

**RECOGNISING THE SEXUAL AUTONOMY OF ADULT WOMEN WITH MILD
DOWN SYNDROME IN SOUTH AFRICA: RE-THINKING VULNERABILITY**

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DECLARATION

I declare that this thesis, ‘Recognising the sexual autonomy of adult women with mild Down syndrome in South Africa: Re-thinking vulnerability,’ which I hereby submit for the degree of Doctor of Laws (LL.D) at the Faculty of Law, University of Pretoria, is my work and has not been previously submitted by me for a degree at this or any other tertiary institution.

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DEDICATION

I dedicate this work to my wonderful daughter, Kaylan Grace, who inspires me to do better.

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The Almighty God who has given me the strength to see this through to the end. Although the journey has not been easy, God has been my ever-present help and comfort.

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ABSTRACT

In South Africa, the Sexual Offences Act protects people from unwanted sexual activity through the crime of rape, and simultaneously respects their sexual decision-making capacity by only criminalising sexual activity that takes place in the absence of consent. For persons with mental disabilities, including mid Down syndrome, the courts determine capacity to consent by questioning how much an individual with such a disability understands about the nature of the sexual act and its reasonably foreseeable consequences, an approach known as the ‘capacity framework.’ Under the ‘capacity framework,’ only those women whose disability meets the stipulated severity threshold will be deemed as lacking capacity to give valid legal consent to sexual intercourse. The law therefore, recognises that some women with mild Down syndrome can give valid legal consent to sexual intercourse. This approach is more progressive compared to the ‘status framework’ adopted in Malawi, Uganda and Zambia, which criminalises sexual activity with all women and girls with intellectual disabilities regardless of the severity of the disability.

This study argues that the ‘capacity framework’ is problematic because it fails to recognise the universal legal capacity of all women with mild Down syndrome to consent to sexual intercourse, in contravention of article 12 (2) of the Convention on the Rights of Persons with Disabilities (CRPD). Article 12 (2) provides that all persons with disabilities have universal legal capacity in all aspects of life, including sexual decision-making. The ‘capacity framework’ therefore perpetuates the de-sexualisation of women with mild Down syndrome. Although the ‘capacity framework’ is used as a starting point, the study recognises that the de-sexualisation of women with mild Down syndrome is not a legal problem that can be addressed by merely critiquing and amending the law, but a wider societal issue. In this context, the law is merely an instrument of cultural expression. The study’s main focus therefore, is on the interrogation of societal systems, institutions and practices that have led to the de-sexualisation of women with mild Down syndrome.

Accordingly, this study argues for a re-conceptualisation of the ‘capacity framework’ through the application of Martha Fineman’s vulnerability analysis, which expands the scope of inquiry beyond individual impairment to include wider societal factors. The study also deploys the support paradigm found in article 12 (3) of the CRPD as well as de-colonial theory to formulate ways of enhancing the sexual decision-making capacity of women with mild Down syndrome through the provision of support that is tailored specifically for the South African context. Moreover, using Michel Foucault’s genealogical theory, the study explains how relations of

power have, over time, produced our current knowledge about the sexuality and sexual identity of women with mild Down syndrome and how power can also be utilised to change the narrative in favour of the recognition of their sexual autonomy.

LIST OF ACRONYMS

AAC	Augmentative and Alternative Communication
AAIDD	American Association on Intellectual and Developmental Disabilities
CEDAW	Convention on the Elimination of all Forms of Discrimination against Women
CERD	Convention on the Elimination of Racial Discrimination
CRC	Convention on the Rights of the Child
CRMW	Convention on the Rights of Migrant Workers
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled People's Organisation
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ILRC	Irish Law Reform Commission
IQ	Intelligence quotient
LGBT	Lesbian, gay, bisexual and transgender
MCA	Mental Capacity Act
PEPUDA	Promotion of Equality and Prevention of Unfair Discrimination Act
STD	Sexually transmitted disease
UDHR	Universal Declaration of Human Rights
WHO	World Health Organisation

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CHAPTER ONE

INTRODUCING INTELLECTUAL DISABILITY AND CAPACITY TO CONSENT TO SEXUAL INTERCOURSE

Sexual regulation in the context of mental disability ... presents tough questions with high stakes and an abundance of legal uncertainty for policymakers, courts, and scholars to address.¹

1. Background

The universality of sexuality is a contentious notion, characterised by divergent views on who is sexually autonomous. Autonomous action is ‘the action of agents who can understand and choose what they do.’² In the realm of sexual relationships, the autonomous individual can control his or her sexuality and has a right to determine when, with whom, and under what circumstances to engage in sexual activity.³ The pertinent question becomes, who is autonomous? Ideally, autonomy ‘is a threshold phenomenon’ and we ‘go from not having it to having it on the basis of the level of development of certain capacities.’⁴ That is to say, that everyone ought to be deemed autonomous by virtue of having reached a certain age.⁵ However, this is not the case for certain population groups such as persons with intellectual disabilities whose sexual self-determination is consistently questioned due to the nature of their disability.⁶ It is, therefore, crucial to interrogate the meaning of the term ‘intellectual disability’ before engaging with the discourse around the sexual autonomy of persons with intellectual disabilities.

1.1 Understanding intellectual disability

The intellectual disability construct has been influenced by the paradigm shift that has occurred in the past thirty years in relation to the concept of disability.⁷ Several value-laden models of disability have been formulated and have influenced definitions of disability, provided explanations of causal attribution and responsibility attribution, guided policy formulation and

¹ JE Harris ‘Sexual consent and disability’ (2018) 93 *New York Law Review* at 499.

² A O’Neill ‘Paternalism and partial autonomy’ (1984) 10 *Journal of Medical Ethics* at 173.

³ GH Murphy ‘Capacity to consent to sexual relationships in adults with learning disabilities’ (2003) 29(3) *Journal of Family Planning and Reproductive Health Care* at 148 – 149.

⁴ A Sneddon *Autonomy* (2013) 12.

⁵ S Foley *Intellectual disability and the right to a sexual life: A continuation of the autonomy/paternalism debate* (2018) 39.

⁶ Foley (n 5) 36.

⁷ ML Wehmeyer et al ‘The intellectual disability construct and its relation to human functioning’ (2008) 46(4) *Intellectual and Developmental Disabilities* at 312.

implementation and shaped the identity of persons with disabilities.⁸ For the purposes of the present study, the medical model and the social model of disability are most significant.⁹ The medical model espouses the idea that disability is ‘a medical problem that resides in the individual.’¹⁰ Conversely, the social model accepts the idea that disability is not inherent in the individual, but is a social construct.¹¹ An early version of the social model was criticised for appearing to claim that disability is entirely a social construct and that impairment makes no contribution to the disabling of people.¹² Tremain rightly argues that impairment does contribute to disablement. For instance, black people cannot be classified as persons with disabilities simply because the environment causes them to experience social disadvantage.¹³ Rather, only people with impairments can be classified as persons with disabilities, therefore it is ‘implicit’ that impairment also contributes to the disadvantaging.¹⁴ Similarly, the Convention on the Rights of Persons with Disabilities (CRPD) acknowledges the roles played by both impairment and the environment.¹⁵ The social model is significant not only because it alters perceptions about the cause of disability but also because it changes ideas about the appropriate solutions or interventions. Under the medical model, the goals of intervention are cure, amelioration of the physical condition to the greatest extent possible, and rehabilitation.¹⁶ However, under the social model, ‘any meaningful solution must be directed at societal change rather than individual adjustment and rehabilitation.’¹⁷

The conceptual shift that has taken place in relation to the concept of disability has also influenced the construct of intellectual disability. The most widely used definition of the term ‘intellectual disability’ is that provided by the American Association on Intellectual and Developmental Disabilities (AAIDD). The AAIDD defines an intellectual disability as a disability ‘characterized by significant limitations both in intellectual functioning and in

⁸ M Retief & R Letšosa ‘Models of disability: A brief overview’ (2018) 74(1) *Theological Studies* at 1.

⁹ Other models of disability include the moral and/or religious model, the identity model, the human rights model, the cultural model, the charity model and the economic model: Retief & Letšosa (n 8) 1.

¹⁰ R Olkin *What psychotherapists should know about disability* (1999) 26.

¹¹ C Barnes et al ‘The social model of disability’ in A Giddens & P Sutton (eds) *Sociology: Introductory readings* (2010) at 163. See also R Traustadottir ‘Disability studies, the social model and legal developments’ in OM Arnardottir & G Quinn (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian perspectives* (2009) at 9.

¹² S Tremain ‘Foucault, governmentality, and critical disability theory: An introduction’ in S Tremain (ed) *Foucault and the government of disability* (2005) at 9-10.

¹³ As above.

¹⁴ As above.

¹⁵ Preamble para e Convention on the Rights of Persons with Disabilities (CRPD), adopted and opened for signature, ratification and accession by General Assembly resolution 61/06 on 13 December 2006 and entered into force on 3 May 2008.

¹⁶ Olkin (n 10) 26.

¹⁷ Barnes et al (n 11) 163.

adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.¹⁸ The three important aspects of this definition is that persons with intellectual disabilities have significant limitations in intellectual functioning, significant limitations in adaptive behaviour, and both are present before the age of 18. The term intellectual functioning/reasoning refers to ‘general mental capacity and involves the ability to reason, plan, solve problems, think abstractly, comprehend complex ideas, learn quickly, and learn from experience.’¹⁹ Intellectual functioning can be measured using an intelligence quotient (IQ) test.²⁰ Varying levels of intellectual disability distinguished using IQ test scores include mild, moderate and severe intellectual disability. Individuals with mild intellectual disabilities have an IQ level of between 55 and 69.²¹ Persons with moderate intellectual disabilities have an IQ level of between 40-54.²² Those with severe intellectual disabilities have an IQ level below 40.²³ The term ‘adaptive behaviour’ refers to the ‘collection of age-appropriate conceptual, social, and practical skills that are learned and performed by people in their everyday lives.’²⁴

The World Health Organisation (WHO) defines an intellectual disability in a similar manner to the AAIDD. An intellectual disability is defined as a:

significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.²⁵

The World Health Organisation’s definition of an intellectual disability, much like that of the AAIDD also factors in the social environment.

There is, however, an important distinction between an operational definition and a constitutive definition.²⁶ An operational definition sets parameters for diagnosticians to

¹⁸ RL Schalock et al *Intellectual disability: Definition, classification, and systems of supports* (2010) 47.

¹⁹ Foley (n 5) 2.

²⁰ MJ Tasse et al ‘The construct of adaptive behavior: Its conceptualization, measurement, and use in the field of intellectual disability’ (2012) 117(4) *American Journal on Intellectual and Developmental Disabilities* at 303.

²¹ AH Bittles et al ‘The influence of intellectual disability on life expectancy’ (2002) 57 *Journal of Gerontology* at 470.

²² As above.

²³ As above.

²⁴ Foley (n 5) 2.

²⁵ World Health Organisation ‘Definition: Intellectual Disability’ <http://www.euro.who.int> (accessed 1 April 2020).

²⁶ JR Thompson et al ‘Conceptualizing supports and the support needs of people with intellectual disability’ (2009) 47(2) *Intellectual and Developmental Disabilities* at 135.

consistently observe and record evidence of the disability whilst a constitutive definition helps us better understand the theoretical underpinnings of the construct.²⁷ The operational definition of the term ‘intellectual disability’ has remained unchanged over time in that limitations in intellectual functioning and adaptive behavior present before the age of 18 years continue to constitute evidence of the existence of an intellectual disability.²⁸ However, the constitutive definition of intellectual disability has changed in response to the change in the manner in which disability is understood as a social construct.²⁹ The change in the constitutive definition of intellectual disability is exemplified in the change in terminology. Throughout history, intellectual disability has been referred to using different terms, all of which provided a descriptive label exemplifying the underlying concept.³⁰ Intellectual disabilities used to be known by other names including ‘mental deficiency’, ‘mental subnormality,’ and ‘mental retardation’.³¹ All of these terms had a common theoretical assumption, which is that disability was inherent in the individual and that it constituted deficit.³² Wehmeyer and others explain this succinctly when they state that:

To have mental retardation was to be defective. The loci of that defect was the mind... The nature of the defect of the mind (mental deficiency) was inferior mental performance (mental subnormality) characterized by mental slowness (mental retardation).³³

‘Mental deficiency’ was diagnosed from a discrepancy between chronological age and mental age, a concept which, as will be shown below, is problematic.³⁴ In response to the developments in relation to the concept of disability, the AAIDD subsequently changed the name of the disability from ‘mental retardation’ to intellectual disability in 1992.³⁵ The fundamental difference between the construct underlying ‘mental retardation’ and intellectual disability is where the disability resides.³⁶ ‘Mental retardation’ viewed the disability as a defect inherent within the person whereas intellectual disability viewed the disability as the ‘fit between the person’s capabilities...and the context in which the person functioned.’³⁷ The significance of

²⁷ As above.

²⁸ As above.

²⁹ Wehmeyer et al (n 7) 312.

³⁰ As above

³¹ As above.

³² As above.

³³ As above.

³⁴ Wehmeyer et al (n 7) 313.

³⁵ As above.

³⁶ As above.

³⁷ Wehmeyer et al (n 7) 314.

this conceptual shift is that it requires a different approach in which society does not try to fix the individual but provides supports to improve human functioning.³⁸

This study focuses on one specific type of intellectual disability, namely adults with Down syndrome. Unlike persons with other intellectual disabilities, persons with Down syndrome have distinct facial features. Goffman describes this as a ‘spoiled identity.’³⁹ Their appearance has a psychological impact on others in that when they look at them they are reminded of their disability and at no point can this fact be forgotten.⁴⁰ They are therefore, always perceived as lacking capacity for sexual self-determination. Most persons with Down syndrome fall within the mild intellectual disability category.⁴¹ For this reason, this research will focus on persons with Down syndrome who fall within the mild intellectual disability category. The terms mild intellectual disability and mild Down syndrome are used interchangeably throughout this research in the light of the fact that persons with Down syndrome also have intellectual disabilities. This does not mean that Down syndrome is synonymous with mild intellectual disability, but rather that, the scope of inquiry is limited to persons with Down syndrome whose intellectual disability falls within the mild category.

It should be noted however, that domestic legislation such as South Africa’s Criminal Law (Sexual Offences and Related Matters) Amendment Act, hereinafter, the Sexual Offences Act, uses the term ‘mental disabilities’ to refer to disabilities affecting mental faculties, including intellectual disabilities.⁴² This study will make reference to provisions from the Sexual Offences Act and where the term ‘mental disabilities’ is used it refers to persons with intellectual disabilities or specifically, mild Down syndrome. Having explained the intellectual disability construct, the study will now turn to the discourse on the sexual agency of adults with mild Down syndrome.

1.2 Misconceptions influencing the de-sexualisation of women with Down syndrome

Adults with mild Down syndrome experience a process of de-sexualisation that involves the failure to recognise and the denial of their sexual agency/autonomy. Three misconceptions have had a particularly harmful influence on society’s perception of the sexual agency of adults with

³⁸ Wehmeyer et al (n 7) 317.

³⁹ E Goffman *Stigma: Notes on the management of spoiled identity* (1990) 3.

⁴⁰ M Shildrick *Dangerous discourses of disability, subjectivity and sexuality* (2009) 39.

⁴¹ Murphy (n 3) 10.

⁴² Criminal Law (Sexual Offences and Related Matters) Amendment Act (Act 32 of 2007).

mild Down syndrome. The first misconception is that persons with mild Down syndrome are perpetual children; the second is that they are asexual and the third is that they are hypersexual.

Society consistently perceives persons with mild Down syndrome as perpetual children – a phenomenon Foley refers to as the ‘Peter Pan subject position.’⁴³ Even when they reach adulthood, they continue to be infantilised and treated as though they are still children.⁴⁴ This stereotype is embedded in the construct of mental or developmental age commonly used in sexual assault prosecutions involving persons with mild Down syndrome.⁴⁵ The concept of mental age was developed during the dispensation of the ‘mental retardation’ paradigm, which viewed the disability as innate in the individual. In spite of the paradigm shift exhibited in the intellectual disability construct the concept of mental age is still in use. Typically, a medical professional will estimate an adult’s mental or developmental age in an effort to help the court to understand the extent of a person’s mental ability. More often than not, the person’s mental age is equated to that of a child. For instance, an adult may have the biological age of 30 years and be said to have the mental or developmental age of a six-year-old child. Mental or developmental age may be helpful in clarifying ability such as mathematical ability, but it is not helpful in understanding persons with mild Down syndrome.⁴⁶ An adult with the mental age of a six-year-old, for example, is not the same as a six-year-old.⁴⁷ Adults have undergone hormonal changes and life experiences that six-year-olds have not.⁴⁸ The concept of mental or developmental age places emphasis on what the person cannot do as opposed to what they can do.⁴⁹ Therefore, it does not holistically describe an adult with an intellectual disability.⁵⁰ Instead, it results in the infantilisation of adults with intellectual disabilities and their eventual de-sexualisation.⁵¹ If an adult is analogous to a six-year-old child, then any sexual activity may be characterised as inappropriate.⁵² Foley summarises the position succinctly when he states that ‘to be intellectually disabled is to be infantilised and to be infantilised is to be desexualised.’⁵³

⁴³ Foley (n 5) 1.

⁴⁴ As above.

⁴⁵ J Benedet & I Grant ‘More than an empty gesture: Enabling women with mental disabilities to testify on promise to tell the truth’ (2013) 25 *Canadian Journal of Women and Law* at 52.

⁴⁶ Benedet & Grant (n 45) 51.

⁴⁷ D Msipa ‘Survivors of sexual assault with intellectual disabilities: Accommodating difference in the courtroom’ LLM thesis, McGill University, 2014 at 100 (on file with the author).

⁴⁸ As above.

⁴⁹ Benedet & Grant (n 45) 51.

⁵⁰ As above.

⁵¹ Benedet & Grant (n 45) 50.

⁵² Benedet & Grant (n 45) 52.

⁵³ Foley (n 5) 1.

The second misconception about persons with mild Down syndrome is that they are asexual, lacking both the capacity for sexual feeling and the right to sexual expression.⁵⁴ This misconception results in the denial of and failure to recognise the sexual agency of persons with intellectual disabilities. If they are asexual, then there is no need for them to engage in any form of sexual activity. At the other extreme, it is also mistakenly believed that persons with intellectual disabilities are hypersexual with an uncontrollable sex drive.⁵⁵ If they are hypersexual, their sex drive has to be curbed and their sexual activities limited or prohibited. These three misconceptions result in the de-sexualisation of adults with mild Down syndrome. For if they are asexual or hypersexual perpetual children, then their sexual activities need to be regulated and controlled by others at all times for their own ‘protection.’⁵⁶

1.3 The institutionalisation of de-sexualisation through the criminal law concept of capacity to consent

The de-sexualisation of persons with intellectual disabilities is so pervasive that it transcends societal boundaries and is replicated in legal concepts that are applied in a manner that perpetuates this de-sexualisation. The criminal law concept of capacity to consent to sexual activities is one such legal concept. The law generally criminalises sexual acts between adults in circumstances where there is lack of consent on the part of one of the individuals involved.⁵⁷ However, if both parties consented to the sexual activity, then no crime will have been committed.⁵⁸ Persons with mild Down syndrome are regarded as lacking the capacity to consent to sexual activities.⁵⁹ This position is the mirror image of the widely held cultural philosophies about sexuality and intellectual disability. The criminal law in this context is an instrument of cultural expression. The study’s main focus, therefore, is not on the criminal law *per se*, but on the wider cultural philosophies influencing and displayed in the criminal law concept of capacity to consent to sexual intercourse. The study will challenge the de-sexualisation of women with mild Down syndrome that is fuelled by cultural misconceptions and stereotypes and argue for the recognition of their sexual autonomy. Because the concept

⁵⁴ H Brown “‘An ordinary sexual life?’”: A review of the normalisation principle as it applies to the sexual options of people with learning disabilities’ (1994) 9(2) *Disability and Society* at 132.

⁵⁵ As above.

⁵⁶ Harris (n 1) 495. These misconceptions (asexuality, hypersexuality and perpetual infancy) are typically associated with all forms of intellectual disability, not just Down syndrome. Therefore, they are applicable not only to women with mild Down syndrome, but also to women with other forms of intellectual disabilities.

⁵⁷ Sexual Offences Act (n 42).

⁵⁸ Legal Exceptions to this rule include incest and, in some countries, homosexual relationships. Current laws in many jurisdictions criminalise these types of relationships regardless of the presence of consent from both parties.

⁵⁹ Sexual Offences Act sec 57.

of consent to sexual intercourse is most relevant in rape trials and the majority of victims in rape trials are women, this research will focus primarily on women with mild Down syndrome in South Africa.⁶⁰ Post-1994 South Africa has been chosen as the jurisdictional focus because it is uniquely positioned as a jurisdiction that has made significant strides in overcoming its history of inequality dating back to the apartheid era and embracing a juridical transformation in harmony with the principles of substantive equality.⁶¹ South Africa's legislative framework and comprehensive equality jurisprudence pave the way for a thorough and meaningful discussion.

There are global and regional International Human Rights Law instruments containing provisions that are relevant to the recognition of the sexual autonomy of women with mild Down syndrome. These are the CRPD at the global level and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities (African Disability Protocol) at the regional level.⁶² The study will however, make reference primarily to the CRPD because South Africa ratified the CRPD on 30 November 2007 but has not yet ratified the African Disability Protocol.⁶³ Therefore, South Africa has an obligation to protect, fulfil and respect the rights in the CRPD. Moreover, the African Disability Protocol is not yet in force because it has not received the fifteen ratifications necessary for it to come into force in accordance with its article 38. The study refers primarily to the CRPD because, in any event, the African Disability Protocol frames rights in a substantially similar manner to the CRPD.⁶⁴ A further reason for relying on the CRPD is that the CRPD Committee has already issued a number of concluding observations and general comments that are pertinent to the topic at

⁶⁰ IL Ochs 'Securing freedom from fear and injustice within the justice system' in D Nelson-Bryen & J Bornman (eds) *Stop Violence against people with disabilities: An international resource* (2014) at 3.

⁶¹ For a discussion on substantive equality, see MH Rioux & CA Riddle 'Values in disability policy and law: Equality' in MH Rioux et al (eds) *Critical Perspectives on Human Rights and Disability Law* (2011) at 44.

⁶² Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (African Disability Protocol), adopted by the thirtieth ordinary session of the Assembly on 29 January 2018 (not yet in force).

⁶³ The South African government signed the African Disability Protocol on 29 April 2019 but has not yet ratified it.

⁶⁴ In its preamble, the African Disability Protocol recalls that the rights of persons with disabilities are affirmed in the CRPD. The Protocol contains many of the same rights that are in the CRPD, with the exception of the right to self-representation found in article 22 and the right of older persons found in article 30. The rights are contextualised to reflect the African reality. For example, article 13 on access to justice is couched in very similar terms as it is in the CRPD but is contextualised as evidenced by the recognition of customary law (article 13 (2)), the requirement for legal aid (article 13 (4)) and the requirement for the provision of accommodations that are gender appropriate (article 13 (1)).

hand.⁶⁵ Reference will only be made to the African Disability Protocol in situations where it adds something new.

2. Problem statement

The concept of capacity to consent to sexual intercourse is founded upon underlying assumptions about who has a right to express themselves sexually. The law on consent imagines a particular sexual being who is not intellectually disabled. Those with intellectual disabilities are excluded through ‘judicial constructions of capacity to consent.’⁶⁶ The Sexual Offences Act in South Africa states that ‘a person who is mentally disabled is incapable of consenting to a sexual act.’⁶⁷ Joubert reiterates this position when he states that capacity to consent may be affected by various factors including ‘mental defect.’⁶⁸ Studies show that persons with ‘mental disability’ who are involved in sexual assault cases do testify in 88% of the cases.⁶⁹ The majority of those who testify (87.2%) are found to lack the capacity to consent to sexual intercourse because of ‘mental disability.’⁷⁰ This indicates that the tests applied in criminal cases usually result in a finding of lack of capacity to consent to sexual relations. The question to ask is whether these findings are merely a reflection of the reality that most women with intellectual disabilities do in fact lack the capacity to consent or whether the test itself is problematic. This study will therefore, interrogate the legal test that the courts in South Africa use to determine capacity to consent to sexual intercourse, with the aim of assessing its impact on the sexual autonomy of women with mild Down syndrome.

However, the legal position on capacity to consent is merely a starting point. The study’s main concern is with the broader societal factors influencing the de-sexualisation of women with mild Down syndrome through restrictive constructions of capacity to consent. As alluded to earlier, the de-sexualisation of women with mild Down syndrome is a societal and cultural phenomenon. Society believes that women with mild intellectual disabilities should be ‘protected’ from sexual relationships.⁷¹ Michael Gill, a disability studies scholar, writes about a personal experience he had whilst working with persons with intellectual disabilities in a

⁶⁵ For example, Committee on the Rights of Persons with Disabilities ‘General comment no. 1 - Article 12: Equal recognition before the law’ (2014) CRPD/C/GC/1/Corr.1.

⁶⁶ Harris (n 1) 498.

⁶⁷ Sexual Offences Act sec 57(2).

⁶⁸ WA Joubert *The Law of South Africa* (2007) 61.

⁶⁹ Harris (n 1) 490.

⁷⁰ As above.

⁷¹ Harris (n 1) 497.

sheltered workshop.⁷² He was put in charge of monitoring and managing sexual activities between two women who had been seen holding hands and kissing. Reflecting back on this experience, Gill states that, ‘though we were supposed to provide employment for these women labeled as intellectually disabled, we were now regulating behaviors not necessarily related to work efficiency.’⁷³ Gill concludes that ‘sexuality was a threat in the workshop [and] was policed based on assumptions about not only when and where one can be sexual, but also who can be sexual.’⁷⁴ Therefore, the study seeks to interrogate the underlying factors responsible for the de-sexualisation of women with mild Down syndrome through restrictive constructions of capacity to consent to sexual intercourse.

3. Research question

The main research question in this study is, how can conceptual boundaries be shifted to allow for the recognition of the sexual autonomy of women with mild Down syndrome. In order to answer this main question, the following sub-questions are interrogated:

- a) What theoretical framework can accommodate a re-conceptualisation of capacity to consent to sexual intercourse?
- b) What effect does the ‘capacity framework’ in South Africa have on the sexual autonomy of women with mild Down syndrome?
- c) How should we understand capacity to consent to sexual intercourse?
- d) How can we change perceptions in order to uphold the sexual autonomy of women with mild Down syndrome?

4. Methodology

This study utilises both desk-based research and empirical research methods to answer the questions under interrogation. Desk-based research was carried out using academic articles, legislation, case-law, theses, text-books, international legal treaties, treaty body publications such as general comments and concluding observations, and other relevant sources. The study referred to textbooks, legislation and case-law to establish the legal position on the capacity of women with mild Down syndrome to consent to sexual acts and how these provisions have been interpreted by the courts. Furthermore, commentaries in academic articles on the

⁷² M Gill *Already doing it: Intellectual Disability and Sexual Agency* (2015) xi. A sheltered workshop is a type of transitional employment for persons with intellectual disability. Sheltered workshops provide on-site training during the course of employment.

⁷³ Gill (n 72) xiii – xv.

⁷⁴ As above.

implications of both the approach taken at law as well as the relevant societal beliefs and practices on the sexual autonomy of women with mild Down syndrome were consulted. Alternative approaches to capacity to consent as well as supports to enable the exercise of sexual autonomy by members of this population were also extracted from academic articles and commentaries.

The project involved empirical research in the form of qualitative research aimed at gathering data from subject matter experts. Specifically, the interviews sought to elicit the research participants' views on the societal factors that impact the capacity of women with mild Down syndrome to consent to sexual intercourse in a South African context. Moreover, the interviews interrogated the measures that may be taken to bolster the capacity of women with mild Down syndrome to consent to sexual intercourse. Ethical approval was obtained prior to conducting the empirical research.

4.1 Theoretical framework

This research seeks to illustrate that law is not neutral but is political in nature and is informed by the social context. Any shortcomings in the law are, therefore, deficiencies in society at large that cannot be remedied by merely altering the letter of the law. Indeed, wider societal and cultural change is required. This research therefore, deploys an interdisciplinary approach in which a socio-legal analysis is conducted. Moreover, the concept of capacity to consent is interrogated in order to provide a better understanding of the underlying values that have influenced the manner in which it is conceived. In order to achieve this, the study relies on three theoretical strands. First, the vulnerability framework developed by feminist scholar and legal philosopher Martha Fineman, which contests traditional notions of vulnerability as an inherent trait, is deployed.⁷⁵ Fineman develops an alternative conception of vulnerability as a universal phenomenon influenced by multiple sources including inherent, situational and pathogenic sources.⁷⁶ Second, the study relies on Michel Foucault's genealogical theory to explain how the sexual identity of women with mild Down syndrome was constructed throughout history. According to the French philosopher, knowledge and identity are produced discursively through the exercise of power relations.⁷⁷ Therefore, since they are produced discursively, then it is logical that they can also be transformed discursively.⁷⁸ Third, de-

⁷⁵ M Fineman 'Equality, autonomy and the vulnerable subject in law and politics' in MA Fineman & A Gear (eds) *Vulnerability: reflections on a new ethical foundation for law and politics* (2013) at 16.

⁷⁶ Fineman (n 75) 21.

⁷⁷ M Foucault *Discipline and Punish: The birth of the prison* (1977) 298.

⁷⁸ As above.

colonial theory is utilised to demonstrate the colonial origins and residual coloniality exhibited in South African criminal law, particularly in relation to capacity to consent to sexual intercourse, with the aim of highlighting the importance of taking local perspectives into account and justifying legislative reform.⁷⁹

5. Literature review

In the past, much of the relevant literature focused on the prevalence of sexual violence and abuse against women with mild intellectual disabilities. Whilst the rate of sexual violence against all persons with disabilities was proved to be disproportionately higher, compared to that of persons without disabilities, studies also show that women with intellectual disabilities, in particular, experience sexual violence at an even higher rate than persons with other types of disabilities.⁸⁰ This literature attributes the prevalence of sexual violence against women with mild intellectual disabilities to their innate characteristics.⁸¹ For example, women with mild intellectual disabilities are considered ‘obedient and suggestible’ and because of these inherent characteristics, they are considered unable to resist inappropriate behaviour.⁸² According to this conception therefore, vulnerability to sexual abuse is inherent in an individual with disability.⁸³ As a direct result of this perception, the sexual agency of persons with intellectual disabilities is subject to regulation and control by society and by the state with the goal of protection.⁸⁴

In recent years however, the discourse in the literature has shifted towards the gradual recognition of the sexual rights of women with mild intellectual disabilities. As a start, researchers conceded that women with intellectual disabilities have sexual feelings and desires, in the same manner that women without disabilities do.⁸⁵ Indeed, research shows that they share the same need for love, affection and have sexual interest as well as reproductive ability.⁸⁶ Nevertheless, there is a great deal of social stigma attached to the sexuality of adults with intellectual disabilities and many remain opposed to the idea of granting them sexual rights as

⁷⁹ See Chapter Two for a detailed discussion of each of these theoretical strands.

⁸⁰ R White et al ‘Testifying in court as a victim of crime for persons with little or no functional speech: Vocabulary implications’ (2015) 16(1) *Child Abuse Research: A South African Journal (CARSA)* at 1.

⁸¹ B Clough ‘Vulnerability and capacity to consent to sex – Asking the right questions’ (2014) 26 *Child and Family Law Quarterly* at 374.

⁸² As above.

⁸³ As above.

⁸⁴ Harris (n 1) 499.

⁸⁵ Clough (n 81) 374.

⁸⁶ G Di Giulio ‘Sexuality and people living with physical or developmental disabilities: A review of key issues’ (2003) 12(1) *The Canadian Journal of Human Sexuality* at 58.

a number of studies show.⁸⁷ Gilmore and Chambers document the negative attitudes of disability support staff and leisure industry employees to the sexuality of persons with intellectual disabilities,⁸⁸ whilst Cuskelly and Bryde record the negative attitudes of parents, support staff and members of the community.⁸⁹ These negative attitudes and perceptions have an adverse impact on the sexual agency of adults with mild Down syndrome. Indeed, societal misconception is regarded as one of the largest barriers that persons with disabilities face in relation to their sexuality.⁹⁰ Esmail and others state that persons with disabilities have been prevented from exploring their sexuality through barriers created by '[e]nthrenched socio-cultural beliefs.'⁹¹ Various societal aspects, such as the lack of public education and exposure to sexuality and disability have contributed to the stifling of sexual expression by persons with intellectual disabilities.⁹² The freedom of persons with intellectual disabilities to experience sexual relationships is often inhibited and restricted by societal rules that do not recognise them as sexual beings.⁹³ While the sexuality of non-disabled people is valued, that of women with mild intellectual disabilities is met with disapproval, hostility and fear.⁹⁴ Indeed sexuality is value laden and is often subjected to regulations that are applied differently.⁹⁵ Weeks states that:

These regulations may take many forms: formal and informal, legal and extra-legal. They tend not to apply in an undifferentiated way for the whole of society. For instance, there are usually different rules for men and women, shaped in ways which subordinate women's sexuality to men's ... they provide the permissions, prohibitions, limits and possibilities through which erotic life is constructed.⁹⁶

Moreover, stigma and societal attitudes are capable of distorting an individual's own self-image.⁹⁷ Esmail and others explain this point succinctly as follows:

⁸⁷ S Esmail et al 'Attitudes and perceptions towards disability and sexuality' (2010) 32(14) *Disability and Rehabilitation* at 1148.

⁸⁸ L Gilmore & B Chambers 'Intellectual disability and sexuality: Attitudes of disability support staff and leisure industry employees' (2010) 35(1) *Journal of Intellectual and Developmental Disability* at 22 – 28.

⁸⁹ M Cuskelly & R Bryde 'Attitudes towards the sexuality of adults with an intellectual disability: Parents, support staff and a community sample' (2004) 29(3) *Journal of Intellectual and Developmental Disability* at 255 – 264.

⁹⁰ Esmail et al (n 87) 1149.

⁹¹ Esmail et al (n 87) 1148.

⁹² As above.

⁹³ RD Brown & T Pirtle 'Beliefs of professional and family caregivers about the sexuality of individuals with intellectual disabilities: Examining beliefs using a Q-methodology approach' (2008) 8(1) at 60.

⁹⁴ Brown (n 54) 128.

⁹⁵ Esmail et al (n 87) 1154.

⁹⁶ J Weeks *Sexuality* (1989a) 27.

⁹⁷ Esmail et al (n 87) 1151.

Stigma can lead individuals to internalise concepts of asexuality and may impact confidence, desire and ability to find a partner while distorting one's overall sexual self-concept due to these socio-cultural barriers.⁹⁸

In some cases, the stigma of being labeled asexual can lead persons with intellectual disabilities to retreat from intimacy and sexuality, thereby becoming a 'self-fulfilling prophecy.'⁹⁹ Consequently, women with mild intellectual disabilities struggle to reclaim their sexuality in the face of societal stigma.¹⁰⁰ So great is the influence of socio-cultural barriers that they 'may be more disabling than the ... impairment itself.'¹⁰¹

Some of the negative perceptions about the sexuality of adults with intellectual disabilities are rooted in the belief that the nature of the disability renders them asexual or unattractive and 'if a disabled person has a sexual problem, it is almost always a result of the disability.'¹⁰² The capacity of women with mild intellectual disabilities to consent to sexual intercourse has been called into question because of the nature of the disability.¹⁰³ In line with the outdated medical model of disability, many still hold fast to the belief that incapacity is determined by nature and severity of one's disability.¹⁰⁴

6. Significance of research

Despite the increase in the literature calling for the recognition of the sexual rights of persons with intellectual disabilities, the area remains relatively underdeveloped.¹⁰⁵ In particular, the capacity of women with mild Down syndrome to consent to sexual intercourse has not been adequately interrogated. Is capacity to consent to sexual intercourse determined solely by inherent factors? What role, if any, do societal factors play in determining their capacity to consent to sexual intercourse? This study contributes to the discourse in this area by addressing these and other pertinent questions with the aim of arguing for the recognition of the sexual autonomy of women with mild Down syndrome.

⁹⁸ Esmail et al (n 87) 1154.

⁹⁹ Di Giulio (n 86) 53.

¹⁰⁰ Esmail et al (n 87) 1151.

¹⁰¹ Esmail et al (n 87) 1148.

¹⁰² MG Brodwin & PC Frederick 'Sexuality and societal beliefs regarding persons living with disabilities' (2010) 76(4) *Journal of Rehabilitation* at 37.

¹⁰³ S Werner 'Individuals with intellectual disabilities: A review of the literature on decision-making since the Convention on the Rights of People with Disabilities (CRPD) (2012) 34(2) *Public Health Reviews* at 13.

¹⁰⁴ See Chapter One section 1.1 above for a discussion of the medical and social models of disability.

¹⁰⁵ Harris (n 1) 499.

7. Chapter outlines

Chapter One introduces the research study by providing a contextual background on the sexuality of women with mild Down syndrome and defining key terms such as intellectual disability. The chapter also identifies the specific problem that the study seeks to address along with the relevant research questions. The methodology that is employed in the study is also explained in this chapter. The literature review explicates the main discourse on the sexuality of women with mild Down syndrome. The chapter concludes by outlining the various chapters in the study.

Chapter Two focuses on the conceptual framework that is used as a lens through which to understand, interrogate and re-conceptualise the capacity of women with mild Down syndrome to consent to sexual intercourse. Specifically, Martha Fineman's vulnerability framework, Michel Foucault's genealogical theory and de-colonial theory are explained in detail in this chapter.

In Chapter Three, the study interrogates how the 'capacity framework' is applied by the courts in South Africa. The chapter also highlights the shortcomings of the 'capacity framework' in relation to upholding the sexual autonomy of women with mild Down syndrome. Finally, using Fineman's vulnerability framework and the support paradigm, the chapter suggests ways of re-conceptualising capacity to consent to sexual intercourse in ways that uphold the sexual autonomy of women with mild Down syndrome.

Chapter Four outlines the research methodology and the findings from the empirical research study, focusing on the situational factors that limit the capacity of women with mild Down syndrome to consent to sexual intercourse in South Africa and the measures that can be taken to boost their capacity.

In Chapter Five, a critical analysis of the research findings is provided relying mainly on Foucault's genealogical theory as a conceptual framework.

Finally, Chapter Six concludes the study by summarising its main findings and arguments before making final reflections for future research to ensure the recognition of the sexual autonomy of women with mild Down syndrome in South Africa.

CHAPTER TWO

AN INTRODUCTION TO VULNERABILITY, GENEALOGY AND DE-COLONIAL THEORY

Deconstruction serves the heuristic purpose of implicating unwanted labels, stigma, disadvantage, marginalisation and exclusion in the historical misrepresentations of ... sexualities.¹⁰⁶

1. Introduction

The disability rights movement has always associated disability justice with human rights and instinctively turns to the CRPD for answers relating to questions on disability justice, including sexual autonomy.¹⁰⁷ However innovative the CRPD may be, human rights law alone, is incapable of achieving the conceptual shift needed for the effective recognition of the sexual autonomy of women with mild Down syndrome.¹⁰⁸ Indeed, their sexual agency is unlikely to be recognised simply because it is a human right enunciated in the CRPD. Rather, underlying assumptions must be unmasked and de-stabilised in order to change mindsets and ultimately behaviour. Therefore, it is necessary to first understand how the sexuality of women with mild Down syndrome came to be constructed.¹⁰⁹ Through de-construction, the institutions and hierarchies of power and privilege that create and perpetuate hegemonic knowledge about the sexuality of women with mild Down syndrome can be exposed and on that basis, a demand for change made.¹¹⁰

Only robust theoretical frameworks can achieve this aim, making it necessary to complement human rights with theory in the effort to recognise the sexual autonomy of women with mild Down syndrome. The main theoretical framework for this research study is feminist scholar and legal philosopher Martha Fineman's vulnerability thesis. Because reliance on one theory limits the scope to fully interrogate the regimes implicated in the historical disablement of the sexual autonomy of women with mild Down syndrome, and to suggest enabling alternatives, the study relies on two additional theoretical strands, Foucault's genealogical theory and de-colonial theory. Each framework complements the other by addressing different, albeit related, aspects of the sexuality of women with mild Down syndrome. Fineman's

¹⁰⁶ C Ngweni *What is Africanness? Contesting nativism in race, culture and sexualities* (2018) 43.

¹⁰⁷ O Onazi *An African path to disability justice: Community, relationships and obligations* (2020) 39.

¹⁰⁸ F Mégret 'The Disabilities Convention: Towards a holistic concept of rights' (2008) 12(2) *The International Journal of Human Rights* 261 – 277.

¹⁰⁹ Ngweni (n 106) 43.

¹¹⁰ As above.

framework exposes flaws in conceptions about their sexuality by contesting traditional notions of vulnerability. However, it does not explain how these constructions came about. By uncovering the historical origins of sexual knowledge and identity, genealogy complements the vulnerability framework in this respect. Genealogy, however, only shows us what is problematic without dictating how to change it. De-colonial theory is deployed to fill that gap. In light of South Africa's colonial legacy, de-colonial theory highlights what needs to be done to formulate an African solution to recognising the sexual autonomy of women with mild Down syndrome.

This chapter introduces Fineman's vulnerability framework, Foucault's genealogical theory and de-colonial theory in three parts. The first part focuses on various aspects of the vulnerability framework. In the second part, genealogical theory's relevance to the sexuality of women with mild Down syndrome is explained. Finally, the third part addresses de-colonial theory.

2. Introducing Fineman's vulnerability framework

Certain population subgroups, including persons with disabilities, children, and older persons, are perceived as inherently vulnerable.¹¹¹ In relation to sexual abuse, persons with intellectual disabilities, including women with mild Down syndrome, are categorised as a vulnerable population because of the individual characteristics of the disability.¹¹² In an interview conducted by Combrinck and Meer in South Africa, one of the research participants explained that persons with intellectual disabilities are vulnerable to sexual abuse because they 'are very friendly and want to chat to everybody and hug everybody' and this carries the risk that such a gesture may be mistaken for a sexual advance.¹¹³ Similarly, a report on the reform of sexual offences in the United Kingdom states that persons with intellectual disabilities 'are a particularly vulnerable group – they are obedient and suggestible, and once adult they may well have sexual feelings and not be able to resist inappropriate behaviour.'¹¹⁴

Although the term 'vulnerable' is commonly used, its meaning remains ambiguous and a precise definition for the socially constructed concept has proved elusive.¹¹⁵ Nevertheless,

¹¹¹ MA Fineman 'The vulnerable subject: Anchoring equality in the human condition' (2008) 20(1) *Yale Journal of Law and Feminism* at 8.

¹¹² Clough (n 81) 374.

¹¹³ T Meer & H Combrinck 'Invisible intersections: Understanding the complex stigmatisation of women with intellectual disabilities in their vulnerability to gender-based violence' (2015) 29(2) *Agenda* at 5.

¹¹⁴ Home Office 'Setting the Boundaries: reforming the law on sexual offences' (2000) https://eige.europa.eu/library/resource/LSE_ALM99144398610302021 at para 4.1.2 (accessed 31 July 2020).

¹¹⁵ P Liamputtong *Researching the vulnerable: A guide to sensitive research methods* (2007) 3.

several authors have attempted to define vulnerability and these definitions highlight some unarticulated assumptions latent in the term. For instance, Moore and Miller define vulnerable people as those who ‘lack the ability to make personal life choices, to make personal decisions, to maintain independence, and to self-determine.’¹¹⁶ Similarly, Liamputtong defines vulnerable people as those who are ‘impoverished, disenfranchised, and/or subject to discrimination, intolerance, subordination and stigma.’¹¹⁷ In discussions on public responsibility, the term ‘vulnerable’ is used to define stigmatised subjects.¹¹⁸ Vulnerability is therefore, laden with negative connotations and is synonymous with victimhood, dependency, and deprivation.¹¹⁹ In accordance with this conception, vulnerable people require special measures to protect their rights.¹²⁰ Consequently, the laws and policies formulated around the idea that certain population groups, such as women with mild Down syndrome, are inherently vulnerable exhibit a strong protectionist agenda. A classic example is legislation criminalising sexual activity with women with intellectual disabilities on the basis that they are vulnerable to sexual abuse and in need of protection.¹²¹ A problem arises from the fact that very often the designation of some groups as ‘vulnerable’ results in their stigmatisation and disadvantaging.¹²² For example, the criminalisation of sexual activity with women with intellectual disabilities results in a denial of other rights such as the right to marry and found a family.¹²³ Therefore, there is a need to formulate a solution that adequately addresses vulnerability and disability.

In recent years, a growing body of literature seeking to theorise and reconceptualise the meaning of vulnerability has emerged and holds great promise for re-conceptualising disability and vulnerability.¹²⁴ Feminist scholar and legal philosopher Martha Fineman, is at the forefront of this work and has developed a framework that redefines the meaning of vulnerability at the political level and explores its implications for law and policy.¹²⁵ Fineman developed the

¹¹⁶ LW Moore & ME Miller ‘Initiating research with doubly vulnerable populations’ (1999) 30(5) *Journal of advanced nursing* at 1034.

¹¹⁷ Liamputtong (n 115) 3.

¹¹⁸ Fineman (n 111) 8.

¹¹⁹ As above.

¹²⁰ Moore & Miller (n 116) 1034.

¹²¹ See for example, the *Zambian Penal Code Act* Chapter 87, sec 39 which makes it an offence to have sexual intercourse with a woman or girl with intellectual and psychosocial disability who is referred to as an ‘idiot’ or an ‘imbecile.’ Refer to Chapter Three, part 2.2 for a detailed discussion on this approach to the capacity of women with mild Down syndrome to consent to sexual intercourse.

¹²² MA Fineman ‘The vulnerable subject and the responsive state’ (2010) 60 *Emory Law Journal* at 266.

¹²³ CRPD art 23. This provision deals with the right to respect for home and family, which addresses matters relating to marriage, family, parenthood and relationships.

¹²⁴ Clough (n 81) 373.

¹²⁵ Fineman (n 111) 8.

vulnerability thesis with a view to argue for a more responsive state.¹²⁶ This required a radical re-conceptualisation of vulnerability, the nature of the human being who is the subject of state laws and policies, and the role of the state. Key aspects of Fineman's vulnerability framework are addressed in detail in the following section.

2.1 Vulnerability is universal

Fineman's vulnerability framework stands in contrast with the original notion of vulnerability.¹²⁷ Her thesis does not locate the source of vulnerability in individual groups such that members of these groups are regarded as vulnerable whilst those who do not belong to those groups are regarded as not vulnerable.¹²⁸ Instead, she posits that vulnerability is universal and stems from our embodiment as humans, which carries with it the possibility of harm.¹²⁹ Therefore, all human beings, not just members of certain population subgroups, are vulnerable. The risk of harm faced by all human beings is constant and cannot be completely eradicated.¹³⁰ Individuals can however, seek to reduce or mitigate the impact of the risk.¹³¹ Furthermore, the risk of harm is beyond human control.¹³² The ageing process and death, for example, are indisputable biological processes that clearly show the inability of human beings to avoid the ultimate consequences of our embodiment.¹³³ We are also susceptible to external forces beyond our control such as injury or loss resulting from floods, drought, famine and fire.¹³⁴ Harms vary in form and intensity. There are bodily harms, economic harms and institutional harms and their intensity may be mild to catastrophically devastating.¹³⁵ Vulnerability is complex and manifests itself in a variety of ways.¹³⁶ For example, our bodily vulnerability means that we are susceptible to illness or injury. In the event that we succumb to such illness or injury, the harm we suffer goes beyond our bodies and disrupts our employment, economic status or relationships.¹³⁷ Furthermore, harms can be accidental or the result of intentional action.¹³⁸

¹²⁶ Fineman (n 111) 9.

¹²⁷ Fineman (n 75) 16.

¹²⁸ Clough (n 81) 374.

¹²⁹ AB Satz 'Disability, vulnerability and the limits of antidiscrimination' (2008) 83(4) *Washington Law Review* at 524. Fineman (n 111) 9.

¹³⁰ Satz (n 129) 525.

¹³¹ Fineman (n 111) 9.

¹³² As above.

¹³³ Clough (n 81) 374.

¹³⁴ Fineman (n 111) 9.

¹³⁵ As above.

¹³⁶ Fineman (n 122) 268.

¹³⁷ As above.

¹³⁸ Fineman (n 122) 267.

Fineman's vulnerability theory is not only crucial in that it locates vulnerability in our embodiment as human beings but also because it acknowledges the multi-variant sources of vulnerability.¹³⁹ Three closely-linked categories of sources of vulnerability have been identified and these are inherent sources, situational sources and pathogenic sources.¹⁴⁰ Inherent sources are those innate in our human embodiment and vary depending on age, gender, disability and health status.¹⁴¹ Situational sources are specific to one's context in terms of personal, social, political, economic and environmental situation.¹⁴² Pathogenic sources comprise of vulnerability that is generated by abusive interpersonal relationships as well as socio-political injustice.¹⁴³ They may also arise in circumstances where a measure designed to ameliorate vulnerability actually has the effect of exacerbating vulnerability or creating new ones.¹⁴⁴

Recognising the universality of vulnerability is important because it has an impact on the response to vulnerability through law and policy. For example, in the sphere of sexual abuse against women with mild intellectual disabilities, recognising that everyone is vulnerable to sexual abuse calls for an intervention different from the paternalistic and protectionist response criminalising sexual activity with all persons with intellectual disabilities. The multi-variant sources of vulnerability must be taken into account. In contrast to the vulnerability framework, human rights law does not recognise that all human beings are vulnerable. Fineman's vulnerability framework, therefore, complements human rights law in advancing the rights of women with mild Down syndrome.

2.2 The experience of vulnerability is particular

Persons with disabilities experience rights violations in a manner that is unique to each individual with a disability.¹⁴⁵ Although persons with different types of disabilities such as, physical, intellectual, psychosocial disabilities, hearing impairments, speech impairments and visual impairments are all categorised as persons with disabilities, their needs differ in form

¹³⁹ Clough (n 81) 374.

¹⁴⁰ C Mackenzie et al *Vulnerability: New essays in ethics and feminist philosophy* (2014) 7.

¹⁴¹ C Mackenzie 'The importance of relational autonomy and capabilities for an ethics of vulnerability' in C Mackenzie et al (eds) *Vulnerability: New essays in ethics and feminist philosophy* (2014) at 38.

¹⁴² Mackenzie (n 141) 7.

¹⁴³ Mackenzie (n 141) 9.

¹⁴⁴ As above.

¹⁴⁵ CRPD preamble para I recognises the diversity of persons with disabilities.

and extent.¹⁴⁶ Even persons with the same type of disability have different needs.¹⁴⁷ Their experience of exclusion and discrimination differs and is particular to the individual. Mégret refers to this as the ‘irreducibility’ of the experience of human rights by specific groups.¹⁴⁸

The vulnerability theory pays heed to individual differences.¹⁴⁹ It contends that our differences are not only the result of our individual characteristics, but are the result of the nature of our social interactions.¹⁵⁰ Fineman identifies two forms of individual difference, namely, embodied differences and the differences that result from the fact that we are ‘social beings *embedded* in social institutions and relationships.’¹⁵¹ Embodied differences are the physical variations upon which anti-discrimination laws are based.¹⁵² They are differences that are common to various members of society and others that ‘evolve within each individual body’ such as age.¹⁵³ Embedded differences are those that occur as the result of our constant and inevitable interaction with others and within institutions.¹⁵⁴ Therefore, Fineman’s vulnerability framework recognises that although vulnerability is universal, it is also particular in that each of us has a unique experience of vulnerability.¹⁵⁵ Although we are all universally vulnerable, at the individual level we have different forms of embodiments and are each positioned differently in relation to economic and institutional relationships.¹⁵⁶ Clough accurately summarises the position when she states that:

[a]n inherent condition may seem to place an individual at risk of harm or exploitation; however, they may not subjectively experience themselves as vulnerable, perhaps due to access to material and social supports promoting resilience.¹⁵⁷

Consequently, our vulnerabilities differ in magnitude and potential depending on the quality and quantity of resources we command.¹⁵⁸ Thus, the vulnerability thesis focuses on the

¹⁴⁶ As above.

¹⁴⁷ M Deal ‘Disabled people’s attitudes toward other impairment groups: A hierarchy of impairments’ (2003) 18(7) *Disability & Society* at 898.

¹⁴⁸ F Mégret ‘The Disabilities Convention: Human rights of persons with disabilities or disability rights?’ (2008) 30 (2) *Human Rights Quarterly* 496.

¹⁴⁹ MA Fineman ‘Vulnerability and inevitable equality’ (2017) 4(3) *Oslo Law Review* at 143.

¹⁵⁰ As above.

¹⁵¹ As above.

¹⁵² Fineman (n 149) 144. See section 2.3 below for a detailed discussion of the identity categories upon which discrimination laws are based.

¹⁵³ Fineman (n 149) 144.

¹⁵⁴ Fineman (n 149) 145.

¹⁵⁵ Fineman (n 111) 10.

¹⁵⁶ As above.

¹⁵⁷ Clough (n 81) 375.

¹⁵⁸ Fineman (n 111) 10.

experience of vulnerability and not simply on a particular condition.¹⁵⁹ A framework focusing solely on the universal nature of vulnerability would risk minimising the experience of vulnerability and negate its conceptual significance.¹⁶⁰ By taking into account the particular experience of vulnerability, the framework bridges the conceptual gap between real human beings and the legal subject as ‘he’ is currently conceived.¹⁶¹

The particularity of the experience of rights is recognised in international human rights law, albeit to a limited extent. The fundamental tenet of human rights discourse is that rights are universal and all human beings, by virtue of their humanity, are entitled to the same inalienable rights.¹⁶² This is referred to as the ‘sameness and unity’ of human beings from which the ideas of equality and universality are derived.¹⁶³ Nevertheless, there is a trend emerging in international human rights law known as the ‘pluralisation of rights.’¹⁶⁴ This trend is characterised by the increasing recognition in human rights of the particular needs of specific groups within humanity.¹⁶⁵ Pluralisation has been achieved through the adoption of various group specific treaties including the Convention on the Elimination of Racial Discrimination;¹⁶⁶ the Convention on the Elimination of Discrimination against Women;¹⁶⁷ the Convention on the Rights of the Child;¹⁶⁸ and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families.¹⁶⁹

However, these group-specific treaties do not go far enough in recognising that each individual’s experience of vulnerability is unique. Although they acknowledge that certain groups experience discrimination differently, there is still an assumption that the experience of

¹⁵⁹ A Timmer ‘A quiet revolution? Vulnerability in the European Court of Human Rights’ in M Fineman & A Grear (eds) *Vulnerability: Reflections on a new ethical foundation for law and politics* (2013) at 148.

¹⁶⁰ Clough (n 81) 374.

¹⁶¹ Timmer (n 159) 148. See section 2.4 below for a detailed discussion on the legal subject.

¹⁶² See Universal Declaration of Human Rights (UDHR), adopted and proclaimed by General Assembly resolution 217 A (III) of 10 December 1948, art 1.

¹⁶³ F Mégret (n 148) 496.

¹⁶⁴ F Mégret (n 148) 495.

¹⁶⁵ As above.

¹⁶⁶ Convention on the Elimination of Racial Discrimination (CERD), adopted and opened for signature and ratification by General Assembly resolution 2106 (XX) of 21 December 1965 and entered into force on 4 January 1969.

¹⁶⁷ Convention on the Elimination of Discrimination against Women (CEDAW) adopted and opened for signature, ratification and accession by General Assembly resolution 34/180 of 19 December 1979.

¹⁶⁸ Convention on the Rights of the Child (CRC) adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989 and entered into force 2 September 1990.

¹⁶⁹ International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (CRMW), adopted by General Assembly resolution 45/158 of 18 December 1990 and entered into force on 1 July 2003.

every member of a certain group is the same.¹⁷⁰ This becomes clear when one considers that group specific treaties simply re-state the rights that are present in the general human rights treaties and make it clear that discrimination on certain grounds, such as race, is particularly unacceptable.¹⁷¹ For example, human rights are cognisant of the fact that racial minorities do not experience discrimination in the same manner as every other human being, hence the adoption of CERD. However, CERD does not take into account the unique experience of discrimination by individuals within a racial minority group. Therefore, human rights do not go far enough in recognising the particularity of the human experience.

The CRPD differs from other group-specific treaties in that it values the particularity of individuals and does not consider that all persons with disabilities have the same experience. Although the CRPD is closely aligned with the social model of disability, which marks a departure from the individualistic medical model to an approach centred on the environment, it still retains focus on the individual as seen through the values of independence, autonomy and self-sufficiency which it upholds.¹⁷² For instance, measures such as habilitation and rehabilitation have the goal of ‘enabling persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability.’¹⁷³ The CRPD is therefore, cognisant of the particularity of the experience of human rights by persons with disabilities and this impacts the manner in which the rights are framed. Both the CRPD and the vulnerability framework value the particular experience of vulnerability. However, the vulnerability framework complements the CRPD by highlighting the factors that influence the individual experience, namely, the quantity and quality of resources at one’s disposal. It is therefore, capable of advancing the rights of women with mild Down syndrome.

2.3 Vulnerability is not tethered to identity categories

Fineman’s vulnerability thesis and non-discrimination law both share the common goal of ensuring equality. However, they employ different approaches to achieve this goal. The non-discrimination paradigm places a narrow focus on identity categories and the characteristics of those identities, whilst the vulnerability paradigm takes a more holistic approach and looks beyond identity categories to focus on the state and its institutions in relation to how they produce privilege and disadvantage for all individuals who share vulnerability.¹⁷⁴

¹⁷⁰ See section 2.3 below for a discussion on intersectionalities.

¹⁷¹ F Mégret (n 148) 497.

¹⁷² Onazi (n 107) 10.

¹⁷³ CRPD, art 26 (1).

¹⁷⁴ Fineman (n 111) 21.

The law on equality and non-discrimination is based on identity and prohibits discrimination on the basis of various identity categories. At national level, the Constitution of the Republic of South Africa prohibits direct and indirect discrimination based on several identity categories (grounds) including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.¹⁷⁵ Similarly, the Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA), which aims to promote equality and eliminate unfair discrimination,¹⁷⁶ prohibits discrimination by the state or any person¹⁷⁷ on several identity categories (grounds) including race,¹⁷⁸ gender,¹⁷⁹ and disability.¹⁸⁰ At the global level, the CRPD prohibits discrimination on the grounds of disability.¹⁸¹ Discrimination on the basis of disability is defined as:

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.¹⁸²

The ICCPR also prohibits discrimination based on the identity categories of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.¹⁸³ Similarly, CESCER, prohibits discrimination in relation to the enjoyment of economic, social and cultural rights, based on the identity categories of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.¹⁸⁴ The very presence of group specific treaties such as the CEDAW, CERD and CRC is further evidence of the fact that equality and non-discrimination law is built around identity categories.

Furthermore, it is generally accepted in equality and non-discrimination law that multiple identities intersect to produce compounded inequality.¹⁸⁵ This theory recognises the fact that people can be members of more than one identity category at the same time and this

¹⁷⁵ Constitution of the Republic of South Africa 1996 sec 9(3).

¹⁷⁶ Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA) No. 4 2000.

¹⁷⁷ PEPUDA sec 6.

¹⁷⁸ PEPUDA sec 7.

¹⁷⁹ PEPUDA sec 8

¹⁸⁰ PEPUDA sec 9.

¹⁸¹ CRPD art 5 (2).

¹⁸² CRPD art 2.

¹⁸³ International Covenant on Civil and Political Rights (ICCPR), adopted and opened for signature, ratification and accession by General Assembly resolution 2200A (XXI) of 16 December 1966 and entered into force 23 March 1976, art 26.

¹⁸⁴ International Covenant on Economic, Social and Cultural Rights (ICESCR), adopted and opened for signature, ratification and accession by General Assembly resolution 2200A (XXI) of 16 December 1966 and entered into force 3 January 1976.

¹⁸⁵ Fineman (n 111) 16.

influences the nature and extent of the social disadvantage that people experience.¹⁸⁶ This is sometimes referred to as ‘hybrid intersectionality’¹⁸⁷ and it means that:

the singly burdened will often simultaneously be in a privileged position relative to others who experience additional axes of subordination. For example, a gay man is privileged in contrast to a lesbian by gender while both are disadvantaged by sexual orientation. The gay man is said to be singly burdened whilst the lesbian is burdened on 2 axes.¹⁸⁸

Women with mild Down syndrome may therefore, be said to be subject to two axes of discrimination, first, as women and second, as persons with disabilities. Sampson accurately describes this when she states that a woman with intellectual disability’s status as a woman and a person with a disability are:

indivisible and come together in a way that creates a distinctive life experience – one that puts women with disabilities at an increased risk of experiencing sexual assault and being denied the full and equal benefit and protection of the criminal law.¹⁸⁹

In a South African study, a participant expressed similar sentiments as follows:

Even if you [women] do not have a disability, you are seen as the lesser, especially in our communities, and, people can take advantage of you. So, when you have a disability it is more [risky] because they think that they can do something to that person and the person cannot defend themselves and cannot be able to say that this is the person that did this to me.¹⁹⁰

The CRPD also expresses concern about the ‘multiple or aggravated’ forms of discrimination experienced by persons with disabilities on various grounds including race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age, or other status.¹⁹¹ Women with disabilities, in particular, face multiple forms of discrimination resulting from the intersection between disability and gender as well as other factors such as race, religion, class, amongst others.¹⁹² These characteristics intersect to create a compounded experience of discrimination that is unique and distinct from the experience of all other women. The CRPD acknowledges the intersection between gender and

¹⁸⁶ Msipa (n 47) 30.

¹⁸⁷ L Hosking ‘Critical disability theory’ (Paper delivered at the 4th Biennial Disability Studies Conference at Lancaster University, September 2-4 2008) [unpublished] at 9.

¹⁸⁸ As above.

¹⁸⁹ F Sampson ‘Beyond compassion and sympathy to respect and equality: Gendered disability and equality rights law’ in D Pothier & R Devlin (eds) *Critical disability theory: Essays in philosophy, politics, policy and law* (2006) at 279.

¹⁹⁰ Meer & Combrinck (n 113) 4.

¹⁹¹ CRPD preamble para p.

¹⁹² LN Murungi & E Durojaye ‘The sexual and reproductive health rights of women with disabilities in Africa: Linkages between the CRPD and the African Women’s Protocol’ (2015) 3 *African Disability Rights Yearbook* at 4.

disability and highlights the ‘need to incorporate a gender perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities.’¹⁹³ The CRPD also expressly recognises the fact that ‘women and girls with disabilities are subject to multiple discrimination.’¹⁹⁴

Fineman argues that this vision of equality based on discrimination along identity lines has not succeeded in dismantling systems of disadvantage that transcend identity lines, such as poverty.¹⁹⁵ Unlike the non-discrimination paradigm, the vulnerability thesis regards all of humanity as universally vulnerable and therefore, places the whole of society under scrutiny, as opposed to a defined minority in making a determination of the protection society owes its members.¹⁹⁶ Furthermore, it recognises that privilege and disadvantage migrate across categories of identity and are therefore, not tethered to identity.¹⁹⁷ In many, not all, situations, disadvantage is produced independently of identity categories such as race, gender, or disability.¹⁹⁸ Fineman’s vulnerability framework is therefore, a ‘post-identity inquiry’ that does not focus only on discrimination against defined groups or identity categories.¹⁹⁹ Instead, her framework focuses on the privilege and favour that is conferred upon certain people by both the state and society acting through their institutions.²⁰⁰ The vulnerability framework is therefore concerned with the societal structures in place to manage humanity’s common vulnerabilities.²⁰¹ Fineman contends that ‘systems of power and privilege ... interact to produce webs of advantages and disadvantages.’²⁰² Individuals occupy different positions in relation to the different asset-conferring systems with some individuals being in a position of privilege whilst others are in a position of disadvantage. The different systems interact in ways that affect positions of privilege and disadvantage.²⁰³

This approach addresses some of the ambiguities and anomalies in the current discrimination model and in the identity categories they are built upon. The focus on the interactions of asset-conferring institutions explains why some individuals who are members of groups typically associated with discrimination categories such as race, gender, disability

¹⁹³ CRPD preamble para s.

¹⁹⁴ CRPD art 6 (1).

¹⁹⁵ Fineman (n 111) 17.

¹⁹⁶ Fineman (n 111) 21.

¹⁹⁷ As above.

¹⁹⁸ Fineman (n 111) 17.

¹⁹⁹ Fineman (n 111) 1.

²⁰⁰ As above.

²⁰¹ As above.

²⁰² Fineman (n 111) 16.

²⁰³ Fineman (n 111) 15.

etc, can still overcome disadvantage and excel where other members of their identity category cannot.²⁰⁴ From this perspective, the justice inquiry, for example, will shift from assessing the individual characteristics of designated groups in society in order to determine whether they are the subjects of animosity.²⁰⁵ Instead, the inquiry will question whether existing institutional arrangements are equally attentive to the shared vulnerability of all individuals, regardless of group identity, and whether assets are equitably conferred.²⁰⁶ In other words, the goal of the inquiry is to determine whether some subgroup is unduly privileged.²⁰⁷ A concrete example of an approach that does not rely on the idea of not discriminating against a particular group but challenges state action that results in a few being privileged and leaving others outside its protective structure can be found in the debates on same-sex marriage.²⁰⁸ Some of the arguments in these cases focus on the privileges associated with marriage that same-sex couples were deprived of. In a vulnerability thesis, those benefits are assets – ‘material and relational advantages that arose from or were conferred by the way that the institution of marriage has been structured.’²⁰⁹

Crucially, the vulnerability framework does not claim that discrimination along identity lines is irrelevant, for it does occur and is likely to continue to occur.²¹⁰ However, it shifts the focus beyond the identity of the disadvantaged in order to reveal the real problems about the organisation of society that are otherwise missed.²¹¹ Fineman puts it quite succinctly when she states that:

The promise of equality must not be conditioned upon belonging to any identity category, nor should it be confined to only certain spaces and institutions, be they deemed public or private. Equality must be a universal resource, a radical guarantee that is a benefit for all.²¹²

Persons with disabilities often face disadvantage that does not result from their inherent condition, but is a result of the way societal and institutional structures are arranged. For example, they are often the poorest members of society not because they have disabilities, but because the way society is arranged places them at a disadvantage. They are often denied the right to education and this negatively impacts their ability to secure gainful employment.

²⁰⁴ Fineman (n 111) 16.

²⁰⁵ Fineman (n 111) 21.

²⁰⁶ Fineman (n 111) 17.

²⁰⁷ As above.

²⁰⁸ Fineman (n 111) 22.

²⁰⁹ As above.

²¹⁰ Fineman (n 111) 17.

²¹¹ Fineman (n 111) 21.

²¹² Fineman (n 111) 23.

Consequently, they become dependent on others for survival and live in poverty. Because the discrimination paradigm places more emphasis on identity categories, it does not direct enough attention to the societal structures that are producing inequality and disadvantage in the lives of persons with disabilities. Fineman's vulnerability framework therefore, has the potential to advance the rights of persons with disabilities because it is capable of shifting the focus from differing identities to institutional arrangements.²¹³

2.4 Re-thinking the nature of the human being

In order to meet the needs of 'real-life' subjects, politics, ethics and law must have a comprehensive vision of the human being and the human experience.²¹⁴ In spite of the existence of a number of human rights treaties and non-discrimination laws prohibiting discrimination on the basis of disability, persons with disabilities continue to face barriers to equal participation in society.²¹⁵ In part, this is because equality law and human rights are constructed around a very specific vision of the human being that does not accurately depict the real human experience.²¹⁶ The vision of the human being that currently dominates political and legal theory is the liberal subject.²¹⁷ This subject is a 'competent social actor capable of playing multiple concurrent societal roles.'²¹⁸ Liberal subjects are self-interested, and have the capacity to independently acquire and manage their own resources.²¹⁹ They can assess their options, negotiate contract terms and make rational decisions.²²⁰ They have the ability to take responsibility for themselves and their dependants.²²¹ Liberal subjects are envisioned as competent and capable and are therefore entitled to autonomy and liberty.²²² This is why the state and its institutions are restrained by privacy principles from interfering with the liberal subjects.²²³ Liberalism idealises notions of independence, autonomy, and self-sufficiency.²²⁴ Liberalism fails to account for the stages in the human existence that are characterised by

²¹³ Fineman (n 111) 17.

²¹⁴ Fineman (n 111) 10.

²¹⁵ CRPD preamble para k.

²¹⁶ F Mégret (n 108) 3.

²¹⁷ M Heikkilä et al 'Disability and vulnerability: A human rights reading of the responsive state' (2020) 24(8) *The International Journal of Human Rights* at 1181.

²¹⁸ As above.

²¹⁹ As above.

²²⁰ As above.

²²¹ As above.

²²² Fineman (n 111) 11.

²²³ As above.

²²⁴ NA Kohn 'Vulnerability theory and the role of government' (2014) 26(1) *Yale Journal of Law and Feminism* at 15.

dependency. These include infancy and old age.²²⁵ Liberal subjects therefore, stand outside of the passage of time and human experience because they can only be presented as adults.²²⁶ Persons with disabilities do not fit into the vision of the liberal subject. They challenge liberalism's idealised notions of independence, autonomy and self-sufficiency. They have varying levels of capacity and often need support in order to exercise their rights. As such, they challenge the liberal notion of autonomy as non-interference.²²⁷

Similarly, the human rights movement has always relied on a particular conception of the human subject that is based on the liberal subject.²²⁸ Mégret argues that human rights do not rely on the existing essence of what it is to be human and then determine what rights are inherent in that embodiment.²²⁹ Instead, human rights 'construct a human essence' or 'construct a human in the image of his/her rights.'²³⁰ He summarises this point succinctly when he states '[h]uman rights, therefore, are the "constitution of the human", a living and evolving portrayal of their subject as bearer of rights.'²³¹ The human being envisioned by human rights is an autonomous, self-determining individual.²³² 'He' has the ability to realise any project 'he' conceives without a fundamental lag and 'he' has the physical and mental capability to do what 'he' pleases.²³³ 'He' is endowed with freedom and the only limits 'he' experiences are those imposed on 'him' by the state.²³⁴ Essentially, this human being is able bodied.²³⁵ Human rights also envision social and power arrangements specifically designed to allow 'him' to maximise 'his' potential.²³⁶ This human being is not isolated from society but 'his' individuality is dependent on keeping the state outside the private sphere.²³⁷ Furthermore, human rights builds specific institutional arrangements designed to ensure that rights are implemented in the best way possible.²³⁸ Persons with disabilities challenge human rights in the following way. On the one hand, they are human enough to be entitled to the same rights as all other human beings.²³⁹ On the other hand, the reality of their life and rights experience is complex and '[o]nly a very

²²⁵ As above.

²²⁶ As above.

²²⁷ See Chapter Three, section 4.2.2 for a detailed discussion on re-conceptualising autonomy.

²²⁸ F Mégret (n 108) 262.

²²⁹ As above.

²³⁰ As above.

²³¹ As above.

²³² As above.

²³³ As above.

²³⁴ As above.

²³⁵ As above.

²³⁶ As above.

²³⁷ As above.

²³⁸ As above.

²³⁹ F Mégret (n 108) 263.

different vision of the human being and type of social settings in which he is set to thrive, can, ... disrupt the permanently divided nature of human rights.’²⁴⁰

Fineman’s vulnerability framework offers this very different vision of the human being. For Fineman, it is imperative that we develop legal and social policies that accurately reflect the lived realities of human subjects.²⁴¹ In contrast with the liberal approach, the vulnerability framework embraces the reality that the abilities of the human subject differ in the span of a lifetime.²⁴² At the beginning of life and towards the end of life, the human subject experiences dependency and the loss of capacity.²⁴³ It is also possible that somewhere in the middle of someone’s life span, they may lose capacity and experience dependency either temporarily or permanently as a result of illness or disability.²⁴⁴ Fineman’s vulnerability framework recognises two separate, yet closely related types of dependency: inevitable dependency and derivative dependency.²⁴⁵ Inevitable dependency arises from the fact that we are embodied beings who are inevitably dependent on others for physical and emotional care.²⁴⁶ The level of inevitable dependency one requires may increase and decrease during the course of life.²⁴⁷ For example, as infants, we need more care and support from others.²⁴⁸ We tend to need less support as we mature physically and emotionally.²⁴⁹ As we age, the level of care and support that we need increases.²⁵⁰ However, persons with intellectual disabilities may still require care and remain dependent on others throughout life. Derivative dependency acknowledges the fact that those who have to care for others are in turn dependent on ‘access to sufficient material, institutional, and physical resources in order to accomplish that care successfully.’²⁵¹ In contrast with inevitable dependency, not everyone experiences derivative dependency because caretaking is not a universal experience, but one that has been left to social institutions like families.²⁵² Fineman posits that the ‘recognition of derivative dependency reveals something

²⁴⁰ As above.

²⁴¹ Fineman (n 111) 12.

²⁴² As above.

²⁴³ As above.

²⁴⁴ As above.

²⁴⁵ MA Fineman ‘Vulnerability and social justice’ (2019) 53(2) *Valparaiso University Law Review* at 360.

²⁴⁶ As above.

²⁴⁷ As above.

²⁴⁸ As above.

²⁴⁹ Fineman (n 245) 361.

²⁵⁰ As above.

²⁵¹ As above.

²⁵² As above.

about the necessity of social organisation in the face of dependency.²⁵³ For Fineman, the only constant throughout one's life is vulnerability – the possibility of harm.²⁵⁴

Persons with disabilities do not fit into the vision of the human subject that liberalism and human rights imagine. The vulnerability framework encompasses the realities for persons with disabilities in a way that liberalism and human rights fail to do.²⁵⁵ The vulnerable subject is therefore, a 'more accurate and complete universal figure to place at the heart of social policy.'²⁵⁶

2.5 Re-conceptualising the role of the state

Persons with disabilities face structural discrimination, which cannot be addressed adequately through simple non-interference by the state.²⁵⁷ There is therefore a need to re-conceptualise state obligations in relation to building resilience in people with shared vulnerability.²⁵⁸

Fineman notes that our constant vulnerability forces us to look to societal institutions for relief.²⁵⁹ These institutions do not make us invulnerable, for that is an impossibility, rather they can bestow resilience by providing means, known as assets, with which to confront, mediate and ameliorate misfortune or harm.²⁶⁰ Societal institutions can provide at least five resources or assets to ameliorate harm, including physical assets, human assets, social assets, ecological or environmental assets and existential assets.²⁶¹ Physical assets are the material goods that determine our quality of life such as housing, food, entertainment and modes of transportation.²⁶² Physical assets can affect the quality of our present life as well as the quality of our future life when they take the form of savings and investments that can provide us with a means of accumulating additional resources in future.²⁶³ Systems that impact the distribution of physical assets include banking rules and regulations, credit and monetary policies, tax and inheritance laws amongst others.²⁶⁴ Human assets or human capital contributes to the development of the human being and allows them to participate in the market and accumulate

²⁵³ Fineman (n 245) 362.

²⁵⁴ Fineman (n 111) 12.

²⁵⁵ As above.

²⁵⁶ Fineman (n 111) 11.

²⁵⁷ Clough (n 81) 383.

²⁵⁸ Heikkilä (n 217) 1185.

²⁵⁹ Fineman (n 122) 268.

²⁶⁰ Heikkilä (n 217) 1185.

²⁶¹ As above.

²⁶² As above.

²⁶³ As above.

²⁶⁴ As above.

material resources that in turn boost their resilience in the face of vulnerability.²⁶⁵ Human assets, like physical assets, therefore, affect an individual's material well-being.²⁶⁶ Human assets are developed primarily through systems that provide education, training, knowledge and experience.²⁶⁷ This in turn allows an individual to gain access to employment, for example, which can provide further resources.²⁶⁸ Social assets are those social networks from which we draw strength and support such as the family, associations in which individuals unite to address vulnerabilities such as political parties, labour or trade unions.²⁶⁹ Ecological or environmental assets refer to the natural environment in which we live.²⁷⁰ The state of our natural environment can have an impact on our needs and well-being. For example, we live in the environment and need clean air to breathe and clean water to drink.²⁷¹ Several agencies and commissions have been granted the mandate through legislation and regulations to protect our natural resources or ecological assets from deterioration.²⁷² Existential assets are those that give us the ability to find meaning and beauty in our existence.²⁷³ They are provided by systems such as religion, culture, or art.²⁷⁴ Cumulatively and independently, these societal institutions provide resources or assets, which give us resilience in the face of our shared vulnerability.²⁷⁵

The state has a responsibility in relation to these various types of asset-conferring institutions for three reasons. The first is that most of the institutions are brought into legal existence through state mechanisms thereby placing such institutions within the state's domain.²⁷⁶ Corporations, schools, workplaces, families or churches are all granted a legitimate status through state mechanisms, through documents such as charters, documents of incorporation, licences or permits.²⁷⁷ The legitimate status confers upon them the benefit and protection of the law.²⁷⁸ Furthermore, many of these entities can only be dissolved through state processes and are therefore within the state's domain.²⁷⁹ Fineman argues that because these entities or institutions distribute important assets or resources, this justifies monitoring

²⁶⁵ Fineman (n 122) 270.

²⁶⁶ As above.

²⁶⁷ As above.

²⁶⁸ As above.

²⁶⁹ Fineman (n 122) 271.

²⁷⁰ As above.

²⁷¹ As above.

²⁷² As above.

²⁷³ Fineman (n 122) 271.

²⁷⁴ As above.

²⁷⁵ Fineman (n 122) 270.

²⁷⁶ Fineman (n 122) 272.

²⁷⁷ As above.

²⁷⁸ As above.

²⁷⁹ As above.

by the state to ensure that assets are distributed not only for profit or gain but with the values of equality and justice in mind.²⁸⁰

The second reason is that though societal institutions can ameliorate individual vulnerability, they are themselves vulnerable and if unchecked, can operate to exacerbate our individual vulnerability.²⁸¹ Societal institutions are susceptible to various internal and external factors.²⁸² These factors include market fluctuations, policy changes, and institutional and political compromises.²⁸³ Societal institutions therefore, need to be monitored, evaluated, updated and reformed by the state when necessary.²⁸⁴ State monitoring should be undertaken in line with the state's mandate to have equal regard to the shared vulnerability of all.²⁸⁵

Third, the vulnerability thesis is concerned with how the state has enabled or curtailed its institutions.²⁸⁶ The state has a responsibility towards its institutions to act in a manner that is consistent with its obligation to support, implement and maintain an equality regime that affords individuals a real opportunity to develop the range of assets they need to be resilient in the face of vulnerability.²⁸⁷ In order to meet the needs of vulnerable subjects, these institutions must be structured in response to the reality of the vulnerable subject.²⁸⁸ They must be cognisant of the fact that our entire life span is characterised by a fragile state rendering us all constantly susceptible to external and internal destructive forces.²⁸⁹ Therefore, the state has a responsibility to assess institutional and structural advantages and disadvantages.²⁹⁰ It must ensure that its institutional structures do not inappropriately benefit some whilst disadvantaging others.²⁹¹ Legislative and executive action must therefore be concerned with the operation and impact of those institutions by assessing the distribution of assets in order to determine whether it privileges and protects some while reinforcing the disadvantage and vulnerability of others.²⁹²

²⁸⁰ As above.

²⁸¹ Fineman (n 122) 273.

²⁸² Fineman (n 111) 12.

²⁸³ As above.

²⁸⁴ Fineman (n 122) 273.

²⁸⁵ As above.

²⁸⁶ Fineman (n 111) 20.

²⁸⁷ As above.

²⁸⁸ Fineman (n 111) 12.

²⁸⁹ As above.

²⁹⁰ Fineman (n 111) 20.

²⁹¹ As above.

²⁹² Fineman (n 111) 21.

Critics have argued that challenging the liberal subject is tantamount to challenging liberalism itself.²⁹³ They fear that not having a competent, responsible adult at the centre of political and social theory will lead to a more authoritarian state.²⁹⁴ However, Fineman envisions an active yet non-authoritarian state whose involvement actually serves to empower the vulnerable subject.²⁹⁵ Fineman accurately summarises what is at stake when she states that ‘[t]he choice, then, is not one of an active versus inactive state per se, but rather whether the state is constructed around a well-defined responsibility to implement a comprehensive and just equality regime.’²⁹⁶ This is essentially a re-conceptualisation of the role of the state.²⁹⁷ The current system is built on ‘myths’ of autonomy and independence and consequently does not acknowledge that the human condition is characterised by vulnerability and dependency.²⁹⁸ It is important to clarify that the vulnerability thesis does not reject autonomy as a value.²⁹⁹ Indeed any response to strengthen resilience must be informed by the overall aim of fostering autonomy.³⁰⁰ Instead, it reconceptualises autonomy as relational rather than individualistic.³⁰¹ If societal institutions have a role to play in the development and sustainment of autonomy, then this brings into question the idea that autonomy and rights are best protected by non-interference.³⁰²

Persons with disabilities have a unique experience of discrimination that requires the state to do more than refrain from certain actions. The state must take an active role in the removal of barriers.³⁰³ Much like the vulnerability framework, the CRPD departs from traditional human rights standards and extends the role of the state in two ways. First, it blurs the divide between negative rights, which require the state to refrain from certain conduct, and positive rights, which require the state to take positive steps to secure rights.³⁰⁴ The CRPD recognises that in practice, the realisation of rights often requires the state to abstain from a certain act and to take positive action at the same time, making the distinction between negative

²⁹³ Fineman (n 111) 19.

²⁹⁴ As above.

²⁹⁵ As above.

²⁹⁶ As above.

²⁹⁷ As above.

²⁹⁸ As above.

²⁹⁹ Mackenzie (n 141) 35.

³⁰⁰ Mackenzie (n 141) 33.

³⁰¹ Mackenzie (n 141) 35. See Chapter Three, section 4.2.2 for a detailed discussion of a re-conceptualised notion of autonomy.

³⁰² Clough (n 81) 383.

³⁰³ Mégret (n 108) 6.

³⁰⁴ S Fredman, ‘Human rights transformed: Positive duties and positive rights’ (2006) *Oxford Law Studies, Research Paper No. 38/2006*.

and positive rights of little practical significance.³⁰⁵ For example, the right to freedom from torture is typically classified as a negative right requiring the state and its agents to refrain from torturing people. However, for the right to be effectively protected the state also has to take positive action to prevent others from committing acts of torture. Second, the CRPD extends the role of the state to the private sphere by bridging the divide between the public and the private sphere.³⁰⁶ Typically, the state's duty is limited to the public sphere.³⁰⁷ The CRPD delves into the private sphere more than any other human rights treaty.³⁰⁸ For example, article 16 on freedom from exploitation, violence and abuse is concerned with protecting persons with disabilities in the private sphere generally.³⁰⁹ This provision does not refer to exploitation by the state since there are other provisions such as the right to freedom from torture that caters for that scenario.³¹⁰ The CRPD requires the state to protect persons with disabilities 'both within and outside the home.'³¹¹ Furthermore, the duty to raise awareness regarding persons with disabilities also applies at the family level.³¹² The situation of persons with disabilities therefore, demands a re-conceptualisation of the role of the state. Fineman's vulnerability thesis encompasses this aspect making it useful in advancing the rights of persons with disabilities.

By re-conceptualising vulnerability, the vulnerable subject and the role of the state, Fineman offers a theoretical framework that is useful for critiquing the concept of capacity to consent to sexual intercourse.³¹³ However, the vulnerability thesis does not explain how current conceptions about sexuality and the sexual identity of women with mild Down syndrome came into existence. For that, Foucault's genealogical theory will be utilised.

3. Introducing Foucault's genealogical theory

Genealogy originated with the work of German philosopher Friedrich Nietzsche, and was subsequently developed by the French academic Michel Foucault.³¹⁴ Foucault's genealogical analysis challenges the established historical and philosophical assumptions about knowledge,

³⁰⁵ As above.

³⁰⁶ Mégret (n 108) 266.

³⁰⁷ As above.

³⁰⁸ CRPD art 16(1).

³⁰⁹ As above.

³¹⁰ Mégret (n 108) 266. See also CRPD art 15 on the right to freedom from torture or cruel, inhuman or degrading treatment or punishment.

³¹¹ CRPD art 16(1).

³¹² CRPD art 8(1)(a).

³¹³ See Chapter Three which applies Fineman's Vulnerability framework to capacity to consent to sexual intercourse.

³¹⁴ U Crowley 'Genealogy, method' *International Encyclopaedia of Human Geography* MS number: 443 at 2.

truth and power.³¹⁵ Genealogists undertake historical inquiries into how knowledge, power and claims of truth interact and form sets of practices while simultaneously reinforcing the discourses that created them.³¹⁶ For Foucault, history is the product of competing power structures, struggles and institutional structures of subjugation.³¹⁷ According to Foucault's 'regime of intelligibility' there is a nexus between discourse and power and these discourses, as well as their meaning are 'transparent' because power is intelligible, rational and reveals itself through strategies and tactics in our history.³¹⁸ Therefore, genealogy's main inquiry is how historical processes have led to human beings developing and embodying particular identities.³¹⁹ Genealogy explicates how discursive and non-discursive practices came into existence and interacted to create social, moral, cultural, and economic institutions that delineate the limits of acceptable knowledge, speech and actions.³²⁰ Therefore, in order to understand what forms, constructs and controls us, we must study history, for that is the pre-requisite to human freedom.³²¹ Genealogy is therefore important for de-constructing the sexuality of women with mild Down syndrome.

3.1 Foucault and feminism: Competing ideals?

The proposed use of Foucault's genealogical theory to complement the feminist vulnerability framework may be perceived as controversial. This is because there are divergent views about the utility of Foucault's work for the feminist project with some feminists rejecting outright the possibility of Foucault's work being a resource for feminism and others applying and extending Foucault's work on genealogy.³²² Indeed, there is no single feminist stance on the applicability of Foucault's work to feminist theory and practice.³²³ However, Foucault's genealogical theory is not opposed to feminist ideals and three similarities can be drawn between the two theories.

First, both Foucault and feminism expand the political realm to include matters that were previously considered private, such as sexual relationships and the body.³²⁴ Foucault rejects as inadequate the liberal framework's understanding of power as originating from the

³¹⁵ As above.

³¹⁶ S Anais 'Genealogy and critical discourse analysis in conversation: Texts, discourse, critique' (2013) 10(2) *Critical Discourse Studies* at 125.

³¹⁷ A Bielskis 'Power, history and genealogy: Friedrich Nietzsche and Michel Foucault' (2009) *Problemos* at 80.

³¹⁸ Bielskis (n 317) 81.

³¹⁹ R Geuss 'Genealogy as critique' (2002) 10(2) *European Journal of Philosophy* at 213.

³²⁰ Anais (n 316) 125.

³²¹ Bielskis (n 317) 81.

³²² MA McLaren 'Foucault and the subject of feminism' (1997) 23(1) *Social Theory and Practice* at 109.

³²³ As above.

³²⁴ McLaren (n 322) 114.

sovereign and imposing itself upon subjects.³²⁵ Foucault posits that power is not property to be possessed by some people or classes and not by others.³²⁶ Consequently, power is not exercised from the top down but from innumerable points that form part of a complex network of multiple force relations.³²⁷ Power is relational and power relationships are everywhere.³²⁸ Crucially, everyone exercises power, including those who are ordinarily considered powerless.³²⁹ They exercise power through ‘deflection, partial submission, resistance and localised action.’³³⁰ Therefore, power relations are more a matter of circulation than domination³³¹ making power something that happens, an event rather than an object.³³² Foucault’s perception of power that is omnipresent and dispersed is similar to feminist claims that power is present in numerous spheres of life and the so called ‘private’ spheres such as the family and the classroom, are in fact not apolitical.³³³ Foucault’s genealogical theory is therefore, consistent with feminism’s rejection of the public/private dichotomy and its analysis of power dynamics in interpersonal relationships.³³⁴

Second, feminism and Foucault both agree that a network of practices, discourses and institutions socially constitute the subject.³³⁵ Foucault rejects the ‘repressive hypothesis’ which assumes that power functions negatively through interdiction, censorship and denial.³³⁶ For Foucault, power is not merely about regulating acts by asking ‘which acts ought to be permitted and which acts ought to be prohibited,’ as the liberal conception of power posits.³³⁷ Instead, Foucault conceives of power as a productive rather than a restrictive force.³³⁸ Foucault’s creative or productive form of power operates through a series of ‘trivial moments of exercise’ rather than ‘spectacular form[s] of legal or social interdiction.’³³⁹ Power operates in a subtle and discrete manner by influencing an individual’s decisions and behaviour through practices

³²⁵ N Fraser ‘Foucault on modern power: Empirical insights and normative confusions’ (1981) 3 *Praxis International* at 280.

³²⁶ P Atterton ‘Power’s blind struggle for existence: Foucault, genealogy and Darwinism’ (1994) 7(4) *History of the Human Sciences* at 6.

³²⁷ As above.

³²⁸ McLaren (n 322) 114.

³²⁹ L Shiner ‘Reading Foucault: Anti-method and the genealogy of power-knowledge’ (1982) 21(3) *History and Theory* at 390.

³³⁰ As above.

³³¹ As above.

³³² L McWhorter ‘Sex, race and biopower: A Foucauldian genealogy’ (2004) 19(3) *Hypatia* at 42.

³³³ McLaren (n 322) 114.

³³⁴ McLaren (n 322) 115.

³³⁵ McLaren (n 322) 121.

³³⁶ Fraser (n 325) 281.

³³⁷ V Tadros ‘Between governance and discipline: The law and Michel Foucault’ (1998) 18(1) *Oxford Journal of Legal Studies* at 77.

³³⁸ Shiner (n 329) 391.

³³⁹ Tadros (n 337) 78.

that are ostensibly adopted freely.³⁴⁰ The exercise of power involves someone taking action to influence the action of others.³⁴¹ Through relations of power, people's range of actions may be either limited or increased.³⁴² This includes acts of believing and discoursing.³⁴³ In that sense, power is therefore, action upon action.'³⁴⁴

The constant struggle to structure the actions of others produces 'tactics which merge into global strategies'.³⁴⁵ The principal effects of power are on the body; specifically, power 'classifies, orders, segments, conditions, manages, trains and makes docile.'³⁴⁶ Power therefore, produces subjects and what we call the 'individual' along with the knowledge we have about that individual is a product of power relations.³⁴⁷ Foucault opposes the idea of an autonomous, rational subject that acts in accordance with self-imposed commands.³⁴⁸ For Foucault, social structures and discourses produce the subject.³⁴⁹ Foucault thoroughly applies his genealogical analytics in *Discipline and Punish* and *The History of Sexuality* (volume 1).³⁵⁰ Foucault's book, *Discipline and Punish* provides a historical account of the transformation in the exercise of power in 18th and 19th century Western society.³⁵¹ Although Foucault examines the prison's organisation and its underlying principles and aims to explain this transformation, the book is not about the penal system but rather it is about 'new modalities of regulation, ...surveillance, control and policing of modern western society.'³⁵² Foucault's genealogy of the prison, as exemplified in the panopticon, demonstrates how that institution produces a prisoner through discourses and practices of power/knowledge.³⁵³

Foucault's second major genealogy, *The History of Sexuality*, focuses on the relationship between power and knowledge.³⁵⁴ Foucault deploys the emergence of sexuality as an organised discourse to demonstrate how power works in modern society.³⁵⁵ People surveil

³⁴⁰ Crowley (n 314) 6.

³⁴¹ Mcwhorter (n 332) 42.

³⁴² R Nola 'Knowledge, discourse, power and genealogy in Foucault' (1998) 1(2) *Critical Review of International Social and Political Philosophy* at 109.

³⁴³ As above.

³⁴⁴ Mcwhorter (n 332) 42.

³⁴⁵ Shiner (n 329) 391.

³⁴⁶ Atterton (n 326) 6.

³⁴⁷ Foucault (n 77) 27.

³⁴⁸ M Bevir 'Foucault, power, and institutions' (1999) XLVII *Political Studies* at 347.

³⁴⁹ As above.

³⁵⁰ Crowley (n 314) 5.

³⁵¹ Crowley (n 314) 6.

³⁵² As above.

³⁵³ R Galvin 'A genealogy of the disabled identity in relation to work and sexuality' (2006) 21(5) *Disability and Society* at 503. See Chapter Five, section 3 for a detailed discussion of how subjects are produced.

³⁵⁴ Crowley (n 314) 8.

³⁵⁵ As above.

themselves by scrutinising their own behaviour in search of signs of sin or abnormality thereby constituting themselves as subjects.³⁵⁶ Similarly, many feminist theories subscribe to the idea of a socially constructed subject and reject the disembodied consciousness of the Enlightenment subject.³⁵⁷ Central to numerous feminist approaches is the embodied subject.³⁵⁸ Feminist thinker Chodorow explained it thus: ‘becoming a person is the same thing as becoming a person in relationship and in social context.’³⁵⁹ Therefore, many feminist theories, like Foucault, agree that the subject is a product of external and internal constraints of regimes of power.³⁶⁰

Third, much of the debate about Foucault’s compatibility with feminism relates to the question of the subject. Those who reject Foucault’s work do so on the basis that feminist theory is essentially political, aimed at eradicating oppression against women, it necessarily subscribes to a conception of a subject that is capable of political and moral agency, and they criticise Foucault’s work for failing to conceive of a subject capable of political and moral agency.³⁶¹ It is their claim that Foucault’s work lacks an adequate theory of the subject.³⁶² In contrast, those feminists who think that Foucault’s work is applicable and relevant to feminism cite his deconstruction of the subject.³⁶³ Foucault rejects the classical philosophical subject and reconceives a subject that is always enmeshed in relations of power.³⁶⁴ Foucault’s explicit rejection of the subject of the Enlightenment is exhibited in the following extracts:

Because what troubles me with these analyses which prioritise ideology is that there is always presupposed a human subject on the lines of the model provided by classical philosophy, endowed with a consciousness which power is thought to seize on.³⁶⁵

Foucault further states that:

One has to dispense with the constituent subject, to get rid of the subject itself, that’s to say, to arrive at an analysis which can account for the constitution of the subject within a historical framework. And this is what I would call genealogy, that is a form of history which can account for the constitution of knowledges, discourses, domains of subjects etc., without having to make reference to a subject which is either transcendental in

³⁵⁶ Bevir (n 348) 350. See Chapter Five, section 3.2 for a detailed discussion of how subjects constitute themselves through self-surveillance.

³⁵⁷ McLaren (n 322) 119.

³⁵⁸ As above.

³⁵⁹ N Chodorow *The reproduction of mothering: Psychoanalysis and the sociology of gender* (1978) 76.

³⁶⁰ Bevir (n 348) 349.

³⁶¹ McLaren (n 322) 109.

³⁶² As above.

³⁶³ As above.

³⁶⁴ As above.

³⁶⁵ M Foucault *Power/knowledge: Selected interviews and other writings, 1972 - 1977* (1980) 58.

relation to the field of events or runs its empty sameness throughout the course of history.³⁶⁶

Feminists who are opposed to Foucault's work argue that his emphasis on the effects of power upon the body reduce social agents to passive bodies and cannot account for individuals that are capable of autonomous action.³⁶⁷ For that reason, they conclude that Foucault's genealogical framework is in conflict with feminism's fundamental project of re-discovering and re-evaluating women's experiences.³⁶⁸ However, Foucault's rejection of an 'a priori subject' is in fact consistent with much of feminist theory and feminist goals as is his reconstruction of the subject.³⁶⁹ Foucault does not reject the subject per se, but contests a particular historical form of consciousness.³⁷⁰ What Foucault challenges is the subject being the condition for the possibility of experience.³⁷¹ Foucault argues instead that it is experience which results in the creation of the subject.³⁷² In an interview, Foucault himself explained that '[w]hat I refused was precisely that you first of all set up a theory of the subject... What I wanted to know was how the subject constituted himself, in such and such a determined form...'³⁷³ For Foucault, the refusal to be what we are frees us from the subjectivity that has been imposed on us through disciplines and practices, thereby opening up new possibilities for being.³⁷⁴ Indeed Foucault is quite clear that power is always subject to reversal through resistance.³⁷⁵ For Foucault, freedom is only possible where power exists. Foucault explains it thus:

Power is exercised only over free subjects, and only insofar as they are free. By this we mean individual or collective subjects who are faced with a field of possibilities in which several ways of behaving, several reactions and diverse comportments may be realised. Where the determining factors saturate the whole there is no relationship of power.³⁷⁶

This conception of the subject acknowledges the role of the network of social relationships that constitute subjects while simultaneously leaving room for moral agency. Therefore, genealogy

³⁶⁶ Foucault (n 365) 117.

³⁶⁷ L McNay 'The Foucauldian body and the exclusion of experience' (1991) 6 *Hypatia* at 125 – 37.

³⁶⁸ As above.

³⁶⁹ McLaren (n 322) 110.

³⁷⁰ McLaren (n 322) 111.

³⁷¹ McLaren (n 322) 112. See also M Foucault 'Final Interview' (1985) 5(2) *Raritan* at 1 – 13.

³⁷² As above.

³⁷³ M Foucault 'The ethic of care for the self as a practice of freedom' in J Bernauer & D Rasmussen (eds) *The Final Foucault* (1988) at 10.

³⁷⁴ McLaren (n 322) 113.

³⁷⁵ McLaren (n 322) 116.

³⁷⁶ As above.

and feminism are not dissimilar, and Foucault's work may be used to complement feminist frameworks such as Fineman's vulnerability thesis.

3.2 Complementing vulnerability with genealogy

Foucault's genealogical method enables an analysis that Fineman's vulnerability framework cannot support and therefore complements Fineman's work in the following ways:

First, Foucault's genealogical theory is capable of unmasking the power dynamics involved in the establishment of concepts and practices thereby revealing their contingent nature.³⁷⁷ Genealogy exposes the fact that our beliefs, practices and concepts are historical and contingent rather than natural and necessary, and creates new possibilities for action, social and personal transformation.³⁷⁸

Second, Foucault's genealogical analysis problematises concepts and practices by showing us what is 'in crisis and therefore stands in need of critique.'³⁷⁹ 'Problematisation' involves clarifying the problems at the core of practices that we would otherwise consider unproblematic.³⁸⁰ Koopman explains 'problematisation' in relation to sexuality as follows:

Foucault's point was not that contemporary sexuality is bad and must be tossed off. Foucault's point was rather that sexuality in the present is in crisis so we must learn to do it differently. Doing something different about sexuality would require, presumably, equipping ourselves with an understanding of how sexuality became the unique kind of problematisation that it is for us, which means equipping ourselves with a history of our sexuality.³⁸¹

Genealogy is commonly used for these two purposes of unmasking and 'problematising.'³⁸²

However, there is a third, and less popular, aspect of Foucault's genealogical analysis known as the 'possibilising' dimension. Foucault's genealogical method has been criticised for lacking the ability to explain why we should resist the power mechanisms whose subjugating effects it reveals.³⁸³ Indeed, genealogy does not concern itself with assessing the truth/falsity of the epistemic contents.³⁸⁴ In other words, it does not ask whether the various knowledge regimes are warranted or adequate.³⁸⁵ Consequently, genealogy is not capable of indicating

³⁷⁷ D Lorenzini 'On possibilising genealogy' (2020) *Inquiry: An Interdisciplinary Journal of Philosophy* at 3.

³⁷⁸ Lorenzini (n 377) 6.

³⁷⁹ C Koopman 'Genealogical pragmatism: How history matters for Foucault and Dewey (2011) 5 *Journal of the Philosophy of History* at 541.

³⁸⁰ Koopman (n 379) 534.

³⁸¹ Koopman (n 379) 541.

³⁸² Lorenzini (n 377) 3.

³⁸³ Lorenzini (n 377) 7

³⁸⁴ Fraser (n 325) 275.

³⁸⁵ As above.

what should be done, whether the concepts and practices it studies should be rejected or altered and if so, what the new practices should be.³⁸⁶ For that reason, it has been criticised as being merely descriptive and value-neutral.³⁸⁷ Nevertheless, genealogy creates a framework for action by which we can commit to resisting arbitrary formations of power/knowledge.³⁸⁸ Foucault posits that resistance is an integral part of relations of power, indicating that all power/knowledge formations have already been contested through multiple forms of counter-conduct.³⁸⁹ This signifies that it is possible to cease doing what we do, thinking what we think and being what we are.³⁹⁰ Foucault's genealogical method reveals the continued existence, albeit in altered forms, of the power/knowledge mechanisms that women and men resisted in past times.³⁹¹ Genealogy therefore recounts:

a history that is still ours, (a history not only of subjection, but also of contestation and resistance), it situates each of us within a (multiplicity of) "we(s)", each carrying with it in an immanent fashion ... a political commitment to fight against a specific power/knowledge apparatus.³⁹²

For Lorenzini, this constitutes the *sui generis* normative force of 'possibilising genealogy.'³⁹³ Although Foucault's genealogies do not tell us what needs to be done, they do make it clear that something needs to be done.³⁹⁴ In Lorenzini's words, 'they commit us to carry on, in one form or another, the struggle against the subjugating effects of the power/knowledge formations that still permeate our lives and whose arbitrariness they reveal.'³⁹⁵ Foucault's genealogy is therefore neither value neutral nor merely descriptive.³⁹⁶ Instead, it creates space for freedom without seeking to fill that space or requiring us to do so.³⁹⁷ Foucault's genealogical theory is therefore, useful for unmasking, 'problematizing' and 'possibilising' discourses of power in a Western society. Its applicability to the African context is considered next.

³⁸⁶ Lorenzini (n 377) 3.

³⁸⁷ Lorenzini (n 377) 16.

³⁸⁸ Lorenzini (n 377) 7.

³⁸⁹ Lorenzini (n 377) 3.

³⁹⁰ Lorenzini (n 377) 3.

³⁹¹ Lorenzini (n 377) 15.

³⁹² Lorenzini (n 377) 16.

³⁹³ As above.

³⁹⁴ As above.

³⁹⁵ As above.

³⁹⁶ As above.

³⁹⁷ Lorenzini (n 377) 6.

3.3 Foucault's relevance to African sexuality

Foucault's work on discourse, power and knowledge focused exclusively on Western societies.³⁹⁸ Indeed Foucault himself acknowledged his own ignorance about societies other than his own Western society.³⁹⁹ However, this does not mean that his genealogical analysis is irrelevant to Africa and to Africans. It is worth recalling the words of the African philosopher, Mungwini, who posits that 'the African encounter with Western modernity defines the context within which much of what unfolds in postcolonial Africa can be understood, including even its ethical and social problems.'⁴⁰⁰ Indeed Africa's encounter with European modernity achieved through the West's imperial project resulted in the forcible creation of a new world and the political, economic and cultural realities of that world have been established by the 'characteristic modalities of modern power.'⁴⁰¹ African modernity continues to experience construction and reconstruction in reaction to processes and developments in a globalising world.⁴⁰² Foucault's work is relevant and applicable to Africa for two reasons.

First, Western states produced discourses about Africa as a way of exerting domination over it.⁴⁰³ Indeed, Western countries have controlled the production of discourse and thus the workings of power and knowledge in the developing world, in various ways.⁴⁰⁴ For example, as Ngwena notes, African identities were constructed in the light of its colonial history.⁴⁰⁵ Colonial discourses are responsible for the 'misrecognised African cultural and racial identities' which were constructed through tactics commonly used in the colonial project such as othering and misrecognition.⁴⁰⁶ The knowledge/power couplet is indispensable in explaining historical and contemporary constructions of African identities, making it difficult to analyse African knowledge and identities without addressing some Western concepts, such as Foucault's concept of power/knowledge.⁴⁰⁷

³⁹⁸ A Escobar 'Discourse and power in development: Michel Foucault and the relevance of his work to the third world' (1984 – 85) *Alternatives X* at 377.

³⁹⁹ Escobar (n 398) 378.

⁴⁰⁰ P Mungwini "'Surveillance and cultural panopticism": Situating Foucault in African modernities' (2012) 31(2) *South African Journal of Philosophy* at 340.

⁴⁰¹ A Talal 'Conscripts of Western civilization' in CW Gailey (ed) *Dialectical Anthropology: Essays in honour of Stanley Diamond* (1992) at 340.

⁴⁰² Mungwini (n 400) 342.

⁴⁰³ Escobar (n 398) 377.

⁴⁰⁴ Ngwena (n 106) 44.

⁴⁰⁵ As above.

⁴⁰⁶ As above.

⁴⁰⁷ As above.

Second, the conceptual tools Foucault developed to analyse power were exported and are capable of being deployed in Africa.⁴⁰⁸ In South Africa, in particular, Foucault's thinking, particularly on governmentality, was received in the early years.⁴⁰⁹ This early reception is attributed to the fact that South African historians were heavily influenced by the French, most notably, the French Annales School.⁴¹⁰ As early as 1985, Jean Comaroff published a history of Christian missionaries in southern Africa relying on Foucauldian concepts to analyse the evolution of discourse and disciplinary power in relation to colonial rule.⁴¹¹ Pesek summarises Comaroff's work as follows:

Her main question is how to locate missionaries into the orbit of colonialism. In contrast to earlier studies, missionaries, neither easily sided with the colonial state nor were positioned outside the colonial project. Foucault surely introduced her to a way of puzzling together the many different agents of colonial rule, and as she later noted, to deconstruct the 'master narrative of European imperial expansion – or, rather, its narrative of mastery – [that] would place the state at the centre of the story.'⁴¹²

In later years, several South African writers have deployed Foucault's genealogical method to analyse discourses and relations of power in South Africa in various contexts. For example, Dirsuweit uses Foucault's concept of panopticism to critique sexual identity within the context of a South African women's prison.⁴¹³ Similarly, Pitsoe and Letseka adopt Foucauldian thinking as a conceptual framework to understand the prevailing disciplinary problems in South African schools and provide an alternative framework for the re-imagining of the practice of school discipline.⁴¹⁴ Moodie relies on Foucault to interrogate the construction of sexuality on South African gold mines.⁴¹⁵ Escobar correctly posits that the spread of Foucault's conception of power to all societies is almost inevitable, given the nature of power and its ability and tendency to assume global forms.⁴¹⁶ Foucault's work is therefore, relevant to Africa because of Western modernity's influence on the continent.

⁴⁰⁸ Escobar (n 398) 377-378.

⁴⁰⁹ M Pesek 'Foucault hardly came to Africa: Some notes on colonial and post-colonial governmentality' (2011) 21 *Zeitschrift für Globalgeschichte und vergleichende Gesellschaftsforschung* at 44.

⁴¹⁰ As above.

⁴¹¹ As above.

⁴¹² As above.

⁴¹³ T Dirsuweit 'Carceral spaces in South Africa: A case study of institutional power, sexuality and transgression in a women's prison' (1999) 30 *Geoforum* at 71 – 83.

⁴¹⁴ V Pitsoe & M Letseka 'Foucault on school discipline: Reflections on South Africa' (2014) 5(23) *Mediterranean Journal of Social Sciences* at 1525 – 1532.

⁴¹⁵ T Dunbar Moodie et al 'Migrancy and male sexuality on the South African gold mines' (1988) 14 (2) *Journal of Southern African Studies* at 228 – 256.

⁴¹⁶ Escobar (n 398) 378.

Therefore, genealogy is useful for complementing Fineman's vulnerability framework because it explains how knowledge and subjects were constructed discursively through relations of power throughout history. However, as mentioned above, genealogy unmasks, problematises and opens up possibilities for action without stating what needs to be done. Because this study seeks to interrogate ways in which the sexual autonomy of women with mild Down syndrome can be recognised, including through legislative reform, a further theory is required to complement the genealogical analysis. De-colonial theory is deployed in this study for that purpose.

4. Introducing de-colonial theory

The period of active colonisation in the history of Africa was relatively brief.⁴¹⁷ It lasted for less than a century, having begun in the late 19th century and continuing until the middle of the twentieth century.⁴¹⁸ Nevertheless, it significantly transformed African traditions and cultures through its radical discourses.⁴¹⁹ To date, the impact of some colonial discourses persists. In response, de-colonial theory was formulated to subvert the continued influence and impact of the West's imperial project by challenging and confronting the 'dominative and assimilative force of colonialism.'⁴²⁰ The theory draws a crucial distinction between 'colonialism' and 'coloniality.'⁴²¹ The term 'colonialism' refers to the 'socio-political domination of a territory' whilst the term 'coloniality' refers to a 'mode of thought that legitimises colonialism and neo-colonialism while espousing universalism.'⁴²² The starting point of de-colonial theory is the recognition that coloniality did not end with the formal termination of colonial states.⁴²³ De-colonial theory is concerned with the various forms of coloniality that still exist long after the end of formal colonial rule.⁴²⁴ Its goal is to expose the coloniality that persists in law and in forms of knowledge.⁴²⁵

⁴¹⁷ VY Mudimbe *The invention of Africa: Gnosis, philosophy and the order of knowledge* (1988) 1.

⁴¹⁸ As above.

⁴¹⁹ As above.

⁴²⁰ N De Lissoy 'Decolonial pedagogy and the ethics of the global' (2010) 31(3) *Discourse: Studies in the Cultural Politics of Education* at 280.

⁴²¹ A Nhemachena 'The notion of the "field" and the practices of researching and writing Africa: Towards decolonial praxis' (2016) 9(7) *Africology: The Journal of Pan-African Studies* at 20.

⁴²² L Salaymeh & R Michaels 'Decolonial comparative law: A conceptual beginning' (2022) *Max Planck Institute for Comparative and International Private Law (Research Paper Series)* at 177.

⁴²³ As above.

⁴²⁴ G Adams & S Estrada-Villalta 'Theory from the South: A decolonial approach to the psychology of global inequality' (2017) 18 *Current Opinion in Psychology* at 39.

⁴²⁵ As above.

In contrast with postcolonial theory, de-colonial theorists believe in the ability to subvert colonising discourses.⁴²⁶ The aim, therefore, is neither to embrace, nor reject these discourses in their entirety, but to critically reclaim them.⁴²⁷ This constructive and critical approach can be realised through the process of de-colonial thinking which involves three actions.⁴²⁸ First, the act of critiquing Western thinking is essential to de-colonial theory.⁴²⁹ This involves highlighting the gaps or limits of Western thinking and illuminating the contrast between what European knowledge claims to do and what it actually delivers.⁴³⁰ Second, de-colonial thinking requires the retrieval of concepts developed from the perspective of the colonised world and formulating new ones.⁴³¹ The retrieval of non-Western knowledge involves the development of new theories and insights adopting the ‘historical and epistemological standpoint’ of the colonised.⁴³² Third, the establishment of a dialogue between these two approaches is necessary.⁴³³ In contrast with Eurocentric thinking, de-colonial critique does not suppress difference but convenes a dialogue between Eurocentric thinking and non-European thinking.⁴³⁴ Barreto states that ‘the dialogical relation between the two initial steps ... implies getting over Eurocentricism while keeping that which has remained valid after being object of critique.’⁴³⁵

In this research study, de-colonial theory is deployed to contest the coloniality that persists in the law relating to the capacity of women with mild Down syndrome in South Africa to consent to sexual intercourse. A similar approach was taken in lesbian, gay, bisexual and transgender (LGBT) discourses, particularly in South Africa and Namibia, to use de-colonial theory as a basis for contesting homophobic and transphobic laws.⁴³⁶ LGBT activists argued that colonialists formalised the legal and social prohibition of homosexuality, thereby introducing homophobia.⁴³⁷ The pro-LGBT camp therefore, sought to dismantle and transform anti LGBT laws, ideologies, institutions and practices associated with foreign occupation and

⁴²⁶ B Mendoza ‘Coloniality of gender and power: From postcoloniality to decoloniality’ in L Disch & M Hawkesworth (eds) *The Oxford Handbook of Feminist Theory* (2016) at 112.

⁴²⁷ JM Barreto ‘Decolonial thinking and the quest for decolonizing human rights’ (2018) 46 *Asian Journal of Social Science* at 486.

⁴²⁸ As above.

⁴²⁹ Barreto (n 427) 487.

⁴³⁰ As above.

⁴³¹ As above.

⁴³² As above.

⁴³³ As above.

⁴³⁴ Barreto (n 427) 487-488.

⁴³⁵ Barreto (n 427) 489.

⁴³⁶ A Currier ‘Decolonising the law: LGBT organisation in Namibia and South Africa (2011) 54 *Studies in Law Politics and Society* at 18.

⁴³⁷ As above.

domination.⁴³⁸ In that sense, therefore, the pursuit of law reform is an act of de-colonisation.⁴³⁹ De-colonial theory informs and justifies interventions through legislative reform, thereby complementing Foucault's genealogical theory, which stops short of dictating what should be done in response to the failure to recognise the sexual autonomy of women with mild Down syndrome.

5. Conclusion

On its own, human rights law is incapable of bringing about the conceptual shift required for the recognition of the sexual autonomy of women with mild Down syndrome. Therefore, this chapter introduced the theoretical frameworks that the study utilises to complement human rights law and de-construct the sexuality of women with mild Down syndrome for purposes of interrogating the regimes that have shaped and influenced their sexuality. Cumulatively, Fineman's vulnerability framework, Foucault's genealogical theory and de-colonial theory, as well as human rights law, will be deployed in order to achieve the ultimate goal of formulating enabling alternatives capable of affording sexual autonomy to women with mild Down syndrome in South Africa.

⁴³⁸ As above.

⁴³⁹ As above.

CHAPTER THREE

PROBLEMATISING AND RE-CONCEPTUALISING THE ‘CAPACITY FRAMEWORK’ IN SOUTH AFRICA: VULNERABILITY AND SUPPORT

[I]t is impossible to lead a *good* human life in the absence of the freedom and opportunity to exercise personal autonomy, by which I mean the capability to make important life decisions and choices.⁴⁴⁰

1. Introduction

There are varying approaches to the capacity of women with mild Down syndrome to consent to sexual intercourse adopted in African legislation. In Malawi, Uganda and Zambia, for example, sexual activity with all women with mild Down syndrome is criminalised, thereby denying sexual autonomy on the basis of disability.⁴⁴¹ In contrast, South African law does not impose a blanket prohibition of sexual intercourse on all women with mild Down syndrome. Instead, capacity to consent is a threshold issue that is determined through the application of a legal test. The Sexual Offences Act declares that women with ‘mental disabilities’ lack capacity to consent to sexual intercourse.⁴⁴² Therefore, no one falling within the ambit of the legal definition of ‘mental disability’ may give valid legal consent to sexual intercourse. Conversely, women with mild Down syndrome who do not meet the requirements of the legal definition are considered as having the capacity to consent to sexual intercourse. In contrast with the approach in Malawi, Uganda and Zambia, which denies all women with intellectual disabilities capacity to consent to sexual intercourse, the South African approach only denies women whose disability meets the stipulated severity threshold, making it a better approach in terms of upholding the right to sexual autonomy.

Nevertheless, this chapter argues that the ‘capacity framework’ adopted in South Africa remains problematic for three main reasons. First, it denies some women with mild Down syndrome sexual autonomy by labelling them as lacking capacity to consent to sexual intercourse. Second, the ‘capacity framework’ violates the right to legal capacity by failing to recognise the universality of this right and by discriminating against women with mild Down syndrome because of disability. Third, it is an example of residual coloniality persisting in the law, rendering its local applicability and legitimacy questionable.

⁴⁴⁰ CA Ball ‘Autonomy, justice and disability’ (2000) 47(3) *University of California Los Angeles Law Review* at 635.

⁴⁴¹ See section 2.2 below for a detailed discussion of the approach in Malawi, Uganda and Zambia.

⁴⁴² Sexual Offences Act (n 42).

In response to these shortcomings, this chapter argues for a re-conceptualisation of the ‘capacity framework’ through an application of Fineman’s vulnerability framework, the support paradigm and de-colonial theory, in order to ensure the recognition of the sexual autonomy of women with mild Down syndrome. Therefore, the aims of this chapter are two-fold. First, it seeks to problematise the ‘capacity framework’ deployed in South Africa. Second, the chapter aims to re-conceptualise capacity to consent to sexual intercourse in an effort to uphold the sexual autonomy of women with mild Down syndrome.

The chapter is divided into four parts. Part one explicates the two approaches to capacity to consent to sexual intercourse adopted in South Africa as well as in Malawi, Uganda and Zambia. In the second part, the chapter illuminates the problems associated with South Africa’s ‘capacity framework.’ The third part addresses how Fineman’s vulnerability framework as well as the support paradigm enunciated in the CRPD can be deployed to re-conceptualise the capacity framework in a manner that upholds the sexual autonomy of women with mild Down syndrome. Part four concludes the chapter by summarising its main arguments.

2. Approaches to the capacity of women with mild Down syndrome to consent to sexual intercourse.

Two distinct approaches to the capacity of women with mild Down syndrome to consent to sexual intercourse are exemplified in legislation in South Africa, Malawi, Uganda, and Zambia. This section explains South Africa’s ‘capacity framework’ and the ‘status framework’ adopted in Malawi, Uganda, and Zambia, and compares the effects of the two approaches on the right of women with mild Down syndrome to sexual autonomy.

2.1 The ‘capacity framework’ in South Africa

In South Africa, all sexual offences are dealt with in the Sexual Offences Act which was enacted to ‘comprehensively and extensively review and amend all aspects of the laws and the implementation of the laws relating to sexual offences, and to deal with all legal aspects of or relating to sexual offences in a single statute.’⁴⁴³ It contains sexual offences including rape,⁴⁴⁴

⁴⁴³ Sexual Offences Act long title.

⁴⁴⁴ Sexual Offences Act sec 3.

compelled rape,⁴⁴⁵ sexual assault,⁴⁴⁶ compelled sexual assault,⁴⁴⁷ and compelled self-sexual assault.⁴⁴⁸

The lack of consent is an essential element in all these offences, such that they can only occur in circumstances where there was no consent on the part of one or more parties involved in the acts. For example, a person (A) who ‘unlawfully and intentionally commits an act of sexual penetration with a complainant (“B”), without the consent of B, is guilty of the offence of rape.’⁴⁴⁹ Consent must therefore, be present in order for the sexual intercourse to be lawful.⁴⁵⁰ Accordingly, in a rape trial, the prosecution must prove that at the time of the offence, the complainant did not subjectively consent to the sexual activity.⁴⁵¹ There is, however, an important exception to this general rule. The Sexual Offences Act provides that persons with ‘mental disabilities’ do not have the capacity to consent to sexual acts.⁴⁵² The relevant provision states that ‘[n]otwithstanding anything to the contrary in any law contained, a person who is mentally disabled is incapable of consenting to a sexual act.’⁴⁵³ Therefore, in a rape trial, where the absence of consent is an essential element of the offence, the question whether a complainant is a person with a ‘mental disability’ is pivotal because it determines whether they could legally consent to the sexual intercourse.

For the purposes of the Sexual Offences Act, ‘mental disability’ is defined as ‘any disorder or disability of the mind’ that reaches the stipulated threshold of severity.⁴⁵⁴ The severity threshold is achieved when the individual satisfies one of four criteria. First, the disability must result in an inability to ‘appreciate the nature and reasonably foreseeable consequences of a sexual act.’⁴⁵⁵ Second, in cases where the person did have an appreciation of the nature and reasonably foreseeable consequences of the act, the disability must result in an inability ‘to act in accordance with that appreciation.’⁴⁵⁶ Third, the severity of the disability

⁴⁴⁵ Sexual Offences Act sec 4.

⁴⁴⁶ Sexual Offences Act sec 5.

⁴⁴⁷ Sexual Offences Act sec 6.

⁴⁴⁸ Sexual Offences Act sec 7.

⁴⁴⁹ Sexual Offences Act sec 3.

⁴⁵⁰ AA Boni-Saenz ‘Sexual advance directives’ (2016) 68 *Alabama Law Review* at 7.

⁴⁵¹ J Benedet & I Grant ‘A situational approach to incapacity and mental disability in sexual assault law’ (2013) 43(1) *Ottawa Law Review* at 1.

⁴⁵² Sexual Offences Act sec 57. This provision deals with the ‘inability of children under 12 years and persons who are mentally disabled to consent to sexual acts’.

⁴⁵³ Sexual Offences Act sec 57(2).

⁴⁵⁴ Sexual Offences Act sec 1.

⁴⁵⁵ Sexual Offences Act sec 1 (1) (a).

⁴⁵⁶ Sexual Offences Act sec 1 (1) (b).

must be such that the person is ‘unable to resist the commission of any such offence’⁴⁵⁷ or fourth, ‘unable to communicate his or her unwillingness to participate in any such act.’⁴⁵⁸ A person who meets one of these four criteria is ‘mentally disabled,’ and cannot validly consent to sexual intercourse.⁴⁵⁹

Whether a complainant’s disability is such that they are unable to consent to sexual intercourse is a question of fact, to be decided on a case-by-case basis.⁴⁶⁰ However, case law provides three broad guidelines to be considered when making this determination. First, a two-stage test, outlined in *Adam Chinridze v the State* (hereinafter, *Chinridze*), must be applied in order to ascertain whether a complainant is a person with a ‘mental disability’ and is therefore, unable to give valid consent to sexual intercourse.⁴⁶¹ The appellant, *Chinridze*, was charged with rape in the Benoni Regional Court.⁴⁶² He was convicted on that charge and sentenced to fifteen years imprisonment. He subsequently appealed to the High Court against conviction and sentence. The appeal Court in *Chinridze* stated that the first leg of this test involves determining whether there was factual consent in a particular case. Essentially, the Court has to decide whether there is evidence that the complainant did in fact consent to the sexual intercourse. If it is apparent, from the facts, that there was no factual consent then the second inquiry falls away and the accused person is convicted of the offence.⁴⁶³ Conversely, if there was factual consent, then the Court must apply the second step of the test, which involves determining whether there was legal consent. This is done by assessing whether there is evidence proving that the complainant falls within one of the four criteria that comprise the legal definition of ‘mental disability.’⁴⁶⁴

In *Chinridze*, Dosio AJ applied the two-step analysis to the facts in that case. In terms of factual consent, the Court found that the complainant consistently testified that the appellant closed her mouth and threatened to beat her.⁴⁶⁵ Dosio AJ concluded that such ‘oppressive behaviour on the part of the appellant is indicative of the intercourse not being consensual.’⁴⁶⁶ He added that ‘it is clear that factually this complainant did not consent at any point, and on

⁴⁵⁷ Sexual Offences Act sec 1(1) (c).

⁴⁵⁸ Sexual Offences Act sec 1(1) (d).

⁴⁵⁹ Sexual Offences Act sec 1 (1).

⁴⁶⁰ JRL Milton *The South African Criminal Law and Procedure: Common-law crimes* (1982).

⁴⁶¹ *Adam Chinridze v The State (Chinridze)* A529/13.

⁴⁶² *Chinridze* at 1.

⁴⁶³ *Chinridze* para 22.

⁴⁶⁴ *Chinridze* para 21.

⁴⁶⁵ *Chinridze* para 24.

⁴⁶⁶ As above.

this basis alone the appellant's appeal in respect to conviction should be dismissed.'⁴⁶⁷ The second inquiry regarding legal consent was therefore, not necessary. Nevertheless, the Court went on to apply the second leg of the test for purposes of providing guidance.

Similarly, in *Vusi Maxwell Mnguni v the State* (hereinafter, *Mnguni*), where the appellant appealed against conviction and sentence for raping a twenty-year old complainant with an intellectual disability, the appeal Court upheld a rape conviction despite the fact that the state had failed to prove that the complainant had a 'mental disability' as defined in the Sexual Offences Act.⁴⁶⁸ The Court arrived at this decision because it considered factual consent first and found that there was evidence that the complainant did not consent to the sexual intercourse.⁴⁶⁹ Louw J stated that:

the evidence of Ms Mountford in this regard was overwhelming. She described in detail the extent of the victim's gynaecological injuries when she examined her. The most serious injury was a tear, which she found that ran through from the posterior fourchette to the fossa navicularis. Such an injury, she said, does not occur even during rough sexual intercourse and usually only happens during childbirth.⁴⁷⁰

The appeal Court therefore, upheld the conviction based only on the lack of factual consent and did not need to establish legal consent.

The order of the 'capacity framework's' two-stage enquiry is significant. It may seem reasonable to conclude that capacity is a pre-requisite for giving and denying consent, such that a woman who cannot legally consent is also incapable of withholding consent.⁴⁷¹ If one adopts this reasoning, it would be logical to determine legal consent before factual consent. For if, one cannot legally consent, then it may not be necessary to inquire into whether they did actually consent. However, the Court does the converse and first considers whether there was factual consent before assessing legal consent. It is only where there is evidence of apparent consent that the inquiry into whether the complainant was capable of giving that consent is made.⁴⁷² The Court follows this order because the relationship between capacity and consent is complex.⁴⁷³ Giving consent requires a higher level of understanding than withholding consent such that a woman who cannot validly consent to a particular sexual act, may still be capable

⁴⁶⁷ *Chinridze* para 29.

⁴⁶⁸ *Vusi Maxwell Mnguni v the State (Mnguni)* Case No: A12/2014 at 3.

⁴⁶⁹ *Mnguni* at 3.

⁴⁷⁰ As above.

⁴⁷¹ J Benedet & I Grant 'Hearing the sexual assault complaints of women with mental disabilities: Consent, capacity, and mistaken belief' (2007) 52 *McGill Law Journal* at 270.

⁴⁷² Benedet & Grant (n 451) 22.

⁴⁷³ Benedet & Grant (n 471) 270.

of withholding consent to the same sexual act.⁴⁷⁴ Benedet and Grant explain it thus: ‘a woman could know that she doesn’t want any physical contact with the man in question, even if she does not understand the sexual nature of the activity or its potential consequences.’⁴⁷⁵ In other words, she may be capable of saying ‘no’ but not capable of saying ‘yes’ in a particular context. Therefore, the pertinent question is whether ‘yes means yes’ as opposed to whether ‘no means no.’⁴⁷⁶ There is therefore, a distinction between capacity to consent and capacity to withhold consent. Indeed, in *Murray John Martyn Bridgman N.O v Witzenberg Municipality and others*⁴⁷⁷ the Western Cape Division of the High Court of South Africa distinguished the question of whether the complainant had capacity to consent to sexual intercourse from the question of whether she had the capacity to deny consent to sexual intercourse.⁴⁷⁸ The significance of the order of the two-stage test is this: A finding of lack of capacity to consent has very serious consequences in that once a label of lacking capacity to consent is placed on a person, it may stay with them for life.⁴⁷⁹ As Clough explains, ‘if a person is deemed to lack capacity to consent to sexual acts, then their freedom to engage in sexual relations will be curtailed by supervision and control to prevent it.’⁴⁸⁰ Therefore, convicting an accused person where there is evidence of non-consent before entering into the capacity inquiry, serves to protect women with mild intellectual disabilities and enables them to say no without being labelled as lacking capacity to consent.⁴⁸¹ This is why Benedet and Grant state that, ‘[i]n our view, incapacity should only be raised where there is some indication that the complainant said ‘yes’ to the sexual activity.’⁴⁸²

The second guideline is that the State, which bears the burden of proving that the complainant is mentally disabled, is required to adduce psychiatric evidence relating to the complainant’s disability.⁴⁸³ The appeal Court in *Mnguni* noted that no psychiatric evidence was led to prove that the complainant was a person with a ‘mental disability.’⁴⁸⁴ At trial, the state called Dr Phangela, a clinical psychologist, as well as Ms Mountford, a registered nurse specialising in sexual assault and physical assault examinations, to testify as expert witnesses

⁴⁷⁴ As above.

⁴⁷⁵ As above.

⁴⁷⁶ A Wertheimer *Consent to sexual relations* (2003) 2.

⁴⁷⁷ *Murray John Martyn Bridgman N.O v Witzenberg Municipality, Jack Jacobus Nicholaas Louw and Elsabe Cornelia Elizabeth Louw (Bridgman v Witzenberg Municipality and others)* Case No 701/2012.

⁴⁷⁸ *Bridgman v Witzenberg Municipality and others* para 13.

⁴⁷⁹ Clough (n 81) 382.

⁴⁸⁰ As above.

⁴⁸¹ Benedet & Grant (n 471) 270.

⁴⁸² Benedet & Grant (n 451) 22.

⁴⁸³ *Mnguni*.

⁴⁸⁴ *Mnguni* at 3.

before the Court.⁴⁸⁵ Neither of these two expert witnesses were psychiatrists so their evidence could not constitute psychiatric evidence.⁴⁸⁶

Similarly, in *Chinridze* the appeal Court had to make a determination on whether the trial Court was correct in concluding that the complainant was a person with a ‘mental disability’ and therefore, unable to consent to sexual intercourse. The appellant’s counsel argued that the State had failed to prove that the complainant had a ‘mental disability’ as defined in section 1(1) of the Sexual Offences Act.⁴⁸⁷ Counsel for the appellant based this argument on the fact that the State did not call a psychiatrist to testify to the fact that the complainant had a ‘mental disability.’⁴⁸⁸ Instead, they called a clinical psychologist, Dr Phangela. Counsel cited the case of *S v Dladla* where Madondo J stated that the question of whether the complainant has a ‘mental disability’ should be ‘determined with the aid of psychiatric evidence.’⁴⁸⁹ Since Dr Phangela was not a psychiatrist, his finding that the complainant has a mental disability does not amount to psychiatric evidence and therefore, no conclusive findings on her ‘mental disability’ could be made as required by section 1 (1) of the Sexual Offences Act. The Appeal Court agreed with this stating that ‘a registered medical practitioner or preferably a psychiatrist should always address the requirements of the definition.’⁴⁹⁰

The third guideline is that the psychiatric evidence must directly address the criteria laid out in the Sexual Offences Act. In *Mnguni* the Court highlighted the fact that the reports submitted by the two expert witnesses did not address the requirements of the definition of mental disability found in section 1 (1) of the Sexual Offences Act.⁴⁹¹ Louw J emphasised that the Sexual Offences Act has a very specific definition of ‘mental disability’ and ‘it is not sufficient for the state to merely prove that the victim is mentally disabled or retarded or challenged.’⁴⁹² The severity of the disability must meet one of the four criteria laid out in section 1(1) of the Sexual Offences Act. The Appeal Court in *Mnguni* held that the evidence led by the state was insufficient to satisfy the requirements of the definition of ‘mental

⁴⁸⁵ *Mnguni* at 4.

⁴⁸⁶ *As above*.

⁴⁸⁷ *Chinridze* para 11.

⁴⁸⁸ *Chinridze* para 14.

⁴⁸⁹ *S v Dladla* 2011 (1) SACR 80 (KZP) per Madondo J at para 16. See also *S v Mahlinza* 1967 (1) SA 408 at 417 F – H.

⁴⁹⁰ *Chinridze* para 35.

⁴⁹¹ *Mnguni* at 2.

⁴⁹² *As above*.

disability.⁴⁹³ Therefore, the life sentence prescribed by the Criminal Law Amendment Act for the rape of a ‘mentally disabled’ person could not apply because the state had failed to satisfy the requirements of the definition of ‘mental disability’ found in the Sexual Offences Act.⁴⁹⁴ The appeal Court proceeded to substitute the life sentence with a ten-year sentence.⁴⁹⁵

Similarly, in *Chinridze*, the Court also emphasised the requirement to assess whether there is evidence proving that the complainant falls within the definition of ‘mental disability’ provided in section 1(1) of the Sexual Offences Act. In this case, the Court could not make any findings as to whether there was legal consent because Dr Phangela did not make conclusions in compliance with that provision.⁴⁹⁶ Dosio AJ stated that ‘it is difficult for this court with certainty to find that the complainant fell within one of the four categories mentioned in section 1(1) and accordingly this court cannot with certainty state that there was no legal consent.’⁴⁹⁷ He went on to urge the Director of Public Prosecutions to ‘ensure that in each case where a complainant is alleged to be mentally retarded that evidence in compliance with the requirements of section 1(1) of the Sexual Offences Act is presented.’⁴⁹⁸ Ultimately, the appellant’s appeal against conviction failed because there was no factual consent in the case and the appeal Court concluded that the appellant’s guilt had been proved beyond a reasonable doubt.⁴⁹⁹

The appeal Court in *Cindi v the State* (hereinafter, *Cindi*) also emphasised the importance of addressing the legal definition of ‘mental disability.’⁵⁰⁰ The facts in *Cindi* are that the appellant approached the complainant, a 22-year-old woman who is mentally and physically disabled, while she was playing with some young children.⁵⁰¹ When the complainant started running away, the appellant tripped her with a stick.⁵⁰² After she fell, he dragged her into his house and raped her twice, once through the vagina and once through the anus.⁵⁰³ In his defence, the appellant testified that he was in a romantic relationship with the complainant and that the sexual intercourse was consensual.⁵⁰⁴ He also testified that he only knew about her

⁴⁹³ *Mnguni* at 3.

⁴⁹⁴ Criminal Law Amendment Act 105 of 1997 sec 51.

⁴⁹⁵ *Mnguni* at 6.

⁴⁹⁶ *Chinridze* para 36.

⁴⁹⁷ *Chinridze* para 36.

⁴⁹⁸ *Chinridze* para 35.

⁴⁹⁹ *Chinridze* para 42.

⁵⁰⁰ *Sifiso Trevor Cindi v the State Case (Cindi)* No A662/2014 para 1 and para 4.

⁵⁰¹ *Cindi* para 5.

⁵⁰² As above.

⁵⁰³ As above.

⁵⁰⁴ *Cindi* para 12.

physical disability and was not aware of her mental disability.⁵⁰⁵ The appellant was subsequently convicted of two counts of rape and sentenced.⁵⁰⁶ On appeal, the appellant's counsel argued that the state failed to prove that the appellant had raped a person with 'mental disability'.⁵⁰⁷ The state did not lead any evidence to prove that the complainant had a 'mental disability' apart from that of her mother who testified that she was 'slow'.⁵⁰⁸ The appeal Court ruled that although the state had proved the rape, it had failed to prove that the complainant was a person with a 'mental disability' as defined in section 1 of the Sexual Offences Act.⁵⁰⁹ The conviction was amended accordingly.

In contrast with the foregoing cases, the requirements of the legal definition of 'mental disability' were addressed in *Christopher Joseph Prins v the State*.⁵¹⁰ The appellant in this case appealed against conviction and sentence on three counts of rape and one count of sexual assault through touching the complainant's vagina.⁵¹¹ Ms Janine Hundermark, a clinical psychologist, who assessed the complainant's capacity to consent to sexual intercourse, concluded that the complainant had moderate intellectual disability.⁵¹² She stated that the complainant, was, in the circumstances, unable to consent to sexual intercourse because although she had received sexuality education at school and could correctly name the male and female reproductive organs, she lacked understanding of sexual matters including, contraception, sexually transmitted illnesses or conception.⁵¹³ Under cross-examination, the psychologist stated the following:

I have a whole lot of criteria and when it comes to an (sic) person with intellectual disability, they need to understand all about sex. She didn't if you ask the questions where does a baby come from or how does somebody become pregnant. So, she didn't know anything about conception. She knows what sex is as in the actual act but she didn't know about conception, contraception, sexually transmitted illnesses so that means she doesn't have the information; she cannot make a decision with that; she cannot give or withhold consent and according to all of those criteria I'm coming to that conclusion.⁵¹⁴

⁵⁰⁵ As above.

⁵⁰⁶ *Cindi* para 1 and para 4.

⁵⁰⁷ *Cindi* para 13.

⁵⁰⁸ *Cindi* para 17.

⁵⁰⁹ As above.

⁵¹⁰ *Christopher Joseph Prins v The State (Prins)* Case number A153/16.

⁵¹¹ *Prins* para 1.

⁵¹² *Prins* para 4.

⁵¹³ *Prins* para 5.

⁵¹⁴ *Prins* para 17.

The appeal against conviction was dismissed because the appeal Court was satisfied that the State had established that because the complainant did not understand conception, and contraception, she could not appreciate the nature and reasonably foreseeable consequences of sexual intercourse. Therefore, the State had proved that the complainant satisfied the requirements of the Sexual Offences Act.⁵¹⁵

In summary, the Sexual Offences Act in South Africa states that persons with ‘mental disability’ lack capacity to give valid consent to sexual intercourse. However, it does not suffice to merely prove that the complainant has a disability that affects mental faculties. The disability must reach one of the four thresholds set out in section 1 (1) of the Sexual Offences Act in order for it to be classified as a ‘mental disability.’ The ‘capacity framework’ is deployed for purposes of determining whether a complainant’s disability reaches one of the stipulated thresholds and therefore, falls within the legal definition of ‘mental disability.’ Three broad guidelines on how to apply the ‘capacity framework’ emerge from case-law. First, a two-stage test is applied which involves determining whether there was factual consent, before determining whether there was legal consent in a particular case. Second, the State is required to provide psychiatric evidence to prove that the complainant is a person with a ‘mental disability.’ Third, such psychiatric evidence must address the requirements of the legal definition of ‘mental disability’ set out in section 1 (1) of the Sexual Offences Act.

Before critiquing the ‘capacity framework,’ adopted in South Africa, it is important to first examine how other jurisdictions address capacity of women with intellectual disabilities to consent to sexual intercourse.

2.2 The ‘status framework’ adopted in Malawi, Uganda and Zambia

The approach to capacity to consent to sexual intercourse taken in South Africa is quite distinct from that in other jurisdictions such as Malawi, Uganda and Zambia. The law in these countries criminalises any sexual intercourse with women with intellectual disabilities, who are inappropriately referred to as ‘idiots and imbeciles.’ Section 139 of the Penal Code in Malawi, section 130 of the Penal Code Act in Uganda, and section 130 of the Penal Code Act in Zambia each create an offence known as ‘defilement of idiots or imbeciles.’ These provisions make it a felony to have or attempt to have sexual intercourse, referred to as ‘carnal knowledge,’ with a woman or girl with an intellectual disability and this offence is punishable by a fourteen-year prison term. Curiously, each of these provisions is couched in exactly the same terms and it is

⁵¹⁵ *Prins* para 22.

worth quoting each of the provisions to demonstrate this point. The Penal Code in Malawi provides that:

Any person, who knowing a woman or girl to be an idiot or imbecile, has or attempts to have unlawful carnal knowledge of her under circumstances not amounting to rape, but which prove that the offender knew at the time of the commission of the offence that the woman or girl was an idiot or imbecile, commits a felony and is liable to imprisonment for fourteen years.⁵¹⁶

The Uganda Penal Code Act reads as follows:

Any person, who knowing a woman or girl to be an idiot or imbecile, has or attempts to have unlawful carnal knowledge of her under circumstances not amounting to rape, but which prove that the offender knew at the time of the commission of the offence that the woman or girl was an idiot or imbecile, commits a felony and is liable to imprisonment for fourteen years.⁵¹⁷

Similarly, the Zambian Penal Code Act states as follows:

Any person, who knowing a woman or girl to be an idiot or imbecile, has or attempts to have unlawful carnal knowledge of her under circumstances not amounting to rape, but which prove that the offender knew at the time of the commission of the offence that the woman or girl was an idiot or imbecile, commits a felony and is liable to imprisonment for fourteen years.⁵¹⁸

Each of these provisions refers to ‘idiots’ and ‘imbeciles,’ language which is both derogatory and outdated and has been struck out of the statute books in other African jurisdictions such as South Africa. The use of such archaic language can perhaps be attributed to the fact that the relevant legislation in Malawi, Uganda and Zambia is quite dated. The Penal Code in Malawi was first enacted in 1930, the Penal Code Act in Uganda in 1950 and the Zambian Penal Code Act in 1931. In South Africa, sexual offence laws have undergone significant reform addressing definitions, evidence and procedure.⁵¹⁹ The current Sexual Offences Act of 2007 is the result of a number of reforms on rape law that took place over an eleven-year period.⁵²⁰ The Sexual Offences Act introduced a number of significant changes to rape law in South Africa.⁵²¹ For instance, the Act changed the definition of rape, from the common law understanding of rape

⁵¹⁶ Penal Code (Chapter 7:01) 1930, sec 139 (Malawi). See also *Kanyinji v R* (116 of 2008) [2008] MWHC 213 (*High Court of Malawi*) where the accused was charged with this offence.

⁵¹⁷ Penal Code Act (Chapter 120) 1950, sec 130 (Uganda). See also *Uganda v Maasa Simon Alias Wamesa* Criminal Case No. HCT-04-CR-SC-0012 of 2009 (High Court of Uganda).

⁵¹⁸ Penal Code Act (Chapter 87) 1931, sec 139 (Zambia). See also *Maybin Ng'uni v the People* Appeal No.37 of 2007 (Supreme Court of Zambia) where the accused was charged with this offence.

⁵¹⁹ C Van der Bijl & PNS Rumney ‘Attitudes, rape and law reform in South Africa’ (2009) 73(5) *The Journal of Criminal Law* at 414.

⁵²⁰ Van der Bijl & Rumney (n 519) 416.

⁵²¹ As above.

as an act involving a male having sexual intercourse with a female without her consent to understanding rape as any unlawful act of sexual penetration by any person without the consent of the other person.⁵²²

Crucially, the approach in Malawi, Uganda, and Zambia regards all women with intellectual and other mental disabilities as lacking capacity to consent to sexual intercourse and criminalises all sexual intercourse with them. Such an approach, which denies all women with intellectual disabilities, sexual agency by virtue of their status as women with mental disabilities is referred to in this research as the ‘status framework.’ In contrast, the ‘capacity framework’ adopted in South Africa is a question of degree and only those women whose disability meets one of the four severity thresholds will be deemed as lacking capacity to consent to sexual intercourse. The ‘capacity framework’ is therefore, more progressive than the ‘status framework.’

This was recognised further afield in Ireland where significant reforms have been made to the law on consent to sexual intercourse.⁵²³ Prior to the reforms to Irish law that took place in 2017, the legislation deployed the ‘status framework’ in matters of consent to sexual intercourse.⁵²⁴ The law in Ireland criminalised sexual activity with an individual who is ‘mentally impaired.’⁵²⁵ Anyone who ‘has or attempts to have intercourse; with ‘a person who is mentally impaired (other than a persons to whom he is married or to whom he believes with reasonable cause he is married) shall be guilty of an offence.’⁵²⁶ This law criminalised most sexual activity involving persons with mental disabilities based on their disability status.⁵²⁷ The Irish Law Reform Commission (ILRC) published two documents analysing this issue and recommended a move from the ‘status framework’ to the ‘capacity framework.’ Consequently, the new law, known as the Criminal Law (Sexual Offences) Act, which was enacted in 2017, no longer criminalises sexual activity with any individual with a ‘mental impairment’ and adopts the ‘capacity framework.’ The new law replaces the term ‘mental impairment’ with ‘protected persons.’⁵²⁸ ‘Protected persons’ are defined as individuals with ‘a mental or intellectual disability or a mental illness,’ who are incapable of ‘understanding the nature, or

⁵²² Van der Bijl & Rumney (n 519) 417. Sexual Offences Act sec 3. See also the discussion in Chapter Two.

⁵²³ A Arstein-Kerslake *Legal capacity and gender: Realising the human right to legal personhood and agency of women, disabled women and gender minorities* (2021) 138.

⁵²⁴ As above.

⁵²⁵ Criminal Law (Sexual Offences) Act 2017 sec 5 (Ireland).

⁵²⁶ Criminal Law (Sexual Offences) Act 2017 sec 5 (1) (a) (Ireland).

⁵²⁷ Arstein-Kerslake (n 523) 138.

⁵²⁸ Criminal Law (Sexual Offences) Act 2017 sec 21 (7) (Ireland).

the reasonably foreseeable consequences’ of the sexual act;⁵²⁹ evaluating relevant information for the purposes of deciding whether or not to engage in the act;⁵³⁰ or ‘communicating ... consent to that act by speech, sign language or otherwise.’⁵³¹ The approach now taken in Ireland is very similar to the approach in South Africa.

The ‘capacity framework’ adopted in South Africa, and now in Ireland, may be preferable because in contrast with the ‘status framework,’ it does not attribute a blanket status of lack of capacity to consent to sexual intercourse on women with mild Down syndrome. Nevertheless, the capacity framework remains problematic as outlined next.

3. Problematising the ‘capacity framework’

The ‘capacity framework’ has three main problems. First, it fails to recognise and uphold the sexual autonomy of all women with mild Down syndrome. Second, it violates the right to legal capacity set out in the CRPD. Third, it is an example of residual coloniality, calling its local relevance into question. Each of these problems is addressed below.

3.1 Failure to recognise the sexual autonomy of all women with mild Down syndrome

The ‘capacity framework’ limits the sexual autonomy of some women with mild Down syndrome. Whilst the order of the two-stage enquiry adopted in South Africa is, to a certain extent, progressive, in that it may protect women with mild intellectual disabilities who have not consented to sexual intercourse, the capacity framework remains a barrier to the sexual agency of women with mild intellectual disabilities who do wish to consent.⁵³² These women may be deemed as lacking capacity to consent, even in circumstances where they did in fact consent. In *Samphi S Hlapho v the State*, the Free State Division of the High Court of South Africa applied the capacity framework’s two-stage test and ruled that legal consent vitiates factual consent.⁵³³ The appellant in this case was convicted of raping the complainant, who was described as having ‘severe mental retardation’ or ‘severe mental incapacity.’⁵³⁴ He was sentenced to life imprisonment.⁵³⁵ He subsequently appealed to the High Court against conviction and sentence.⁵³⁶ Accordingly, the Court first examined whether there was factual consent. Despite the appellant’s contention that he did not have sexual intercourse with the

⁵²⁹ Criminal Law (Sexual Offenses) Act 2017 sec 21 (7) (a) (Ireland).

⁵³⁰ Criminal Law (Sexual Offenses) Act 2017 sec 21 (7) (b) (Ireland).

⁵³¹ Criminal Law (Sexual Offenses) Act 2017 sec 21 (7) (c) (Ireland).

⁵³² See section 2.1 above.

⁵³³ *Samphi S Hlapho v The State (Hlapho)* Appeal number A292/2010 (South Africa).

⁵³⁴ *Hlapho* para 5.

⁵³⁵ *Hlapho* para 1.

⁵³⁶ As above.

complainant, the trial Court found sufficient evidence to the contrary, a finding that the appeal Court endorsed.⁵³⁷ Eyewitnesses testified that they saw the accused and the complainant having sexual intercourse and that it did not appear as though the complainant was being forced.⁵³⁸ Accordingly, the Court ruled that factually, the complainant had consented to the sexual intercourse.⁵³⁹ The appeal Court therefore, had to proceed to the second stage of the test and determine whether the complainant was a person with a ‘mental disability’ such that she could not validly consent to the sexual intercourse. In support of its finding that there was no legal consent, the Court stated that:

On the strength of the evidence before us, the complainant’s factual consent was rendered null and void by her mental retardation. Since she was legally incapable to give consent – there was no legal consent to legitimise her sexual penetration by the appellant. Lack of legal consent overrides factual consent.⁵⁴⁰

The appeal Court ruled that notwithstanding the factual consent, the complainant could not give valid legal consent.⁵⁴¹ Accordingly, the appeal against conviction was dismissed.⁵⁴² Therefore, a finding of incapacity to legally consent to sexual acts, is tantamount to a finding of lack of consent such that even when a woman with a ‘mental disability’ consents to sexual intercourse, her partner may still be convicted of rape.⁵⁴³ The effects of this is to deny women with mild Down syndrome sexual agency and perpetuate harmful misconceptions about their sexuality.⁵⁴⁴ Arstein-Kerslake explains it aptly as follows:

Capacity to consent to sex law reaches into the intensely private sphere of sexual intimacy. While it professes to provide protection against sexual abuse of people with intellectual disabilities ... the removal of agency that it embodies may actually be causing more disempowerment and vulnerability than protection. It has the power to further stigmatise by holding people with intellectual disabilities to a different standard of sexual decision-making than people without intellectual disabilities.⁵⁴⁵

⁵³⁷ *Hlapho* para 17.

⁵³⁸ *Hlapho* para 15.

⁵³⁹ As above.

⁵⁴⁰ *Hlapho* para 16.

⁵⁴¹ *Hlapho* para 17.

⁵⁴² As above.

⁵⁴³ D Pollack et al ‘The capacity of a mentally retarded person to consent: An American and Jewish legal perspective’ (2000) 20 *New York Law School Journal of International and Comparative Law* at 227.

⁵⁴⁴ A Arstein-Kerslake & E Flynn ‘Legislating consent: Creating an empowering definition of consent to sex that is inclusive of people with cognitive disabilities’ (2016) 25(2) *Social and Legal Studies* at 228.

⁵⁴⁵ A Arstein-Kerslake ‘Understanding sex: The right to legal capacity to consent to sex’ (2015) 30(10) *Disability and Society* at 1468.

The capacity framework therefore, limits the sexual agency of women with mild Down syndrome who wish to consent to sexual intercourse on the basis that they fall within the legal definition of ‘mental disability’ and cannot give valid legal consent.

The ‘capacity framework’s’ failure to recognise the sexual agency of all women with mild Down syndrome can be attributed to its narrow focus on inherent traits. The ‘capacity framework’ relies on the original concept of vulnerability, according to which women with mild Down syndrome are perceived as inherently vulnerable to sexual abuse. The framework assumes that disability is constitutive of incapacity and requires women with mild intellectual disabilities to demonstrate their ability to validly consent to sexual intercourse.⁵⁴⁶ The Court in *Moeniep Pullen v the State (hereinafter, Pullen)* emphasised that for purposes of determining whether a complainant can provide legal consent, ‘it is not sufficient for the State merely to prove that the victim is mentally disabled or challenged.’⁵⁴⁷ Rather, the State must prove that the *disability is so severe* that the complainant satisfies the requirements of the definition of ‘mental disability.’⁵⁴⁸ Consequently, the scope of inquiry narrowly focuses on the extent of the complainant’s mental disability to the exclusion of wider societal factors that may contribute to incapacity. Indeed, in the majority of cases in South Africa, expert evidence on capacity to consent focuses on intelligence quotient (IQ) test scores as well as on the problematic concept of mental age.

In *Chinridze*, the prosecution led evidence from Dr Phangela, a clinical psychologist who examined the complainant prior to the trial.⁵⁴⁹ Specifically, he assessed her IQ, and found that she had an IQ level of 60 and below.⁵⁵⁰ He therefore, concluded that she had a mild intellectual disability.⁵⁵¹ He also testified that due to her low IQ level, the complainant could be easily manipulated.⁵⁵² Dr Phangela also relied on the concept of mental age stating that although the complainant’s biological age was sixteen years at the time of the examination, her mental age was below seven years.⁵⁵³ He based this conclusion on the fact that she had difficulty performing a number of everyday tasks such as telling the time on a clock,

⁵⁴⁶ A Arstein-Kerslake & E Flynn (n 544) 226.

⁵⁴⁷ *Moeniep Pullen v The State (Pullen)* Case number CA&R 3319/2013 para 4.

⁵⁴⁸ *Pullen* para 4. Empasis added.

⁵⁴⁹ *Chinridze* at 6.

⁵⁵⁰ As above.

⁵⁵¹ As above.

⁵⁵² As above.

⁵⁵³ As above.

understanding the concept of money and change and performing simple mathematical calculations.⁵⁵⁴

Similarly, in *S v Dyantyi* the accused was charged with raping a 14-year-old girl who was described as ‘mentally retarded.’⁵⁵⁵ In his defence, the accused claimed that he was in a romantic relationship with the complainant and that the sexual intercourse was consensual.⁵⁵⁶ Ms Karen Andrews, a clinical psychologist, assessed the complainant.⁵⁵⁷ In concluding that she had a ‘mental disability’ and could not consent to sexual intercourse, the psychologist relied on the concept of mental age.⁵⁵⁸ She testified that the complainant had ‘moderate’ retardation and had the mental age of an eight-year-old.⁵⁵⁹ In reaching this conclusion, the psychologist considered several matters including the complainant’s inability to function independently, her inability to count, lack of appreciation of social conventions, and her inability to write her name.⁵⁶⁰ Moreover, the psychologist added that the complainant was vulnerable because she was incapable of planning and could not perceive danger until it was too late.⁵⁶¹

The psychologist in *Mnguni*, also relied on the concept of mental age stating that the complainant is ‘mentally retarded and appears to be functioning below the age of 13 years.’⁵⁶² The psychologist also alluded to the complainant’s ‘poor ability to understand instructions, her slow working pace and difficulty understanding relationship between figures and patterns.’⁵⁶³

A similar reliance on the concept of mental age can also be found in *Pullen* where the medical expert concluded that the 22-year-old complainant is ‘mentally retarded’ with an estimated mental age of 6 – 7 years.⁵⁶⁴

Relying on IQ test scores is problematic because a person’s IQ level does not necessarily translate to a lack of capacity to consent because there is no ‘objective threshold of capacity to consent that can be scientifically measured, such as, for example, through an IQ test.’⁵⁶⁵ The concept of mental age is equally problematic because it infantilises women with

⁵⁵⁴ As above.

⁵⁵⁵ *S v Mncedisi Dyantyi (Dyantyi)* Case No. CC95/2008 (South Africa).

⁵⁵⁶ *Dyantyi* para 1.

⁵⁵⁷ *Dyantyi* para 2.

⁵⁵⁸ *Dyantyi* para 7.

⁵⁵⁹ *Dyantyi* para 5.

⁵⁶⁰ As above.

⁵⁶¹ *Dyantyi* para 6.

⁵⁶² *Mnguni* at 2.

⁵⁶³ As above.

⁵⁶⁴ *Pullen* para 5.

⁵⁶⁵ Benedet & Grant (n 471) 287.

mild intellectual disabilities.⁵⁶⁶ Once a sixteen-year-old is viewed as a seven-year-old girl, then their engagement in any sexual activity may be perceived as inappropriate, thereby desexualising women with mild intellectual disabilities.⁵⁶⁷ Moreover, as Benedet and Grant put it, it ‘is impossible to relate one’s inability to read novels or do fractions to one’s expected responses to sexual pressure or manipulation.’⁵⁶⁸ Therefore, there is no correlation between a complainant’s inability to, for example, tell the time on the clock, understand the concept of money and perform simple mathematical calculations with sexual decisions.

The capacity framework’s assumption that the disability is solely responsible for a complainant’s lack of capacity to consent is too narrow and obscures from view the impact of situational factors such as poverty, dependency, social isolation, inadequate understanding of appropriate intimate relationships and lack of accessible sexual education on a person’s understanding of the sexual act and its consequences.⁵⁶⁹ Consequently, the ‘capacity framework’ may fail to appreciate the fact that capacity is not a trait, but is a state that is subject to change over time.⁵⁷⁰ Lyden states that:

[a]t one point in time, an individual with intellectual disabilities may be found incapable of having sexual relations due to knowledge deficits. Subsequently, if that person receives sufficient training, education, counselling, and exposure to various social situations it may be possible to remedy the knowledge deficits. In a case like this, a repeat sexual consent capacity assessment may yield a finding that the individual has achieved capacity.⁵⁷¹

There is therefore, a need to shift the focus from the complainant’s limitations, perceived or actual, to the factors that create an imbalance of power between the complainant and the accused.⁵⁷²

3.2 Violating the right to legal capacity

From a human rights perspective, the ‘capacity framework’ is about the denial of the right to legal capacity. Although the text of article 12 (2) of the CRPD does not expressly mention sexual decision-making, it is accepted that this falls within the ambit of article 12 (2) of the CRPD, as this section will demonstrate.⁵⁷³ Article 12 (2) provides that all persons with

⁵⁶⁶ Benedet & Grant (n 451) 9.

⁵⁶⁷ As above.

⁵⁶⁸ As above.

⁵⁶⁹ Arstein-Kerslake & Flynn (n 544) 227.

⁵⁷⁰ M Lyden ‘Assessment of sexual consent capacity’ (2007) 25 (1) *Sexuality and Disability* at 5.

⁵⁷¹ As above.

⁵⁷² J Benedet & I Grant (n 451) 13.

⁵⁷³ Arstein-Kerslake (n 545) 1461.

disabilities have a right to ‘enjoy legal capacity on an equal basis with others in *all aspects of life*.’⁵⁷⁴ The term ‘all aspects’ includes sexual decision-making.

The right to legal capacity itself is not a new right, but one that dates back to the adoption of the Universal Declaration of Human Rights (Universal Declaration) in 1948.⁵⁷⁵ It is also present in other international human rights instruments such as the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW).⁵⁷⁶ Nevertheless, article 12 of the CRPD introduces a paradigm shift in two ways. First, it recognises universal legal capacity irrespective of the type and severity of the disability.⁵⁷⁷ This is in stark contrast with the laws in many jurisdictions, which formally deny some persons with intellectual disabilities the right to legal capacity on the basis of the nature and severity of their disability through substituted decision-making regimes such as guardianship.⁵⁷⁸ In South Africa for example, legal capacity is denied through common law curatorship and under the legislative process of appointing administrators in accordance with the Mental Health Care Act of 2002.⁵⁷⁹ The Mental Health Care Act permits the Master of the High Court to appoint an administrator to ‘care for and administer’ the property of a ‘mentally ill’ person or a person with severe or profound intellectual disability.⁵⁸⁰ In contrast, the CRPD subscribes to universal legal capacity for all persons with disabilities irrespective of the type and severity of the disability.⁵⁸¹

The meaning of the term ‘legal capacity’ was the subject of rigorous contestation during the CRPD drafting process.⁵⁸² At issue was the question whether the term encompassed both capacity to hold rights (legal personality) and capacity to act in order to exercise those rights (legal agency).⁵⁸³ There was consensus that all persons with disabilities are indeed persons before the law with the capacity to hold rights.⁵⁸⁴ However, there were divergent views on whether all persons with disabilities have the capacity to act in order to exercise those rights.⁵⁸⁵

⁵⁷⁴ CRPD, art 12 (2). Emphasis added.

⁵⁷⁵ K Booth-Glen ‘Supported decision-making and the human right of legal capacity’ (2015) 3(1) *Inclusion* at 6.

⁵⁷⁶ CEDAW art 15.

⁵⁷⁷ CRPD art 12 (2).

⁵⁷⁸ A Arstein-Kerslake ‘A call to action: The realization of equal recognition under the law for people with disabilities in the EU’ (2014) 5 *European Yearbook of Disability Law* at 75.

⁵⁷⁹ W Holness & S Rule ‘Legal capacity of parties with intellectual, psycho-social and communication disabilities in traditional courts in KwaZulu-Natal’ (2018) 6 *African Disability Rights Yearbook* at 42.

⁵⁸⁰ Mental Health Care Act 17 of 2002 sec 59 (1).

⁵⁸¹ CRPD Committee General Comment No 1 para 25.

⁵⁸² 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 and Commerce* at 439.

⁵⁸³ Dhanda (n 582) 442.

⁵⁸⁴ Dhanda (n 582) 439.

⁵⁸⁵ As above.

In other words, there was no agreement about whether the term ‘legal capacity’ entails both legal personality and legal agency. In the interests of progress, the compromise to include the right to legal capacity in the CRPD without defining its exact meaning was made, leaving doubt about the precise meaning of the term.⁵⁸⁶ However, six years after the CRPD came into force, the Committee on the Rights of Persons with Disabilities (CRPD Committee) subsequently clarified the meaning of ‘legal capacity’ in its first General Comment issued in 2014.⁵⁸⁷ The CRPD Committee unequivocally stated that ‘legal capacity’ includes ‘the capacity to be both a holder of rights and an actor under the law.’⁵⁸⁸ The Committee added that the legal agency of persons with disabilities is exemplified in article 12 (5) of the CRPD, which requires states parties to ensure that persons with disabilities enjoy the right to own or inherit property, control their own financial affairs and have equal access to bank loans, mortgages and other forms of financial credit.⁵⁸⁹ Moreover, emphasis was placed on the fact that the legal capacity (legal personhood and legal agency) of *all* persons with disabilities must be recognised in *all* spheres of life, including the sexual realm.⁵⁹⁰ Therefore, recognising an individual’s capacity to consent to sexual intercourse is tantamount to recognising their legal agency as envisaged in article 12 (2) of the CRPD.⁵⁹¹ Consequently, the ‘capacity framework’ is essentially a regulation of the legal capacity of women with mild intellectual disabilities.⁵⁹² Moreover, the ‘capacity framework’s’ focus on mental capacity to determine legal consent, brings the enquiry squarely within the scope of the right to legal capacity enshrined in article 12 (2) of the CRPD.⁵⁹³

The ‘capacity framework’ denies women with mild Down syndrome legal capacity based on the functional approach. Generally, the right to legal capacity in the sexual realm is denied using one of two approaches, both of which recognise capacity to hold rights but limit capacity to act in order to exercise those rights.⁵⁹⁴ The first is the status approach, according to which the mere presence of disability results in the presumption of incapacity.⁵⁹⁵ Laws based

⁵⁸⁶ As above.

⁵⁸⁷ CRPD Committee General Comment No 1.

⁵⁸⁸ CRPD Committee General Comment No 1 para 14.

⁵⁸⁹ CRPD art 12 (5).

⁵⁹⁰ Arstein-Kerslake & Flynn (n 544) 226. Emphasis added.

⁵⁹¹ Arstein-Kerslake & Flynn (n 544) 227.

⁵⁹² Arstein-Kerslake (n 545) 1461.

⁵⁹³ See section 2.1 above for a detailed discussion on the focus on mental capacity within the ‘capacity framework.’

⁵⁹⁴ There is a third approach to the denial of legal capacity known as the outcome approach. This involves assessing the decision made by a woman with a mild intellectual disability and attributing incapacity on the basis that they have arrived at a decision or outcome that is not socially acceptable. Their capacity to act is contested based on ‘bad’ decisions that they may have made in the past, which are relied on as justification for limiting their capacity to act in the future. See Dhanda, (n 582) 431. This approach is beyond the scope of this research.

⁵⁹⁵ Dhanda (n 582) 431.

on this approach include the ‘status framework’ adopted in Malawi, Uganda and Zambia, according to which the very presence of a mental disability automatically results in a finding of incapacity to consent, hence, all sexual intercourse with women with ‘mental disabilities’ is criminalised.⁵⁹⁶ Although such a woman’s ability to hold rights may not be in question, a limitation is placed on her ability to act in order to exercise those rights indicating a denial of the right to legal capacity. The status approach is therefore, a violation of article 12 (2) of the CRPD.

Second, legal capacity is denied using the functional approach.⁵⁹⁷ The functional approach violates the right to legal capacity in two ways. First, it fails to recognise that the right to legal capacity is universal. Under the functional approach, an individual who is unable to perform a specific function, because of disability, lacks capacity to act.⁵⁹⁸ The ‘capacity framework’ adopted in South Africa is an example of the functional approach. If a complainant is unable to demonstrate her ability to ‘appreciate the nature and reasonably foreseeable consequences of a sexual act;’⁵⁹⁹ ‘act in accordance with that appreciation;’⁶⁰⁰ ‘resist the commission of any such offence;’⁶⁰¹ or ‘communicate ... her unwillingness to participate in any such act,’⁶⁰² she is precluded from consenting to sexual acts, and denied legal capacity. The functional approach adopted by the ‘capacity framework’ therefore conflates the distinct concepts of mental capacity and legal capacity.⁶⁰³ Legal capacity is ‘the state’s recognition of the individual as a holder of rights and an actor under the law,’ whereas mental capacity refers to an individual’s cognitive abilities and decision-making skills.⁶⁰⁴ In contravention of article 12 (2), the ‘capacity framework’ conflates the two concepts by treating an individual’s mental incapacity as synonymous with lack of legal capacity.⁶⁰⁵ The CRPD Committee condemned the conflation of these two concepts as follows:

In most of the State Party reports that the Committee has examined so far, the concepts of mental and legal capacity have been conflated so that where a person is considered to have impaired decision-making skills, often because of a cognitive or psychosocial disability, his or her legal capacity to make a particular decision is consequently

⁵⁹⁶ See section 2.2 above for a detailed discussion of the ‘status approach’ relied on in Malawi, Uganda and Zambia.

⁵⁹⁷ Dhanda (n 582) 431.

⁵⁹⁸ As above.

⁵⁹⁹ Sexual Offences Act sec 1 (1) (a).

⁶⁰⁰ Sexual Offences Act sec 1 (1) (b).

⁶⁰¹ Sexual Offences Act sec 1(1) (c).

⁶⁰² Sexual Offences Act sec 1(1) (d).

⁶⁰³ Arstein-Kerslake (n 545) 1461.

⁶⁰⁴ As above.

⁶⁰⁵ As above. See section 4 below for a detailed discussion of the conflation of legal capacity and mental capacity.

removed. ... a person's disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity...⁶⁰⁶

Consequently, the 'capacity framework' fails to recognise universal legal capacity, thereby violating the right to legal capacity.

Second, the functional approach violates the right to legal capacity because it discriminates on the basis on disability. Article 12 (2) of the CRPD requires States Parties to respect the legal capacity of persons with disabilities 'on an equal basis with others.'⁶⁰⁷ This means that if there is to be any denial of legal capacity, it must be effected in a non-discriminatory manner.⁶⁰⁸ Contrary to article 12 (2), the 'capacity framework' involves differential treatment. Before the functional test can be applied, one must be shown to be a person with a 'mental disability.'⁶⁰⁹ Only individuals with this kind of disability are subjected to this test.⁶¹⁰ Arstein-Kerslake opines that 'functional tests of legal capacity to consent to sex force people with intellectual disabilities to meet a standard of decision-making that is not applied to the rest of the population.'⁶¹¹ Although the 'capacity framework' is considered preferable to the 'status framework' both approaches are not compliant with article 12 (2) of the CRPD.

3.3 Perpetuating coloniality

The 'capacity framework' adopted in South Africa is similar to that applied in England and Wales indicating the persistence of coloniality in law. This is not surprising, given the enormous influence that English law has had on South African law. Decades after the formal end of imperial rule in South Africa, the country's colonial legacy persists in the criminal justice system, which is largely based on Roman-Dutch and English law.⁶¹² Roman-Dutch law exerted a powerful influence on principles of liability in South African common law crimes.⁶¹³ However, in the early 19th century, English criminal procedure was imported into South Africa and gradually replaced the existing Roman-Dutch system.⁶¹⁴ Throughout the 19th century, English law exerted a significant influence on the formulation of general principles of liability

⁶⁰⁶ CRPD Committee General Comment number 1 para 15.

⁶⁰⁷ Arstein-Kerslake (n 545) 1463.

⁶⁰⁸ CRPD Committee General Comment No 1 paras 25 and 32 – 34.

⁶⁰⁹ Arstein-Kerslake (n 545) 1463.

⁶¹⁰ As above.

⁶¹¹ As above.

⁶¹² JRL Milton 'Criminal Law in South Africa, 1976 – 1986' (1987) *Acta Juridica* at 36.

⁶¹³ As above.

⁶¹⁴ As above.

as well as definitions of common law crimes.⁶¹⁵ For example, various pre-trial processes, such as the requirement to obtain warrants of arrest, search and seizure, as well as detainees' right to legal counsel, are all based on English law.⁶¹⁶ So substantial is the influence of English law on South African law that by the start of the twentieth century, the South African criminal justice system, though not identical to the English system, was, in Milton's words, 'very recognisably a relative of it and was much in its thrall.'⁶¹⁷ One need only examine rape law in South Africa to demonstrate English law's lasting influence. Though rooted in Roman-Dutch law, South African rape law has undergone significant revision due to the influence of English law.⁶¹⁸ For instance, under Roman Dutch Law, violence is an essential element of the crime of rape.⁶¹⁹ However, South African law is modelled on English law and violence is not an element of the offence.⁶²⁰ Instead, lack of consent is an essential element of rape in both South African and English law.⁶²¹ Furthermore, the South African common law definition of rape has been amended to replace the narrower concept of 'sexual intercourse,' present in Roman Dutch law, with the broader concept of 'penetration' found in English law.⁶²²

In both jurisdictions, the 'capacity framework' is used to determine whether a complainant with an intellectual disability can validly consent to sexual intercourse. Complainants who fall within the ambit of the relevant legal test are regarded as lacking capacity to consent, whilst those who do not satisfy the requirements are considered capable of consenting to sexual intercourse. In England and Wales, matters of capacity to consent to sexual intercourse are addressed in two pieces of legislation, the Sexual Offences Act of 2003 and the Mental Capacity Act of 2005. The Sexual Offences Act applies in the criminal law context.⁶²³ It contains various offences that can be committed against persons with a 'mental disorder impeding choice.'⁶²⁴ For instance, it is an offence to engage in sexual activity 'with a person with a mental disorder impeding choice.'⁶²⁵ This offence is committed where a person (A), intentionally touches another person (B),⁶²⁶ and the touching is sexual,⁶²⁷ and 'B is unable

⁶¹⁵ As above.

⁶¹⁶ Milton (n 612) 36 – 37.

⁶¹⁷ Milton (n 612) 36.

⁶¹⁸ Van der Bijl & Rumney (n 519) 417.

⁶¹⁹ As above.

⁶²⁰ *R v K* 1958 3 SA 420 (A) on 423 B-C. *R v C* 1952 4 SA 117 (O). Van der Bijl & Rumney (n 519) 417.

⁶²¹ Van der Bijl & Rumney (n 519) 417.

⁶²² As above.

⁶²³ Sexual Offences Act 2003 (England and Wales) secs 30 to 33.

⁶²⁴ As above.

⁶²⁵ Sexual Offences Act 2003 (England and Wales) sec 30.

⁶²⁶ Sexual Offences Act 2003 (England and Wales) sec 30 (1) (a).

⁶²⁷ Sexual Offences Act 2003 (England and Wales) sec 30 (1) (b).

to refuse because of or for a reason related to a mental disorder.’⁶²⁸ Various kinds of touching are within the ambit of this provision. These include ‘penetration of B’s anus or vagina with a part of A’s body or anything else;’⁶²⁹ ‘penetration of B’s mouth with A’s penis;’⁶³⁰ ‘penetration of A’s anus or vagina with a part of B’s body;’⁶³¹ or ‘penetration if A’s mouth with B’s penis.’⁶³²

Moreover, the Sexual Offences Act requires that A either knows, or can be reasonably expected to ‘know that B has a mental disorder and that because of it or for a reason related to it B is likely to be unable to refuse.’⁶³³ Crucially, the Sexual Offences Act clarifies that B is unable to refuse if ‘he lacks the capacity to choose whether to agree to the touching (whether because he lacks sufficient understanding of the nature, or reasonably foreseeable consequences of what is being done, or for any other reason).’⁶³⁴ Alternatively, B is unable to refuse if he is ‘unable to communicate such a choice to A.’⁶³⁵

The Mental Capacity Act 2005 (MCA) applies broadly to different kinds of decision-making particularly in the civil law context.⁶³⁶ The test for capacity to consent to sexual relations in England and Wales is set out in section 3 (1) of the Mental Capacity Act 2005. Anyone who is unable to undertake one or more of the four functions stipulated in section 3 (1) of the Mental Capacity Act 2005 lacks capacity to make a decision. A person must be able to understand the information relevant to the decision.⁶³⁷ They must also be able to retain that information.⁶³⁸ A person must also be able to use or weigh that information in order to make decision.⁶³⁹ Finally, a person must be able to communicate their decision by any means including talking, sign language or any other means.⁶⁴⁰ The Mental Capacity Act has been applied in many cases to determine whether an individual has capacity to consent to sexual

⁶²⁸ Sexual Offences Act 2003 (England and Wales) sec 30 (1) (c).

⁶²⁹ Sexual Offences Act 2003 (England and Wales) sec 30 (3) (a).

⁶³⁰ Sexual Offences Act 2003 (England and Wales) sec 30 (3) (b).

⁶³¹ Sexual Offences Act 2003 (England and Wales) sec 30 (3) (c).

⁶³² Sexual Offences Act 2003 (England and Wales) sec 30 (3) (d).

⁶³³ Sexual Offences Act 2003 (England and Wales) sec 30 (1) (d).

⁶³⁴ Sexual Offences Act 2003 (England and Wales) sec 30 (2) (a).

⁶³⁵ Sexual Offences Act 2003 (England and Wales) sec 30 (2) (b). See *R v C* [2008] EWCA Crim 1155 (United Kingdom) where the appellant was convicted of the offence of ‘sexual activity with a person with a mental disorder impeding choice’ contrary to the Sexual Offences Act 2003.

⁶³⁶ Mental Capacity Act 2005 (England and Wales).

⁶³⁷ Mental Capacity Act 2005 sec 3 (1) (a) (England and Wales).

⁶³⁸ Mental Capacity Act 2005 sec 3 (1) (b) (England and Wales).

⁶³⁹ Mental Capacity Act 2005 sec 3 (1) (c) (England and Wales).

⁶⁴⁰ Mental Capacity Act 2005 sec 3 (1) (d) (England and Wales).

intercourse.⁶⁴¹ For example, in *R v KL*, the appellant was convicted of three counts of rape involving a 29-year-old complainant with learning disabilities.⁶⁴² The psychologist who assessed the complainant testified that she lacks the capacity to consent to sexual relations.⁶⁴³ In reaching this decision, the psychologist considered whether the complainant was capable of understanding ‘what is proposed and its implications.’⁶⁴⁴ This means that the complainant must be able to understand the sexual act and its implications or consequences. Secondly, the psychologist considered whether the complainant is able to exercise choice.⁶⁴⁵ Counsel for the appellant challenged this conclusion. In directing the jury, the trial court stated the following:

In deciding whether you are sure that she was incapable of giving valid consent, the test is not, was she handicapped; nor is it was she severely handicapped? The test is: was she so severely handicapped as to be incapable of consenting to sexual intercourse? Only if your answer to that is, ‘Yes, we are sure she was incapable’ can you convict this defendant of rape.⁶⁴⁶

The appeal court agreed with the trial judge’s direction and accordingly, dismissed the appeal against conviction.⁶⁴⁷

Munby J stated that:

capacity to consent to sexual intercourse depends upon a person having sufficient knowledge and understanding of the nature and character – the sexual nature and character – of the act of sexual intercourse, and of the reasonably foreseeable consequences of sexual intercourse, to have the capacity to choose whether or not to engage in it, the capacity to decide whether to give or withhold consent to sexual intercourse ...⁶⁴⁸

In 2014, the Court of Appeals provided some direction on the application of the Sexual Offences Act and the Mental Capacity Act. In *IM v LM* the Court had to decide whether LM could consent to sexual relationships. The Court held that in criminal cases, a person specific test for capacity to consent to sexual intercourse should be used. This would inquire into whether ‘a person can consent to sex with a particular person at a particular point in time.’⁶⁴⁹ Where the Court has to determine whether an individual could ever have the ability to give

⁶⁴¹ See for example, *Re S (An adult) (Capacity: Non-recognition of foreign marriage)* [2015] EWHC 3534 (Fam) (England and Wales).

⁶⁴² *R v KL* [2002] EWCA Crim 2171 at 1 (England and Wales).

⁶⁴³ *R v KL* at 4 (England and Wales).

⁶⁴⁴ As above.

⁶⁴⁵ As above.

⁶⁴⁶ *R v KL* at 6 (England and Wales).

⁶⁴⁷ *R v KL* at 8 (England and Wales).

⁶⁴⁸ *MM (an adult)* [2007] EWHC Fam 2003 para 87. (England and Wales).

⁶⁴⁹ Arstein-Kerslake (n 545) 1468.

consent, then an issue-specific test should be used.⁶⁵⁰ This would involve asking ‘whether the individual has the general ability to give consent.’⁶⁵¹ The Sexual Offences Act applies retrospectively whilst the Mental Capacity Act applies to decisions in the future.⁶⁵²

The colonial footprint, in the form of English law, is therefore still present in South Africa’s contemporary criminal law despite the end of colonial rule. This calls into question the relevance of the ‘capacity framework’ in a South African context. In line with the first step in de-colonial thinking, this study interrogates the gaps and limits of the ‘capacity framework’ rather than calling for the approach to be discarded outright.⁶⁵³ In the following chapter, this study will address the second step in de-colonial thinking by engaging with local voices and perspectives before convening a dialogue between the English approach and South African discourses and perspectives.

As shown above, the ‘capacity framework’ is far from flawless. Rectifying these shortcomings is not simply a matter of amending laws to align them with the CRPD without addressing the deeper fundamental assumptions that resulted in the framing of these approaches in the first place. As Quinn and Rekas-Rosalbo correctly note, ‘newly-minted international law like the UNCRPD – will not, on its own, drive the reform debate forward.’⁶⁵⁴ Even when a new law strikes out in a different direction, as the CRPD does, this does not mean that it will automatically bring about change.⁶⁵⁵ It is necessary for the values underlying that new law to be understood and accepted if it is to succeed in bringing about change.⁶⁵⁶ In the context of capacity to consent, it is important to alter the manner in which the concept of capacity is understood.

4. Re-conceptualising capacity to consent

This section seeks to address the first two shortcomings of the ‘capacity framework’, namely, its failure to recognise the sexual autonomy of all women with mild Down syndrome and its contravention of the right to legal capacity.⁶⁵⁷ Specifically, the section will re-conceptualise

⁶⁵⁰ As above.

⁶⁵¹ As above.

⁶⁵² As above.

⁶⁵³ The three steps of de-colonial thinking are outlined in Chapter Two, section 4.

⁶⁵⁴ G Quinn & A Rekas-Rosalbo ‘Civil death: Rethinking the foundations of legal personhood for persons with a disability’ 56 *Irish Jurist* at 290.

⁶⁵⁵ As above.

⁶⁵⁶ As above.

⁶⁵⁷ The third shortcoming relating to persisting coloniality exemplified in the ‘capacity framework’ will be addressed in Chapter Four.

capacity to consent by applying Fineman's vulnerability framework as well as the support paradigm.

4.1 Expanding the scope of inquiry for determining capacity to consent

As shown above, the 'capacity framework' deems some women with mild Down syndrome as lacking capacity to consent to sexual intercourse. This is primarily due to the framework's narrow focus on the perceived or actual inherent traits of women with mild Down syndrome. It is submitted that this problem can be remedied by an expansion of the scope of inquiry into capacity to consent to include situational factors. Such an expansion can be achieved through the application of Fineman's vulnerability framework.

As a starting point, it is crucial to inquire what makes women with mild intellectual disabilities vulnerable. In contrast with the original conception of vulnerability, which posits that it is a trait inherent in particular individuals, such as women with mild intellectual disabilities, Fineman's vulnerability framework conceives of universal vulnerability.⁶⁵⁸ In the context of sexual abuse, this means recognising that all women are vulnerable.⁶⁵⁹ The incidence of rape and sexual offences against women in South Africa is alarmingly high.⁶⁶⁰ In fact, the prevalence of rape in South Africa is considered to be among the highest in the world.⁶⁶¹ All women, not just women with mild intellectual disabilities, are at risk. Recognising universal vulnerability is the first step in acknowledging that vulnerability is not a trait inherent in women with mild intellectual disabilities. At the same time, one should remain mindful of the unique experience of women with mild intellectual disabilities.⁶⁶²

Fineman's vulnerability framework recognises that the experience of vulnerability is particular.⁶⁶³ Research shows that sexual violence against women with intellectual disabilities is higher compared to sexual violence against women without disabilities.⁶⁶⁴ One study indicates that women with intellectual disabilities are two to ten times more likely to be sexually assaulted than women without disabilities.⁶⁶⁵ This is attributed to a set of circumstances that are unique to women with intellectual disabilities. For example, these

⁶⁵⁸ See Chapter Two, section 2 for a detailed discussion of Martha Fineman's vulnerability framework.

⁶⁵⁹ A Pillay 'An audit of competency assessments on court-referred rape survivors in South Africa' (2008) *Psychological Reports* at 764.

⁶⁶⁰ As above.

⁶⁶¹ L Vetten 'Paradox and policy: Addressing rape in post-apartheid South Africa' in N Westmarland & G Gangoli (eds) *International approaches to rape* (2011) at 169.

⁶⁶² Benedet & Grant (n 471) 287.

⁶⁶³ See Chapter Two, section 2.2 for a detailed discussion on this aspect of the vulnerability framework.

⁶⁶⁴ A Pillay (n 659) 764.

⁶⁶⁵ Benedet & Grant (n 471) 255.

women are dependent on caregivers for support with daily living.⁶⁶⁶ Studies show that caregivers usually make up a significant portion of those who sexually abuse women with mild intellectual disabilities.⁶⁶⁷ The caregivers who have easy access to these women include teachers, doctors, and residential workers, amongst others.⁶⁶⁸ This makes it difficult for them to leave abusive situations.⁶⁶⁹ Another factor is learned compliance resulting from the fact that other people often have control over the lives of women with mild intellectual disabilities.⁶⁷⁰ Coupled with the lack of sexuality education, they may not be aware that they can say no if they do not want to participate in a sexual activity.⁶⁷¹ Women with mild intellectual disabilities also tend to have very limited financial resources, forcing them to remain in abusive situations and environments.⁶⁷² Researchers found that offenders consider women with mild intellectual disabilities easy targets who can be abused with impunity because they usually do not report abuse to the authorities.⁶⁷³ Even when the assaults are reported, the cases may not be prosecuted because they are regarded as unreliable witnesses.⁶⁷⁴ Moreover, women with mild intellectual disabilities may experience unique consequences of reporting sexual assault or rape.⁶⁷⁵ While, all complainants experience trauma as a result of the criminal trial process, reporting an assault or rape results in women with mild intellectual disabilities being subjected to a greater level of control in the name of ‘protection.’⁶⁷⁶ There may be greater efforts to limit their freedom and access to a sexual life through strengthened controls.⁶⁷⁷ Acknowledging that women with mild intellectual disabilities’ experience of vulnerability is particular, permits a wider focus on societal factors that have an impact on their specific experience of sexual abuse and their ability to consent. This allows for a shift in focus from perceived or actual individual limitations to situational causes of vulnerability.

According to Fineman, vulnerability is not tethered to identity categories, such as disability, but may result from systems that create disadvantage.⁶⁷⁸ Research shows that situational factors such as restrictive living environments, and negative attitudes about the sexuality of women

⁶⁶⁶ Benedet & Grant (n 471) 257.

⁶⁶⁷ As above.

⁶⁶⁸ As above.

⁶⁶⁹ As above.

⁶⁷⁰ As above.

⁶⁷¹ As above.

⁶⁷² As above.

⁶⁷³ As above.

⁶⁷⁴ As above.

⁶⁷⁵ Benedet & Grant (n 471) 289.

⁶⁷⁶ As above.

⁶⁷⁷ As above.

⁶⁷⁸ See Chapter Two, section 2 for a detailed discussion of Fineman’s vulnerability framework.

with mild intellectual disabilities all have an impact on the vulnerability and the capacity of women with mild intellectual disabilities to consent to sexual intercourse. Chapter Four of this study explores in detail the relevant situational factors for women with mild intellectual disabilities in South Africa, so these will not be addressed in the present chapter. However, it is important to point out that because the vulnerability framework adopts a more contextualised approach, it allows for a more robust conception of vulnerability and capacity to consent to sexual intercourse. Understanding the various sources of vulnerability informs a response to sexual abuse that does not focus solely on the individual's limitations, but takes into account the systems and structures that create this vulnerability. The solution then is not to 'protect' women with intellectual disabilities by keeping them from having sexual intercourse because they are inherently vulnerable. Rather, the solution is to address the social structures that create the vulnerability and by so doing, build resilience in women with mild intellectual disabilities.

4.2 Incorporating support

To remedy the 'capacity framework's' violation of the right to legal capacity, the support paradigm should be incorporated into the understanding of capacity to consent. Article 12 (3) of the CRPD requires States Parties to provide access to the supports necessary to enable persons with disabilities to exercise their legal capacity.⁶⁷⁹ Therefore, States Parties to the CRPD have a duty to ensure access to the supports necessary for sexual decision-making by persons with disabilities.⁶⁸⁰ This marks a conceptual shift from perceiving the need for support as an indication of lack of legal capacity and a justification for its denial to perceiving the need for support as legitimate and necessary for the exercise of legal capacity. Consequently, persons with disabilities should not be denied legal capacity simply because they require support, but should receive support in order to exercise their legal capacity.⁶⁸¹ One author puts it quite succinctly when she states that:

The fact that a person requires high support was not a reason to surmise absence of capacity. As irrespective of its quantum, such support will have to be provided without undermining the rights and capacity of the person with disability, be free from conflict of interest and undue influence, while respecting the will and preferences of the person.⁶⁸²

Therefore, the 'question can no longer be: Does a person have the mental capacity to exercise their legal capacity? ... Rather, the question is: What types of supports are required for the

⁶⁷⁹ CRPD, art 12 (3).

⁶⁸⁰ Arstein-Kerslake (n 545) 1462.

⁶⁸¹ Dhanda (n 582) 439 - 440.

⁶⁸² Dhanda (n 582) 445.

person to exercise his or her legal capacity?’⁶⁸³ Therein lies the paradigm shift in the CRPD, which essentially legitimises the provision of support.⁶⁸⁴ Because the CRPD recognises universal legal capacity, the support paradigm applies to all persons with disabilities including those with high support needs.⁶⁸⁵

It is important to note that there is a fundamental distinction between the ‘support paradigm’ and ‘supported decision-making.’⁶⁸⁶ Article 12 (3) requires the provision of support in the exercise of legal capacity, not supported decision-making.⁶⁸⁷ The term ‘supported decision-making’ was first used by the CRPD Committee in General Comment Number One to refer to a wide range of supports provided for the exercise of decision-making.⁶⁸⁸ The difference between the two terms is that the term ‘support’ refers to a wide range of supports, whereas the term ‘supported decision-making’ refers to one type of support for exercising legal capacity.⁶⁸⁹ Disability scholars Series and Nilsson, contend that the term ‘supported decision-making’ has confused some into thinking that the CRPD merely requires the provision of support to assist persons with disabilities to make decisions for themselves.⁶⁹⁰ This obscures the breadth of the support paradigm found in article 12 (3).⁶⁹¹ Supported decision-making is therefore simply a category involving receipt of support from one or more trusted persons to make, express or implement a decision.’⁶⁹² The preferred term for the purposes of this research is ‘support paradigm.’

Although the support paradigm is the foundation underpinning universal legal capacity, the CRPD does not provide guidance on what support means or entails.⁶⁹³ However, the meaning of support is considered elsewhere. The CRPD Committee addressed the support paradigm in detail in General Comment Number One.⁶⁹⁴ The Committee clarified that article 12 (3) means that States Parties must, in addition to refraining from denying persons with

⁶⁸³ M Bach & L Kerzner ‘A new paradigm for protecting autonomy and the right to legal capacity: Advancing substantive equality for persons with disabilities through law, policy and practice’ (2010) *Law Commission of Ontario* at 59.

⁶⁸⁴ Dhanda (n 582) 446.

⁶⁸⁵ L Series & A Nilsson ‘Article 12 CRPD: Equal recognition before the law’ in I Bantekas, MA Stein & D Anastasiou (eds) *The UN Convention on the Rights of Persons with Disabilities: A commentary* (2018) at 25.

⁶⁸⁶ As above.

⁶⁸⁷ As above.

⁶⁸⁸ As above.

⁶⁸⁹ As above.

⁶⁹⁰ As above.

⁶⁹¹ As above.

⁶⁹² For example, the Representation Agreement Act 1995 (British Columbia). See also Series & Nilsson (n 685) 28.

⁶⁹³ Series & Nilsson (n 685) 25.

⁶⁹⁴ CRPD Committee General Comment No 1 para 3.

disabilities their legal capacity, ‘provide persons with disabilities access to the support necessary to enable them to make decisions that have legal effect.’⁶⁹⁵ The Committee proceeded to highlight three aspects of support.

First, support includes both formal and informal support arrangements.⁶⁹⁶ Formal support schemes are underpinned by legislation whilst informal schemes exist and operate as a matter of practice, without any legal regulation.⁶⁹⁷ Examples of informal support arrangements include, asking a trusted person/s to assist with a specific decision, peer support, advocacy, and assistance with communication.⁶⁹⁸ Examples of formal support arrangements include measures requiring private and public actors, such as banks and other financial institutions, to ensure universal design or accessibility by, for example, providing information in accessible formats and providing professional sign language interpretation to assist persons with disabilities to exercise their rights to open bank accounts, conclude contracts, or conduct other social transactions.⁶⁹⁹ Formal schemes allow for a greater level of control for the supporter, clearer recognition of the supporter’s role by third parties, stricter regulation of how the person is supported and incorporating procedural safeguards to prevent abuse.⁷⁰⁰ Nevertheless, informal support schemes are also important and can be very effective.⁷⁰¹

Second, the support must be in accordance with the ‘rights, will and preferences’ of persons with disabilities.⁷⁰² This is a shift from the best interest standard adopted in substituted decision-making regimes such as guardianship.⁷⁰³ Essentially, the support person is required to act to give effect to the rights, will and preferences of the person with a disability, not to make decisions on their behalf and in their best interests. The Committee recognises that there may be situations in which it may not be practicable to determine a person’s will and preferences.⁷⁰⁴ In such circumstances, the ‘best interpretation of will and preferences’ and not the ‘best interests’ standard is applicable and is considered compliant with the support paradigm.⁷⁰⁵

⁶⁹⁵ CRPD Committee General Comment No 1 para 16.

⁶⁹⁶ CRPD Committee General Comment No 1 para 17.

⁶⁹⁷ Series & Nilsson (n 685) 28.

⁶⁹⁸ CRPD Committee General Comment No 1 para 17.

⁶⁹⁹ As above.

⁷⁰⁰ Series & Nilsson (n 685) 28.

⁷⁰¹ As above.

⁷⁰² CRPD Committee General Comment No 1 para 17.

⁷⁰³ CRPD Committee General Comment No 1 paras 17 and 21.

⁷⁰⁴ Series & Nilsson (n 685) 25.

⁷⁰⁵ CRPD Committee General Comment No 1 para 21.

Third, the Committee added that support varies between persons with disabilities in terms of type and intensity.⁷⁰⁶ This is in line with CRPD's acknowledgement of the diversity of persons with disabilities.⁷⁰⁷ Indeed one of the CRPD's general principles is the 'respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.'⁷⁰⁸ Therefore, the type of support a person with a disability requires will be determined by their individual needs making it necessary for the determination to be made on a case-by-case basis.

Literature on the support paradigm provides some guidance on its meaning and what it entails. Disability rights scholar Arstein-Kerslake aptly describes the support paradigm as:

a system in which people work together to understand an individual's desires and choices and then provide the means for that person to exercise legal capacity and live life in the way she or he chooses as opposed to a way imposed by someone else's decision made on her or his behalf.⁷⁰⁹

Bach and Kerzner suggest three main types of supports: Support with exploring the range of choices at one's disposal and making a decision, support in making agreements with others to give effect to one's decision, and support to act on the decisions that one has made.⁷¹⁰

The support paradigm provides a number of benefits for persons with disabilities. Freedom of choice may seem daunting both to persons with disabilities and their families or caregivers.⁷¹¹ Persons with disabilities may find it difficult to take on the new responsibility of decision-making whilst their parents and caregivers may fear that they will not be able to make the best decisions.⁷¹² The fears of both groups can be allayed through the support paradigm.⁷¹³ The more persons with disabilities are permitted the opportunity to make decisions, with support, the less fearful they will be of decision-making.⁷¹⁴ Support in making decisions, makes it less likely for persons with disabilities to make bad decisions.⁷¹⁵ The supported decision-making paradigm enables persons with disabilities to self-determine while allowing 'communal involvement and support' in decision-making.⁷¹⁶ The 'dignity of risk' allows

⁷⁰⁶ CRPD Committee General Comment No 1 para 18.

⁷⁰⁷ CRPD art 3 (d).

⁷⁰⁸ As above.

⁷⁰⁹ A Arstein-Kerslake 'Legal capacity and supported decision-making: Respecting rights and empowering people' (2016) *University of Melbourne Legal Studies Research Paper No. 736* at 7.

⁷¹⁰ Bach & Kerzner (n 683) 74.

⁷¹¹ Arstein-Kerslake (n 709) 10.

⁷¹² As above.

⁷¹³ As above.

⁷¹⁴ As above.

⁷¹⁵ As above.

⁷¹⁶ As above.

persons with disabilities to make choices that others may view as unwise.⁷¹⁷ Arstein Kerslake describes the benefits of the support paradigm as follows:

The support paradigm's humanistic approach – adapting to the needs of all individuals and not allowing the law to sanction one person taking control of the decisions of another person – has the potential to provide a much lower risk of exploitation than guardianship and other substituted decision-making systems. Studies have shown that where autonomy is fostered and where individuals are given meaningful choices, intrinsic motivation is increased and the overall well-being of the individual is enhanced which is supported by self-determination theory... Therefore, it can be argued that legal capacity systems that recognise every individual as a decision-maker, may serve to foster autonomy and create stronger individuals who are better able to protect themselves from abuse and exploitation.⁷¹⁸

The idea of providing support to persons with intellectual disabilities in order to exercise their legal capacity is therefore undoubtedly attractive, holding great potential to bestow dignity and rights on persons with intellectual disabilities. It is capable of restoring their voice by allowing them to receive decision-making support whilst simultaneously retaining control over decisions pertaining to their lives.⁷¹⁹ However, the support paradigm remains a novel concept about which there is little research.⁷²⁰ Consequently, implementing it is far from straightforward. A number of pertinent questions arise. Booth asks, 'what will implementation mean to existing legal structures? And, perhaps most challenging as well as most relevant, how do we get there from here?'⁷²¹

The Committee's interpretation of the support paradigm does not provide sufficient practical guidance on its application.⁷²² Questions relating to the practical implementation of the support paradigm remain and the relationship with legal processes is yet to be determined.⁷²³ Several attempts to develop models for the implementation of the support paradigm have been made in different parts of the world.⁷²⁴ In South Africa, the South African Law Reform Commission has drafted the Supported Decision-Making Draft Bill, which provides for 'measures to enable persons with disability to access the support they may require

⁷¹⁷ C Kong 'The Convention on the Rights of Persons with Disabilities and article 12: Prospective feminist lessons against the "will and preferences" paradigm' (2015) 4(4) *Laws* at 710.

⁷¹⁸ Arstein-Kerslake (n 709) 9.

⁷¹⁹ D Zhang et al 'A call to society for supported decision-making: Theoretical and legal reasoning' (2019) 28 *Journal of Child and Family Studies* at 1804.

⁷²⁰ As above.

⁷²¹ Booth Glen (n 575) 3.

⁷²² CRPD Committee General Comment Number 1.

⁷²³ KA Shogren & ML Wehmeyer 'A framework for research and intervention design in supported decision-making' (2015) 3(1) *Inclusion* at 18.

⁷²⁴ Series & Nilsson (n 685) 28.

in exercising their legal capacity on an equal basis with others.⁷²⁵ The Bill recognises and regulates existing informal support measures⁷²⁶ and introduces and regulates alternative formal support methods.⁷²⁷ The Draft Bill addresses support in making specific decisions such as financial and health care decisions. Specifically, it provides for formal support in exercising legal capacity in matters relating to property.⁷²⁸ The term ‘property’ includes ‘any movable or immovable property situated in the Republic,’⁷²⁹ ‘any intellectual property,’⁷³⁰ ‘any right of action,’⁷³¹ ‘any right or interest in property,’⁷³² ‘any contingent interests in property,’⁷³³ and ‘any contractual right to property.’⁷³⁴ The Bill also addresses formal support in exercising legal capacity with regard to personal welfare, providing for the formal appointment of a welfare supporter.⁷³⁵ The definition of personal welfare in the Bill ‘includes matters relating to day-to-day issues (such as living, care, and employment arrangements), health care, and the general personal well-being of a person with disability, but excludes matters relating to property.’⁷³⁶ Crucially, the Bill expressly excludes from its ambit supports relating to consent to sexual relations.⁷³⁷ The Bill states that this ‘[a]ct does not affect the current legal position with regard to consent to sexual relations.’⁷³⁸ Consequently, the Bill does not address any supports that can be provided to women with mild intellectual disabilities to make decisions regarding sexual intercourse.

A possible explanation for the exclusion of sexual decision-making is that it is relatively easier to envision support for making certain types of decisions such as financial and medical decisions than it is to formulate supports relating to sexual decisions. For example, in terms of medical decisions, support can be provided by explaining medical procedures in a variety of ways including models, drawings or other visual aids.⁷³⁹ A person with an intellectual disability

⁷²⁵ South African Law Reform Commission ‘Supported Decision-Making Bill’ in *Project 122: Assisted decision-making report* (2015) available at https://www.justice.gov.za/salrc/reports/r_pr122-Assisted-Decision-Making-Dec2015.pdf sec 2 (a) (accessed 12 August 2021).

⁷²⁶ Supported Decision-Making Bill sec 2 (a) (i).

⁷²⁷ Supported Decision-Making Bill sec 2 (a) (ii).

⁷²⁸ Supported Decision-Making Bill Chapter 3.

⁷²⁹ Supported Decision-Making Bill sec 1 (a).

⁷³⁰ Supported Decision-Making Bill sec 1 (b).

⁷³¹ Supported Decision-Making Bill sec 1 (c).

⁷³² Supported Decision-Making Bill sec 1 (d).

⁷³³ Supported Decision-Making Bill sec 1 (e).

⁷³⁴ Supported Decision-Making Bill sec 1 (f).

⁷³⁵ Supported Decision-Making Bill sec 45.

⁷³⁶ Supported Decision-Making Bill sec 1.

⁷³⁷ Supported Decision-Making Bill sec 3 (2) (b).

⁷³⁸ Supported Decision-Making Bill sec 3 (2) (b).

⁷³⁹ Booth-Glen (n 575) 10.

might also be supported to make a medical decision by visiting a hospital to see what a hospital stay might involve or they may speak to a person who has undergone the same treatment or procedure about their experience.⁷⁴⁰ In contrast, it may not be as easy to envision support for sexual decision-making. In the African context in particular, sexual matters are taboo and open discussions about them are considered undignified and frowned upon.⁷⁴¹ Consequently, sexual matters are shrouded with secrecy and relegated to the private realm. Yet, it remains necessary to interrogate the nature and limits of the supports that may be provided in relation to sexual decision-making. Chapter Four of this study will address the question of supports that may be provided to women with mild Down syndrome in the sexual realm. However, it is important to first consider the conceptual significance of the support paradigm for capacity to consent.

4.2.1 The support paradigm: Recognising the interdependence of humanity

The support paradigm is based on a presumption that everyone has decision-making ability.⁷⁴² It does not subscribe to a ‘binary model of capacity or incapacity’ and does not perceive a category of people who are ‘legally incapacitated.’⁷⁴³ The support paradigm is a reflection of the social model of disability, which understands disability as a social construct resulting from the interaction between a person with impairment and environmental and attitudinal barriers.⁷⁴⁴ It ‘demands that society adjust to individuals’ differing needs and act in a way that eliminates the barriers to legal capacity by providing adequate assistance for the exercise of that legal capacity.’⁷⁴⁵

The support paradigm recognises that every individual needs decision-making support and focuses on exploring that support.⁷⁴⁶ It is implicit within the concept of support that ‘our personhood is primarily shared – that the very stuff of our personhood emerges from and through an ongoing iterative process with others.’⁷⁴⁷ It therefore, subscribes to the idea that we are all social beings and symbolises a move towards the recognition of an ‘interconnected and interdependent vision of humanity.’⁷⁴⁸ It essentially acknowledges that ‘all decisions – even

⁷⁴⁰ As above.

⁷⁴¹ R DePalma & D Francis ‘Silence, nostalgia, violence, poverty...: What does “culture” mean for South African sexuality educators?’ (2014) 16(5) *Culture, Health and Sexuality* at 550.

⁷⁴² Arstein-Kerslake (n 709) 9.

⁷⁴³ As above.

⁷⁴⁴ Arstein-Kerslake (n 709) 7.

⁷⁴⁵ Arstein-Kerslake (n 709) 8.

⁷⁴⁶ Arstein-Kerslake (n 709) 9.

⁷⁴⁷ Quinn & Rekas-Rosalbo (n 654) 305.

⁷⁴⁸ Series & Nilsson (n 685) 25.

those of prime ministers – are connected to a network of supports and influences.’⁷⁴⁹ Harris puts it succinctly when she states that this ‘normative shift more accurately reflects the consultative, relational manner in which almost all people (those with and without disabilities) make decisions – with support from trusted friends, advisors, and family members.’⁷⁵⁰ Therefore, it is merely a reflection of the reality that we all need varying levels of support in making decisions, depicted for the first time in an international legal instrument.⁷⁵¹ The fact that some need more support than others should not be a justification for removing the freedom to make decisions.⁷⁵² Our idea of humanity has a great influence on how legal relationships and social institutions are shaped.⁷⁵³ It is therefore, important to go back to basics and interrogate what it means to be human.

Implicit in the support paradigm is the re-definition of the legal subject. The support paradigm is inconsistent with the predominant vision of humanity as the liberal legal subject.⁷⁵⁴ The legitimacy of support stems from the fact that we all need and are entitled to a support system. The vision of humanity as the vulnerable subject is more consistent with the support paradigm because it recognises that all human beings are vulnerable and therefore dependent on one another.⁷⁵⁵ It is therefore, clear that the support paradigm does not rely on the liberal legal subject, but on a completely different vision of humanity. The next logical question is to determine how the support paradigm relates to the closely-related concept of autonomy.

4.2.2 Recognising autonomy through the support paradigm

The support paradigm is significant because it is capable of upholding autonomy.⁷⁵⁶ Autonomy is central in the CRPD. Long before the enactment of the (CRPD), the disability rights movement sought to end centuries of exclusion, relegation and subjugation of persons with disabilities by advocating for disability justice in predominantly rights based terms.⁷⁵⁷ Although the movement consisted of numerous groups with varying goals and aspirations, each group shared a common persuasion that autonomy, self-reliance and independence are the

⁷⁴⁹ As above.

⁷⁵⁰ JE Harris ‘The role of support in sexual decision-making for people with intellectual and developmental disabilities’ (2016) 77 *Ohio State Law Journal Furthermore* at 84.

⁷⁵¹ Arstein-Kerslake (n 709) 10.

⁷⁵² As above.

⁷⁵³ MA Fineman (n 245) 355.

⁷⁵⁴ See Chapter Two, section 2.4 for a discussion of the liberal legal subject.

⁷⁵⁵ See Chapter Two, section 2.4 for a detailed discussion of the vulnerable subject.

⁷⁵⁶ Although the term ‘autonomy’ has been used from the beginning of this study, its meaning was not previously addressed until this point. This was intentional as the author intended to discuss the concept in relation to the support paradigm.

⁷⁵⁷ Onazi (n 107) 39.

‘founding ideals’ of the movement.⁷⁵⁸ The CRPD continued the legacy of the disability rights movement by retaining the autonomy of persons with disabilities as one of its core ideals.⁷⁵⁹ Indeed one of the general principles in the CRPD is the ‘[r]espect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons.’⁷⁶⁰ In its preamble, the CRPD recognises, the ‘importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices.’⁷⁶¹ Moreover, the idea of autonomy is linked to various rights in the CRPD such as accessibility,⁷⁶² personal mobility,⁷⁶³ habilitation and rehabilitation,⁷⁶⁴ living independently and being included in the community,⁷⁶⁵ and, more importantly for the purposes of this research, legal capacity.⁷⁶⁶ Indeed, the purpose of providing support, including in the context of sexual decision-making, is to enable women with mild intellectual disabilities to exercise autonomy.⁷⁶⁷ Individual or personal autonomy is crucial for the enjoyment of rights and inclusion of persons with disabilities in society.⁷⁶⁸

Despite the importance of autonomy in the CRPD, the term is not defined anywhere in the instrument. However, the meaning of the term has been considered elsewhere. Traditionally, autonomy is understood in individualistic and rationalistic terms as the ‘capacity of an individual to make rational choices free from undue interference of others.’⁷⁶⁹ This definition is based on the vision of human beings as liberal legal subjects endowed with autonomy and independence whose primary demand is for liberty or freedom from state

⁷⁵⁸ As above.

⁷⁵⁹ F Mégret (n 148) 511.

⁷⁶⁰ CRPD art 3 (a).

⁷⁶¹ CRPD preamble para n.

⁷⁶² CRPD art 9. In relation to accessibility, the CRPD in art 9 (1) requires states to ensure the accessibility of the physical environment, transportation, information and communications in order to ‘enable persons with disabilities to live independently and participate fully in all aspects of life.’

⁷⁶³ CRPD art 20. The CRPD requires states parties to ‘ensure personal mobility with the greatest possible independence for persons with disabilities.’

⁷⁶⁴ CRPD art 26 (1). In terms of habilitation and rehabilitation, states parties are required to take effective and appropriate measures to ‘attain and maintain maximum independence’ for persons with disabilities.

⁷⁶⁵ CRPD art 19 (a). The commitment to the ideals of independence and autonomy is exemplified in the right to live independently and to be included in the community, which consists of giving persons with disabilities the ‘opportunity to choose their place of residence and where and with whom they live.’

⁷⁶⁶ CRPD art 12 (2). The CRPD requires states parties to ensure that all persons with disabilities enjoy legal capacity on an equal basis with others. In article 12 (5) the CRPD specifically requires states parties 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.’

⁷⁶⁷ Arstein-Kerslake (n 545) 1462.

⁷⁶⁸ G Stefánsdóttir et al ‘Autonomy and people with intellectual disabilities who require more intensive support’ (2018) 20(1) *Scandinavian Journal of Disability Research* at 163.

⁷⁶⁹ As above.

interference.⁷⁷⁰ This classical definition is based on the individual's reasoning capacity and ability to assess their own situation.⁷⁷¹ In other words, it is linked to mental capacity and often results in the marginalization of persons with intellectual disabilities.⁷⁷² Persons with intellectual disabilities do not fit into the mold because they may need extensive support, may not be able to communicate verbally, and are perceived as lacking reason or other cognitive capacities.⁷⁷³ They are therefore, denied the ethical status of 'autonomous agents' and are consequently accorded a lesser moral standing.⁷⁷⁴ The classical definition of autonomy is clearly at odds with the disability inclusion agenda.

In recent years, the term 'individual autonomy' has been subject to significant re-conceptualisation in response to the shortcomings of the classical definition of autonomy. This re-conceptualisation is characterised by a shift from a conception of autonomy based on an 'individualistic, rational and free self' to one based on the understanding that we are complex social beings.⁷⁷⁵ Known as relational autonomy, this conception acknowledges that our context has an impact on autonomy and permits an evaluation of external influences on individual autonomy.⁷⁷⁶ Relational autonomy emphasises the fact that individuals are 'socially constituted agents who define their principles and express their will or intent by making decisions based on their social connections, commitments and interdependencies.'⁷⁷⁷ In other words, we make decisions 'in the context of interpersonal processes.'⁷⁷⁸ Relational autonomy 'highlights how the ability to have control and agency in one's life requires interdependence, not isolated independence.'⁷⁷⁹ McKenzie and Stoljar explain it as follows:

...persons are socially embedded and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender and ethnicity. Thus the focus of relational approaches is to analyse the implications of intersubjective and social dimensions of

⁷⁷⁰ See Chapter Two, section 2.4 for a discussion on the liberal legal subject. Fineman (n 245) 355.

⁷⁷¹ Stefánsdóttir et al (n 768) 163.

⁷⁷² Stefánsdóttir et al (n 768) 162.

⁷⁷³ Stefánsdóttir et al (n 768) 163.

⁷⁷⁴ As above.

⁷⁷⁵ As above. See also L Davy 'Philosophical inclusive design: Intellectual disability and the limits of individual autonomy in moral and political theory' (2015) 30(1) *Hypatia* at 132.

⁷⁷⁶ Stefánsdóttir et al (n 768) 163.

⁷⁷⁷ E Salami & B Lashewicz 'More than meets the eye: Relational autonomy and decision-making by adults with developmental disabilities' (2015) 32(2) *Windsor Yearbook of Access to Justice* at 94.

⁷⁷⁸ As above.

⁷⁷⁹ S Dowling et al 'Managing relational autonomy in interactions: People with intellectual disabilities' (2019) 32 *Journal of Applied Research in Intellectual Disabilities* at 1059.

selfhood and identity for conceptions of individual autonomy and moral and political agency.⁷⁸⁰

If, as the social model of disability contends, disability is located at the interface between impairment and the environment, then it is logical to conclude that relationships have a part to play in disabling or enabling persons with intellectual disabilities.⁷⁸¹ Relational autonomy holds great promise for persons with intellectual disabilities. The key elements of relational autonomy are support, advocacy and enablement of autonomy.⁷⁸² Support includes emotional support from family and friends, and financial support.⁷⁸³ Advocacy refers to allowing the expression of the agent through interpretation and translation of meaning.⁷⁸⁴ This is particularly important for persons who do not communicate verbally.⁷⁸⁵ Enablement refers to ‘being able to cultivate one’s autonomy capacities.’⁷⁸⁶ The focus is therefore, on conserving agency through support, advocacy and enablement, as opposed to reason, language and non-interference.⁷⁸⁷ Given the CRPD’s emphasis on autonomy and support, it is logical to conclude that the CRPD relies on the relational conception of autonomy.

Both the CRPD and the vulnerability framework rely on the idea of autonomy as a relational concept. For Fineman, the state’s role is to foster the autonomy of its citizens by developing appropriate social, political and legal institutions.⁷⁸⁸ Recognizing that the state has a role to play in fostering autonomy challenges the idea that autonomy is best protected through non-interference.⁷⁸⁹ This is essentially a re-conceptualisation of the role of the state.

4.3 Re-conceptualising the role of the state

The researcher has thus far advocated for a re-conceptualisation of the concept of capacity to consent through an application of Fineman’s vulnerability framework as well as the support paradigm. Both the vulnerability framework and the support paradigm require a re-

⁷⁸⁰ C Mackenzie & N Stoljar *Relational autonomy: Feminist perspectives on autonomy, agency, and the social self* (2000) 4.

⁷⁸¹ Dowling (n 779) 1059.

⁷⁸² Stefánsdóttir et al (n 768) 163.

⁷⁸³ As above.

⁷⁸⁴ As above.

⁷⁸⁵ As above.

⁷⁸⁶ As above.

⁷⁸⁷ As above.

⁷⁸⁸ C Mackenzie (n 141) 42.

⁷⁸⁹ Clough (n 81) 383.

conceptualisation of the role of the state. Therefore, the third and final way of re-conceptualising capacity to consent is by expanding the role of the state.

For Fineman, the vulnerable subject must look to asset-conferring societal institutions, including schools, workplaces, families and churches, which can bestow the resilience required to ameliorate harm.⁷⁹⁰ According to Fineman, societal institutions are themselves vulnerable and if unchecked, can operate to exacerbate our individual vulnerability.⁷⁹¹ Furthermore, because these societal institutions distribute important assets or resources, the state has a duty that goes beyond simple non-interference to active monitoring and the assessment of institutional and structural advantages and disadvantages in order to uphold the values of equality and justice.⁷⁹² This is essentially a re-conceptualisation of the role of the state from a restrained state to a responsive state.⁷⁹³

Implicit in the CRPD is the understanding that there is a need to re-conceptualise the role of the state. The CRPD delves into matters of implementation of rights by states in a way that no other international human rights instrument does.⁷⁹⁴ It highlights how the rights are to be protected, implemented and guaranteed.⁷⁹⁵ This focus on means in the CRPD stands in contrast with international human rights ideology.⁷⁹⁶ Typically, rights are termed in a 'performative fashion' imposing obligations on the state without much regard as to the means of implementation.⁷⁹⁷ In part, this is because international human rights law avoids involvement in debates around political systems, leaving the question of implementation to the states as in instruments such as the Universal Declaration and the ICCPR.⁷⁹⁸ In contrast, the CRPD delves into issues of implementation and sometimes describes exactly what states are required to do.⁷⁹⁹ For instance, in the CRPD's general obligations, states are required to implement rights in a number of ways, including, repealing or adopting certain laws,⁸⁰⁰ undertaking or promoting research,⁸⁰¹ and training of professionals and staff working with

⁷⁹⁰ See Chapter Two, section 2.5 for a detailed discussion on re-conceptualising the role of the state.

⁷⁹¹ See Chapter Two, section 2.5 for a detailed discussion on this.

⁷⁹² The relevant societal institutions responsible for conferring assets relating to sexual decision-making by women with mild intellectual disabilities are discussed in detail in Chapter Four.

⁷⁹³ See Chapter Two, section 2.5 for a detailed discussion on re-conceptualising the role of the state.

⁷⁹⁴ Mégret (n 148) 504.

⁷⁹⁵ As above.

⁷⁹⁶ As above.

⁷⁹⁷ As above.

⁷⁹⁸ As above.

⁷⁹⁹ As above.

⁸⁰⁰ CRPD art 4 (1) (b).

⁸⁰¹ CRPD art 4 (1) (f).

persons with disabilities,⁸⁰² amongst others. The support paradigm, in particular, creates obligations for states that typify a re-conceptualised state role. The CRPD Committee highlights the breadth of state obligations stemming from the support paradigm in art 12 (3) of the CRPD. The Committee lays out five guidelines to ensure implementation at the national level.⁸⁰³

First, states parties must recognise that persons with disabilities are persons before the law with legal personality and legal capacity in all aspects of life.⁸⁰⁴ States can achieve this by abolishing substituted decision-making regimes and adopting statutory language that upholds the right to legal capacity on an equal basis for all.⁸⁰⁵ The Committee has, in various concluding observations on States parties' initial reports stated that States parties must 'review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will and preferences.'⁸⁰⁶ The obligation to abolish substituted decision-making regimes requires states to also develop supported decision-making alternatives.⁸⁰⁷ Substituted decision-making regimes should not co-exist with supported decision-making systems.⁸⁰⁸

Second, States Parties are required to establish, recognise and provide access to a broad range of supports.⁸⁰⁹ A number of additional obligations arise from this requirement. For example, States Parties must ensure that supported decision-making is available to all persons with disabilities regardless of their level of support needs.⁸¹⁰ The Committee further clarified that the person's mode of communication should not prevent them from obtaining support.⁸¹¹ Even persons who use non-verbal forms of communication are entitled to support.⁸¹² Furthermore, states have an obligation to ensure that the lack of finances is not a barrier to accessing support, which must be available at little or no cost to persons with disabilities.⁸¹³ The Committee also added that support, including intensive support, must be based on the

⁸⁰² CRPD art 4 (1) (i).

⁸⁰³ CRPD Committee General Comment No 1 part V.

⁸⁰⁴ CRPD Committee General Comment No 1 para 50 (a).

⁸⁰⁵ As above.

⁸⁰⁶ CRPD Committee General Comment No 1 para 26.

⁸⁰⁷ CRPD Committee General Comment No 1 para 28.

⁸⁰⁸ As above.

⁸⁰⁹ CRPD Committee General Comment No 1 para 50 (b).

⁸¹⁰ CRPD General Comment No 1 para 29 (a).

⁸¹¹ CRPD Committee General Comment No 1 para 29 (c).

⁸¹² As above.

⁸¹³ CRPD Committee General Comment No 1 para 29 (e).

person's will and preference, not their perceived best interests.⁸¹⁴ The state's obligation to provide supports also entails ensuring that the support person elected by the person with a disability, is legally recognised, and that such recognition must be available and accessible.⁸¹⁵ States are also required to facilitate support, especially for people who live in isolation.⁸¹⁶ Moreover, they have an obligation to provide mechanisms that enable third parties to be able to verify the identity of a support person and enact mechanisms allowing third parties to challenge the support person where they are not acting in accordance with the will and preference of the person with a disability.⁸¹⁷ In addition, states must ensure that persons with disabilities have the right to refuse, terminate or alter the support relationship at any time.⁸¹⁸ The CRPD Committee also stated that the provision of support should not be based on mental capacity assessments and that states should formulate non-discriminatory methods of ascertaining an individual's support needs.⁸¹⁹

Moreover, safeguards premised on respect for the rights, will and preferences of persons with disabilities must also be established.⁸²⁰ The CRPD requires states parties to ensure that safeguards are in place to guarantee that support respects the will and preferences of persons with disabilities.⁸²¹ The safeguards must be 'proportional to the degree to which such measures affect the person's rights and interests.'⁸²² Support must be free from undue influence which occurs where the 'quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation.'⁸²³

Third, states parties should consult and actively involve persons with disabilities in the process of developing and implementing legislation, policies and other 'decision-making processes that give effect to article 12.'⁸²⁴

⁸¹⁴ CRPD Committee General Comment No 1 para 29 (b).

⁸¹⁵ CRPD Committee General Comment No 1 para 29 (d).

⁸¹⁶ As above.

⁸¹⁷ As above.

⁸¹⁸ CRPD Committee General Comment No 1 para 29 (g).

⁸¹⁹ CRPD Committee General Comment No1 para 29 (i).

⁸²⁰ CRPD Committee General Comment No1 para 50 (b).

⁸²¹ CRPD art 12 (4).

⁸²² As above.

⁸²³ CRPD Committee General Comment No1 para 22.

⁸²⁴ CRPD Committee General Comment No1 para 50 (c).

Fourth, the Committee encouraged states parties to commit resources to the research and development of best practices in relation to respecting the right to legal capacity and support in the exercise of legal capacity.⁸²⁵

Finally, the Committee encouraged States parties to provide persons with disabilities with the opportunity to make choices in their lives including ‘opportunities to build social networks; opportunities to work and earn a living on an equal basis with others; multiple choices for place of residence in the community; and inclusion in education at all levels.’⁸²⁶

These detailed guidelines have been set out in an effort to ensure that the state is responsive to the needs of persons with disabilities. Therefore the CRPD, particularly the support paradigm, is consistent with the vulnerability framework that also calls for a responsive state that enacts laws and policies that are responsive to our ‘universal and continuous’ vulnerability.⁸²⁷ Therefore, both the vulnerability framework and the support paradigm shift the burden from women with mild Down syndrome to prove that they have capacity to consent to the state, which must ensure that societal institutions provide the necessary support to build the capacity of women with mild Down syndrome to consent to sexual intercourse.

5. Conclusion

Although South Africa’s ‘capacity framework’ is preferable to the ‘status framework’ in Malawi, Uganda and Zambia, which attributes blanket incapacity to all women with intellectual disabilities, it has three significant limitations nonetheless. First, it continues to deny some women with mild Down syndrome sexual agency primarily because of its narrow focus on perceived or actual inherent limitations. Second, by failing to recognise the universal legal capacity for sexual decision-making by women with mild Down syndrome and its discriminatory application, it violates the right to legal capacity enunciated in the CRPD. Third, the ‘capacity framework’ perpetuates residual coloniality stemming from English law and may not sufficiently take the local South African context into account. In light of these shortcomings, the ‘capacity framework’ will remain incapable of recognising the sexual autonomy of women with mild Down syndrome, unless the concept is re-conceptualised. This study recommends re-conceptualising capacity to consent by expanding the scope of inquiry, incorporating support and expanding the role of the state to include the obligation to monitor asset-conferring societal institutions to ensure that they are responsive to the needs of women

⁸²⁵ CRPD Committee General Comment No1 para 51.

⁸²⁶ CRPD Committee General Comment No1 para 52.

⁸²⁷ Fineman (n 149) 134.

with mild Down syndrome. This is necessary to enable the recognition of the right to sexual autonomy. As Ball puts it in the epigraph, ‘it is impossible to lead a *good* human life in the absence of the freedom and opportunity to exercise personal autonomy, by which I mean the capability to make important life decisions and choices.’⁸²⁸

⁸²⁸ Ball (n 440) 635.

CHAPTER FOUR

TOWARDS A FRAMEWORK FOR SUPPORTED SEXUAL DECISION-MAKING: EMPIRICAL RESEARCH FINDINGS

I think women with mild learning disabilities absolutely could have the capacity, but for a lot of them they are disadvantaged, not because of their disability, but because they haven't had the education.⁸²⁹

1. Introduction

In Chapter Three, capacity to consent to sexual intercourse was re-conceptualised to encompass the understanding that it is not an inherent trait, but rather the result of a range of situational factors. However, these factors were not articulated. Chapter Three also demonstrated that women with mild Down syndrome require support in order to bolster their capacity to consent to sexual intercourse, but the exact supports that are necessary were not explained. It is therefore, necessary to build upon the conceptual foundation laid in the previous chapter by articulating the situational factors that limit the capacity of women with mild Down syndrome to consent to sexual intercourse and exploring the nature of support that can be provided to bolster their capacity. Accordingly, this chapter serves two purposes: first, to expound the situational factors limiting capacity to consent and second, to interrogate the supports necessary for enhancing capacity to consent.

In accordance with the second stage of de-colonial thinking, which requires the retrieval of local perspectives, the researcher conducted empirical research with the aim of interrogating the situational factors and supports that limit and enhance, the sexual decision-making capacity of women with mild Down syndrome in a South African context.⁸³⁰ Specifically, interviews with experts were conducted to elicit their views on these matters. This chapter discusses the empirical research in three sections. The first section explains the research methods and processes employed by the researcher in conducting the empirical research. In the second section, the research findings are outlined, starting with the findings relating to the situational factors that limit capacity to consent in a South African context before proceeding to the types

⁸²⁹ Quote from expert number seven. Expert number seven is from the United Kingdom where they use the term learning disabilities to refer to intellectual disabilities.

⁸³⁰ See Chapter Two, section 4 for a detailed discussion on de-colonial theory and the three stages of de-colonial thinking.

of supports that can be provided to strengthen sexual decision-making capacity. The third and final section concludes the chapter by summarising its main arguments.⁸³¹

2. Methods

2.1 Research design

The study employed a qualitative research design. The aim of the research study, which was to gather data on the supports that may be provided to enhance the capacity of women with mild Down syndrome to consent to sexual intercourse, informed the choice of the research design. The researcher elected to employ the non-numerical qualitative research design rather than the numerical quantitative research design⁸³² because qualitative research methods are suitable for answering questions about participants' perspectives, experiences and understanding.⁸³³ Indeed, qualitative research is defined as the 'organized, systematic exploration of some portion of human experience.'⁸³⁴ An important distinction between quantitative and qualitative research methods is that the former aims to achieve statistical significance, whilst the latter seeks to obtain a full understanding.⁸³⁵ Therefore, when the aim of a study involves understanding a little known phenomenon and discovering common emergent themes, as is the case in the present study, the qualitative research design is most appropriate.⁸³⁶

The specific qualitative research method employed by this study is the interview method. Semi-structured interviews were selected because their relatively unstructured nature avoids 'pigeon-holing' the participants' responses.⁸³⁷ The researcher is at liberty to react and to adapt the interview as necessary, for example, by providing the opportunity to seek further clarification and more detailed explanation than structured interviews.⁸³⁸ In a research study involving a sensitive and complex subject such as the capacity of women with mild Down syndrome to consent to sexual intercourse, the opportunity to seek further clarification is crucial. The researcher had an interview guide/schedule consisting of a list of questions covering very specific topics, but provided the interview participants a great deal of leeway in

⁸³¹ The present Chapter simply outlines the research findings. The findings are analysed in the following Chapter Five.

⁸³² I Dobinson & F Johns 'Legal research as qualitative research' in M McConville & W Hong Chui (eds) *Research methods for law* (2017) (2nd edition) at 19.

⁸³³ K Hammarberg et al 'Qualitative research methods: when to use them and how to judge them' (2015) *Human Reproduction* at 499.

⁸³⁴ JG Donalek & S Soldwisch 'An introduction to qualitative research methods' (2004) 24(4) *Urological Nursing* at 354.

⁸³⁵ Donalek & Soldwisch (n 834) 355.

⁸³⁶ Donalek & Soldwisch (n 834) 354.

⁸³⁷ A Bryman *Social research methods* (2015) 467.

⁸³⁸ Foley (n 5) 11.

how they answered questions.⁸³⁹ Through the semi-structured interviews, the researcher was able, in response to participants' answers, to ask questions that were not in the interview guide/schedule.⁸⁴⁰ The interview process itself was flexible and the researcher placed emphasis on how the participants framed and understood the issues.⁸⁴¹

2.2 Selection and recruitment of participants

The selection of research participants was informed in part by the research method chosen. Rather than randomly selecting a sample that is representative of a larger population, as one would when using the quantitative research method, the researcher selected participants (or samples) based on their knowledge of or ability to describe the phenomenon under study, an approach that is characteristic of qualitative research methods.⁸⁴² The research questions also influenced the selection of participants in that they directly influenced and guided the categories of people who were sampled.⁸⁴³ Participants were therefore, strategically selected with a purpose in mind, an approach known as the purposive sampling.⁸⁴⁴ With the aims of understanding the situational factors that impact sexual decision-making capacity and interrogating what sexual decision-making support entails, the researcher selected participants with extensive experience and knowledge in supporting sexual decision-making for women with mild intellectual disabilities. The research participants therefore, had to be experts of the subject matter. Criterion sampling was used to sample all individuals that meet particular criteria.⁸⁴⁵ Participants were included in the study based on their experience and knowledge in five areas. First, participants were included in the study based on their extensive knowledge or experience working with women with mild intellectual disabilities. Second, inclusion was based on knowledge and/or experience in providing sexuality education to women with mild intellectual disabilities. The third criterion was experience and knowledge of the use of augmentative and alternative communication with women with mild intellectual disabilities. Fourth, research participants were included in the study based on their knowledge of the CRPD, particularly, the provisions in article 12 on the right to legal capacity. The fifth and final criterion for inclusion was a working knowledge of the capacity framework used by the courts

⁸³⁹ Bryman (n 837) 468. See Appendix Two for the interview guide/schedule.

⁸⁴⁰ As above.

⁸⁴¹ As above.

⁸⁴² Donalek & Soldwisch (n 834) 354 – 355.

⁸⁴³ Bryman (n 837) 408.

⁸⁴⁴ Bryman (n 837) 407.

⁸⁴⁵ Bryman (n 837) 409.

in rape or sexual assault trials in South Africa. Participants who did not meet these criteria were excluded from the study.

With these criteria in mind, the researcher went on to recruit research participants. The researcher contacted several stakeholders including organisations of persons with disabilities and academic departments seeking recommendations on professionals who meet the above criteria primarily, but not exclusively in South Africa. The decision to include participants who were not from South Africa was made in order to determine whether the data would differ by geographical location. The researcher received twenty-five recommendations for individuals who may meet the stipulated criteria. Each of the twenty-five individuals were invited to take part in the research study via e-mail.⁸⁴⁶ Sixteen individuals declined the invitation to participate in the study on the basis that they did not think that they had enough knowledge and experience in the area.

Ultimately, nine experts who are professionals from various disciplines participated in the research study. Expert number one has expertise in Augmentative and Alternative Communication (AAC) and has worked extensively on communicating with persons with intellectual disabilities in South Africa. Expert number two is a clinical psychologist by profession who has assessed the capacity of numerous women with mild intellectual disabilities to consent to sexual intercourse and has written reports for the courts in the Western Cape Province of South Africa. Expert number three is a post-doctoral researcher in the Western Cape Province in South Africa who wrote her doctoral thesis on the sexuality of persons with intellectual disabilities. Expert number three is also currently conducting research in this area. Expert number four is a Professor in Learning Disabilities at a university in the United Kingdom.⁸⁴⁷ She has done extensive research in the area of the sexual rights of women with intellectual disabilities. Expert number five is an expert in AAC and has conducted projects providing sexuality education for women with intellectual disabilities in the Gauteng Province of South Africa. Expert number six is a registered counsellor and sexuality education trainer in South Africa. She has extensive experience providing comprehensive sexuality education to persons with intellectual disabilities in South Africa. Expert number seven is based in the UK. She wrote her doctoral thesis on the sexuality of persons with intellectual disabilities and thereafter established an organisation that supports persons with intellectual disabilities to have intimate relationships. Expert number eight is a speech therapist with expertise in AAC. She

⁸⁴⁶ See Appendix One for a copy of the invitation e-mail sent to prospective participants.

⁸⁴⁷ In the United Kingdom, the term 'learning disabilities' is used to refer to intellectual disabilities.

has also been involved in sexuality education programmes for women with intellectual disabilities in South Africa. Expert number nine is from Kenya and works in an organisation that represents persons with intellectual disabilities. She has extensive experience running sexuality education programmes for young people with intellectual disabilities.

It was difficult to determine at the outset the number of people to be interviewed, as is often the case with qualitative research.⁸⁴⁸ Therefore, the researcher made the decision about sample size on an ongoing basis without having set a maximum or minimum number from the onset using the principle of theoretical saturation as a measure for assessing the adequacy of the sample size.⁸⁴⁹ The researcher determined that the nine interviews were adequate because data saturation had been achieved.⁸⁵⁰ Data saturation is achieved when the same themes appear repeatedly (thematic exhaustion) and the researcher has a sense that a full understanding has been reached.⁸⁵¹ Furthermore, the sample was relatively homogenous, being made up of subject matter experts, and the scope of the research was relatively narrow such that data saturation may be reached at an earlier point.⁸⁵² It is accepted that research based on qualitative interviews can rely on small samples, particularly when theoretical saturation is used to determine the adequacy of the sample.⁸⁵³ Indeed, sample sizes in qualitative research are typically small.⁸⁵⁴ Larger sample sizes have the disadvantage of sacrificing depth to breadth as they may produce too much data for adequate analysis.⁸⁵⁵ The advantages of a smaller sample size is that it improves the researcher's chances of close interaction with the participants and generating detailed data for the study.⁸⁵⁶

2.3 Ethical considerations

Prior to commencing the interviews, the researcher applied for and was granted ethical clearance by the Faculty of Law Research Ethics Committee at the University of Pretoria.⁸⁵⁷ Throughout the process, the researcher adhered to ethical practices. First and foremost, the researcher obtained the informed consent of all the research participants in writing through a written participant information and informed consent form that was sent to each of the nine

⁸⁴⁸ A Bryman (n 837) 416.

⁸⁴⁹ A Bryman (n 837) 417.

⁸⁵⁰ As above.

⁸⁵¹ Donalek & Soldwisch (n 834) 355.

⁸⁵² A Bryman (n 837) 417.

⁸⁵³ As above.

⁸⁵⁴ Hammarberg et al (n 833) 500.

⁸⁵⁵ As above.

⁸⁵⁶ A Bryman (n 837) 417.

⁸⁵⁷ See Appendix Three for the Ethical Clearance Certificate.

participants by e-mail prior to the interviews.⁸⁵⁸ The participant information and informed consent form served three purposes: First, it provided participants with background information on the aim of the study, the importance of participating in this kind of research and why they were invited to participate in the study. Second, it set out the terms of participating in the study which are as follows. Participation is voluntary and there is no penalty or loss of benefit for choosing not to take part in the research study. Moreover, participants also have a right to withdraw from the research study at any time without having to explain why. In fact, a tenth research participant who had initially agreed to participate subsequently exercised her right to withdraw from the study without explanation, leaving nine research participants. Participation in the research is also anonymous and confidential. Furthermore, participants were assured that all the information that they disclose during the interview would be kept confidential and used only for the purposes of conference presentations, journal articles, and to write a thesis. Participants were also informed that they have a right to access their data at any time. The researcher disclosed to the participants that the interviews would be recorded and that such recording would only be used for the purposes of transcribing the interview. Finally, participants were informed that they have a right to ask questions about the study before signing the informed consent form. Third, the form served as an invitation to participate in the study. Signing the participant information and informed consent form was an indication that the participant freely chooses to take part in the research study. After signing the consent form, participants were asked to return the form to the researcher by e-mail.

2.4 Data collection

In depth one on one interviews were conducted with each of the experts. Each interview lasted between 45 to 60 minutes. Due to Covid-19- related travel and meeting restrictions, the interviews took place virtually via zoom. Virtual interviews also made it possible to interview the two participants based outside South Africa. The researcher asked a number of questions including introducing questions, follow up questions, probing questions and specifying questions.⁸⁵⁹ At the end of each interview, participants were given the opportunity to add any further information that had not been covered by the interview questions. Each interview was recorded for the purpose of enabling the researcher to subsequently transcribe the interviews

⁸⁵⁸ See Appendix Four for the participant information and informed consent form. L Blaxter et al *How to research* (2001) 158.

⁸⁵⁹ Bryman (n 837) 473.

and effectively capture interview data.⁸⁶⁰ Recording the interviews also made it possible for the researcher to concentrate exclusively on the ongoing interview.⁸⁶¹ After each interview, the researcher played back the recording and transcribed the interviews verbatim. The researcher played each recording back a second time to check for accuracy and correct any spelling or other errors and punctuation.⁸⁶² The researcher also anonymised the transcript by removing any identifying information such as names, places and significant events.⁸⁶³ Each participant was assigned a number and the transcripts refer to the participants by number, such as expert number one, two, three and so forth, and not by name.

2.5 Data analysis

The data gathered from the individual interviews was analysed using thematic content analysis.⁸⁶⁴ Thematic analysis involves drawing together codes from various transcripts to enable coherent and meaningful presentation of qualitative research findings.⁸⁶⁵ The process of thematically analysing transcripts therefore, begins with coding, which involves identifying topics, issues, similarities or differences in each of the transcripts.⁸⁶⁶ Once the researcher completed transcribing and checking the transcripts, the process of coding began. The codes that were frequently referenced by the participants were treated as themes.⁸⁶⁷ The themes were identified after thoroughly reading and re-reading the interview transcripts.

2.6 Limitations

The study's main limitation is that women with mild Down syndrome themselves were not interviewed. Interviewing them would have provided data that is rich and based on personal experience. However, women with mild Down syndrome could not be interviewed due to challenges related to obtaining ethical clearance to interview them.

3. Research findings

The research participants highlighted a number of themes relating to the capacity of women with mild Down syndrome to consent to sexual intercourse. For ease of reference, the themes are divided into two main categories. The first category addresses situational factors that have

⁸⁶⁰ S Jamshed 'Qualitative research method – interviewing and observation' (2014) 5(4) *Journal of Basic and Clinical Pharmacy* at 87.

⁸⁶¹ As above.

⁸⁶² J Sutton & Z Austin 'Qualitative research: Data collection, analysis and management' (2015) 68(3) *The Canadian Journal of Hospital Pharmacy* at 228.

⁸⁶³ As above.

⁸⁶⁴ Bryman (n 837) 584.

⁸⁶⁵ Sutton & Austin (n 862) 229.

⁸⁶⁶ Sutton & Austin (n 862) 228.

⁸⁶⁷ Bryman (n 837) 586.

an adverse impact on their sexual decision-making capacity. The second category deals with the supports that may be provided to bolster the capacity of women with mild Down syndrome to consent to sexual intercourse. The findings in each of these categories are addressed in turn.

3.1 Situational factors limiting the sexual decision-making capacity of women with mild Down syndrome

Two main themes/findings relevant to the situational factors limiting capacity to consent to sexual intercourse emerged from the interviews. The first finding relates to the meaning of the often-misunderstood concept of capacity to consent to sexual intercourse, which is that capacity is linked to the level of one's knowledge and understanding about sexual matters. The second finding is that most women with mild intellectual disabilities do not receive adequate sexuality education for a number of reasons as outlined below.

3.1.1 Capacity to consent and knowledge are inextricably linked

Any discussion concerning concepts as complex and contentious as capacity to consent ought to begin with interrogating the meaning of the concept. Expert number six conceded that capacity to consent to sexual intercourse is a 'very complex concept' that is often not articulated and is 'done through behaviour.' Accordingly, the research participants addressed the meaning of capacity to consent to sexual intercourse. The participants consistently linked capacity to consent to sexual intercourse with the level of one's knowledge and understanding of sexual matters. Expert number three stated that capacity to consent refers to being 'knowledgeable of what one is consenting to.'

Similarly, expert number eight stated that women with mild intellectual disabilities could have capacity to consent to sexual intercourse 'provided they have a good grasp and understanding of what sexual intercourse is, what it entails ... what the consequences are.' Expert number seven echoed the same sentiments by stating that capacity to consent varies amongst women with mild intellectual disabilities 'depending on the kind of education they have had.' The more knowledge one has, the more capacity one is deemed to have. Therefore, capacity to consent depends on the amount of knowledge that one has about sexual matters, not on the type of disability that one has. Consequently, it is erroneous to conclude that women with mild intellectual disabilities, as a class, lack capacity to consent to sexual intercourse.

The determination as to whether women with mild intellectual disabilities have capacity to consent to sexual intercourse must therefore, as expert number three stated, be made on a

case-by-case basis. Crucial to making this determination is the exact kind of knowledge one must have in order to be considered as having capacity.

The research participants specified the knowledge one is required to have. First, one is expected to understand the nature of the sexual act. As expert number three clarified, they should know, ‘the actual activity, what it entails.’ Expert number four explained that understanding the nature of the sexual act means understanding the ‘mechanics’ of the act. Secondly, one is expected to know and understand the reasonably foreseeable consequences of the sexual act. In other words, as expert number three put it, ‘do they know the implications ... [or] possible results of the act?’ For example, expert number four stated that one should be aware that ‘a woman could get pregnant or that a sexually transmitted infection could occur between the two people.’ Expert number two added that ‘if it is penetrative, are they aware of what they might need to protect themselves from, can they actually ask for condom usage if there is going to be anal penetration.’ Thirdly, one is required to know and understand that they have a right to withhold consent. Expert number four stated that they should be ‘able to say no without any consequences.’ She added that consent must be freely given and the person with a disability must understand that they are ‘in a position to freely give their consent... without any kind of duress or fear.’ Expert number two expressed the same point by stating that one must have an ability to ‘negotiate difference or conflict or assertiveness within ... relationships.’ Finally, as expert number two noted, one must know that sexual intercourse ‘is supposed to be pleasurable – this is supposed to be nice – it is supposed to be something they are going to enjoy.’

In addition to specifying the kind of knowledge that is required, the research participants also specified the level of knowledge one is required to have in order to be deemed as having capacity. The research participants stated that one is not required to possess knowledge in great detail. Expert number four described it as a ‘low level of information’ whilst expert number two referred to the standard as a ‘low bar.’ In terms of the requirement to know about the consequences of the sexual act, expert number one stated that it is not necessary to know the exact consequences in detail, just the possibility. Expert number one explained that:

all of us make decisions that we do not know the outcome 100%, we can’t predict everything. But we have to have some kind of concept of what could be the consequences of deciding either way.

Similarly, expert number two explained the point clearly by stating that:

I don't necessarily expect the person to have detailed understanding of STDs, but at the very least, I expect them to know what is actually going to happen if somebody is proposing sex, I expect them to have some idea of what that means. Some idea that, if it's a heterosexual relationship that there's a possibility of pregnancy and I expect them to have some idea about the possible dangers that they might need to protect themselves from. But not necessarily in detail because so many non-disabled people don't know about that in detail.

For the participants, capacity to consent to sexual intercourse is determined by one's knowledge of various aspects of sexual intercourse, not by one's disability.

3.1.2 Most women with mild intellectual disabilities do not receive adequate sexuality education

Data that were gathered from this study indicate that most women with mild intellectual disabilities do not receive adequate formal sexuality education. Expert number one stated that 'in a lot of the special schools, sexuality education is struck out of the curriculum.' It is important to note that the lack of formal sexuality education is not unique to women with mild intellectual disabilities. The participants also highlighted that even persons without disabilities may not have received any detailed formal sexuality education. For instance, expert number two indicated that when conducting a training workshop for prosecutors and police officers, she asked those who had received 'detailed, relaxed, comprehensive and repeated sexuality education' to raise their hands. In an auditorium with about one hundred people, only two to three people raised their hands. Therefore, both persons with disabilities and persons without disabilities may not have received adequate formal sexuality education.

However, the lack of formal sexuality education may not be as detrimental for persons without disabilities as it is for persons with disabilities, particularly, women with mild intellectual disabilities. Expert number four noted that most non-disabled people obtain the bulk of their sexuality education informally, through the internet, magazines, television and conversations with peers or friends. Similarly, expert number two stated that for 'non-disabled people we can find out, we can read stuff, we can speak to people.' However, women with mild intellectual disabilities may not be able to access any sexuality information informally for a number of reasons. For example, as expert number four stated, women with mild intellectual disabilities may sometimes struggle with literacy and may not be able to access all these other informal sources of information and they often have limited opportunities to interact with friends. Expert number one noted that although most people obtain information on sexual

matters from the internet this ‘option is often not the best for people with intellectual disabilities.’ She explained that this is because:

there is a lot of information out there written in a format that is not very accessible or its misinformation that can actually do more harm than good and I think persons with intellectual disabilities might not always be able to discern what is good information and not so good information.

Therefore, in addition to not receiving adequate formal sexuality education, women with mild intellectual disabilities are generally unable to obtain informal sexuality education leaving them with insufficient information about sexual matters.

This lack of information and knowledge about sexual matters negatively impacts women with mild intellectual disabilities in two ways. First, the lack of adequate information and knowledge about sexual matters prevents women with mild intellectual disabilities from gaining capacity to consent to sexual intercourse. Expert number seven stated that the factors preventing women with mild intellectual disabilities from having the capacity to consent ‘fundamentally come down to education.’ Expert number five added that ‘if the person does not understand what it is they are giving consent to – so if the choices and the options are not explained to them well enough’ this can prevent someone from gaining the capacity to consent to sexual intercourse. This makes the provision of adequate sexuality education to women with mild intellectual disabilities of absolute importance. As expert number two stated, there is a need to devote ‘time and energy into detailed and repeated sexuality education for women with mild intellectual disabilities.’

Second, it leaves them vulnerable to sexual abuse. Expert number one conceded that statistics do show that women with intellectual disabilities are more likely to be sexually abused and exploited, however, she proceeded to explain that the lack of information to enable them to make informed decisions makes them more vulnerable. Expert number seven stated that ‘we find that lots of women with learning disabilities are really overprotected as they’re seen as much more vulnerable, and that is true, to an extent, because they haven’t been given the same education as women without a learning disability.’ Expert number two emphasized the importance of sexuality education by stating that ‘one has to provide some information so that you know what is ok and what is not okay.’ Expert number two added that ‘I do think that unless people with disabilities are given some knowledge, they are enormously vulnerable.’ Expert number one stated that the provision of sexuality education is a necessity to help build the resilience of women with mild intellectual disabilities against sexual abuse. For the

participants, the provision of sexuality education is important for building the capacity of women with mild intellectual disabilities to consent to sexual intercourse and for building their resilience against sexual abuse. As expert number three aptly summed up, ‘nothing beats education that is repetitive and regular.’

In line with Fineman’s vulnerability framework, the research participants proceeded to highlight the situational factors that contribute to the denial of formal sexuality education for women with mild intellectual disabilities.

The misconception that capacity to consent is an inherent trait

The common misconception that capacity to consent is, as expert number six explained, ‘something that you have or don’t have,’ results in women with mild intellectual disabilities not receiving any sexuality education. It is erroneously believed that adults without disabilities have capacity to consent to sexual intercourse, whilst women with mild intellectual disabilities do not. This misconception stems from a broader trend known as the de-sexualisation of women with intellectual disabilities, which the research participants attribute to two further misconceptions. The first misconception is that women with mild intellectual disabilities are, as expert number nine put it, ‘forever children.’ Women with mild intellectual disabilities are perceived and treated as children, even when they are adults and this is known as infantilisation. Expert number three alluded to this phenomenon when she stated that ‘because, you know, some of them are just infantilised throughout their lives.’ The infantilisation phenomenon is also exemplified in legal concepts such as mental age. Expert number two stated that ‘we’ve got big issues about people with intellectual disabilities being sexual people and one of the issues is this terrible concept of mental age which tends to sort of freeze adults at child level.’ Expert number two proceeded to explain the problem with the concept of mental age thus:

everyone has a huge problem with it but it’s such an issue in South Africa we seem to be lagging far behind [other] people internationally. This sort of mental age thing is stuck here not just in the legal fraternity but in a lot of our colleagues, mental health colleagues, who still will say she’s got a mental age of five or whatever and they are talking about a thirty year old. And it’s like a short hand and it’s really very pervasive. How can you then think of that person as having rights in terms of their sexuality? It feels like you’re doing something completely perverse. So that way of thinking about adults is undermining of the idea of their right to have some sort of sexuality and it’s an enormous problem I think.

The infantilisation of women with mild intellectual disabilities is one of the factors fuelling the de-sexualisation of women with mild intellectual disabilities, preventing them from receiving sexuality education and developing their capacity to consent to sexual intercourse.

The second misconception fuelling the de-sexualisation of women with mild intellectual disabilities is that they are, due to their disability, asexual. Expert number eight noted that women with mild intellectual disability are erroneously believed to be asexual and this explains why they are not provided with information on sexuality matters. Similarly, expert number five stated that ‘people tend to think that just because a person has a mild intellectual disability ... that they don't have sexuality needs or that they shouldn't be engaging in sexuality activities.’ Expert number five went on to describe how she ended up conducting sexuality training for adults with intellectual disabilities in a group home in Pretoria. She stated that:

this one group home in Pretoria ... said, no, ... the adults in that group home don't engage in sexuality behaviour and then not long after that the medical students did a survey there and then a very high percentage of those young people had been infected with sexually transmitted diseases. So there was this whole question about, how can you have an STD, if you don't have sex... And that was when the programme started off trying to train people.

Cumulatively, the infantilisation and misconception of women with mild intellectual disabilities as asexual beings results in their desexualisation, which negates the need to provide them with sexuality education. This perceived lack of capacity on the part of women with mild intellectual disabilities is attributed to the presence of an intellectual disability. They are therefore, perceived as inherently lacking capacity to consent, making it unnecessary for them to receive any sexuality education. Expert number six explained the effect of this perception by stating that ‘if people deem consent as something that you have or don't have it's presumed perhaps they don't have and then all of that support or information is withheld.’

The misconception that sexuality education is dangerous for women with mild intellectual disabilities

The research participants pointed out that sexuality education and information is withheld from women with mild intellectual disabilities because families and caregivers are suspicious about sexuality education for three reasons. First, parents and caregivers tend to fear that providing sexuality education to their adult daughters with mild intellectual disabilities will encourage them to engage in sexual activity. Expert number five stated that:

for any older parent to give you permission to train their daughter about sexuality was challenging because somehow there's this perception that we are going to heighten the sexuality drive if we train them about sexuality. Because people have this idea that sex and sexuality that that's the same concept, which we know it's not and that they think that if we are going to want to talk about sexuality then we are only going to focus on sex which is not the case, that's just one small part of it. So, it really is about getting

rid of a lot of the stigma, the taboos, the myths, all of those things just to get the training started.

Expert number nine recounted an experience she had when her organisation first introduced a programme on sexuality education for women with mild intellectual disabilities. She stated that:

I remember ... when we started this programme quite a number of families came ... and they pulled out their daughters from the programme. Like you know you want to initiate them into sex they don't need this kind of information they need therapy, they need, you know, access to other things, but not this.

Secondly, families and caregivers are resistant to sexuality education because they often feel the need to protect women with intellectual disabilities from rejection. Expert number two explained the concerns of parents and care givers thus:

it worries people ... are you just going to be opening a terrible can of worms? Are you going to be making people vulnerable to rejection because if they learn about sexuality and they suddenly start feeling that they can have boyfriends and girlfriends, and they're just going to get rejected because they are not going to get chosen? And what if they then feel like they want to get married and they want to have children and what if they can't? So, let's rather make them feel that they are children.

Third, parents oppose sexuality education because they want to keep their daughters with mild intellectual disabilities safe from abuse. Expert number seven stated that 'parents are particularly very overprotective. So even if their ... daughters probably do have capacity, we found that some parents are still really anxious about them having a relationship in case they get hurt or abused.' Expert number two added that:

it's enormously difficult and it's extra difficult here [South Africa] because of our high rates of sexual abuse and because people with disabilities are targeted, and that can make people very afraid of sort of encouraging sexuality and what people don't realise is that sex education actually protects people. It doesn't make them more vulnerable. It makes them safer.

These three misconceptions cumulatively result in parents and caregivers denying women with mild intellectual disabilities any formal sexuality education.

The practice of gatekeeping

Parents and caregivers generally perceive intimate sexual relationships involving their adult daughters with mild intellectual disabilities in a negative light and can act as gatekeepers preventing them from learning about and experiencing sexual relationships. Most caregivers have not received sexuality education and training themselves and have limited understanding

of sexual matters. Expert number three stated that ‘some of the attitudes are actually not just because people just choose to be negative, but it’s because they have not been exposed to another way of seeing it.’ Expert number five expressed a similar view when she stated that ‘because parents didn’t have proper education and they feel very uncomfortable with a lot of these ideas, it’s difficult for them to be guiding their children.’ Parents and caregivers have negative attitudes towards the sexuality of women with mild intellectual disabilities for a number of reasons. Expert number three noted that most parents and caregivers associate sexual autonomy with pregnancy and reproduction and they ‘worry what will happen when there is a baby involved.’ Expert number three added that caregivers think that ‘whatever they allow this person to do has implications on them such as having to bear the additional burden of looking after a child and this is the reason why most caregivers choose to ignore sexuality altogether.’ She further stated that parents and caregivers are so fearful that they ‘sometimes forget that there are ways to prevent pregnancy.’

According to expert number three parents and caregivers are also opposed to women with mild intellectual disabilities engaging in sexual relationships because they ‘tend to want to focus more on what they perceive as the needs of their daughter or relative with mild intellectual disability, and sexuality is not perceived as a need.’ Parents and caregivers often fail to appreciate the benefits of intimate sexual relationships for women with mild intellectual disabilities. The participants stated that it is important to help parents and caregivers to see the benefits of intimate relationships for women with mild intellectual disabilities. Expert number three believes that there is a need to show parents and caregivers that ‘just as they have partners, husbands and wives, their daughters or relatives with mild intellectual disabilities also have the same physical needs.’ Expert number six shared similar sentiments. Specifically, expert number six thought it important to help parents and caregivers to see the ‘possibility of a relationship being a life enhancing positive component of a person’s life.’ Expert number two opined that helping parents and caregivers see how having warm, close relationships can improve one’s quality of life is the reason ‘why this [sexuality education] is really worth trying to develop.’

It is equally important to educate parents and caregivers about the cost of denying women with mild intellectual disabilities sexual relationships. Expert number six added that ‘often relationships are just seen in terms of risk and we don’t see the cost of denying people relationships.’ Expert number six explained that denying people relationships can make them vulnerable to secret relationships and leave them open to exploitation from others. She further

explained that ‘in some people the longing for a relationship is so intense it can you know, increase loneliness and depression.’

The research participants consistently alluded to the powerful influence that the attitudes and beliefs of family members and caregivers have on women with mild intellectual disabilities. Women with mild intellectual disabilities rely on their family members, other caregivers, and support workers for various day-to-day tasks. The views, attitudes and beliefs of family members, caregivers, and support staff can impact the sexual decision-making capacity of women with mild intellectual disabilities. Expert number three stated that caregivers have a ‘huge influence when it comes to the issue of capacity to consent to sex or sexuality in its broad sense, whether its sexuality education or whatever.’ According to expert number three, the influence is exhibited in the general tendency of women with mild intellectual disabilities to internalise the views and the treatment that they hear and receive on a regular basis from their caregivers. Indeed, expert number three aptly described the nature of the relationship between the caregiver and the person with a disability as ‘almost intertwined.’ Expert number six explained this succinctly as follows:

‘they’re [i.e. women with mild intellectual disabilities] so tied into, whatever their family or their caregivers think or feel about their lives or their beliefs around what’s okay and what’s not okay. And that’s a matter of kind of acceptance and survival isn’t it, you know most young people at some point, tend to sort of move away and think well actually I don’t agree with what mom or parents say. I want my own life. It’s so hard for someone with an intellectual disability to do that and survive so in a sense, they have to absorb the beliefs and values of those around them.’

If the family members and caregivers have a negative attitude about sexuality, this can be an enormous limitation on the ability of women with mild intellectual disabilities to gain capacity to consent to sexual intercourse. Expert number one stated that ‘if people don’t believe that you can make the decision, then you might not be given the opportunity to make it.’ Expert number one added that people might ‘either actively or passively block that opportunity to make the decision because they believe you cannot make it or it’s not appropriate for you.’ Referring to sexuality education, expert number three explained that ‘if the caregivers, whether formal caregivers or family, do not allow it to happen, I believe it will not happen.’ Expert number three added that this is because ‘the nature of their disability requires that they get support from other people and they are under life-long care.’

A reluctance to discuss sexual matters rooted in African culture and religion

The research participants noted a general reluctance to discuss sexual matters amongst the parents and caregivers of women with mild intellectual disabilities. The participants stated that culture and religion inform restrictive attitudes and beliefs of families and caregivers. Expert number three stated that parents and caregivers' perceptions about the sexuality of women with mild intellectual disabilities are shaped and influenced by wider issues such as culture and religion. The research participants highlighted that in African culture, sexuality is a taboo, an undignified topic that is often characterised by secrecy and even shame. When it comes to the sexuality of their daughters and relatives with mild intellectual disabilities, expert number three noted that most parents and care givers 'bury their heads in the sand and hope that they will never have to deal with this area of their child or family member's life.' Then they 'get awakened in a rude way when they have to deal with something like a sudden pregnancy.'

The participants further noted that culture and religion also have an enormous influence on women with intellectual disabilities themselves. Expert number nine noted that culturally, discussions around sexuality are usually shunned, and even more so when they involve women with mild intellectual disabilities and this is exhibited in the behaviour of the women themselves who are often very secretive about sexual matters and are reluctant to openly discuss these issues and ask for support. Expert number nine also reported noting that the women with mild intellectual disabilities are often conflicted and find it difficult to reconcile their desire to engage in sexual relations and their cultural and religious beliefs and this comes through in discussions with self-advocates on this issue. Expert number two pointed out the complexities that may arise for women with mild intellectual disabilities who are from families that are 'deeply religious' and do not condone sexual activity before or outside of marriage.

During the course of conducting this empirical research, the researcher also found that personnel working in Disabled People's Organisations (DPOs) are also reluctant to discuss sexuality matters. The researcher invited twenty-five individuals to take part in this research study. Sixteen of those individuals declined the invitation to participate on the basis that they did not feel that they had enough knowledge and experience on the subject.

The reluctance to discuss sexuality matters is so pervasive that it affects parents, caregivers, women with mild intellectual disabilities themselves as well as personnel from disabled people's organisations, who are the very people these women should turn to for support. Because the topic is often shunned, women with mild intellectual disabilities may not

even seek support. If they were to seek support, they would likely do so from parents and care givers on whom they rely for support generally, or personnel from disabled people's organisations. It is a matter of great concern that the parents, caregivers and personnel from disabled people's organisations are reluctant to discuss these matters, leaving women with mild intellectual disabilities with little or no support when it comes to sexuality matters.

The influence of restrictive environments

Most women with mild intellectual disabilities live in controlled and restrictive environments. This can either be in a family home where they are under the strict supervision of parents or care givers or in a group home setting under the care of support workers. Both environments can restrict the freedom of women with mild intellectual disabilities to learn about and explore sexual relationships. For instance, in the absence of formal sexuality education, most people learn about sexuality through, as expert number three put it, 'organic means' such as speaking to friends, reading and even experimenting. Expert number three noted that women with mild intellectual disabilities do not get exposed to such opportunities and spaces both in the family home and in the group home setting. Expert number one stated that their living arrangements may restrict their opportunities to go out and meet people and have private spaces to experiment sexually. In the group home setting, support workers may restrict sexual relationships because they fear criminal sanctions. Because having sexual intercourse with a woman with a mild intellectual disability who lacks capacity to consent to sexual intercourse can result in criminal charges, organisations and support workers are reluctant to allow sexual relationships to take place. Expert number seven explained it thus:

staff can be very cautious and they can be very frightened to let people explore their sexuality or even to bring it up. We find that organizations don't talk about sex and relationships a lot...I think the law doesn't help in the definition of consent, you know how they described mental disability as someone who cannot consent. So I think that's often interpreted literally. And so, people are afraid of giving sexuality education, because they think, well then it's going against the law... they're also then afraid to encourage people to perhaps have sexual relationships, because will ...they then be breaking the law if they do it?

These factors result in the denial of formal and informal sexuality education for women with mild intellectual disabilities. This lack of education results in women with mild intellectual disabilities having insufficient knowledge about sexual matters, ultimately leading to a lack of capacity to consent to sexual intercourse.

With this background in mind, the research participants proceeded to highlight the supports that are necessary for building the capacity of women with mild intellectual disabilities to consent to sexual intercourse.

3.2 Supports to enable women with mild intellectual disabilities to build capacity to consent

The research study sought to build on the support paradigm by eliciting the views of the expert research participants on the kinds of supports required to build the capacity of women with mild intellectual disabilities to consent to sexual intercourse. Three main types of supports were identified, namely, information and sexuality education, emotional and relational support, as well as support in the form of experiential freedom facilitated through independent living arrangements. This section addresses each of these supports in turn.

3.2.1 Information and sexuality education

The research participants unanimously perceived the provision of information and sexuality education as one of the most important supports necessary for building the capacity of women with mild intellectual disabilities to consent to sexual intercourse. The research participants highlighted a number of characteristics of sexuality education.

Sexuality education must be comprehensive

There was consensus amongst the research participants that sexuality education should be comprehensive and cover various aspects of relationships. Expert number five stated that it is important to not only focus on the physical sexual act itself but to place matters in context by dealing with broader comprehensive issues such as relationships. Expert number seven shared these sentiments and stated that sexuality education should ‘focus on all areas of relationships, not just sex.’ The research participants highlighted various topics that comprehensive sexuality education should address. Expert number one stated that sexuality education should include the ‘types of relationships where sexual intercourse might be one of the aspects of the relationship, one of the stages in the relationship, one of the expectations in the relationship, what kind of a relationship is that, how does one start such a relationship.’ Moreover, expert number one added that sexuality education should deal with understanding relationships, understanding what a healthy relationship is, the boundaries in relationships, and the signs of an unhealthy relationship. Expert number one added that it is important to teach women with mild intellectual disabilities that:

relationships do have stages, they have progression, and that in the end sexual intercourse should be something positive and something enjoyable, not something that you feel violated about or feel awkward about. As soon as you have those feelings, how can you deal with them? What would be appropriate avenues to get support?

Sexuality education should also address other types of relationships. Expert number five stated that sexuality education should include lessons about other relationships such as friendships and explain the difference between a stranger, a friend and an intimate romantic partner. The training should also address topics such as greeting; how to greet someone who is just a friend, someone who you are intimate with, and a stranger. Expert number five stated that ‘we have to tell them that you can hug people in these circles, but not in these other circles and what are the alternative ways of greeting people.’

Sexuality education should also address the distinction between public and private. Expert number five stated that it is important to provide women with mild intellectual disabilities with information about public and private spaces as well as public and private body parts. In relation to public and private spaces, expert number five explained as follows:

with public and private I’m thinking about public and private places because we often see that people with intellectual disabilities could, for example, do things like public masturbation. And that, that leads to a lot of confusion and misconceptions that they have a heightened sexuality drive, etc. Really that isn’t the issue. The issue is that they don’t necessarily know what these cultural norms are so to explain to them, that that is an activity that belongs in a private place. So in your bedroom, but not in the lounge where all of the people come together or whatever.

In terms of public and private body parts, expert number five stated that it is important to talk about them, specifically, ‘what are the types of body parts that you can expose to other people and which ones are more private?’ Expert number seven added that it is important to teach women with mild intellectual disabilities about who can touch their private body parts and their public body parts.

Comprehensive sexuality education should also address touching. Expert five explained that in the past, there used to be a distinction between ‘good touch and bad touch.’ In recent years however, this term is gradually being replaced by appropriate touch and inappropriate touch.’ Expert number five stated that this is because women with mild intellectual disabilities need to understand that ‘bad touching can feel good.’ For instance, one can be sexually aroused after being touched in the context of an abusive situation. However, the fact that it feels good, does not negate the fact that it is still an inappropriate relationship and therefore, the touching is also inappropriate.

Sexuality education should also address the distinction between good secrets and bad secrets. Expert number one stated that ‘there is a difference between privacy and unhealthy secrecy that creates a space for abuse’ and it is important for this distinction to be adequately addressed during sexuality education.

Comprehensive sexuality education should also address the risks associated with sexual relationships. Expert number six stated that information should be provided about the dangers of contracting sexually transmitted diseases, and getting pregnant. Expert number seven opined that women with mild intellectual disabilities should learn about contraception to avoid contracting sexually transmitted infections and pregnancy.

Sexuality education should also address the question of safety to help women with mild intellectual disabilities avoid sexual abuse. Expert number seven stated that women with mild intellectual disabilities should be informed about their right to say no to sexual intercourse and what to do if they do say no and someone forces them to engage in intercourse nonetheless.

It is also important for sexuality education to address the positive aspects of an intimate relationship as well. Expert number six observed that ‘people are quite resistant to giving sexuality education, but they are even more resistant to framing it within the possibility of a positive, pleasurable relationship.’ Nevertheless, it remains crucial to address the positive aspects of an intimate relationship and to teach the women that, as expert number six puts it, ‘it is possible for a sexual relationship to feel good.’

Expert number three stated that sexuality education needs to be comprehensive and should not cause confusion by leaving some things out. As shown above, sexuality education is in fact broad and sexual intercourse is only one aspect of sexuality education. This is why, as expert number six explained, the preferred term is comprehensive sexuality education. This term emphasises the broad nature of the topic.

Sexuality education must begin early

The research participants also addressed the question of when sexuality education should start. In terms of when it should start, the participants were unanimous that it should start at an early age. Experts number seven and nine both stated that sexuality education should start at primary school level. Significantly, experts number five and seven emphasised that girls with intellectual disabilities should start receiving sexuality education at the same age as girls without disabilities. Expert number five added that sexuality education should be taught in an

age appropriate manner. Starting sexuality education early helps the women with intellectual disabilities to receive the correct information and this can help them avoid acting on misinformation. Expert number nine explained this point by stating that:

when we started this particular programme, we got women with intellectual disabilities from around 16 to 30 years and we thought we were the first ones to discuss with them this particular subjects only for them to tell us that you know they've had so much in the community, not from their families, not from schools, but from their peers in the community, and they confessed to you know, making a lot of very wrong decisions out of peer pressure. So, this tells us that you know the education should start very early in life, and early enough in life, when other children are being taught about this, they should be part of these programmes as well.

Expert number one expressed similar sentiments as follows:

I've read about medical decision-making which is a much more obvious and open type of discussion because you sit with your family and your health care provider and you discuss options for treatment. And that needs to be very open and everybody needs to be sure that I am making this decision on my own and I am not forced etcetera. Whereas I think a decision to engage in sexual intercourse as I say is maybe a much more private and much less mediated and less pre-meditated. I think it would be best to prepare the person for the fact that such decisions may come up in relationships. Rather than maybe trying to support them in the actual situation and on the spot, I think it would be best for the person to understand that this is the type of decision that you might want to make in a relationship of a certain nature and to be able to, before such a situation arises, to understand what could be consequences, under what circumstances would you want to make such a decision, and when would you want to say yes and when would you want to say no.

Participants opined that providing sexuality education from an early age can actually help women with mild intellectual disabilities to prevent abuse. Expert number four stated that:

You're never going to prevent it, because you know it could happen to any of us at any time whether we have learning disabilities on or not, it's, you know, it's a possibility. But in terms of reducing the risks to people with learning disabilities, I guess I go back to what I was saying before, which is to start at a young age with people about you know, just teaching them that their bodies belong to them and to try and teach them to be assertive and to be able to tell the difference between, you know, a good relationship and a bad relationship.

Sexuality education must be frequent and repetitive

The research participants stated that sexuality education should be repetitive. Expert number three stated that it needs to be refreshed in situations where someone has gone for a long time without being in a relationship. She stated that 'it's necessary to do that sort of general education every now and then to sort of just keep reminding them of what they need to know.' Expert number seven expressed similar sentiments and stated that sexuality education needs to

be ‘refreshed’ because ‘sometimes people with learning disabilities can find it hard to retain information so if they don’t use that skill, for a long time ... it can be good to refresh that.’ Sexuality education also needs to be repeated when someone starts a new relationship. Expert number seven stated that ‘people need to be aware that it does need to be refreshed, so just because someone had support around this one, maybe if that relationship ends and they start a new relationship, they might need support again.’

Sexuality education should take multiple formats

Sexuality education can take many forms. Specifically, it can be formal or informal. Expert number seven explained that formal sexuality education is that which is facilitated by specialist trainers whilst informal sexuality education is that provided by lay people such as family members, care givers and support workers. Sexuality education can therefore, take many formats. For instance, sexuality education can be delivered to women with mild intellectual disabilities in a group setting such as a workshop (expert number three). Group trainings can either be facilitated by expert trainers or by peer trainers. Expert number seven stated that peer led training which involves other people with mild intellectual disabilities talking to their peers about sexuality matters is quite impactful. The women with mild intellectual disabilities are inspired by their peers to believe that it is possible for them to have healthy relationships. The research participants also stated that this kind of group education is not sufficient. Expert number three highlighted the fact that women with mild intellectual disabilities need continuous support including on an individual case by case basis when they want to enter into intimate relationships. Expert number three stated that ‘for those who show interest or are already in sexual relationships, I definitely think there is a need for someone to sit with them regularly and, you know, just check how things are going and all that, where they can even ask questions and get guidance.’

Emphasis was placed on the need for couple counselling for those women with mild intellectual disabilities who are already in relationships. Expert number six stated that ongoing couples’ counselling is necessary to mitigate the risk of abuse and sexual practices that are not pleasurable. She recounted an incident in which she spoke to a married couple and the husband liked to have anal sexual intercourse, whilst the wife did not. It was necessary for the couple to speak openly about how they felt about the sexual relationship. Expert number three stated that there is a need for this sort of couple counselling ‘where someone, a professional, who is trained in that actually maybe sits with them and keeps guiding them. For example, they may be

thinking of having a baby, I don't think it's something that they can just decide and go ahead with so they can actually be encouraged to talk about such things - then someone sits with them and very openly lays out what are the implications and things like that so that they know.'

Sexuality education should be provided at various levels

Having highlighted the importance of sexuality education for enabling women with mild intellectual disabilities to build capacity to consent to sexual intercourse, the next question is whose responsibility is it to provide this sexuality education? The research participants shared their views on this, which are that the support should come from various levels. Expert number nine stated that support should be provided at the family level. Expert number nine added that the community and the larger family set-ups (the natural support systems) should also be involved in providing sexuality education, people like grandmothers, aunties should also provide this information. However, they rarely do because they think that it is inappropriate to do so. According to expert number nine, these conversations need to be happening in places like faith-based organisations such as churches and mosques as well as in schools.

Some of the experts also thought that members of the medical fraternity should also be providing sexuality education. Expert number five stated that medical professionals such as community health nurses could also provide this support. Expert number five explained that:

in my own PhD study that I did, I was working with children with intellectual disability and that was now in a totally different topic, but in that study, I realized the important role that community nurses play in our country because there is really one of these community health clinics within walking distance from every person so, even people living in very rural areas and these nurses are typically from the communities and they've been there for a long time and they are trusted in the communities. And they are very often the people that the mothers would confide in. And even mothers of adult children, so I think we really need to also think about how do we empower those nurses to be able to provide some of the, the basic skills because in in the cities, I mean, there it's a little bit different because there are just many more opportunities for this type of information to be shared and I do think, you know, there are lots of ways in which information can be shared. But I think the primary responsibility should lie with trusted adults like in the workshop sheltered workshops, community health nurses.

Expert number nine also opined that health and medical practitioners can play a part in educating women with mild intellectual disability about sexual matters. A large number of women with mild intellectual disabilities go to hospitals to seek information about intimacy and sexual relationships. Expert number five stated that medical professionals such as community health nurses could also provide this support. Expert number five stated that for

women living in group homes, the sexuality education can be provided by support workers and social workers.

Expert number three stated that though it would be ideal for family and community members to provide this education, she expressed concern that they may not actually do it making it necessary for professionals to provide this training. Currently, independent organisations are providing this training and the participants emphasised the need for governments to take charge of the provision of sexuality education. Expert number seven stated that ‘it would help if it was funded’ by the government to make it easier for women with intellectual disabilities to receive that kind of support. Expert number seven stated that currently these services are provided by independent organisations who do not receive funding from the government. They therefore, are not able to provide the service in all parts of the country, therefore, not all women with mild intellectual disabilities are receiving this much needed sexuality education. Expert number nine also echoed these sentiments and stated that although civil society organisations are currently providing sexuality education, it is the obligation of the government to provide it because they have the ‘mechanisms and resources’ that independent civil society organisations do not.

The ideal situation would be for sexuality education to be provided by all these different individuals and organisations. In reality, however, this is not the case and the person’s living arrangements have a bearing on whether and how the individual receives sexuality education.

Sexuality education should be provided in accessible formats

The research participants stated that women with mild intellectual disabilities are completely capable of understanding sexuality education as long as it is provided in an accessible format. Expert number five stated that ‘there is no reason why they should not be able to understand ... because a lot of the issues around sexuality and intercourse ... can be made very concrete.’ Expert number five proceeded to state that:

For example, at the one group home ... we had a project where the young people, all with mild intellectual disabilities, ... could participate in sexual behaviour pending certain rules. ... they had to make sure that they understood what it was that was happening. And in that project it was very clear that they could understand what it was all about.

The research participants provided some examples of how sexuality education could be made accessible. Expert number five emphasised the importance of providing information in an

understandable way. She proceeded to explain that this involves avoiding the use of jargon, complex terminology and metaphors. For example, expert number five discouraged the use of statements such as ‘time flies’ as this is likely to cause confusion. Similarly, expert number nine stated that sexuality education should be ‘be as open and as simple as possible and that is why her organisation uses the local language as well as the ‘street language’ that the women with mild intellectual disabilities are already familiar with.

The participants indicated the importance of avoiding the use of abstract ideas and making the training as concrete as possible. For instance, expert number five stated that ‘I had to go to a sex shop and actually buy a plastic penis and show them exactly what it looks like’ and that it can be hard or soft.’

Communication aids can also be utilised to make sexuality education accessible. There was consensus on the utility of pictures in making sexuality education accessible. Expert number seven stated that she uses pictures during the training. Expert number five also stated that she employs pictures which she finds helpful for improving understanding. Expert number five explained that the pictures should be culturally and age appropriate. The pictures should also not have too much unnecessary background information as this can distract from the main message.

The participants stated that training should be as interactive as possible. Expert number nine stated that she encourages the use of conversations to make the training interactive. Expert number seven gets people to role play how they would approach a first date. In addition, she also uses interactive games in which the participants are given red and green cards. She then reads out a story about a relationship and they have to lift their red cards when they think that a person in the story is behaving in an unsafe manner and a green card when they think that the behaviour is acceptable. Expert number seven also stated that she makes use of videos. In one of the videos, there are two people who are in a relationship and one of them wants to have sexual intercourse whilst the other does not. This video is used to discuss how to manage the situation and how to say no. Another video depicts two people in a healthy relationship and the women with intellectual disabilities are asked to explain why they think the relationship is healthy. Expert number seven stated that ‘people really enjoy the videos because I think it gives them something to focus on.’

Written materials may also be used during the sexuality training involving women with intellectual disabilities who are literate. However, these materials must be in easy-read format

so that the women can understand them. Furthermore, as expert number five explained, the font should be basic and of a reasonably big size. Finally all sentences must be short.

The research participants also recommended short sessions. Expert number seven stated that she conducts sessions that are no longer than two hours and ensures that there are breaks in between with some light refreshments such as biscuits and tea.

The participants also stated that trainers should avoid making generalisations when providing sexuality education. Expert number five stated that ‘it’s so important that we realize that generalization is one of the biggest challenges that people with intellectual disabilities have.’ Expert number five proceeded to state that:

So for example, if we are training them about who is a stranger, we can’t say strangers, are people like the people in the Wimpy ... we have to say ... [strangers are the people] in Wimpy and ... in Checkers or the people that you see at the Spaza shop ... So we’ve got to make sure that we cover all of those options and don’t leave things to just self-interpretation.

In terms of deciding the type of materials to use, it is worth quoting expert number five verbatim who explained it as follows:

the training programme that you would have would typically have a whole range of different materials available. And I think that if we look at intellectual disability for example, we know that there is a particular developmental sequence. So always real objects are the easiest ones to understand because they are in 3D. So they are objects that you can touch and that you can feel and that you can understand. Then if people understand real objects the next level would be things like photographs. So making sure that very logical very clear, very easy to use photographs and after the level of photographs we get to basic line drawings and with line drawings again, there is a whole different range of different types of line drawings. So from ones that are much more graphic and much more concrete to ones that are a little bit more abstract. Now the beauty of using a more abstract symbol is that you can actually also start to convey more abstract concepts, because if you using a picture then, of course, something like explaining consent, for example, is a difficult thing because how do you draw a picture of consent. Whereas if you using one of the more abstract symbol systems like for example bliss symbols, these are specific symbols, because you can describe the construct. So saying consent is something that you mean to say yes. And that you mean yes with your heart and with your mouth and with your head and so that you can understand what the construct is and then if people are on that level, then we only move to literacy. So we have to make sure and then we can use the written words. So depending on the level, the specific level at which these individuals, all of that you training. That’s what would guide the type of material that you would use.

Participants also pointed to the lack of accessible training materials to use for sexuality training. Expert number nine stated that the lack of accessible tools and information such as Easy Read,

audio and video formats has made it difficult for her organisation to provide sexuality support in Kenya. She added that they had to start developing their own materials to help them facilitate the sexuality education workshops better.

3.2.2 Emotional and relational support

The second form of support for sexual decision-making by women with mild intellectual disabilities is emotional and relational support. Parents, caregivers and support workers are best placed to provide this form of support because they are primarily responsible for taking care of women with mild intellectual disabilities. The research participants highlighted some crucial aspects of this form of support as follows:

Emotional and relational support begins with educating parents and caregivers

The research participants emphasised the fact that emotional and relational support begins with educating parents and caregivers. Expert number three stated that ‘any support that is given to a person with intellectual disability should start with supporting the people who are responsible for taking care of that individual ... because there is some strong gate-keeping that can happen.’ As stated earlier, much of this gate keeping is a result of the fact that parents and caregivers lack adequate knowledge and information on sexual matters. Expert number six stated that ‘parents are often so ill equipped because perhaps they haven’t had any sexuality education themselves’ so they may not appreciate the importance of sexuality education or know how to support their adult daughters and relatives with mild intellectual disabilities. As expert number two noted, the provision of sexuality education to women with mild intellectual disabilities has to be ‘negotiated somehow with families, in terms of at least protection.’ Expert number two added that ‘families have to be involved in some way to make sure the person is safe and to assist them with things like contraception and with managing private places to have sex.’ Expert number six noted that parents and care givers need support to understand that:

it will benefit your ... daughter to get information; it will benefit you both to have the words to be able to talk about these things, because when challenges happen later down the line, you may then feel more equipped to respond to the challenges if you’ve already started to talk about body parts or privacy or rights or choices or sexual feelings. If you’ve got those words with your son and daughter, later on, if there are challenges around relationships or ... any kind of ... sexual behaviour you can at least start trying to engage with it.

One of the research participants noted the practical benefits of educating parents and caregivers. Expert number nine stated that training family members and caregivers really makes a difference. She stated that ‘so many families now are coming out and supporting it. She stated that when they started training families some of the families opened up and started supporting the process. One parent said ‘we were just closing our eyes to this, we knew that it was happening. We are already burdened by the stigma and discrimination on disability, so we didn’t want to bring up the whole conversation about intimacy.’

Parents and caregivers also lack adequate information and knowledge on mild intellectual disabilities. Expert number three stated as follows:

from some of my work I learnt that some parents were expecting that their daughter with Down syndrome was not even going to start menstruating. Because to them it’s like this intellectual disability impacts all the other, you know, developmental issues. So when someone, thinks like that, I don’t think they can even get to space of imagining this daughter of theirs you know, being with someone and being a sexually autonomous person.

The negative impact of inadequate knowledge and understanding is further compounded by myths and misconceptions around the sexuality of women with mild intellectual disabilities. Expert number six put it succinctly when she stated that:

There’s those old myths around people with intellectual disability being oversexed or being forever children. So, to do sexuality education is very disruptive of those beliefs which I think raises a lot of anxiety in people so unless educators or parents get a space to explore those beliefs, they remain pretty much unchallenged. And so, if you try and introduce sexuality education without giving people space to sort of unpack some of those feelings and fears they’re gonna be resistant and they’ll just sort of maybe do the stuff which they think is important, which is abuse protection.

Expert number two stated that families need ‘enormous support’ particularly in the form of ‘space to think and talk about things on a number of levels.’ Therefore, providing education to family members and caregivers is important for dispelling myths and misconceptions around the sexuality of women with mild intellectual disabilities.

Research participants also highlighted that in the same way that parents and care givers need support, support workers also need to receive support. Expert number two highlighted the complexity involved in, for example, a residential care facility supporting women with mild intellectual disabilities to have sexual relationships. For example, support staff would need to be trained and be afforded the opportunity to talk about how to deal with certain situations. Expert number two states that ‘there would be couples not knowing how to keep certain stuff private ... and people would just be so embarrassed about it all.’ Expert number seven stressed

the importance of providing support workers in social care organisations with training to enable them to ‘feel confident’ about supporting someone with a mild intellectual disability in the area of sexual decision-making. Expert number seven highlighted that it is important for support workers to understand how to deliver that support and to understand that they should not teach their own personal values such as the belief that ‘masturbation is dirty.’

Parents, caregivers and support workers all need to receive support in the form of education to build their capacity to provide emotional and relational support to women with mild intellectual disabilities.

Education for parents and caregivers should begin as early as possible

The research participants also stated that parent and caregiver education should begin as early as possible while their daughters are still young. Expert number three explained that an early start is necessary ‘for them to get to a point of accepting and acknowledging the need for support.’ She further explained that:

the earlier it starts the better because if care givers can be taught to think about and handle their children’s sexuality right from when they are little in an age appropriate manner, like we do with any child, it can actually come more naturally to them that okay, now, this person is definitely growing and maturing and we will need to get into this place where we deal with these things.

Educators should adopt a compassionate approach to educating parents and caregivers

Research participants further stated that there is a preferable approach to delivering education to family members and caregivers. Crucially, as expert number three noted, families and caregivers should not be forced to take part in this education. Furthermore, expert number two stated that a ‘top-down approach’ or a human rights approach in which families and caregivers are told that ‘you have got to do this because this is a human right’ is unhelpful and is often met with resistance. Expert number three reported hearing a parent state that ‘they were telling me that it’s my child’s human right to have sex and to, you know, be in love with whoever they want but that doesn’t make sense to me at all. I am the parent, I am the one who should dictate what is acceptable for my child.’ Expert number three concluded that when dealing with parents and caregivers, a compassionate approach is better than a rights approach. Accordingly, expert number three added that there is a need to develop resources that use ‘compassionate approaches and language, acknowledging how difficult it is for the family caregivers, but at the same time, educating them and helping them to acknowledge the need for that kind of support.’ Moreover, expert number three pointed out that caregiver to caregiver education is

best. She stated that ‘I have learnt that caregivers learn better from other caregivers. If there are others who have sort of success stories with their own children who are comfortable with talking about it, I think they could be the best educators for the other care givers.’

3.2.3 Experiential freedom

The third and final type of support that the research participants identified is experiential freedom facilitated through independent living arrangements. The experts who were interviewed highlighted the fact that a person’s living arrangements can either foster or restrict the development of capacity to consent depending on the level of freedom one is afforded within the context of one’s living environment. Expert number three pointed out the importance of exposure and having space and opportunities to meet and socialise with other people in the same age group for the development of capacity to consent to sexual intercourse. One’s living arrangements have a bearing on the level of exposure that one has. Expert number six explained this by stating that ‘their living arrangements will affect their experience of privacy and will affect perhaps the amount of freedom they have, the amount of risk or the amount of experience in their daily life. That will shift depending on the living arrangements.’ The research participants highlighted the fact that generally, the family home environment tends to be more restrictive compared to the group home setting in which the women with mild intellectual disabilities live in supported environments with support workers. Expert number seven noted that women with mild intellectual disabilities who live in group homes tend to get a bit more sexuality education than women who live at home with their families. This is because group homes sometimes allow organisations to come in and conduct some training on this issue. In contrast, families may not be willing to discuss sexuality matters with their daughters with mild intellectual disabilities. Expert number three explained that ‘the whole issue of sexuality itself, being one that is wrought with taboos and all those things, it’s not in every family where people will talk openly about sex. So, I definitely think that the family set up will limit the amount of support that they can get.’ Expert number three also noted that those who live at home with parents do not have as many opportunities to socialise as those who live in group homes with group home managers. Expert number three added that it is not easy for parents to ‘let go’ and allow their adult daughters with mild intellectual disabilities to explore their sexuality. However, the group home setting is not without its challenges. Expert number seven stated that ‘a shared living environment sometimes can be very detrimental to relationships.’ For example, expert number seven stated that ‘I have heard of people being stopped having their partner around because it causes tension among the other people.’ Expert number seven added that

sometimes it's the environments themselves that can be problematic. The rooms in care homes are often small with single beds that are not big enough for two people. Moreover, support workers' attitudes can also be a hindrance. Expert number seven stated that 'I heard about one support worker saying they didn't want someone having sex in the room, next to them in case they heard it and I was like, but it is their home, surely we should just ask them to be quiet and as we would in their own home.'

The research participants opined that independent living can be a potent form of support for sexual decision-making. Expert number three stated that 'if there was a way that our society can get to a point where these people are given options for independent living and are well looked after and supported outside the family home, I think it will make a big difference in that area.' She added that 'any form of ... out of home supported living, I think will enable them to get more support in that area.'

4. Conclusion

The research found that there is a correlation between one's capacity to consent to sexual intercourse and one's knowledge about sexual matters. The more knowledge one has the more likely they are to be deemed as having capacity to consent to sexual intercourse. The converse is true, the less knowledge one has, the more likely they are to be regarded as lacking capacity to consent to sexual intercourse. Because women with mild intellectual disabilities do not receive adequate formal and informal sexuality education, they are unable to build capacity to consent to sexual intercourse. Women with mild intellectual disabilities do not receive adequate sexuality education for a number of reasons. Chief amongst them is the misconception that they inherently lack capacity to consent and therefore, have no need for sexuality education. The misconception that sexuality education exposes women with mild intellectual disabilities to sexual abuse by awakening sexual desires and curiosity in them also contributes to the denial of sexuality education for women with mild intellectual disabilities. Furthermore, women with mild intellectual disabilities are erroneously de-sexualised by being perceived as either asexual beings with no need for sexuality education or oversexed beings whose sexual drive and exposure to sexual material should be curbed. Moreover, sexual relationships involving women with mild intellectual disabilities are generally viewed as negative and dangerous and this explains why sexuality education is withheld from these women. In African culture, discussing sexual matters is taboo and this is a reason why women with mild intellectual disabilities, who are constantly infantilised are prevented from accessing any knowledge on sexual matters. Parents and caregivers often prevent women with mild intellectual disabilities from accessing

sexuality education in an effort to protect them. By so-doing, they act as gatekeepers. Finally, most women with mild intellectual disabilities live in restrictive environments with little or no opportunity to experience sexual relationships. This lack of adequate sexuality education leaves women with mild intellectual disabilities with very little knowledge about sexual matters which results in their being deemed as lacking capacity to consent to sexual intercourse. The research therefore found that women with mild intellectual disabilities are regarded as lacking capacity to consent because they do not receive adequate sexuality education.

Building on the support paradigm, the research identified three main supports necessary to bolster the capacity of women with mild intellectual disabilities to consent to sexual intercourse. The first form of support is the provision of comprehensive and repeated sexuality education. The second form of support is emotional and relational support from family and other care givers. The third and final support is independent living arrangements that provide women with mild intellectual disabilities with the opportunity and freedom to experience intimate sexual relationships.

CHAPTER FIVE

THE ROLE OF POWER IN THE CONSTRUCTION OF THE SEXUALITY AND SEXUAL IDENTITY OF WOMEN WITH MILD DOWN SYNDROME: AN ANALYSIS OF RESEARCH FINDINGS

First the rules are made up and then the teams are chosen. Some people are not allowed to play, they may be sent off into a corner to kick the ball against a wall, or to set up an inferior game with old cans as goal posts. Some take their balls home with them, some stay on to cheer on the sidelines, some greet their exclusion with relief, others with longing, some gang together to set up an alternative scene, some choose at the outset not to play the game...⁸⁶⁸

1. Introduction

The empirical research study outlined in Chapter Four yielded some findings that are crucial to understanding how the sexuality of women with mild Down syndrome has been constructed. These findings are analysed in the present Chapter using Foucault's genealogical theory. For the purposes of this chapter, my analytical framework does not seek to assess the validity of the research findings. Instead, it focuses on the underlying and hidden forces that are responsible for them. The main argument in this chapter is that power is central to the evolution of sexuality and indeed the sexual identity of women with mild Down syndrome. I use Foucault's genealogy of power to explain how sexuality and the sexual identity of women with mild intellectual disabilities have been made.⁸⁶⁹ Genealogy challenges the assumption that any concept is self-evident and has always existed in its current form.⁸⁷⁰ The knowledge that people profess to have about sexuality and the sexual identity of women with mild intellectual disabilities has not always existed but was discursively produced. As Foley puts it, 'people do not come into the social world with *a priori* knowledge of themselves and others. Rather, such knowledge is produced and disseminated via the power/knowledge nexus.'⁸⁷¹ For example, the genealogical analytic explains how we are already socialised into thinking that women with mild Down syndrome are inherently vulnerable. Therefore, the sexuality of women with mild Down syndrome can be understood as a product of relations of power between them and society, particularly, parents and caregivers.

This chapter analyses the key findings from the empirical research study with four objectives in mind. First, to interrogate the significance of the shift from understanding capacity

⁸⁶⁸ Brown (n 54) 137.

⁸⁶⁹ See Chapter Two, section 3 for a detailed discussion of Foucault's genealogy of power.

⁸⁷⁰ Galvin (n 353) 500.

⁸⁷¹ Foley (n 5) 68.

to consent to sexual intercourse as an inherent trait to perceiving it as a function of knowledge about sexual matters. Second, to probe the underlying assumptions behind the de-sexualisation of women with mild intellectual disabilities. Third, to examine the powerful influence that parents and caregivers exert on the sexuality of women with mild Down syndrome. Fourth, to analyse the supports to bolster the capacity of women with mild Down syndrome to consent to sexual intercourse.

The chapter is divided into four sections. The first section contests the conception of sexuality as a natural phenomenon arguing that sexuality is discursively constructed. In the second section, the construction of the sexual identity of women with mild intellectual disabilities is explored. The third section addresses the participation of women with mild intellectual disabilities in relations of power through resistance, mounted in the form of supports. Finally, the fourth section concludes the chapter by summarising its main arguments.

2. Shifting perspectives: The construction of sexuality

The research participants identified a shift that has occurred over time from perceiving capacity to consent to sexual intercourse as an inherent trait to perceiving it as a function of knowledge.⁸⁷² According to the former conception, which is in line with the capacity framework, women with mild Down syndrome lack capacity to consent to sexual intercourse because of their inherent traits, i.e., their disability, whereas the latter conception links the lack of capacity to consent to sexual intercourse to the lack of sufficient and accurate knowledge about sexual matters. The fact that there has been a shift in understanding capacity to consent to sexual intercourse challenges the general assumption that sexuality is an objective concept free from societal influence.⁸⁷³ If sexuality is indeed objective, then presumably, it should remain constant. How then does one explain the shift in understanding capacity to consent to sexual intercourse? The shift raises a fundamental question - what is the basis of our sexuality? Relying on Foucault's conception of power as a productive force capable of producing knowledge, this section addresses the question by interrogating the significance of the shift from understanding capacity to consent to sexual intercourse as an inherent trait to understanding it as a function of knowledge through sexuality education.⁸⁷⁴

⁸⁷² See Chapter Four.

⁸⁷³ Brown (n 54) 130.

⁸⁷⁴ McLaren (n 322) 114.

In contrast with early thinkers who theorised and portrayed sexuality as exclusively natural, sexuality is increasingly being conceptualised as a constructed concept.⁸⁷⁵ Foucault rejects the contention that sexuality is natural, arguing that it is created by a system of discourses and practices that are part of modern society's increasing surveillance, regulation and control of individuals.⁸⁷⁶ The construction of African sexualities, in particular, is rooted in Africa's colonial legacy as exemplified by the coloniality that persists in forms of knowledge about African sexuality. Colonial explorers and missionaries produced the earliest written records of studies on African sexualities in the late 19th century.⁸⁷⁷ This period saw the expansion of colonisation and African sexualities rapidly became the focal point for justifying and legitimising the imperial project – 'to civilise the barbarian and savage natives'.⁸⁷⁸ A clear pattern emerged in the texts and reports compiled by Western explorers and missionaries.⁸⁷⁹ African sexualities were constructed and depicted in a racist manner as primitive and immoral.⁸⁸⁰ African women's sexualities were particularly antithetical to the conservative European social norms.⁸⁸¹ Victorian women, for example, dressed and behaved in a manner that muted and erased their sexuality.⁸⁸² Those who dressed or behaved differently were branded as prostitutes.⁸⁸³ African women were depicted as 'insatiable, amoral, barbaric beings'.⁸⁸⁴ Although a substantial amount of information about African sexuality is present in traditional African systems of knowledge such as, traditional songs, folklore, folk art, dance, clothing, jewellery, body markings etc., this information remains largely secret owing to the fact that these systems of knowledge are considered inferior in comparison to mainstream research.⁸⁸⁵ Coetzee and du Toit argue that sexual violence in South Africa is also part of the colonial legacy.⁸⁸⁶ Writing from a theoretical framework of de-colonial feminist theory, Coetzee and du Toit argue that the logic of coloniality continues to shape subjective sexualities

⁸⁷⁵ Brown (n 54) 130.

⁸⁷⁶ Crowley (n 314) 9.

⁸⁷⁷ S Tamale 'Researching and theorizing sexualities in Africa' in S Correa et al (eds) *Sexuality and Politics: Regional dialogues from the global South* (2016) at 21.

⁸⁷⁸ As above.

⁸⁷⁹ Tamale (n 877) 22.

⁸⁸⁰ As above.

⁸⁸¹ As above.

⁸⁸² As above.

⁸⁸³ As above.

⁸⁸⁴ Tamale (n 877) 23.

⁸⁸⁵ Tamale (n 877) 21.

⁸⁸⁶ A Coetzee & L du Toit 'Facing the sexual demon of colonial power: Decolonising sexual violence in South Africa' (2018) 25(2) *European Journal of Women's Studies* at 216.

as well as unconscious sexual drives and desires.⁸⁸⁷ They contend that sex and race influence colonialism's ongoing legacy.⁸⁸⁸ Knowledge about sexuality also needs to be de-colonised.

It is worth recounting Foucault's explanation of how the Western discourse on sexuality came to be constructed. In the nineteenth and twentieth centuries, there was exponential growth in the discourse on sexuality.⁸⁸⁹ For Foucault, this proliferation of sexuality discourse, did not serve to oppress sexuality, but to construct it.⁸⁹⁰ For instance, the authoritarian discourse on children's sexuality had the effect of sexualising both the infantile body as well as the relation between parent and child rather than repressing sexuality.⁸⁹¹ Similarly, classifications of different perversions led to the construction of sexuality as opposed to its repression.⁸⁹² Moreover, the Catholic Church, which claimed authority concerning its moral teachings, provided knowledge to people on how to behave, to be moral and to care for others and for themselves.⁸⁹³ Departing from these teachings was sin.⁸⁹⁴ People were educated to monitor theirs and well as others' bodies, behaviours, actions, thereby perpetuating and reproducing the authority of the Church's discourse.⁸⁹⁵ This signified the beginning of self-regulation and self-discipline.⁸⁹⁶

Even the idea of the 'natural' is not immune from social influence. What is considered 'natural' at any given time, is in fact the result of power and economic relations and consequently, whatever is created or packaged as 'normal' serves commercial and ideological interests.⁸⁹⁷ Writing about women workers, Rowbotham cautions against taking the word 'natural' at face value, and suggests that 'for the word "natural" ... it is always sensible to read either "conditioned" or "profitable."'⁸⁹⁸ Therefore, sexuality is not an innate human trait that was repressed by conservative Victorian values only to be liberated by liberal values.⁸⁹⁹ Foucault puts it succinctly when he states that '[s]exuality is far more of a positive product of power than power was ever repression of sexuality.'⁹⁰⁰

⁸⁸⁷ As above.

⁸⁸⁸ Coetzee & du Toit (n 886) 216.

⁸⁸⁹ Bielskis (n 317) 80.

⁸⁹⁰ As above.

⁸⁹¹ Mcwhorter (n 332) 42.

⁸⁹² Bielskis (n 317) 80.

⁸⁹³ Crowley (n 314) 9.

⁸⁹⁴ As above.

⁸⁹⁵ As above.

⁸⁹⁶ As above.

⁸⁹⁷ Brown (n 54) 136.

⁸⁹⁸ S Rowbotham *Women's consciousness, man's world* (1973) 84.

⁸⁹⁹ Galvin (n 353) 502.

⁹⁰⁰ Foucault (n 365) 30.

The regulation of sexual behaviour takes place on the basis that there is ‘normal’ sexual intercourse and there are ‘normal’ people.⁹⁰¹ Heterosexual genital intercourse is considered ‘normal’ and acceptable whilst homosexual intercourse is considered ‘abnormal’ and is morally stigmatised.⁹⁰² Sexual intercourse is often perceived as a ‘privilege of the white, heterosexual, young, single, non-disabled person.’⁹⁰³ The idea of people who are not considered ‘normal’ trying to have ‘normal’ sexual intercourse is perceived as problematic.⁹⁰⁴ Indeed the eugenics movement attempted to prevent people who are not ‘normal’ – people with intellectual disabilities – from having ‘normal’ sexual intercourse and procreating because it was feared that they would birth children who are not ‘normal’ like them and increase ‘their kind’ in the population.⁹⁰⁵ For women with mild intellectual disabilities, both their female bodies and their intellectually disabled minds are devalued as deviant and inferior.⁹⁰⁶ This is why women with mild intellectual disabilities constantly struggle to assert their sexuality in the face of these societal barriers.⁹⁰⁷

This normalisation process is problematic because there is no one ‘normal’ sexuality and there are no ‘normal’ people – only a diverse humanity endowed with diverse interests and capabilities.⁹⁰⁸ There are in fact many sexualities rather than a single unified and whole sexuality.⁹⁰⁹ For example, there are class sexualities, sexualities that are specific to gender and race.⁹¹⁰ In relation to women with mild intellectual disabilities, it is worth quoting Brown who explains it succinctly as follows:

There are sexualities born out of institutionalisation, and sexualities which are allowed to emerge in group homes. There are sexualities which are shaped by the fact that many adults with learning disabilities do not leave their parental home and there are sexualities which are coloured by being on the receiving end of personal care into adolescence and adulthood. There are sexualities which feed on abuse and the sexualisation of punishment and violence and there are sexualities validated by respect for peers and support from advocates.⁹¹¹

⁹⁰¹ Brown (n 54) 135.

⁹⁰² Brown (n 54) 132.

⁹⁰³ Esmail et al (n 87) 1151.

⁹⁰⁴ Brown (n 54) 135.

⁹⁰⁵ As above.

⁹⁰⁶ Esmail et al (n 87) 1151.

⁹⁰⁷ Brown (n 54) 134.

⁹⁰⁸ Brown (n 54) 135.

⁹⁰⁹ Weeks (n 96) 41.

⁹¹⁰ As above.

⁹¹¹ Brown (n 54) 134.

Moreover, when one considers the origins of definitions of ‘normal’ it becomes apparent that normalisation is a product of power relations.⁹¹² One interest group may have the power to define values at any given point in history.⁹¹³ Consider for example the media’s creation of the image of ‘normal’ women and their bodies.⁹¹⁴ The image of the ‘normal’ woman propagated by the media is that of a petite slim figure that is touched up.⁹¹⁵ Most people look to media images for reflections of themselves and their society and are presented with a touched up picture of ‘normality.’⁹¹⁶ In reality, most women are bigger, older and a completely different shape from that which is portrayed in media images.⁹¹⁷ Feminists have rightly argued that what is considered ‘normal’ is in fact a distortion of reality.⁹¹⁸ Moreover, women with mild Down syndrome whose disability is visible are usually absent from these pictures altogether reinforcing the idea that they are not ‘normal.’⁹¹⁹ The process of normalisation creates boundaries that divide those who are considered sexy from the unsexy, the desirable from the undesirable.⁹²⁰ This results in a stratified society that values certain characteristics over others thereby defining the level of love, respect and self-esteem one enjoys.⁹²¹

The power relations exemplified in the process of normalisation involve the establishment of rules and values about sexuality. These power relations result in the constitution of a field of knowledge about the sexuality of women with mild intellectual disabilities.⁹²² Power creates a discourse of sexuality that simultaneously controls sexual behaviour and forms it.⁹²³ Sexuality can therefore, be understood as a product of Foucault’s model of power, which conceives of positive and productive power.⁹²⁴ Recalling the game analogy quoted at the beginning of this chapter, the construction of sexuality is in fact the making up of the rules of the ‘game.’

Examining sexuality through a genealogical lens illuminates the influence of social forces and relations of power on sexuality that were previously obscured by the conception of sexuality as a ‘natural’ concept. Sexuality is discursively produced over time through relations

⁹¹² Bielskis (n 317) 80.

⁹¹³ Brown (n 54) 135.

⁹¹⁴ As above.

⁹¹⁵ Brown (n 54) 136.

⁹¹⁶ As above.

⁹¹⁷ Brown (n 54) 135.

⁹¹⁸ Brown (n 54) 136.

⁹¹⁹ As above. See also Foley (n 5) 4.

⁹²⁰ Galvin (n 353) 503.

⁹²¹ As above.

⁹²² Foucault (n 77) 27.

⁹²³ Bielskis (n 317) 80.

⁹²⁴ McLaren (n 322) 114.

of power. The construction of sexuality is not a single event that occurred in the past but is a continuous process.⁹²⁵ This explains the shift in understanding capacity to consent that was noted by the research participants. Writing about sexuality, Weeks contends that ‘far from being the most important natural element in social life, the most resistant to cultural moulding, it is perhaps one of the most susceptible to organisation.’⁹²⁶

3. The construction of sexual subjects

The research participants identified and challenged the trend of de-sexualising women with mild intellectual disabilities.⁹²⁷ A number of misconceptions about the sexuality of women with mild intellectual disabilities fuel their de-sexualisation. The first misconception is that, due to their disability, they are infantile.⁹²⁸ Consequently, women with mild intellectual disabilities are perceived as asexual.⁹²⁹ The second misconception is that women with mild intellectual disabilities are hypersexual.⁹³⁰ Although these misconceptions are contradictory, positioning women with mild intellectual disabilities as asexual and hypersexual, they work in concert to de-sexualise them. If women with mild intellectual disabilities are infantile and asexual, then their engagement in sexual activity is grossly inappropriate. Similarly, if they are hypersexual, then their sexuality needs to be curbed and controlled for their own ‘protection’ and that of others. Though contradictory, these misconceptions are both premised on the idea that the sexuality of women with mild intellectual disabilities is rooted in their disability. In other words, their disability makes them infantile, asexual and hypersexual beings and can be likened to conceptions of vulnerability as an inherent trait. This conception relies on a specific vision of the intellectually disabled subject – one that is incapable of sexual agency due to disability. It also relies on the underlying assumption that one’s biology determines one’s identity. Before dismissing these misconceptions as archaic and inaccurate, this section examines how they came to exist in the first place. It further explains how modern society constructs subjects. Relying on Foucault’s conception of power as a productive force capable of producing subjects, this section demonstrates that the sexual subject is discursively produced through relations of power. First, the section discusses how society constructs the subject using Foucault’s concept of disciplinary power. Second, the section demonstrates how women with mild intellectual

⁹²⁵ Weeks (n 96) 41.

⁹²⁶ Weeks (n 96) 24.

⁹²⁷ See Chapter Four.

⁹²⁸ As above.

⁹²⁹ As above.

⁹³⁰ As above.

disabilities construct themselves as subjects through relations of power relying specifically on Foucault's bio-power.

3.1 How society constructs the subject

Biological and medical discourses posit that an individual's identity is wholly biologically constructed.⁹³¹ These discourses perceive the body as a 'pre-social, biological basis on which the superstructure of the self and society are founded'⁹³² According to this conception, the identity of women with mild intellectual disabilities is exclusively a product of biology.⁹³³ However, an examination of the emergence of the disabled identity demonstrates *that* identity is in fact constructed as opposed to exclusively biological.

For Ngwena, it is more accurate to think of identities as 'relational' rather than true representations.⁹³⁴ These representations are bound to certain types of knowledge and power.⁹³⁵ 'Truth' is the product of knowledge that is linked to power.⁹³⁶ Representations that are socially constructed through relations of power cumulatively form a 'regime of truth' that in turn dominates and instructs groups of people.⁹³⁷ The knowledge that represents that which is considered 'true' and that which is considered 'false' is socially constructed and is thus 'always in a state of becoming and being.'⁹³⁸ As Ngwena aptly put it, '[w]e never quite finish knowing.'⁹³⁹ Consequently, those with power over us are constantly constructing our identities.⁹⁴⁰ By the same measure, we are also always constructing our own identities. Indeed the knowledge that is used to construct our identities does not exist in a vacuum but is always contextual.⁹⁴¹ It is therefore, impossible to acquire knowledge merely by passively observing what is perceived to be reality.⁹⁴² Rather, knowledge is always a product of conscious and unconscious interaction between the 'source of the knowledge – the primary repository – and the individual or political community that appropriates the knowledge to make it their own –

⁹³¹ C Loeser et al 'Disability and sexuality: Desires and pleasures' (2018) 21(3) *Sexualities* at 258.

⁹³² As above.

⁹³³ A O'Shea & P Frawley 'Gender, sexuality and relationships for young Australian women with intellectual disability' (2020) 35(4) *Disability and Society* at 656.

⁹³⁴ Ngwena (n 106) 41.

⁹³⁵ S Hall 'Cultural identity and diaspora' in J Rutherford (ed) *Identity: Community, culture, difference* (1990) at 225-226. Foucault (n 921) 27.

⁹³⁶ Ngwena (n 106) 41.

⁹³⁷ As above.

⁹³⁸ Ngwena (n 106) 42.

⁹³⁹ As above.

⁹⁴⁰ As above.

⁹⁴¹ As above.

⁹⁴² As above.

the secondary repository.⁹⁴³ Our perception of truth is relative, and our knowledge of the world is ‘situated knowledge.’⁹⁴⁴ Thus, knowledge is the outcome of interactions between persons in a relationship and not driven by forces of nature or the result of hypotheses that have been tested and proven.⁹⁴⁵ Therefore, our perception of the world is not based on empirical truths but on exchanges between persons and social groups, situated in history.⁹⁴⁶

Foucault’s genealogical method disrupts the concepts that we take for granted by searching for turning points in history where new meaning was created.⁹⁴⁷ The turning point in the emergence of the disabled identity, occurred in Western societies during the 18th and 19th centuries at about the time capitalism, positivist science, the administrative state and liberal philosophy came into being.⁹⁴⁸ It was during this period that disability became ‘administrative, medicalised, institutionalised, [and] calibrated.’⁹⁴⁹ Before industrialisation, which brought with it factory production, persons with disabilities were not a socially recognised group and people with varying functional and sensory impairments could take part in productive activities through the provision of accommodations.⁹⁵⁰ However, the subsequent introduction of large-scale factory production required mechanisation and the use of the timetables putting those who lacked the qualities necessary for this kind of labour at a disadvantage.⁹⁵¹ As Marks argues, ‘[m]echanised production required a uniform workforce...and work was not organised to cater for the range of intellectual and bodily differences between people.’⁹⁵² Thereafter, those who could not meet the demands of the modern labour force were termed ‘disabled’.⁹⁵³ Industrialisation therefore, resulted in the construction of the disabled subject indicating that the disabled identity is not exclusively a product of biology. Genealogy therefore shows us *that* the disabled identity is a result of modern power relations.⁹⁵⁴ A close examination of Foucault’s

⁹⁴³ As above.

⁹⁴⁴ As above. KJ Gergen ‘The social constructionist movement in modern psychology’ (1985) 40(3) *American Psychologist* at 266.

⁹⁴⁵ Ngwena (n 106) 42. Gergen (n 944) 266 – 267.

⁹⁴⁶ Ngwena (n 106) 42. Gergen (n 944) 267.

⁹⁴⁷ Galvin (n 353) 500.

⁹⁴⁸ As above.

⁹⁴⁹ As above.

⁹⁵⁰ K Paterson & B Hughes ‘Disabled bodies’ in P Hancock et al (eds) *The body, culture and society: An introduction* (2000) at 36.

⁹⁵¹ Galvin (n 353) 501.

⁹⁵² D Marks *Disability: Controversial debates and psychosocial perspectives* (1999) 80.

⁹⁵³ Galvin (n 353) 501.

⁹⁵⁴ Mcwhorter (n 332) 43.

conception of disciplinary power exemplified in his genealogy of the prison demonstrates *how* modern power constructs the subject.⁹⁵⁵

Foucault's genealogy of the prison demonstrated how this institution produced the prisoner through discourses and practices of power.⁹⁵⁶ Foucault's book, *Discipline and Punish* provides a historical account of the transformation in the exercise of power in 18th and 19th century Western society.⁹⁵⁷ Foucault demonstrates how the penal system changed from utilising violence depicted in the regicide, Damiens' public torture, dismemberment and execution in Paris in 1757, to the more subtle method of using observation, judgement and calculated punishment to discipline individuals with perceived behavioural anomalies.⁹⁵⁸ This method of constant and pervasive supervision and observation was used on young offenders in a reformatory in Paris 80 years after the execution of Damiens.⁹⁵⁹ The shift from feudal forms of power practiced in 1757 to disciplinary power exercised in the 18th century is exemplified in the Panopticon as designed by Jeremy Bentham.⁹⁶⁰ The panopticon is a polygon shaped prison building with twelve sides and a central tower from which the supervisor can observe and monitor the inmates' behaviour while he himself remains unobserved by them.⁹⁶¹ Though never built, the panopticon was designed to transform the inmates' morals by controlling time, space and bodies.⁹⁶² The inmates in the Panopticon did not know when and whether they were actually being watched, causing them to internalise the gaze and in effect surveil themselves.⁹⁶³

Although Foucault examines the prison's organisation and its underlying principles and aims to explain this transformation, *Discipline and Power* is not about the penal system but rather it is about new modalities of regulating, controlling and surveilling modern western society.⁹⁶⁴ These differing styles and practices of social control were the result of changing socio-economic conditions.⁹⁶⁵ The micro-practices employed in disciplinary institutions were responses to the problem of population management that later became the main problem of modern politics.⁹⁶⁶ As such, they were subsequently integrated into global political strategies

⁹⁵⁵ Galvin (n 353) 499. See also Foucault (n 365) 117.

⁹⁵⁶ D Boyarin & EA Castelli 'Introduction: Foucault's "The History of Sexuality": The Fourth Volume, or, a field left fallow for others to till' (2001) 10(3/4) *Journal of the History of Sexuality* at 359.

⁹⁵⁷ Crowley (n 314) 6.

⁹⁵⁸ Crowley (n 314) 7.

⁹⁵⁹ As above.

⁹⁶⁰ As above.

⁹⁶¹ As above.

⁹⁶² As above.

⁹⁶³ Fraser '(n 325) 277.

⁹⁶⁴ Crowley (n 314) 6.

⁹⁶⁵ Crowley (n 314) 7.

⁹⁶⁶ Fraser '(n 325) 277.

in modern times.⁹⁶⁷ This new model of discipline ‘became a model of control for an entire society and applicable to all forms of social governance.’⁹⁶⁸

Modern power, which makes use of disciplinary tactics, is quite different from pre-modern power mechanisms.⁹⁶⁹ The main difference between them is not only that the former is less violent than the latter but that disciplinary tactics cause power to operate continuously.⁹⁷⁰ Pre-modern power mechanisms required the presence of an agent to enforce them and thus operated discontinuously and intermittently.⁹⁷¹ However, modern power does not require such a presence and employs the constraint of uninterrupted and covert visibility.⁹⁷² Modern power is everywhere – even in the bodies, gestures and habits of the targets themselves.⁹⁷³

Foucault describes this micro-practice or technique of power/knowledge as ‘the gaze’.⁹⁷⁴ It involves the organisation of populations in such a way that they can be known, surveilled and controlled by means of visibility.⁹⁷⁵ Foucault describes two types of visibility - synoptic and individualising visibility.⁹⁷⁶ Synoptic visibility was based on architectural innovations that made it possible to obtain an overview of the population.⁹⁷⁷ It is exemplified in Bentham’s panopticon, and in the separation of hospital patients according to their ailments or students in a classroom in accordance with their abilities.⁹⁷⁸ Individualising visibility made detailed observation of individuals and their habits possible.⁹⁷⁹ This visibility constitutes individuals who are objects of inquiry and targets of power.⁹⁸⁰ The gaze was unidirectional in character in that it was only the warden, for example, who could see the inmates, but the inmates could not see the warden.⁹⁸¹ This causes individuals to internalise discipline and surveillance to the point that each individual oversees their own behaviour.⁹⁸² Crowley aptly describes how modern power works as follows:

⁹⁶⁷ As above.

⁹⁶⁸ Crowley (n 314) 7.

⁹⁶⁹ Fraser (n 325) 278.

⁹⁷⁰ Fraser (n 325) 277.

⁹⁷¹ Fraser (n 325) 278.

⁹⁷² As above.

⁹⁷³ As above.

⁹⁷⁴ Fraser (n 325) 277.

⁹⁷⁵ As above.

⁹⁷⁶ As above.

⁹⁷⁷ As above.

⁹⁷⁸ As above.

⁹⁷⁹ As above.

⁹⁸⁰ As above.

⁹⁸¹ As above.

⁹⁸² Crowley (n 314) 8.

Many of our everyday activities are, as in the Panopticon, regulated as much by the *threat* of observation as by *actual* observation, for example, surveillance cameras, police check points, threat of a tax audit, not carrying a licence (failure to be readily identifiable), being caught without car insurance and so on.⁹⁸³

Therefore, disciplinary power functions positively as well as oppressively to shape individuals into particular subjects.⁹⁸⁴

Mungwini demonstrates how Foucault's theory of panopticism functions in indigenous African communities that had no modern technologies of surveillance and yet managed to effect social control and harmony in much the same way that Foucault's panoptic gaze does.⁹⁸⁵ Indigenous African communities utilised the belief in ancestors as a form of social control.⁹⁸⁶ Practices such as respect for elders, the spirit of brotherhood, communal solidarity and belonging, were all based on African spirituality. Belief in ancestors created a panoptic effect resulting in self-surveillance which produced self-discipline and self-monitoring. Mungwini states that 'a belief in the ancestors was a form of social control as the ancestors were believed to demand social harmony in order to continue to protect and bring good fortune on the community.'⁹⁸⁷

The African ideal of community is also in line with Foucault's work. Through the community's ever-present gaze, individuals judge themselves in accordance with what is considered 'normal' in their community in an effort to constitute themselves as members of the community.⁹⁸⁸ The famous aphorism, 'I am because we are and since we are therefore I am', places the individual in a network of relationships and obligations necessary for the formation of personhood.⁹⁸⁹ This 'I-we' relationship, which also encompassed the living dead, provided a normative framework within which relationships between people and with the entire surrounding environment were defined and understood.⁹⁹⁰ Indeed '[e]veryone was a child of the community; a community which played a significant role in the formation of persons.'⁹⁹¹ Individuals remained conscious of the eyes and ears of the community as they proceeded to conduct their daily affairs, bringing about panopticism in traditional African communities.⁹⁹²

⁹⁸³ Crowley (n 314) 10.

⁹⁸⁴ Crowley (n 314) 7.

⁹⁸⁵ Mungwini (n 400) 351.

⁹⁸⁶ Mungwini (n 400) 347.

⁹⁸⁷ As above.

⁹⁸⁸ Mungwini (n 400) 348.

⁹⁸⁹ As above.

⁹⁹⁰ As above.

⁹⁹¹ As above.

⁹⁹² Mungwini (n 400) 348 – 349.

Therefore, through its omnipresent eyes and ears, the community is capable of producing self-discipline and self-regulation in its members.⁹⁹³ Although Foucault wrote from a Western perspective, his genealogical theory is pertinent to Africa and his concept of disciplinary power is useful for understanding how the disabled sexual subject in Africa is constructed.

The subjectification of persons with disabilities becomes clearer when one examines the intersection between sexuality and disability. Historically, the debate about the inclusion of persons with intellectual disabilities in society and the models of care/regulation flowing from them have always had a sexual dimension characterised by the projection onto persons with intellectual disabilities of fears and myths about sexuality.⁹⁹⁴ When disability and sexuality intersect, the person with a disability is marginalised in one of two ways.⁹⁹⁵ They are either characterised as asexual or as perverted (hypersexual).⁹⁹⁶

Various service models flowing from the misconception of persons with intellectual disabilities as either asexual ‘innocents’ or ‘oversexed perverts’, sought to maintain sexual boundaries between persons with intellectual disabilities and persons without disabilities.⁹⁹⁷ The ‘innocence’ models create boundaries by emphasising the need to protect persons with intellectual disabilities from persons without disabilities.⁹⁹⁸ In early times, the imperative of acceptance of persons with disabilities, was predicated on the religious perception of persons with intellectual disabilities as innocent and simple, imbued with the ‘aura of human existence before the Fall from Paradise.’⁹⁹⁹ This idealisation is problematic because it is easy to confuse ignorance with innocence.¹⁰⁰⁰ This double standard is explained in the context of the women’s rights movement as follows:

The idealisation of women is incongruous in a revolutionary feminist movement. It belongs rather to the sentimentalism, which elevates powerless people into innocents. Innocence is impossible when people have never had the choice of becoming corrupt from dominating others.¹⁰⁰¹

⁹⁹³ As above.

⁹⁹⁴ Brown (n 54) 125.

⁹⁹⁵ Galvin (n 353) 502.

⁹⁹⁶ As above.

⁹⁹⁷ Brown (n 54) 125.

⁹⁹⁸ As above.

⁹⁹⁹ T Weighs *Children in need of special care* (1971) 136. See also Brown (n 1) 126.

¹⁰⁰⁰ Brown (n 54) 126.

¹⁰⁰¹ Rowbotham (n 898) 84.

Furthermore, the idealisation of persons with intellectual disabilities as innocents justifies the need for asylum and protection, ideas that are antithetical to empowerment.¹⁰⁰²

The categories of ‘asexual’ or ‘oversexed perverts’ can best be understood in relation to the norm.¹⁰⁰³ Persons with disabilities are often perceived as lacking in the ability to engage in ‘normal’ sexual practices or to incite ‘normal’ sexual desire in others leading to their characterisation as asexual beings.¹⁰⁰⁴ Generally, asexuality is a stereotype, a perception of persons with disabilities as lacking sexual potential or potency.¹⁰⁰⁵ Asexuality is predominantly perceived as a damaging myth imposed on persons with disabilities.¹⁰⁰⁶ Persons with disabilities have been likened to children and have been denied capacity for sexual feeling.¹⁰⁰⁷ Some authors explain that disability and sexuality are erroneously perceived as incompatible, ‘the first automatically precluding the second.’¹⁰⁰⁸ Within the same century, there was a shift from protecting the ‘holy innocents’ from the public to protecting the public from ‘degenerates and perverts.’¹⁰⁰⁹

During the industrial revolution, persons with intellectual disabilities, and people who were poor, unemployed, elderly or otherwise dependent, were blamed for the deterioration of the ‘stock.’¹⁰¹⁰ The culmination of this was the eugenics movement, characterised by segregated female and male institutions built to prevent procreation between people who were deemed as threats to public order.¹⁰¹¹ The ‘degenerate’ models, create boundaries by focusing on the need to protect persons without disabilities from persons with intellectual disabilities.¹⁰¹² Maintaining a sexual identity is considered inconceivable and unacceptable.¹⁰¹³ Where persons with disabilities persist in engaging in sexual activity, their behaviour and desires are construed in terms of deviance.¹⁰¹⁴ The concept of perversion serves to set boundaries around what is considered a desirable identity or way of being.¹⁰¹⁵ Moreover, anyone that finds a person with

¹⁰⁰² Brown (n 54) 126.

¹⁰⁰³ Galvin (n 353) 502.

¹⁰⁰⁴ As above.

¹⁰⁰⁵ T Shakespeare et al *The sexual politics of disability: Untold desire* (1996) 10.

¹⁰⁰⁶ E Kim ‘Asexuality in disability narratives’ (2011) 14(4) *Sexualities* at 480.

¹⁰⁰⁷ Shakespeare et al (n 1005) 10.

¹⁰⁰⁸ CJ O’Toole & JK Bregante ‘Disabled women: The myth of the asexual female’ in SS Klein (ed) *Sex equity and sexuality in education* (1992) at 273.

¹⁰⁰⁹ Brown (n 54) 126.

¹⁰¹⁰ As above.

¹⁰¹¹ As above.

¹⁰¹² Brown (n 54) 125.

¹⁰¹³ Galvin (n 353) 502.

¹⁰¹⁴ As above.

¹⁰¹⁵ Galvin (n 353) 503.

disability attractive is considered a fetishist. In that sense, therefore the concept of perversion constitutes a ‘double bind’ for persons with disabilities.¹⁰¹⁶

These ‘authoritative knowledges’ about intellectual disabilities are so dominant that they appear to represent the whole truth while silencing other knowledges.¹⁰¹⁷ Ultimately, these discourses determine how women with intellectual disabilities are constructed, that is, ‘how they can (and cannot) know themselves and be known by others.’¹⁰¹⁸

The identity of women with mild intellectual disabilities is not the result of their biological makeup. Rather, it is the result of a discursive regime, characterised by dominant and de-sexualising assumptions that women with mild intellectual disabilities are either asexual innocents or hypersexual perverts. Crucially, these misconceptions determine the manner in which society surveils and ultimately constructs the sexual identity of women with mild intellectual disabilities. It is considered inappropriate for these infantile and asexual women to engage in sexual intercourse and it serves the public interest to protect the public from these ‘oversexed perverts.’ Through disciplinary power, women with mild intellectual disabilities discipline themselves and police their own behavior in accordance with these exclusionary social ideologies. By constructing the disabled sexual subject in this manner, modern society engages in the exercise of choosing who will play the ‘game’ and who will be sent home. Society chooses to send women with mild intellectual disabilities home.

3.2 How subjects construct themselves

In *The History of Sexuality: An introduction (vol 1)* Foucault presents his genealogy of sexuality and analyses the changes in internal controls linked to the positive aspect of power.¹⁰¹⁹ This work focuses less on the creation of docile bodies through direct surveillance that is characteristic of disciplinary power and more on how individuals internalise societal norms and practices.¹⁰²⁰ Specifically, Foucault focuses on how people take part in their own subjectification and how they come to recognise themselves as subjects, how they monitor and judge others and themselves in an attempt adapt to societal norms.¹⁰²¹ Foucault therefore, locates the process of subjectification in the subject – in his or her own practices of self-knowledge and self-control.¹⁰²² Relying on Foucault’s conception of bio-power, this section

¹⁰¹⁶ As above.

¹⁰¹⁷ O’Shea & Frawley (n 933) 656.

¹⁰¹⁸ As above.

¹⁰¹⁹ Bevir (n 348) 350.

¹⁰²⁰ Crowley (n 314) 8.

¹⁰²¹ As above.

¹⁰²² Boyarin & Castelli (n 956) 359.

shows how women with mild intellectual disabilities construct themselves through the productive effects of power by internalising the beliefs and attitudes of their parents and caregivers.

The research participants noted that parents and caregivers exert a powerful influence on women with mild intellectual disabilities. The beliefs and attitudes of women with mild intellectual disabilities tend to mirror those of their parents and caregivers.¹⁰²³ This is primarily because women with mild intellectual disabilities depend on their parents and caregivers for care and support throughout life.¹⁰²⁴ They also rely on them for support relating to sexual matters including sexuality education and the provision of opportunities and freedom to engage in intimate relationships.¹⁰²⁵ However, many parents and caregivers have negative views and attitudes towards the sexuality of women with mild intellectual disabilities. Research indicates that attitudes are directly linked to one's level of knowledge and exposure to sexuality education.¹⁰²⁶ Liberal views are associated with higher levels of education.¹⁰²⁷ Conversely, the lack of education, knowledge and exposure to sexuality and disability leads to a narrow understanding of sexuality.¹⁰²⁸ Restricted viewpoints and understanding of sexuality have led to 'misinformation, misconceptions and prejudice both towards, as well as for, individuals ... with a disability.'¹⁰²⁹ Cultural factors and religious beliefs also contribute to the negative beliefs and attitudes about disability and sexuality.¹⁰³⁰ Historically, a large number of services of women with intellectual disabilities have existed and operated under the auspices of religious organisations and religion still has a significant influence on professional caregivers.¹⁰³¹ Regardless of the root cause of the negative attitudes women with mild intellectual disabilities may internalise them. By internalising these negative attitudes and beliefs, women with mild intellectual disabilities engage in a process of constructing their own sexual identities in line with the negative beliefs and perceptions held by their parents and caregivers.

Most parents subscribe to the innocence paradigm, viewing their adult daughters with mild intellectual disabilities as infantile and asexual.¹⁰³² Therefore, they consider it

¹⁰²³ E Healy et al 'Sexuality and personal relationships for people with an intellectual disability. Part I: Service user perspectives' (2009) 53(11) *Journal of Intellectual Disability Research* at 906.

¹⁰²⁴ Brown & Pirtle (n 93) 60.

¹⁰²⁵ Gilmore & Chambers (n 88) 22.

¹⁰²⁶ Esmail (n 87) 1152.

¹⁰²⁷ Gilmore & Chambers (n 88) 23.

¹⁰²⁸ Esmail (n 87) 1154.

¹⁰²⁹ Esmail (n 87) 1152.

¹⁰³⁰ Healy et al (n 1023) 906.

¹⁰³¹ As above.

¹⁰³² Gilmore & Chambers (n 88) 22.

inappropriate for their adult daughters with mild intellectual disabilities to engage in relationships of a sexual nature.¹⁰³³ Flowing from this perception, parents consistently point out that their children are dependent, vulnerable, and have limited capacity for understanding the consequences of sexual activity.¹⁰³⁴ Consequently, parents experience high levels of anxiety and fear about their daughters with mild intellectual disabilities being sexually abused and exploited.¹⁰³⁵ Parents often see their role as that of protector of their innocent and vulnerable daughters with mild intellectual disabilities.¹⁰³⁶ They achieve this protection by suppressing the sexuality of their adult daughters with mild intellectual disabilities.¹⁰³⁷ For instance, parents often withhold information about sexuality fearing that the provision of sexuality education will arouse sexual desire in their adult daughters with mild intellectual disabilities. Without receiving sexuality education from their parents and caregivers, women with mild intellectual disabilities may not obtain it anywhere else, leaving them without sexual agency. Generally, parents' role as sexuality educators is crucial to the sexual development of their children.¹⁰³⁸ Many parents fail to effectively discharge this role and assist their children to reach psychosexual maturity.¹⁰³⁹ Nevertheless, most children eventually achieve this maturity in spite of rather than because of their parents.¹⁰⁴⁰ Therefore, parents of children with intellectual disabilities need not be judged more severely than parents of children without disabilities.¹⁰⁴¹ There is, however, a difference between parents of children with intellectual disabilities and parents of children without disabilities, namely that the former tend to retain control of the lives of their adult children with intellectual disabilities.¹⁰⁴² Women with mild intellectual disabilities may therefore, never have the freedom to obtain sexuality education elsewhere leaving them with little or no capacity to consent to sexual intercourse due to lack of sufficient knowledge. In some cases, parents go further than withholding sexuality education by deliberately misinforming women with mild intellectual disabilities about sexuality in order to

¹⁰³³ As above.

¹⁰³⁴ Werner (n 103) 13.

¹⁰³⁵ M Ballan 'Parents as sexuality educators of their children with developmental disabilities' (2001) 29 *SIECUS Report* at 14.

¹⁰³⁶ Gilmore & Chambers (n 88) 22.

¹⁰³⁷ Ballan (n 1035) 14.

¹⁰³⁸ A Dupras & H Dionne 'The concern of parents regarding the sexuality of their child with a mild intellectual disability' (2014) 23 *Sexologies* at 79.

¹⁰³⁹ A Craft 'Sexuality and mental retardation: A review of the literature' in M Craft & A Craft (eds) *Sex education and counselling for mentally handicapped people* (1983) at 4.

¹⁰⁴⁰ As above.

¹⁰⁴¹ J Lesseliers & G Van Hove 'Barriers to the development of intimate relationships and the expression of sexuality among people with developmental disabilities' (2002) 27(1) *Research and Practice for Persons with Severe Disabilities* at 69.

¹⁰⁴² As above.

discourage them from engaging in sexual activity.¹⁰⁴³ For instance, some women with mild intellectual disabilities believe that sexual intercourse wounds women, and that masturbation causes lesions because this is the information they have received.¹⁰⁴⁴ When women with mild Down syndrome construct a flawed sexual identity by internalising negative perceptions about their inherent vulnerability and dangerous sexuality.

Negativity towards the sexuality of women with mild intellectual disabilities is also evident in the fact that parents fail to prioritise sexuality because they do not consider it a need. In the South African context, research indicates that family caregivers prioritise what they perceive to be the needs of adults with intellectual disabilities over their right to freely express and develop their sexuality.¹⁰⁴⁵ The study by Kahonde and others indicates that in South Africa, parents of adult children with intellectual disabilities perceived as needs only those matters involving their general welfare and safety.¹⁰⁴⁶ They tend to suppress anything that they perceive as a threat to the general well-being of their children with intellectual disabilities and sexuality is viewed as such a threat.¹⁰⁴⁷ The risk of sexual abuse and exploitation makes sexuality a threat to the well-being of women with mild intellectual disabilities.¹⁰⁴⁸ Moreover, few parents see sexuality as an enriching experience for their adult daughters with mild intellectual disabilities.¹⁰⁴⁹ Indeed, many parents consider the sexuality of their daughters with intellectual disability a 'burden' because of the fear that their daughter is vulnerable to sexual abuse and the belief that they are not capable of making independent sexual choices.¹⁰⁵⁰

Professional caregivers in residential services can also exert a powerful influence on women with intellectual disabilities through spoken and unspoken reactions to the women's sexual behavior and aspirations.¹⁰⁵¹ Most professional caregivers have little knowledge and no training on the subject of sexuality.¹⁰⁵² Moreover, institutional policies in residential facilities often do not provide for the sexual aspect of women with intellectual disabilities leaving

¹⁰⁴³ G Di Giulio 'Sexuality and people living with physical or developmental disabilities: A review of key issues' (2003) 12(1) *The Canadian Journal of Human Sexuality* at 58.

¹⁰⁴⁴ G Bazzo et al 'Attitudes of social service providers towards the sexuality of individuals with intellectual disability' (2006) 20 *Journal of Applied Research in Intellectual Disabilities* at 110 – 111.

¹⁰⁴⁵ CK Kahonde et al 'Discourse of needs versus discourse of rights: Family caregivers responding to the sexuality of young South African adults with intellectual disability (2019) 21(3) *Culture, Health and Sexuality* at 282.

¹⁰⁴⁶ Kahonde et al (n 1045) 283.

¹⁰⁴⁷ As above.

¹⁰⁴⁸ As above.

¹⁰⁴⁹ Lesseliers & Van Hove (n 1041) 70.

¹⁰⁵⁰ As above.

¹⁰⁵¹ R McConkey & D Ryan 'Experiences of staff in dealing with client sexuality in services for teenagers and adults with intellectual disability' (2001) 45(1) *Journal of Intellectual Disability Research* at 83.

¹⁰⁵² Bazzo et al (n 1044) 111.

professional care staff to make decisions based on their own personal beliefs about sexuality and disability.¹⁰⁵³ Research indicates that attitudes to sexuality vary amongst professional caregivers. Factors such as staff age, professional qualifications, and religious affiliation have an influence on the attitudes of staff towards client sexuality.¹⁰⁵⁴ Older support staff generally hold more conservative attitudes about the sexuality of persons with disabilities than younger support staff.¹⁰⁵⁵ Therefore, attitudes to sexuality vary amongst the staff and this adds confusion to the already complex issues around sexuality for women with intellectual disabilities as they often find themselves having to constantly adjust to different staff attitudes.¹⁰⁵⁶ In the absence of clear organisational policies about how to handle sexuality matters, staff will rely on their own personal attitudes and beliefs about the sexuality of persons with intellectual disabilities.¹⁰⁵⁷ Professional caregivers have their own ideas about what constitutes a ‘good’ decision, and any decision made by women with intellectual disabilities that does not align with their own ideas is considered illegitimate.¹⁰⁵⁸ For instance, caregivers tend to view displays of affection between two people of the same sex as undesirable and these views are expressed through reacting in a negative and discriminatory manner to such expressions of sexuality.¹⁰⁵⁹ Therefore, for women with mild intellectual disabilities who live in residential services, their sexual lives depend largely on the beliefs, attitudes and actions of the professional caregivers.¹⁰⁶⁰

Some professional caregivers have negative attitudes about sexual activity amongst the residents with intellectual disabilities for a number of reasons including, the fear of unwanted pregnancy, inappropriate sexual behavior.¹⁰⁶¹ Furthermore, professional caregivers may be reluctant to provide sexuality education and permit sexual interactions for ethical and legal reasons.¹⁰⁶² Research indicates that some caregivers are indisposed to permitting freedom for sexual expression because of an ‘unspoken contract’ between the organisation and the parents

¹⁰⁵³ As above.

¹⁰⁵⁴ McConkey & Ryan (n 1051) 84.

¹⁰⁵⁵ Gilmore & Chambers (n 88) 23.

¹⁰⁵⁶ McConkey & Ryan (n 1051) 83.

¹⁰⁵⁷ McConkey & Ryan (n 1051) 84.

¹⁰⁵⁸ Werner (n 103) 13.

¹⁰⁵⁹ A Kramers-Olen ‘Sexuality, intellectual disability and human rights legislation’ (2016) 46(4) *South African Journal of Psychology* at 510. D Abbott ‘Nudge, nudge, wink, wink: Love, sex and gay men with intellectual disabilities – A helping hand or a human right?’ (2013) 57 *Journal of Intellectual Disability Research* at 1079–1087. See also VJ Wilkinson et al “‘As normal as possible’: Sexual identity development in people with intellectual disabilities transitioning to adulthood’ (2015) 33 *Sexuality and Disability* at 93–105.

¹⁰⁶⁰ Bazzo (n 1044) 111.

¹⁰⁶¹ Brown & Pirtle (n 93) 61.

¹⁰⁶² Healy et al (n 1023) 906.

of women with mild intellectual disabilities.¹⁰⁶³ Most residential facilities emphasise their educational, training and habilitation agendas to parents without ever discussing sexuality.¹⁰⁶⁴ Nevertheless, parents expect these facilities to discharge the responsibility of protecting women with mild intellectual disabilities from sexual exploitation and abuse as well as sexual expression.¹⁰⁶⁵ Failure to do so constitutes a breach of the ‘unspoken contract’ between them.¹⁰⁶⁶ Indeed, Brown opines that ‘part of the eugenic agenda is still alive and well in the services that are *supposed to* act as a container and regulator of the sexual behaviour of people with learning disabilities.’¹⁰⁶⁷ Furthermore, professional caregivers fear legal sanctions particularly in situations where the woman’s capacity to consent to sexual intercourse may be in question.¹⁰⁶⁸ Other professional caregivers may not explore sexuality issues for fear of intruding on their client’s privacy.¹⁰⁶⁹ Whatever the reason for the negative attitudes and beliefs, women with mild intellectual disabilities ultimately internalise these negative attitudes leaving them unable to construct a healthy sexual identity.

An equally damaging, but little-known manifestation of negativity towards sexuality is the discursive silence around the sexuality of women with mild intellectual disabilities. In African cultures, in particular, silence is equally as powerful and empowering as speech.¹⁰⁷⁰ One of the findings of the research is that there is a reluctance to discuss the sexuality of women with mild intellectual disabilities. The topic is generally considered private and taboo.¹⁰⁷¹ Even in the family setting, there is little discussion between persons with disabilities and their family members and friends about sexual matters.¹⁰⁷² While parents are concerned about their children’s sexual lives, their desire to avoid the topic of sexuality keeps them from initiating any discussion with their children about the subject.¹⁰⁷³ Similarly, sexuality remains taboo in many residential homes.¹⁰⁷⁴ The topic of sexuality is not discussed except in the form of obscene jokes, casual talk, or in response to specific situations that have arisen and must be addressed.¹⁰⁷⁵ The reluctance to address sexuality and disability transcends the boundaries of

¹⁰⁶³ Brown (n 54) 130.

¹⁰⁶⁴ As above.

¹⁰⁶⁵ As above.

¹⁰⁶⁶ As above.

¹⁰⁶⁷ Brown (n 54) 129 – 130.

¹⁰⁶⁸ Healy et al (n 1023) 906.

¹⁰⁶⁹ As above.

¹⁰⁷⁰ Tamale (n 877) 19.

¹⁰⁷¹ Esmail et al (n 87) 1148.

¹⁰⁷² Esmail et al (n 87) 1152.

¹⁰⁷³ Lesseliers & Van Hove (n 1041) 69.

¹⁰⁷⁴ Lesseliers & Van Hove (n 1041) 70.

¹⁰⁷⁵ As above.

the home and residential settings. Sexual portrayals of women with mild intellectual disabilities are also absent from mass media.¹⁰⁷⁶ Similarly, in formal sexuality education and social conversations, there is no discussion of sexuality and disability creating the alienating illusion that disabled sexuality is non-existent.¹⁰⁷⁷ Even in disability studies, sexuality and disability were peripheral topics.¹⁰⁷⁸ However, over the last two decades or so, there has been greater focus on sexuality in an effort to ‘undermine the power of discursive silence.’¹⁰⁷⁹ Nevertheless, much of the discussion that has taken place historically and currently about sexuality and disability is limited to two specific situations.¹⁰⁸⁰ The first situation is when the sexuality of persons with disabilities is perceived as a threat to others ‘through the purported expression of hyper-sexuality or aggression, or at least as a troubling attribute of individuals perceived (or forced) to be asexual.’¹⁰⁸¹ The second situation is when persons with disabilities, particularly women and children with disabilities, are considered as needing protection from sexual violence, abuse and exploitation.¹⁰⁸² While justifiable because of the high rates of abuse and exploitation, the focus on women and children with disabilities needing protection from sexual violence and abuse has the unintended effect of reinforcing misconceptions about the vulnerability, dependence, sexual passivity and asexuality of women with disabilities.¹⁰⁸³ Sexual rights are seldom discussed and this silence is perhaps fueled by the perception of sexuality as a desire, rather than a need.¹⁰⁸⁴ Therefore, the deafening silence about the sexual rights of women with mild intellectual disabilities still persists.

For Foucault, silences are also important to the production of discourses.¹⁰⁸⁵ Even silence holds power.¹⁰⁸⁶ Schaaf states that the failure to acknowledge disabled sexuality is a way of regulating it.¹⁰⁸⁷ Thus, the silences surrounding disability and sexuality are equally as important to the production and reproduction of normative discourses as the popular images about what are considered acceptable forms of sexuality.¹⁰⁸⁸

¹⁰⁷⁶ Brodwin & Frederick (n 102) 39.

¹⁰⁷⁷ Esmail et al (n 87) 1152.

¹⁰⁷⁸ M Schaaf ‘Negotiating sexuality in the Convention on the Rights of Persons with Disabilities’ (2011) 8(14) *International Journal on Human Rights* at 114.

¹⁰⁷⁹ Schaaf (n 1078) 115.

¹⁰⁸⁰ Schaaf (n 1078) 114.

¹⁰⁸¹ As above.

¹⁰⁸² As above.

¹⁰⁸³ Schaaf (n 1078) 115.

¹⁰⁸⁴ As above.

¹⁰⁸⁵ Galvin (n 353) 502.

¹⁰⁸⁶ Schaaf (n 1078) 114.

¹⁰⁸⁷ As above.

¹⁰⁸⁸ Galvin (n 353) 503.

Parents and professionals continue to struggle to find the right balance between allowing women with mild intellectual disabilities to live independent, fulfilled and self-determined lives and keeping them safe and protected.¹⁰⁸⁹ Most favour safety and protection over independence and self-determination.¹⁰⁹⁰ Although some parents and professionals may recognise the right to sexuality in theory, they struggle with its practical implementation.¹⁰⁹¹ They continue to harbor negative attitudes and beliefs about the sexuality of women with mild intellectual disabilities. The stigma surrounding the sexuality of women with mild intellectual disabilities is evident in the attitudes of parents, caregivers, society at large and through the discursive silence. By inhibiting and restricting the sexuality of women with mild intellectual disabilities, this stigma minimises their sexuality.¹⁰⁹² The impact of this external stigma is that women with mild Down syndrome may internalise societal attitudes and beliefs about their sexuality to such an extent that they begin to see and think of their own sexuality as their parents, caregivers and the rest of society do.¹⁰⁹³ By internalising these negative attitudes and beliefs, these women engage in a process of subjectification. It is through this process of subjectification that the teams are selected.

4. Creating new pathways through resistance

What then shall we conclude in light of the foregoing? If the sexual identity of women with mild intellectual disabilities is discursively produced, and the women themselves internalise the stigma and negative societal attitudes towards their sexuality in such a way that they construct their own subjectivity in line with these attitudes, are they doomed to live without sexual agency throughout their lives? For the research participants, the answer is no - the provision of supports is capable of enabling women with mild intellectual disabilities to build and exercise their capacity to consent to sexual intercourse and enjoy their sexual agency. The power and influence exerted by parents and caregivers on women with mild intellectual disabilities can be transformed into a positive force capable of equipping women with mild intellectual disabilities with the capacity to make sexual decisions. Therefore, the participants suggested supports that essentially reconfigure the relations of power between women with mild intellectual disabilities and their parents and caregivers. The first support recommended by the research participants is the provision of comprehensive sexuality education for women

¹⁰⁸⁹ Lesseliers & Van Hove (n 1041) 70.

¹⁰⁹⁰ As above.

¹⁰⁹¹ As above.

¹⁰⁹² Esmail et al (n 87) 1151.

¹⁰⁹³ As above.

with mild intellectual disabilities. Under Fineman's vulnerability framework, this refers to human assets that are developed primarily through systems that provide education, training, knowledge and experience.¹⁰⁹⁴ The role of parents and caregivers remains integral to this in that not only are they encouraged to provide some of this education, they also need to facilitate attendance at sexuality education programmes conducted by professional sexuality educators. The second support recommended by the research participants is the provision of relational and emotional support. Under Fineman's framework, this refers to social assets and networks from which we draw strength and support such as the family.¹⁰⁹⁵ Essentially, this involves training and educating parents and caregivers to encourage and equip them to provide relational and emotional support to women with mild intellectual disabilities. The third and final support recommended by the research participants is the provision of experiential freedom which is also a social asset. This support essentially involves parents and caregivers altering their behaviour from limiting the opportunities of women with mild intellectual disabilities to experience sexual relationships to providing such opportunities. This section demonstrates that these three broad categories of supports are a form of resistance playing out in relations of power in an attempt to alter the behavioural options of women with mild intellectual disabilities.¹⁰⁹⁶

Before turning to resistance, it is necessary to explain why some people decide not to comply with the rules of the game using the concept of positionality. While it is true that discourses produce sexual subjects, individuals still have the possibility of choice, even if limited, in terms of how to engage with discursive practices.¹⁰⁹⁷ The practice of recognising one's agency and locating oneself in one category as opposed to another, is known as positionality.¹⁰⁹⁸ Positionality is a conceptual tool that recognises the constitutive potential of discourse as well as the place of individuals within the discourse, how they converse with it and the positions they adopt as their own.¹⁰⁹⁹ The ability of individuals to self-reflect means that they are not trapped by a discourse in a particular position, but they can construct their own stories and position themselves within a discourse.¹¹⁰⁰ Positionality 'envisages the

¹⁰⁹⁴ Fineman (n 122) 270. See Chapter Two, section 2 for a detailed discussion of Fineman's vulnerability framework.

¹⁰⁹⁵ Fineman (n 122) 271.

¹⁰⁹⁶ Mcwhorter (n 332) 42.

¹⁰⁹⁷ Ngwena (n 106) 38.

¹⁰⁹⁸ Ngwena (n 106) 38. B Davies & R Harré 'Positioning: The discursive production of selves' (1990) 20 *Journal of the Theory of Social Behaviour* at 46.

¹⁰⁹⁹ Ngwena (n 106) 38.

¹¹⁰⁰ Ngwena (n 106) 38. Davies & Harré (n 1098) 53.

possibility of choice in how we engage with discursive practices in ways that create the possibility of negotiating new positions to make the practices our own and to reflect our individual subjectivities, even in the face of external constraining forces.’¹¹⁰¹ Positionality accounts for the practices of ‘subjective self-constitution.’¹¹⁰²

Hall succinctly explains how, through positionality, individuals can resist an identity ascribed to them by discourse as follows:

The question which remains is whether we require ... a theory of what the mechanisms are by which individuals as subjects identify (or do not identify) with the ‘positions’ to which they are summoned; as well as how they fashion, stylize, produce and ‘perform’ these positions, and why they never do so completely, for once and all time, and some never do, or are in a constant, agonistic process of struggling with, resisting, negotiating and accommodating the normative or regulative rules which they confront and regulate themselves.¹¹⁰³

Positionality produces numerous subjectivities and contradictory discursive practices. Therefore, the sexuality of women with mild intellectual disabilities varies depending on how each individual actor positions themselves within their own discursive practices and those of others.¹¹⁰⁴ In articulating identities, individuals are always ‘positioned historical subject[s]’ as opposed to ‘nameless, neutral disinterested observer[s].’¹¹⁰⁵ Identities and identification are essentially matters of representation occurring in a particular historical context and emanating from specific standpoints.¹¹⁰⁶

Foucault’s concept of resistance also explains how discourses can be altered. According to Foucault, power is an event – a struggle in which everyone attempts to affect others and everyone resists the effects of others on them.¹¹⁰⁷ Power is everywhere and it is impossible to abandon all power relations in the sense of eliminating them altogether, however, people can exercise power through resistance.¹¹⁰⁸ Resistance is therefore an integral part of relations of

¹¹⁰¹ Ngwena (n 106) 38.

¹¹⁰² Ngwena (n 106) 38 – 39.

¹¹⁰³ S Hall ‘Who needs “identity”?’ in J Evans & P Redman (eds) *Identity: A reader* (2000) at 27.

¹¹⁰⁴ Ngwena (n 106) 39.

¹¹⁰⁵ As above.

¹¹⁰⁶ Ngwena (n 106) 39. Hall (n 935) 222.

¹¹⁰⁷ Mcwhorter (n 332) 42.

¹¹⁰⁸ As above.

power.¹¹⁰⁹ Indeed, there can be no power relations without resistance.¹¹¹⁰ For Foucault, this constant micro resistance makes new desirable power relations possible.¹¹¹¹

There is a crucial distinction between relationships of domination and relationships of power.¹¹¹² The main difference between the two types of relationships is the possibility of reversal.¹¹¹³ Relationships of domination are irreversible static power relations whereas relationships of power are characterised by the possibility of reversal.¹¹¹⁴ In relationships of domination, reversal is only possible through revolution or collective resistance, whereas, in Foucault's relationships of power, resistance is not only possible, but is an integral part of relations of power.¹¹¹⁵ As McLaren rightly points out, '[p]ower is always relational and always subject to reversal.'¹¹¹⁶ The relationship between women with mild intellectual disabilities and their parents and caregivers, is a relationship of power in which resistance is possible. Indeed, the attempt to reconfigure the dynamics of the relations between women with mild intellectual disabilities and their parents and caregivers through supports, is an exercise, a relation, an event of power as shown below.¹¹¹⁷

The first form of support recommended by the research participants is the provision of comprehensive sexuality education to women with mild intellectual disabilities. It is trite that sexuality education has many benefits. Studies show that there is a direct correlation between improvements in knowledge about sexuality matters and improvements in the ability to make sexual decisions.¹¹¹⁸ Appropriate educational intervention can improve the decision-making capacity of women with mild intellectual disabilities.¹¹¹⁹ Individualised one-to-one educational intervention has been proved to be particularly effective.¹¹²⁰ However, research shows that most women with mild intellectual disabilities do not receive sexuality education. Moreover, existing programmes are not accessible for this population because the programmes are

¹¹⁰⁹ M Foucault *Foucault Reader* (1986) 46.

¹¹¹⁰ As above.

¹¹¹¹ Bielskis (n 317) 82.

¹¹¹² McLaren (n 322) 116.

¹¹¹³ As above.

¹¹¹⁴ As above.

¹¹¹⁵ As above.

¹¹¹⁶ McLaren (n 322) 114.

¹¹¹⁷ Mcwhorter (n 332) 42.

¹¹¹⁸ E Dukes & BE McGuire 'Enhancing capacity to make sexuality-related decisions in people with an intellectual disability' (2009) 53(8) *Journal of Intellectual Disability Research* at 732.

¹¹¹⁹ Dukes & McGuire (n 1118) 734.

¹¹²⁰ Dukes & McGuire (n 1118) 733.

designed without women with mild intellectual disabilities in mind.¹¹²¹ This results in their exclusion from sexuality training programmes.¹¹²² The few instances in which women with mild intellectual disabilities are provided with sexuality education, occur reactively when the women are found to have become sexually active.¹¹²³ Very few sexuality education programmes proactively include women with mild intellectual disabilities.¹¹²⁴ This reactive approach increases the likelihood that a large number of women with mild intellectual disabilities will remain both uninformed as well as misinformed.¹¹²⁵ The lack of sexuality education leaves women with mild intellectual disabilities without a proper understanding of consent to sexual intercourse, which in turn makes it difficult for them to distinguish between healthy and abusive relationships leaving them highly susceptible to sexual abuse.¹¹²⁶ Furthermore, it prevents women with mild intellectual disabilities from gaining the capacity to consent to sexual relations thereby impeding the establishment of sexual relationships.¹¹²⁷ The lack of sexuality education is therefore a way in which women with mild intellectual disabilities are excluded from playing the sexual the ‘game’ and sent home.

In light of the fact that women with mild intellectual disabilities have been sent home it is crucial to determine whether the goal of sexuality education should be to teach them the rules of the main league so they can ultimately play the ‘normal’ game?¹¹²⁸ Or should the goal be to help them design their own rules and set up a game for those who have been excluded?¹¹²⁹ In other words, should sexuality education seek to teach women with mild intellectual disabilities to behave in accordance with the mainstream rules about sexuality? Or should sexuality education teach them the survival skills necessary for them to define their own sexual identity and realise their sexual agency in spite of the exclusionary mainstream rules?¹¹³⁰ It is likely that even if women with mild intellectual disabilities sought to rejoin play, they may be sent home again.¹¹³¹ Moreover, people are not the same and they may not want to play the same game.¹¹³² Therefore, it is important not to premise sexuality education on what is considered

¹¹²¹ J Bornman & L Rathbone ‘A sexuality and relationship training program for women with intellectual disabilities: A social story approach’ (2016) 34 *Sexuality and Disability* at 270.

¹¹²² As above.

¹¹²³ As above.

¹¹²⁴ As above.

¹¹²⁵ As above.

¹¹²⁶ Healy et al (n 1023) 906.

¹¹²⁷ As above.

¹¹²⁸ Brown (n 54) 137.

¹¹²⁹ As above.

¹¹³⁰ As above.

¹¹³¹ As above.

¹¹³² As above.

‘normal’ but to aim to help women with mild intellectual disabilities to find a sexuality that expresses who they are.¹¹³³ New approaches to sexuality education are required. The discourse around asexuality may help clarify this point.

Through the self-advocacy movement, women with mild intellectual disabilities are beginning to define their own unique social and sexual identity.¹¹³⁴ Historically, women with mild intellectual disabilities have been subjected to the misconception that they are asexual. The term ‘asexuality’ in relation to persons with disabilities first appeared in the 1960s and bore very negative connotations.¹¹³⁵ In an effort to discredit this misconception, disability rights activists claim that all persons with disabilities *are* sexual.¹¹³⁶ Although disability rights activists generally acknowledge that some persons with disabilities live an asexual lifestyle, this is perceived as a demonstration of internalised rejection and self-fulfilling prophecy.¹¹³⁷ An autistic blogger who describes herself as asexual explained the difficulty in being accepted in the disability community as follows: ‘my saying I am asexual in the disabled community can be interpreted as my affirming and reinforcing those stereotypes, which tends to make people rather angry.’¹¹³⁸ However, in recent years, asexuality has emerged as an identity.¹¹³⁹ Donna Williams, a woman with autism who self identifies as asexual, writes in her memoir *Somebody Somewhere* ‘I have no interest. I’m not holding myself back from anything. I think it is more normal to admit a lack of feelings and interest than to pretend to have them.’¹¹⁴⁰ She adds that ‘[a]sexuality has nothing to do with frigility or being celibate or being gay.’¹¹⁴¹ Although it is right for disability rights activists to challenge the pervasive and harmful perception that all persons with disabilities are asexual, it may not be appropriate to make the universalising claim that all persons with disabilities are sexual.¹¹⁴² This kind of generalisation assumes that asexuality is unnatural and denies the possibility of recognising asexuality as a positive sexual identity that some women with intellectual disabilities can legitimately choose for themselves.¹¹⁴³ Sexuality education should therefore, seek to allow women with mild

¹¹³³ Brown (n 54) 138.

¹¹³⁴ Brown (n 54) 137.

¹¹³⁵ R Garland-Thomson *Extraordinary bodies: Figuring physical disability in American culture and literature* (1997). See also Kim (n 1005) 481.

¹¹³⁶ Kim (n 1006) 481.

¹¹³⁷ Kim (n 1006) 482.

¹¹³⁸ Kaz ‘Disability and asexuality’ <http://disabledfeminists.com/2009/11/06/guest-post-disability-and-asexuality/> (accessed 2 January 2022).

¹¹³⁹ Kim (n 1006) 480.

¹¹⁴⁰ D Williams *Somebody somewhere* (1994) 217.

¹¹⁴¹ As above.

¹¹⁴² Kim (n 1006) 482.

¹¹⁴³ As above.

intellectual disabilities to define their own sexual identity, rather than seek to teach them the rules of the ‘normal’ game in order for them to rejoin play. In this manner, it is a form of resistance.

The second type of support that the research participants recommended is emotional and relational support to bolster the capacity of women with mild intellectual disabilities to consent to sexual intercourse. This kind of support can be provided through the creation of support networks, which provide women with mild intellectual disabilities with the opportunity and freedom to express themselves.¹¹⁴⁴ It may be helpful to think of people living in various communities rather than living in the community.¹¹⁴⁵ For instance, people can belong to various supportive networks such as women’s groups, men’s groups, gay men’s groups, lesbian women’s groups, groups for survivors of sexual assault and groups for older women.¹¹⁴⁶ In recent years, self-advocacy groups have gained popularity. They provide members with the opportunity to share their ideas and feelings thereby empowering women with mild intellectual disabilities to make their own decisions and communicate these to others.¹¹⁴⁷ Belonging to one or more of these support groups is important for obtaining relational and emotional support.

Professional caregivers are encouraged to engage with generic organisations that provide sexuality counselling in order to provide better support to women with mild intellectual disabilities.¹¹⁴⁸ Instead of interacting with these organisations merely for the purposes of obtaining services such as contraception or STD clinics or dealing with a crisis such as an assault as they do now, professional caregivers should also collaborate with them to provide sexuality education to women with mild intellectual disabilities.¹¹⁴⁹

Collaboration between parents and professional caregivers is also encouraged.¹¹⁵⁰ Specifically, professional caregivers are encouraged to engage with parents in order to explore ways of supporting women with intellectual disabilities within their own cultural and religious tradition and not challenging the family’s sexual values.¹¹⁵¹

Parents and caregivers play a key role in the provision of the various relational and emotional supports. Depending on their personal attitudes and beliefs about the sexuality of

¹¹⁴⁴ Brown (n 54) 140.

¹¹⁴⁵ As above.

¹¹⁴⁶ As above.

¹¹⁴⁷ Werner (n 103) 13.

¹¹⁴⁸ Brown (n 54) 139.

¹¹⁴⁹ As above.

¹¹⁵⁰ As above.

¹¹⁵¹ As above.

women with mild intellectual disabilities, parents and caregivers can either impede or enable the provision of emotional and relational support. As shown above, most parents and caregivers harbour negative attitudes towards the sexuality of women with mild intellectual disabilities. However, research indicates that attitudes towards a stigmatised group such as persons with disabilities can be altered through education.¹¹⁵² Accordingly, the participants recommended educating parents and caregivers in order to change their perspective and persuade them to provide women with mild intellectual disabilities with the support they need.¹¹⁵³ Doing so is a form of exercise of power through resistance.

The third type of support recommended by the research participants is providing women with mild intellectual disabilities with experiential freedom to enter into and explore sexual relationships. Of note are two approaches that have been put forward. The first is Brown's 'active support model', which involves taking proactive steps to counter loneliness and isolation by helping individuals to meet potential partners and to maintain existing contacts.¹¹⁵⁴ This model marries people's aspirations to their knowledge and understanding.¹¹⁵⁵ Similarly, Foley suggests the use of 'facilitated sex' to enable persons with intellectual disabilities to experience sexual intercourse.¹¹⁵⁶ Without engaging in a debate about the merits and de-merits of these approaches, it is submitted that for such approaches to work, a significant attitudinal shift for parents and caregivers is required. Residential facilities in particular would need to be less rigid and offer a wider range of options.¹¹⁵⁷ These include having the option to choose who to live with (when they do not like the person they are living with) and living as couples.¹¹⁵⁸ These measures are examples of attempting to effect change and alter the range of behavioural options for women with mild intellectual disabilities through resistance.

The three broad categories of supports recommended by the research participants essentially involve reconfiguring the attitudes and beliefs of parents and caregivers about the sexuality of women with mild intellectual disabilities. They are in fact ways of resisting the discourses and practices that constitute the subject. Through resistance, new avenues of behaviour and new sexual identities are possible. Through resistance, women with mild

¹¹⁵² Esmail et al (n 87) 1152.

¹¹⁵³ DS Evans et al 'Sexuality and personal relationships for people with an intellectual disability. Part II: Staff and family carer perspectives' (2009) 53(11) *Journal of Intellectual Disability Research* at 914.

¹¹⁵⁴ Brown (n 54) 139.

¹¹⁵⁵ As above.

¹¹⁵⁶ Foley (n 5) 131.

¹¹⁵⁷ Brown (n 54) 140.

¹¹⁵⁸ As above.

intellectual disabilities can reinvent the rules of the game rather than play the game using everyone else's rules. Therefore, since knowledge, and indeed the disabled sexual subject are discursively produced, they can also be discursively altered.

5. Conclusion

The primary purpose of this chapter was to analyse the key research findings using Foucault's genealogical method as a theoretical framework. The shift from understanding capacity to consent to sexual intercourse as an inherent trait to understanding it as a function of knowledge highlights the influence of social factors and relations of power in constructing sexuality. Contrary to earlier beliefs, sexuality is not a natural concept but a construct of discourses and relations of power. By constructing sexuality in line with dominant societal values, the rules of the game are made up. Similarly, the sexual subject is not exclusively a product of biology as biological and medical discourses posit. The sexual subject is constructed through the process of subjectification. Modern society constructs the disabled sexual subject through pervasive de-sexualising assumptions about women with mild intellectual disabilities, such as the assumption that they are 'asexual innocents' or 'hypersexual perverts.' Through disciplinary power, women with mild intellectual disabilities surveil and discipline themselves in line with these societal ideologies. This is how players are chosen to either play the sexual game or go home. Foucault's conception of bio-power illuminates how parents' and caregivers' negative attitudes and beliefs about the sexuality of women with mild intellectual disabilities exerts a powerful influence by causing them to internalise these beliefs and construct their own sexual identity in a negative and exclusionary manner. The teams are selected through the process of subjectification. Genealogy therefore, shows that both sexuality and sexual subjects are constructed through discourses and power relations. However, this does not mean that women with mild intellectual disabilities should resign to a life without sexual agency. Implicit within Foucault's conception of power is the concept of resistance through which people can create a new reality and indeed new identities for themselves. The supports recommended by the research participants are all forms of resistance in that they are intended to reconfigure the negative attitudes of parents and caregivers, which have been largely responsible for the failure of women with mild intellectual disabilities to bolster their capacity to consent to sexual intercourse and enter into sexual relationships. This is an attempt to use the influence exerted by parents and caregivers in a positive and empowering way. Through these supports women with mild intellectual disabilities can reinvent the rules of the game and be empowered to enjoy their sexual agency. Foucault's genealogical method therefore provided a means to understand

how sexuality and the sexual identity of women with mild intellectual disabilities came to exist. Moreover, it also provides a means to understand how to effect change. For if sexuality and indeed the sexual identity of women with mild intellectual disabilities is discursively produced, then they can also be discursively altered. Foucault's conception of power is therefore central to sexuality, sexual identity and provision of supports for women with mild intellectual disabilities.

CHAPTER SIX

CONCLUSION

The central challenge then, is how to define the risks and stakes so as to reconcile the state's legitimate interests in protection with the interests in sexual agency of people with disabilities and their potential partners.¹¹⁵⁹

1. Introduction

This study sought to interrogate the relationship between sexual autonomy and the concept of capacity to consent to sexual intercourse by women with mild Down syndrome. As a starting point, the study examined the 'capacity framework' deployed by South African courts, in the context of rape trials, to determine whether women with 'mental disabilities,' which include mild Down syndrome, have the capacity to consent to sexual intercourse. The 'capacity framework' makes judgements about who has a right to express themselves sexually.¹¹⁶⁰ In essence, the law imagines a particular sexual being who is not intellectually disabled, resulting in the de-sexualisation of women with mild Down syndrome.¹¹⁶¹ Crucially, the de-sexualisation of this population sub-group transcends legal boundaries and is a broader societal practice that has merely been institutionalised in the criminal law concept of capacity to consent to sexual intercourse.

The universality of sexuality has always been contentious with value judgements being made about who is sexually autonomous.¹¹⁶² In contrast with persons without disabilities, the sexual autonomy of women with mild Down syndrome is not a matter of threshold where they go from not being autonomous to being autonomous by virtue of reaching a particular age.¹¹⁶³ Women with mild Down syndrome are generally regarded as lacking sexual autonomy due to the nature of their disability.¹¹⁶⁴

Throughout history, persons with intellectual disabilities have always been considered 'mentally deficient' as exemplified in some of the terminology that has been used to refer to them, including 'mental retardation.'¹¹⁶⁵ Historically, intellectual disability was seen as an

¹¹⁵⁹ Harris (n 1) 496 – 497.

¹¹⁶⁰ See Chapter One, section 2.

¹¹⁶¹ As above.

¹¹⁶² O'Neill (n 2) 173.

¹¹⁶³ Foley (n 5) 39. See Chapter One section 1.

¹¹⁶⁴ As above.

¹¹⁶⁵ Wehmeyer et al (n 7) 312. See Chapter One section 1.1.

inherent trait with the loci of the defect being the mind.¹¹⁶⁶ This perception is rapidly changing with the introduction of the social model that views disability as the result of the interaction between impairment and external social factors.¹¹⁶⁷ In response to the conceptual shifts relating to disability generally, from the medical to the social model, the AAIDD, changed the terminology from ‘mental retardation’ to ‘intellectual disability’ in 1992.¹¹⁶⁸ This was not simply a change in terminology, but a change in the constitutive definition of intellectual disability.¹¹⁶⁹ There was a fundamental difference in the underlying concepts between the terms ‘mental retardation’ and ‘intellectual disability’ with the former regarding the disability as a ‘defect’ inherent within the person and the latter recognising disability as an interactional process between a person with impairment and disabling social factors.¹¹⁷⁰

The understanding of disability as an inherent trait has had a significant influence on how the sexuality of women with mild Down syndrome is perceived. For centuries, women with mild Down syndrome have been de-sexualised because of their disability.¹¹⁷¹ One need only consider some common myths and misconceptions about their sexuality in order to appreciate the gravity of this paradigm. For example, women with mild intellectual disabilities are, because of their disability, wrongly believed to be asexual beings with no need for sexual autonomy.¹¹⁷² They are also perceived as inherently hypersexual beings with a heightened sexual appetite that needs to be curbed at all times.¹¹⁷³ Moreover, women with mild Down syndrome are considered as children, for whom it is inappropriate to enter into sexual relationships, regardless of their biological age. Cumulatively, these misconceptions have resulted in the cultural practice of de-sexualising women with mild Down syndrome. By considering women with ‘mental disabilities’, which include mild Down syndrome, the Sexual Offences Act in South Africa replicates and is complicit in the cultural de-sexualisation of this population sub-group.¹¹⁷⁴ This makes the criminal law, in this context, an instrument of cultural expression.

Though replicated in the criminal law through the ‘capacity framework, the de-sexualisation of women with mild Down syndrome, is not a legal problem that can be

¹¹⁶⁶ As above.

¹¹⁶⁷ Barnes et al (n 11) 163. See also Traustadottir (n 11) 9. See Chapter One section 1.1.

¹¹⁶⁸ Wehmeyer et al (n 7) 313. See Chapter One section 1.1.

¹¹⁶⁹ Thompson et al (n 26) 135. See Chapter One section 1.1.

¹¹⁷⁰ Wehmeyer (n 7) 314.

¹¹⁷¹ See Chapter One, section 1.2.

¹¹⁷² As above.

¹¹⁷³ As above.

¹¹⁷⁴ See Chapter One, section 1.3.

understood by merely critiquing the law, nor can it be addressed only by amending the law.¹¹⁷⁵ Even the application of international human rights law principles, such as those found in the CRPD, cannot provide a robust conceptual framework, capable of interrogating the complex societal structures and dynamics that have resulted in the widespread de-sexualisation of women with mild Down syndrome.¹¹⁷⁶ At the heart of the problem are complex and deep-seated relations of power that have shaped and influenced the production of knowledge about the sexuality of women with mild Down syndrome as well as their sexual identity.¹¹⁷⁷ Therefore, this research study was concerned with interrogating the societal systems, institutions and practices that have led to the denial of the sexual autonomy of women with mild Down syndrome through the concept of capacity to consent to sexual intercourse.

In order to achieve this goal, this research study deployed three theoretical strands to supplement disability and human rights law principles.¹¹⁷⁸ These include, Martha Fineman's vulnerability thesis, Michel Foucault's genealogical theory, and de-colonial theory, each complementing the other by approaching the subject from a different vantage points.¹¹⁷⁹ Fineman's vulnerability framework contests traditional notions of vulnerability as an inherent trait, which have been used as a justification for limiting the sexual agency of women with mild Down syndrome for their own 'protection.'¹¹⁸⁰ It illuminates the role of societal factors in the disablement of the sexual autonomy of women with mild Down syndrome.¹¹⁸¹ However, it does not explain how the sexual identity and the sexuality of women with mild Down syndrome are constructed, making it necessary to rely on a second theoretical framework that addresses this point.¹¹⁸² Foucault's genealogical theory explains how configurations of power are responsible for the historical de-sexualisation of women with mild Down syndrome.¹¹⁸³ However, it does not show us how to formulate empowering alternatives for the future.¹¹⁸⁴ De-colonial theory complements genealogical theory in that respect. De-colonial theory emphasises the need to prioritise African voices, narratives and perspectives in the formulation

¹¹⁷⁵ As above.

¹¹⁷⁶ See Chapter Two, section 1.

¹¹⁷⁷ See Chapter One, section 1.3.

¹¹⁷⁸ See Chapter Two.

¹¹⁷⁹ See Chapter Two section 1.

¹¹⁸⁰ As above.

¹¹⁸¹ See Chapter Two section 2.

¹¹⁸² As above.

¹¹⁸³ See Chapter Two section 3.

¹¹⁸⁴ As above.

of solutions to problems that are rooted in coloniality.¹¹⁸⁵ Each of these theories were applied at different points throughout the research study.

The main research question that this study sought to address is how the conceptual boundaries of capacity to consent to sexual intercourse can be shifted to allow for the recognition of the sexual autonomy of women with mild Down syndrome. This question was addressed from four vantage points. First, Chapter Two explained the conceptual frameworks required to critique and re-conceptualise capacity to consent to sexual intercourse. Second, the adverse effect of South Africa's 'capacity framework' was demonstrated in Chapter Three. Third, the alternative way of conceptualising capacity to consent in an empowering manner through the application of Fineman's vulnerability framework and the support paradigm was addressed in Chapter Three and Chapter Four. The fourth and final point on how to uphold the sexual autonomy of women with mild Down syndrome was made in Chapter Five, which demonstrated, through Foucault's genealogical theory as well as de-colonial theory, that the sexuality of women with mild Down syndrome is discursively produced and can also be discursively altered. A number of significant findings were made in this study.

2. Main research findings

The study made a number of significant findings as outlined below:

2.1 The 'capacity framework does not adequately recognise the sexual autonomy of women with mild Down syndrome

South Africa's 'capacity framework' is an improvement on the 'status framework that is deployed in Malawi, Uganda and Zambia for one main reason. The 'capacity framework' permits some women with mild intellectual disabilities to retain their sexual agency by not labelling them as lacking capacity to consent to sexual intercourse. The courts in South Africa apply a two-stage test, which entails determining factual consent before legal consent.¹¹⁸⁶ Where there is evidence that the complainant did not consent to the sexual intercourse, the court must convict the accused person and need not proceed to the second stage of the test.¹¹⁸⁷ Determining factual consent first, protects women with mild intellectual disabilities from rape without requiring them to first prove whether they have the capacity to consent to sexual intercourse.¹¹⁸⁸ They are able to say no without the risk of being labeled as lacking capacity to

¹¹⁸⁵ See Chapter Two, section 4.

¹¹⁸⁶ *Chinridze*.

¹¹⁸⁷ *As above*.

¹¹⁸⁸ Benedet & Grant (n 471) 270.

consent to sexual intercourse.¹¹⁸⁹ This is an advantage because once one is labeled as lacking capacity to consent to sexual intercourse, they are likely to retain that label for life and will have their sexual autonomy further restricted through control and supervision aimed at preventing a person who lacks capacity to consent from engaging in sexual intercourse.¹¹⁹⁰ Therefore, this allows some women with mild intellectual disabilities to retain their sexual agency.

Moreover, even where the court does proceed to the second stage of the test in order to determine whether the complainant can give valid legal consent, it is not enough to merely prove that a complainant has a disability that affects mental faculties.¹¹⁹¹ The State is required to provide proof that the severity of the disability is such that it satisfies one of the four criteria laid out in section 1 (1) of the Sexual Offences Act.¹¹⁹² This means that under the capacity framework, not all women with mild intellectual disabilities will be labeled as lacking capacity to consent to sexual intercourse.

In contrast, the ‘status framework’ deployed in Malawi, Uganda and Zambia, criminalises all sexual intercourse with women and girls with intellectual disabilities.¹¹⁹³ In other words, all women with mild intellectual disabilities are, denied sexual autonomy because of their disability status, making the ‘status framework’ a much more oppressive regime than the ‘capacity framework.’

Indeed, the Law Reform Commission in Ireland recognised this when they repealed legislation deploying the ‘status framework’ in matters relating to capacity to consent to sexual intercourse in favour of the ‘capacity framework’ that was adopted in the Criminal Law (Sexual Offences) Act of 2017.¹¹⁹⁴

Nevertheless, the ‘capacity framework’ remains problematic for three reasons. First, it limits the sexual autonomy of some women with mild intellectual disabilities, particularly those wish to consent to sexual intercourse. In the absence of any evidence of lack of consent, the courts proceed to the second stage of the legal test in order to determine whether the severity of the complainant’s disability is such that it satisfies one of the four criteria laid out in section

¹¹⁸⁹ As above.

¹¹⁹⁰ Clough (n 81) 382.

¹¹⁹¹ *Mnguni* at 2.

¹¹⁹² As above.

¹¹⁹³ Penal Code (Chapter 7:01) 1930, sec 139 (Malawi); Penal Code Act (Chapter 120) 1950, sec 130 (Uganda); Penal Code Act Chapter 87 1931, sec 139 (Zambia).

¹¹⁹⁴ Arstein-Kerslake (n 523) 138. Criminal Law (Sexual Offences) Act 2017 (Ireland).

1 (1) of the Sexual Offences Act. If it does, then the complainant is deemed incapable of legally consenting to sexual intercourse and any consent she may have in fact given, is considered invalid.¹¹⁹⁵ The capacity framework therefore, continues to deny some women with mild Down syndrome sexual autonomy.

Second, the ‘capacity framework’ violates human rights principles by denying some women with mild Down syndrome their right to legal capacity and failing to recognise universal legal capacity. Article 12 (2) of the CRPD recognises universal legal capacity for all persons with disabilities. By denying some women with mild Down syndrome sexual autonomy, the ‘capacity framework’ effectively denies them the right to legal capacity through the functional approach.¹¹⁹⁶ According to the functional approach, a person lacks capacity to act if, because of disability, they are deemed as unable to perform a specific function.¹¹⁹⁷ The capacity framework is an example of the functional approach because complainants who, because of their disability, are unable to perform certain functions such as appreciating the nature and reasonably foreseeable consequences of the sexual act;¹¹⁹⁸ acting in accordance with that appreciation;¹¹⁹⁹ resisting the commission of the offence;¹²⁰⁰ or communicating their unwillingness to participate in the act¹²⁰¹ are denied the capacity to consent to sexual intercourse. Therefore, by failing to recognise the universal legal capacity of all persons with disabilities, the functional approach violates article 12 (2) of the CRPD. Moreover, the functional approach infringes the right to legal capacity by discriminating on the basis of disability.¹²⁰² Article 12 (2) of the CRPD requires States Parties to respect the legal capacity of all persons with disabilities on an ‘equal basis with others.’¹²⁰³ Therefore, if there is to be any denial of legal capacity, it must be effected in a non-discriminatory manner.¹²⁰⁴ However, the functional approach adopted in the capacity framework is discriminatory in that it is only applied to persons with mental disabilities.¹²⁰⁵ Therefore, the capacity framework is not in line with human rights principles set out in the CRPD.

¹¹⁹⁵ *Hlapho*.

¹¹⁹⁶ Dhanda (n 582) 431.

¹¹⁹⁷ As above.

¹¹⁹⁸ Sexual Offences Act sec 1 (1) (a).

¹¹⁹⁹ Sexual Offences Act sec 1 (1) (b).

¹²⁰⁰ Sexual Offences Act sec 1(1) (c).

¹²⁰¹ Sexual Offences Act) sec 1(1) (d).

¹²⁰² CRPD Committee, General Comment No 1 paras 25 and 32 – 34.

¹²⁰³ Arstein-Kerslake (n 545) 1463.

¹²⁰⁴ CRPD Committee, General Comment No 1 paras 25 and 32 – 34.

¹²⁰⁵ Arstein-Kerslake (n 545) 1463.

Third, the ‘capacity framework’ is an example of coloniality persisting in law. The South African approach to capacity to consent to sexual intercourse is similar to that in England and Wales. The Sexual Offences Act of 2003 and the Mental Capacity Act of 2005 regulate capacity to consent to sexual intercourse in criminal and civil cases, respectively, in England and Wales. Complainants falling within the ambit of the relevant legal tests are deemed as lacking capacity to consent whilst those who do not meet the requisite legal tests are considered capable of consenting to sexual intercourse. The similarities between South African law and English law are not surprising given the enormous influence that English law has had on South African law, even after the end of colonial rule.¹²⁰⁶ This raises questions about whether the ‘capacity framework’ in South Africa is responsive to the needs and experience of women with mild Down syndrome in South Africa.

With this background in mind, it is necessary to re-conceptualise capacity to consent if women with mild Down syndrome in South Africa are to enjoy sexual autonomy.

2.2 The ‘capacity framework’ can be re-conceptualised to enable the recognition of sexual autonomy

In order to rectify the limits that the capacity framework places on the sexual autonomy of some women with mild Down syndrome, the focus/scope of the inquiry must be altered/expanded. The ‘capacity framework’ treats vulnerability and incapacity as inherent traits and obscures the role of societal factors. The courts focus narrowly on the complainant’s mental disability to the exclusion of wider societal factors. They rely on psychiatric evidence, which focuses on the complainant’s IQ scores and mental age.¹²⁰⁷ Because of this narrow focus, the courts may not appreciate that capacity is a state rather than a trait.¹²⁰⁸ The capacity framework can be re-conceptualised through an application of Fineman’s vulnerability framework.

Although Fineman’s vulnerability framework conceives of universal vulnerability, it also takes into account the particularity of the experience of vulnerability.¹²⁰⁹ It allows a wider focus on the societal factors specific to women with mild intellectual disabilities, such as living in controlled environments and having to rely on others for support with daily living, that have an impact on their specific experience of sexual abuse and their ability to consent to sexual

¹²⁰⁶ The influence that English law exerts on South African criminal law is addressed in Chapter Three, section 3.3.

¹²⁰⁷ *Chinridze* at 6.

¹²⁰⁸ Lyden (n 570) 5.

¹²⁰⁹ *Benedet & Grant* (n 471) 257.

intercourse.¹²¹⁰ This allows a shift in focus from perceived or actual individual limitations to situational causes of vulnerability. Moreover, for Fineman, vulnerability results from systems that produce disadvantage, rather than identity categories and this allows for a more robust conception of vulnerability and capacity to consent.¹²¹¹

In order to remedy the ‘capacity framework’s’ infringement of the right to legal capacity, it must be re-conceptualised such that it recognises universal legal capacity and is not applied in a discriminatory way. Therefore, in order for the Sexual Offences Act in South Africa to provide equality for sexual decision-making for persons with disabilities, the Act should clearly state that it applies to all persons, not just persons with disabilities.¹²¹² Moreover, the legislation should be implemented in a disability-neutral manner.¹²¹³ Fineman’s vulnerability framework provides a rationale for the provision to apply to all persons, not just persons with disabilities. Fineman’s vulnerability framework conceives of universal vulnerability, meaning that all women are vulnerable to sexual abuse, not just women with mild Down syndrome.¹²¹⁴ Viewed in this way, it does not make sense to have a law that is specifically intended for women with ‘mental disabilities’ because vulnerability is not a trait that is inherent in women with mild Down syndrome. Universal legal capacity can be respected by applying the support paradigm. Under article 12 (3) of the CRPD, States Parties have a duty to ensure that women with mild intellectual disabilities have access to the supports they require for sexual decision-making.¹²¹⁵

The shift in focus from individual limitations to societal barriers as well as the need to recognise universal legal capacity through the support paradigm necessitates a re-conceptualisation of the role of the State. The capacity provisions were enacted with the objective of providing protection to persons with mental disabilities.¹²¹⁶ Therefore, the role of the state is through the criminal courts, to protect those whose disability is so severe through legal concepts of capacity to consent to sexual intercourse. Whereas the capacity framework merely views that role of the State as that of ‘protecting’ women with mild Down syndrome from sexual abuse through legal concepts such as capacity to consent, both the support paradigm and Fineman’s vulnerability framework envision a more active state. The role of the

¹²¹⁰ As above.

¹²¹¹ See Chapter Two, section 2 for a detailed discussion of Fineman’s vulnerability framework.

¹²¹² Arstein-Kerslake (n 545) 1467.

¹²¹³ As above.

¹²¹⁴ Pillay (n 659) 764.

¹²¹⁵ Arstein-Kerslake (n 545) 1462.

¹²¹⁶ Arstein-Kerslake (n 545) 1467.

state is not limited to no-interference but involves the active monitoring and assessment of asset-conferring institutions to which women with mild Down syndrome must look in order to build their resilience. Only by re-conceptualising the role of the state can we have a state that is truly responsive to the needs of women with mild Down syndrome in relation to sexual decision-making.¹²¹⁷ Recognising the numerous sources of vulnerability to sexual abuse necessitates a response that is not merely aimed at ‘protecting’ women with mild Down syndrome from sexual abuse by denying them sexual agency because they are presumed inherently vulnerable. Instead, the solution is to address the social structures that produce disadvantage and vulnerability and build the resilience of women with mild Down syndrome.

The coloniality that is exemplified in the ‘capacity framework’ can be rectified through an application of de-colonial theory, according to which, there is a need to engage with local perspectives. To this end, the researcher conducted empirical research in the form of interviews in order to unearth the situational and societal factors that impede the sexual decision-making capacity of women with mild Down syndrome in South Africa. The interviews also sought to discover the types of supports that women with mild Down syndrome need in order to build their capacity to consent to sexual intercourse.

2.3 Situational factors limiting capacity to consent in a South African context

Data that were collected through the interviews indicate that the research participants subscribe to the same notion as the ‘capacity framework,’ that one’s capacity to consent to sexual intercourse is linked to the level of one’s knowledge about sexuality. However, there are divergent views about the source of one’s level of knowledge. Whilst, the ‘capacity framework’ attributes one’s level of knowledge to one’s disability, the research participants opine that the level of one’s knowledge about sexuality is not determined by their disability but by situational factors.¹²¹⁸ The research study also found that most women with mild intellectual disabilities do not receive adequate formal sexuality education and this limits their capacity to consent to sexual intercourse. In the South African context, the research participants identified five situational factors that prevent women with mild Down syndrome from receiving adequate sexuality education and therefore, gaining capacity to consent are as follows:

¹²¹⁷ See Chapter Two, section 2.5 for a detailed discussion on re-conceptualising the role of the state.

¹²¹⁸ See Chapter Four, section 3.1.1.

First, there is a common misconception that capacity to consent is an inherent trait. Therefore, if women with mild intellectual disabilities inherently lack this capacity, then there is no need for them to receive sexuality education.¹²¹⁹

Second, the misconception that sexuality education is dangerous prevents women with mild Down syndrome from receiving sexuality education. Parents and caregivers wrongly believe that sexuality education is only about sexual intercourse and will encourage women with mild Down syndrome to become sexually active. They are mistaken in their belief that preventing women with mild Down syndrome from engaging in sexual relationships is necessary in order to protect them from abuse, rejection and pregnancy.¹²²⁰

Third, the common practice of gatekeeping which is practiced by parents and caregivers prevents women with mild Down syndrome from receiving sexuality education. Parents and caregivers, who themselves, have not had any sexuality education, keep their daughters and relatives with mild Down syndrome from receiving sexuality education because they harbour negative attitudes and beliefs about the sexuality of women with mild Down syndrome.¹²²¹ The negative attitudes of parents and caregivers have an enormous influence on the capacity of women with mild Down syndrome to consent to sexual intercourse. Because most parents and caregivers do not think that women with mild Down syndrome have the capacity to decide to engage in sexual intercourse, they tend to deny them the opportunity to make the decisions by restricting their freedom.¹²²² Moreover, women with mild intellectual disabilities internalise the negative views of their parents and caregivers.

Fourth, there is a reluctance to discuss sexual matters rooted in African culture and religion.¹²²³ Culture and religion influence parents and caregivers into avoiding discussions about sexuality with their daughters or relatives with mild Down syndrome.¹²²⁴ Similarly, culture and religion also exert an influence on women with mild Down syndrome themselves, leading them to be secretive about sexual matters and reluctant to ask for support.¹²²⁵

Fifth, women with mild Down syndrome are often kept in restrictive environments, thereby denying them the opportunity to learn about and explore sexual relationships. Cumulatively,

¹²¹⁹ See Chapter Four section 3.1.2.

¹²²⁰ As above.

¹²²¹ As above.

¹²²² As above.

¹²²³ As above.

¹²²⁴ As above.

¹²²⁵ As above.

these factors result in women with mild Down syndrome being denied formal and informal sexuality education resulting in their having limited knowledge about sexuality and ultimately perpetuating the misconception that women with mild Down syndrome inherently lack capacity to consent to sexual intercourse.¹²²⁶

2.4 Supports to bolster capacity to consent to sexual intercourse

The research participants identified three main types of supports necessary to build the capacity of women with mild Down syndrome to consent to sexual intercourse.¹²²⁷

First, information and sexuality education is an indispensable form of support.¹²²⁸ The research participants stated that sexuality education must be comprehensive and address topics other than the physical act itself. These related topics include relationship types, stages and expectations, healthy and unhealthy relationships, public and private body parts and spaces, touching, secrets, risks of sexual relationships, sexual abuse, etc. Comprehensive sexuality education should begin as early as possible in life. Moreover, it must be frequent and repetitive.¹²²⁹ Crucially, trainers must provide sexuality education in accessible formats that will enable women with mild Down syndrome to understand the information. Sexuality education should take place formally and informally as well as in group settings and in individual or couples counselling sessions.¹²³⁰

The second type of supports that the research participants identified is emotional and relational support.¹²³¹ This type of support begins with educating parents and caregivers about the benefits of sexuality education and sexual relationships for women with mild Down syndrome. The purpose of educating parents and caregivers is to change their negative perspectives about the sexuality of women with mild Down syndrome in an effort to eliminate the practice of gate-keeping.¹²³² This education should begin as early as possible while their daughters and relatives with mild Down syndrome are still young. Moreover, it should adopt a compassionate approach that acknowledges the difficulties that parents and caregivers face in their everyday life while simultaneously addressing their fears and anxieties.¹²³³

¹²²⁶ As above.

¹²²⁷ See Chapter Four section 3.2.

¹²²⁸ See Chapter Four section 3.2.1.

¹²²⁹ As above.

¹²³⁰ As above.

¹²³¹ See Chapter Four section 3.2.2.

¹²³² As above.

¹²³³ As above.

The third type of support identified by the research participants is experiential freedom facilitated through independent living arrangements.¹²³⁴ Because one's living arrangements have a bearing on one's level of exposure to sexuality education and opportunities to experience sexual relationships, they can either limit or build one's capacity to consent to sexual intercourse.¹²³⁵ Therefore, the research participants encouraged independent living arrangements that foster experiential freedom as an important form of support.

2.5 Asset conferring institutions

In accordance with Fineman's vulnerability framework, the research participants identified the asset conferring institutions that women with mild Down syndrome look to for resilience. Specifically, these institutions are responsible for providing comprehensive sexuality education to women with mild Down syndrome. They include families, communities, faith-based organisations, schools, medical fraternity, civil society and government. The state has a duty to monitor and assess these institutions in order to ensure that they are not creating disadvantages for women with mild Down syndrome.

2.6 The discursive altering of perceptions about the sexuality of women with mild Down syndrome

Because the aim of this research study is to understand how conceptual boundaries can be shifted to allow for the recognition of the sexual autonomy of women with mild Down syndrome, it is important to understand how their sexuality and sexual identity came about. Michel Foucault's genealogical theory is deployed for this purpose. When the research findings are analysed using a genealogical lens, it becomes clear that power is central to the construction of sexuality and the sexual identity of women with mild Down syndrome. Sexuality is not an exclusively natural phenomenon but is discursively produced over time through systems and practices that form part of modern society's increasing surveillance.¹²³⁶ Genealogical theory illuminates the influence of social factors and relations of power on sexuality that were previously hidden by the conception of sexuality as 'natural.'

Similarly, the sexual subject is discursively produced through relations of power. In contrast with biological and medical discourses that posit that one's identity is biologically constructed, Foucault's concept of disciplinary power explicates how society constructs the

¹²³⁴ See Chapter Four section 3.2.3.

¹²³⁵ As above.

¹²³⁶ Crowley (n 314) 9.

subject.¹²³⁷ Women with mild Down syndrome are wrongly believed to be asexual innocents or hypersexual perverts and these misconceptions influence how society surveils and ultimately constructs the sexual identity of women with mild Down syndrome. It is ‘inappropriate’ for infantile and asexual women with mild Down syndrome to engage in any sexual intercourse, leading to their de-sexualisation. Similarly, it is considered within the public interest to curb the sexuality of these ‘oversexed perverts.’ Through disciplinary power, women with mild Down syndrome surveil their own behavior in accordance with these exclusionary ideas.¹²³⁸

Through Foucault’s bio-power, women with mild Down syndrome construct themselves as disabled sexual subjects by internalising society’s negative attitudes about their sexuality. Parents and caregivers, in particular, harbor negative attitudes and beliefs about the sexuality of women with mild Down syndrome and exert a powerful influence on them. As women with mild Down syndrome internalise societal attitudes and beliefs, they are engaging in a process of subjectification and will begin to see and think of their own sexuality as their parents, caregivers do.¹²³⁹

The fact that ideas about sexuality and sexual identity are discursively produced implies that they may also be discursively altered.¹²⁴⁰ This change can be achieved through the process of resistance, which is integral to relations of power.¹²⁴¹ In the context of sexual decision-making, this resistance can take the form of supports. The research participants identified supports, which essentially involve the transformation of attitudes and beliefs of parents, caregivers, and women with mild Down syndrome about sexuality. These supports are a form of resistance against the disabling discourses and practices that constitute the disabled sexual subject. This resistance paves the way for new avenues of behaviour and new sexual identities. This is how knowledge and the disabled sexual subject can be discursively altered.

3. Concluding reflections and agendas for future research

Proponents of the ‘capacity framework’ defend it on the basis that it protects women with mild Down syndrome by allowing the courts to return a guilty verdict where there is evidence of non-consent without first determining the complainant’s capacity to consent. Moreover, it may be argued that the ‘capacity framework’ protects women with Down syndrome who, because

¹²³⁷ See Chapter Five section 3.1.

¹²³⁸ As above.

¹²³⁹ Esmail et al (n 87) 1151.

¹²⁴⁰ See Chapter Four section 4.

¹²⁴¹ Foucault (n 1109) 46.

of the severity of their disability, cannot consent to sexual intercourse, from exploitation and abuse by allowing the courts to vitiate such a complainant's consent. The consequent denial of sexual autonomy is perceived as an acceptable price to pay in the legitimate pursuit of the protection of women with mild Down syndrome who are considered inherently vulnerable. Protection and sexual autonomy are therefore, perceived as competing interests incapable of co-existing.

However, the researcher contends that it is possible to simultaneously uphold the sexual autonomy of women with mild Down syndrome and protect them from abuse and violence. Foucault's genealogical theory helps us understand how the perception of women with mild Down syndrome as inherently vulnerable to sexual abuse was constructed through relations of power. By discursively re-configuring the concept of capacity to consent through Fineman's vulnerability framework and the support paradigm, it is possible to uphold their sexual autonomy whilst protecting them from violence and abuse. Their sexual agency can be recognised by altering the perception that incapacity is an inherent trait and expanding the scope of inquiry to include situational factors that are specific to the South African context. As the research participants pointed out, support in the form of sexuality education provides women with mild Down syndrome with the resilience they need to recognise and avoid abusive situations as far as is reasonably possible, thereby affording them protection. In line with decolonial theory, the 'capacity framework' in South Africa needs to be re-conceptualised and the law amended to take into account the local situational factors. The legislative amendment must also recognise universal legal capacity and the provision must be applied in a disability-neutral manner. The exact form of such a legislative provision and approach is beyond the scope of this study and is a subject for future research that must take into account the views of those in the legal fraternity.

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Appendix One: Invitation e-mail

Dear ...

I hope this finds you well and safe. My name is Dianah Msipa. I am a Doctor of Laws (LLD) candidate at the Centre for Human Rights, Faculty of Law, University of Pretoria. I was referred to you by ...

I am doing my doctoral research on how the law in South Africa can uphold the sexual autonomy of women with Down syndrome/intellectual disabilities. Specifically, I am interrogating the different supports that women with Down syndrome or women with intellectual disabilities can receive in order to empower them to make more informed sexual decisions. Given your knowledge and expertise in this area, I am writing to invite you to participate in an online interview as an expert.

I attach an invitation letter with further details on this as well as a sample letter of authority which, if you are willing to participate in the research, I kindly request that you edit, sign and return to me. I would be most grateful if you could recommend other people who are working in this field if you are not able to participate.

I also attach an abstract that summarises my LLD research for your information.

I look forward to a favourable response from you.

Kind regards

Dianah

Appendix Two: Interview schedule

LLD research project title:	Recognising the sexual autonomy of adult women with mild Down syndrome in South Africa: Re-thinking vulnerability
LLD candidate name:	Dianah Msipa
Student number:	18179917
Supervisor:	Professor Charles Ngwena

Interview schedule

1. What do you understand by **capacity to consent** to sexual intercourse?
2. What do you understand by **informed consent** to sexual intercourse?
3. Do you think that the lack of capacity to consent is **inherent** in women with intellectual disabilities?
4. Do you think that **social factors** also affect a woman with mild intellectual disability's capacity to consent? Please explain your answer
5. Do you think that women with mild intellectual disabilities **can give informed consent** to sexual intercourse?
6. What factors might **prevent** a woman with mild intellectual disabilities from giving informed consent?
7. What factors might **enable** a woman with mild intellectual disabilities from giving informed consent?
8. What do you understand by **sexuality education**?
9. What does sexuality education for women with mild intellectual disabilities **entail**?
10. Do you think sexuality education can **improve** the capacity of a woman with mild intellectual disability to consent to sexual intercourse?

Appendix Three: Ethical Clearance Certificate



Faculty of Law

DEPARTMENT OF PUBLIC LAW

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8 January 2021

**Approval Certificate
New Application**

Ethics Reference No.: L033/20

Title: Recognising the sexual autonomy of adult women with mild Down syndrome in South Africa: Re-thinking vulnerability

Dear Ms D Msipa

The **New Application** as supported by documents received between 2020-11-11 and 2021-01-08 for your research, was approved by the Faculty of Law Research Ethics Committee.

Please note the following about your ethics approval:

- Please remember to use your protocol number (L033/20) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, monitor the conduct of your research, or suspend or withdraw ethics approval.

Ethics approval is subject to the following:

- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research project.

Yours sincerely



Ms Rani Pillay
Chairperson: Research Ethics Committee
Faculty of Law

Appendix Four: Participant Information and Informed Consent Form

Online interviews with subject matter experts

Participant information and informed consent form

LLD Project title: Recognising the sexual autonomy of adult women with mild Down syndrome in South Africa: Re-thinking vulnerability

Doctoral candidate: Dianah Msipa

E-mail: dianah.msipa@up.ac.za

Supervisor: Prof Charles Ngwena

E-mail: charles.ngwena@up.ac.za

My name is Dianah Msipa; I am a Doctor of Laws (LLD) candidate at the Centre for Human Rights, Faculty of Law, University of Pretoria. In partial fulfilment of the requirements of this degree programme, I am required to conduct a research project. I hereby invite you to participate in this research as part of a group of experts who will be interviewed online by me.

You were selected to be part of the group of experts based on your knowledge and expertise in one of the following areas, sexuality education, sexual autonomy of adults with mild intellectual disabilities and in augmentative and alternative communication.

Aim of research study: The aim of this study is to explore the different ways in which women with mild intellectual disabilities, in particular, Down syndrome, can be supported to make informed sexual decisions in an effort to uphold their sexual autonomy.

What will be expected from you as a participant? You will be requested to take part in an online interview via zoom, google meet, skype or any other similar online platform of your choice. You will then be interviewed individually by me on a date to be agreed in future. The questions and discussion will be on supporting women with mild intellectual disabilities to give informed consent to sexual intercourse. It is anticipated that the interviews will last between 45 to 60 minutes.

Benefits of participation and assurances: Since the coming into force of the Convention on the Rights of Persons with Disabilities in 2008, many governments, including the government of South Africa, are grappling with the practical implications of recognising the sexual

autonomy of women with intellectual disabilities. This research will contribute to this complex subject by exploring the supports that may be provided to women with mild intellectual disabilities to enable them to exercise their sexual autonomy. The benefit that participants will derive from this is knowing that they have participated in knowledge production in an important and relatively novel area of study with the potential for making a significant difference in the lives of adult women with mild intellectual disabilities. There are no foreseeable risks to you participating in this study.

Your participation is voluntary and you may withdraw from the study at any time without any negative consequences. You have the opportunity to ask questions about the proposed study before signing the consent form and participating in the interview. If you consent to participate in the online interviews, your identity and data (views, comments and opinions) will be kept confidential and used only for research purposes, conference presentations, journal articles and to write a thesis. Your name will not appear on the interview transcripts to keep your identity anonymous. Documents will be in the safekeeping of the Centre for Human Rights, Faculty of Law, University of Pretoria for 15 years for archival purposes and for future use of data.

Please complete and submit this form via email to the doctoral candidate at dianah.msipa@up.ac.za

Your Name:

Your Title:

Your Profession:

Your Contact details (e-mail):

I, _____ (name and surname) hereby confirm that I understand
that:

- 1) My participation is voluntary and there will be no penalty or loss of benefit for deciding not to take part in this research study
- 2) My identity will be kept confidential

- 3) I have the right to withdraw from the research at any time without having to explain why
- 4) I have the opportunity to ask questions about the proposed study before signing the informed consent form
- 5) I have the right to access my data
- 6) Any information I disclose during the interview will be used for the sole purpose of current and future promotion and advancement of the right to sexual autonomy of women with mild intellectual disabilities
- 7) My interview may be tape recorded and such recording shall only be used for purposes of allowing the researcher to transcribe the interview and the audio recording shall not be used for any other purpose
- 8) The findings from the research study will be kept confidential and used only for research purposes, conference presentations, journal articles and to write a thesis.

(Please indicate your preferred option by marking with an X)

I give consent to participate in this study		I do not give consent to participate in this study	
---	--	--	--

Signature: _____

Date: _____

Upon completion, I would like to obtain a copy of the Doctoral thesis: Yes _____ No _____