taking care of her or her child? Yes [ ] No [ ]
    c) If she gets pregnant once? Yes [ ] No [ ]
    d) If she gets pregnant twice? Yes [ ] No [ ]
    e) If she gets pregnant three times and above? Yes [ ] No [ ]
    f) To prevent her from being sexually abused? Yes [ ] No [ ]
    g) To prevent un-cleanliness during menstruation? Yes [ ] No [ ]
    h) To avoid fears about menstruation/blood? Yes [ ] No [ ]

SECTION C: CONVENTION FOR THE RIGHTS OF PERSONS WITH DISABILITIES (CRPD)

11. Have you heard about the Convention for the Rights of Persons with Disabilities (CRPD)? Yes [ ] No [ ]
12. If yes, how did you hear about the CRPD? Media[ ] Work[ ] Friends[ ] Internet[ ] Others [ ]
13. Have you heard about CRPD’s concept of “supported decision-making”? Yes [ ] No [ ]
14. If your answer to question 13 is yes, what do you understand “supported decision-making” to mean?
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SECTION D: LEGAL CAPACITY AND SUPPORTED DECISION-MAKING

15. Please indicate by ticking the option that applies to you -SA=Strongly agree; A=Agree; SD=Strongly disagree; D=Disagree

S/N		**A**	**SA**	**D**	**SD**
(a)	My daughter has a right to give birth to children				
(b)	My daughter should be given the opportunity to give birth to children				
(c)	My daughter has the ability to make medical decisions on her own				

(d)	My daughter has the ability to make medical decisions if she is given appropriate support				
(e)	My daughter is capable of taking care of her children if she is given appropriate support				
(f)	My daughter can make decisions about contraception if she is given appropriate support				
(g)	I should make medical decisions for my daughter				
(h)	I should make decisions about contraception for my daughter				
(i)	I should make decisions about sterilisation for my daughter				
(j)	I should involve, inform and consult my daughter when making medical decisions for her				
(k)	I should involve, inform and consult my daughter when making decisions about contraception for her				
(l)	1should involve, inform and consult my daughter if I make decisions about sterilisation for her				
(m)	Sterilisation is a suitable contraceptive option for my daughter				

16. Do you believe that with age appropriate support adolescent girls with intellectual disabilities can make decisions about contraception, including sterilisation, in Nigeria? Yes [ ] No [ ]

17. Please state the reason for your answer to question 16 above.

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Appendix 19: Semi-structured interview schedule

1. **Background Questions**

- How old are you?
- Are you married?
- What is your educational qualification? (Prompts: NCE, Degree, MBBS etc)
- What is your job description? (prompts: What is that you do here)
- What type of employment are engaged in? (Prompts: private, civil service, Public service)
- How long have you worked here?
- Do you have formal training in working with children with intellectual disabilities? If yes what type of training?

2. **Intellectual disability and involuntary sterilisation**

- What do you think causes intellectual disability?
- Have you heard or do you know of situations where adolescent girls have been sterilised? Please can you shed light on what you heard or know?
- Do you believe that adolescent girls with intellectual disabilities have the right to bear children?
- Do you believe they should be allowed to give birth to children?
- Do you believe they are capable of taking care of their children?
- Do you believe that sterilisation is a suitable contraceptive method for adolescent girls with intellectual disabilities? (Prompts: do you think they should be sterilised to prevent pregnancy? (why/why not?)
- Do you believe the sterilisation of a girl with intellectual disability is justified in any of the following circumstances? -
    i. To prevent her from giving birth to children with intellectual disability?
    ii. If her parents are financially incapable of taking care of her or her child?
    iii. If she gets pregnant once?
    iv. If she gets pregnant twice?
    v. If she gets pregnant three times and above?
    vi. To prevent her from being sexually abused?
    vii. To prevent un-cleanliness during menstruation?
    viii. To avoid fears about menstruation/blood?

3. **Convention on the Rights of Persons with Disabilities (CRPD)**

- Have you heard about the Convention for the Rights of Persons with Disabilities (CRPD)? How did you hear about it?
- Have you heard about CRPD's concept of "supported decision-making"? What do you understand it to mean?

4. **Legal Capacity**

- Do you believe that adolescent girls with intellectual disabilities can make medical decisions? (Prompts: is their disability a factor?)
- Do you believe that they can make decisions about contraception? Do you believe they can make decisions about whether or not they can be sterilised?
- Do you believe they should make such decisions about contraception and sterilisation?

- In your experience as a teacher/doctor, do they have the right to legal capacity? (prompt: are they allowed to make such decisions in school or in hospitals? Who makes the decisions for them?)

5. **Supported Decision-Making**

I had told you earlier about the CRPD's concept of supported decision-making.

- Do you believe with support adolescent girls with intellectual disabilities can take care of their children?
- Do you believe that with appropriate support they can make medical decision? Do you believe with appropriate support they can make decisions about contraception? Sterilisation?
- In your experience as a teacher/doctor, are they supported in decision making in the school/hospitals?
- Do you think that supported decision-making is viable in Nigeria for adolescent girls with intellectual disabilities?

THANK YOU VERY MUCH FOR YOUR TIME