

CHAPTER 5

MY RIGHT TO KNOW: DEVELOPING SEXUALITY EDUCATION RESOURCES FOR LEARNERS WITH INTELLECTUAL DISABILITIES IN THE WESTERN CAPE, SOUTH AFRICA

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Summary

In South Africa, the continuing HIV pandemic and high prevalence of sexual abuse focus attention on the vulnerability of persons with intellectual disabilities and highlight the need to provide them with comprehensive sexuality education. Access to sexuality education is intrinsic to supporting sexual health as well as any possibility of informed consent (or self protection) in relation to sexual behaviour with others or sexual health treatment, such as contraception. The right to access information relating to sexual health programmes is enshrined by the UN Convention on the Rights of Persons with Disabilities and South African law, such as the Constitution.

Learners and adults with intellectual disabilities are frequently denied this information due to negative beliefs toward their sexuality and learning capabilities compounded in Southern Africa by a paucity of programmes, training and resources to accommodate their learning needs. Over the past 10 years, the Western Cape Forum for Intellectual Disability (WCFID) has developed materials to enable educators and health care workers to provide sexuality education to this neglected population group. This article broadly describes the content and methodology of one such programme for learners with intellectual disabilities alongside contextual and other factors that impact on sexuality education for people with intellectual disabilities in South Africa.

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1 Introduction

The UN Convention on the Rights of Persons with Disabilities (CRPD)¹ provides a framework for the elimination of discrimination, and champions equality in all aspects of life. Sexuality cannot be detached from human experience and demands its presence in any document that promotes the rights of people with disabilities, especially in view of the ‘interdependence, and interrelatedness’ of human rights, as stated by the CRPD.² The provision of comprehensive³ and accessible sexuality education is integral to a rights-based framework. This mandate is supported by international research⁴ and a growing body of African research into the need for sexuality education for people with intellectual disabilities,⁵ as well as South African law relevant to this area.⁶ However, the provision of comprehensive sexuality education for the youth in Southern Africa, especially those with disabilities, is inadequate despite the high rate of HIV and unacceptable levels of sexual violence toward women and girls.⁷

The implementation of comprehensive sexuality education is hindered by an ambivalence toward acknowledging the sexuality of adolescents, leaving them more vulnerable and unprepared for their sexual lives.⁸ This resistance is amplified as far as the sexuality of people with disabilities is concerned,⁹ and even more so in relation to people with intellectual

1 UN General Assembly, Convention on the Rights of Persons with Disabilities (CRPD): Resolution adopted by the General Assembly, 24 January 2007, A/RES/61/106.

2 CRPD Preamble, para (c).

3 UNESCO *Young people today, time to act now: Why adolescents and young people need comprehensive sexuality education and reproductive health services in Eastern and Southern Africa* (2013) 21.

4 NA Gougeon ‘Sexuality education for students with intellectual disabilities: A critical pedagogical approach; outing the ignored curriculum’ (2009) 9 *Sex Education* 277; G Katz & E Lazcano-Ponce ‘Sexuality in subjects with intellectual disability: An educational intervention proposal for parents and counsellors in developing countries’ (2008) 50 *Salud publica de mexico* 239; T Gardiner & E Braddon ‘A right to know. Facilitating a relationship and sexuality programme for adults with intellectual disabilities in Donegal’ (2009) 37 *British Journal of Learning Disabilities* 327; A Craft *Practice issues in sexuality and learning disabilities* (1994); JK Carter ‘Sexuality education for students with specific learning disabilities’ (1999) 34 *Intervention in School and Clinic* 220; L Lofgren-Martenson ‘I want to do it right! A pilot study of Swedish sex education and young people with intellectual disability’ (2012) 30 *Sex and Disability* 209.

5 T Aderemi ‘Teachers’ perspectives on sexuality and sexuality education of learners with intellectual disabilities in Nigeria’ (2014) 32 *Sexuality and Disability* 247; J Hanass-Hancock et al ‘The cross-cultural validation to measure the needs and practices of educators who teach sexuality education to learners with a disability in South Africa’ (2014) 32 *Sex and Disability* 279; P Rohelder & L Swartz ‘Providing sex education to persons with learning disabilities in the era of HIV/AIDS. Tensions between discourses of human rights and restriction’ (2009) 14 *Journal of Health Psychology* 601.

6 Constitution of the Republic of South Africa, 1996; National Health Act 61 of 2003; Children’s Act 38 of 2005.

7 UNESCO (n 3 above).

8 UNESCO *International Technical Guidance on Sexuality Education. An evidence-informed approach for schools, teachers and health educators* (2009) 2.

9 M Schaaf ‘Negotiating sexuality in the UN Convention on the Rights of Persons with Disabilities’ (2011) (14) *International Journal on Human Rights* 114.

disabilities.¹⁰ Ambivalence may lead to the denial of a person's sexuality, or the reframing of their sexual needs solely within an abuse prevention focus.

The article aims to describe a sexuality education programme and resources for learners and adults with mild, moderate and high severe intellectual disabilities who attend LSEN (Learners with Special Educational Needs) schools in the Western Cape, South Africa.¹¹ In addressing these aims, the article examines the contextual and other factors that impact on sexuality education for people with intellectual disabilities in South Africa.

2 Defining sexuality, sexual health and comprehensive sexuality education

Any discussion of sexuality education will be framed by the meaning attached to the construct of sexuality. The World Health Organisation (WHO) defines sexuality as 'a central aspect of being human throughout life'.¹² Sexuality includes private sexual behaviour, sexual orientation, identity and feelings, alongside the social expression of sexual identity in gender roles, values and relationships. Social, cultural and historical contexts will shape personal experiences and the social construction of sexuality at any point in time. Within this view, it is not possible to limit our discussion of sexual health as simply the absence of disease or as excluding any sector of any population. The WHO defines of sexual health as

a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.¹³

10 M Perlin & A Lynch 'Love is a four-letter word: Sexuality, international human rights and therapeutic jurisprudence' (2014) *SSRN Electronic Journal* 10 doi 10.2139/ssrn.2380714 (accessed 18 March 2016).

11 The Western Cape Forum for Intellectual Disability (WCFID) has published resources to support sexual health in children and adults with intellectual disabilities: R Johns 'All about me: A life skills, sexuality and HIV/AIDS education programme for learners with intellectual disability' (2007) WCFID; <http://www.wcfid.co.za> (accessed 18 March 2016).

12 World Health Organisation (WHO) *Defining sexual health: Report of a technical consultation on sexual health 28-31 January 2002 Geneva* (2006) 5.

13 WHO (n 12 above) 5.

Comprehensive sexuality education is underpinned by this view of sexual health and supports the youth to develop a positive view of their sexuality.¹⁴ The United Nations (UN) Population Fund (UNFPA) describes comprehensive sexuality education as ‘a rights-based and gender-focused approach to sexuality education’.¹⁵ The United Nations Educational, Scientific and Cultural Organisation (UNESCO) International Technical Guidance on Sexuality Education states that alongside scientifically accurate information, sexuality education provides ‘opportunities for young people to explore their values and practise decision making and other life skills they will need to be able to make informed choices about their sexual lives’.¹⁶ Just as sexual health does not only focus on the absence of disease, comprehensive sexuality education goes beyond a narrow focus of preventing pregnancy and sexual disease and is underpinned by universal human rights relating to health and education for all.¹⁷

3 How do we understand intellectual disability?

3.1 Models of disability

In the past, the medical model dominated our understanding of intellectual disability, resulting in a paternalistic approach to care that prioritised protection and separate, specialised services. The social ecological model, as the theoretical framework of the CRPD, challenges the medical model through conceptualising disability as the result of a discriminatory social system.¹⁸ The CRPD recognises the need to protect the human rights of all, including those who ‘require more intensive support’,¹⁹ which is relevant to the different support needs of people with different levels of intellectual disability.

Different levels of cognitive ability within intellectual impairment, described as mild, moderate, severe or profound,²⁰ present a diverse

14 UN Population Fund (UNFPA) Operational Guidance for Comprehensive Sexuality Education (2014) 6.

15 UNFPA (n 14 above).

16 UNESCO (n 8 above) 2.

17 UNFPA (n 14 above).

18 Schaaf (n 9 above) 116.

19 CRPD, Preamble (j).

20 Mild intellectual disability is indicated by an IQ of between 50 and 69 and accounts for about 80 percent of people with intellectual disability. Moderate intellectual disability is indicated by an IQ of between 35 and 49 and accounts for about 10 percent of people with intellectual disability. Severe intellectual disability is indicated by an IQ of between 20 and 34 and accounts for 4 percent of all people with intellectual disability. Profound intellectual disability is indicated by an IQ score usually below 20 and accounts for 2 percent of all people with intellectual disability. See C Adnams ‘Assessment of levels of intellectual disability and adaptive behaviour’ in R Johns & C Adnams (eds) *Understanding intellectual disability: A handbook for families, staff, students and professionals* (2016) 14.

population group and, thus, diverse support needs. An acknowledgment of these different levels is inevitably framed within a medical discourse. However, the more recent bio-pyscho social model²¹ provides a more integrated view by acknowledging social barriers and discrimination alongside diverse impairments that may require individual treatment and accommodation. Current debates reflect the difficulty of ethically and equitably addressing the different abilities of people with intellectual disabilities in relation to their rights.²²

Discerning the appropriate focus of sexuality education for children and adults with more severe levels of cognitive impairment, namely the high support needs of those with severe to profound intellectual disability, is difficult due to their significantly-reduced understanding and autonomy: 'A person with profound intellectual disability cannot understand verbal requests, has very limited communication, no self-care skills and is usually incontinent.'²³ One approach is to engage caregivers to acknowledge and understand the rights and needs of this group in relation to their sexual health.²⁴ The issues related to 'recognising the dignity' and sexual health rights of these individuals are complex and, although outside of the scope of the article, need urgent engagement in relation to policy and practice²⁵ in special care facilities, residential facilities and community settings.

3.2 Problem of terminology

People with intellectual disabilities have always been 'marginalised and stigmatised'.²⁶ The terminology used to describe intellectual disability has continually changed, reflecting the attempt to 'define difference differently' and 'remove the stigma associated with a particular term'.²⁷ The article uses the current, internationally-accepted term 'intellectual

21 WHO 'International classification of functioning, disability and health' (ICF) Geneva (2001).

22 Submission to the Committee on the Rights of Persons with Disabilities from the Cambridge Intellectual and Developmental Disabilities Research Group' (2011) <http://www.cidrgrg.org.uk> (accessed 18 March 2016); A Dimopoulos 'The legal capacity of persons with disabilities in light of the United Nations Convention on the Rights of Persons with Disabilities' Brunel University <http://www.era-comm.eu/UNCRPD/kiosk/speakers-contributions/111OV69/Dimopoulos-pres-pdf> (accessed 14 March 2016).

23 D Clarke 'What is intellectual disability?' in A Roy, M Roy & D Clarke *The psychiatry of intellectual disability* (2006) in NJ Wilson et al 'Conditionally sexual: Men and teenage boys with moderate to profound intellectual disability' (2011) 29 *Sex and Disability* 275.

24 R Johns *Thinking ahead: The sexual development and sexual health of children and young adults with severe or profound intellectual disability: A guide for parents and caregivers* (2011).

25 See D Kulick & J Rydstrom *Loneliness and its opposite: Sex disability, and the ethics of engagement* (2015).

26 Perlin & Lynch (n 10 above) p 2.

27 L Lomofsky & M Skuy 'Educational needs related to intellectual and cognitive difference' in P Englebrecht & L Green (eds) *Promoting learner development. Preventing and working with barriers to learning* (2001) 192.

disability',²⁸ although previously-used terms, such as 'mental handicap', 'mental retardation' or 'learning disabilities' often remain more familiar to the general public as well as professionals working outside the sector. The CRPD uses the umbrella term 'persons with disabilities', additionally defining intellectual disability as 'long-term' 'mental or intellectual impairment'.²⁹

South African law relevant to the sexual health of those with intellectual disabilities, such as the Sterilisation Act³⁰ and the Sexual Offences Amendment Act,³¹ use the term 'mental disability'. Within the South African educational system, the terminology varies. The move toward creating an inclusive education system, as outlined by White Paper 6,³² reflects a social model of education³³ in the need to redress a segregated, inequitable school system under apartheid. LSEN schools provide for 'children with barriers to learning'.³⁴ Some LSEN schools refer to catering for learners with intellectual impairments, while the new LSEN curriculum (in draft process) caters for 'learners with severe intellectual disability who are enrolled in special as well as ordinary schools'.³⁵ LSEN schools for learners with intellectual disabilities generally provide for a broad mix of cognitive abilities, and include learners with mild, moderate and high severe intellectual disabilities.

3.3 Mental age

The way in which intellectual disability is perceived remains shaped by a medical discourse dominated by intelligence (IQ) testing³⁶ and the concept of 'mental age' estimated a child's intellectual performance in relation to typical age-related results.³⁷ Although the concept of mental age is no longer used in intelligence tests,³⁸ it remains current and misunderstood in relation to people with intellectual disabilities and results in caregivers feeling justified in treating an adult as a five year-old. The concept of mental age perpetuates negative beliefs about the sexuality of adults with

28 American Psychiatric Association (APA) 'Intellectual disability fact sheet' DSM V (2013) APA Publishing <http://www.dsm5.org> (accessed 17 March 2016).

29 Art 1 CRPD.

30 Sterilisation Amendment Act 3 of 2005.

31 Sexual Offences (and Related Matters) Amendment Act 5 of 2015.

32 Department of Education White Paper 6 *Special needs education. Building an inclusive education and training system* (2001).

33 M Maher 'Information and advocacy: Forgotten components in the strategies for achieving inclusive education in South Africa' (2009) 6 *Africa Education Review* 19.

34 <https://www.westerncape.gov.za/directories/facilities/788> (accessed 14 March 2016).

35 Department of Education *The new curriculum for learners with severe intellectual disability currently in process* <http://www.gov.za/basic-education-development-vocational-learning-programme> (accessed 14 March 2016).

36 Intelligence quotient (IQ) describes a score on a test that rates a person's intellectual functioning as compared to the general population. See Adnams (n 20 above) 14.

37 N Holt et al *Psychology: The science of mind and behaviour* (2012).

38 Holt (n 37 above) p 367.

intellectual disabilities where they are infantilised³⁹ and, thus, denied age-appropriate information.

Currently, a diagnosis of intellectual disability takes into account a person's IQ score alongside an assessment of their adaptive skills across three domains of the conceptual, practical and social. A person's lower intellectual functioning leads to reduced adaptive functioning.⁴⁰ A life span perspective⁴¹ sees development and learning as lifelong and is extremely relevant to challenging negative perceptions that adults with intellectual disabilities are incapable of continued learning.

4 Need for sexuality education for children and adults with intellectual disabilities

Bornman states that 'a silent victim is the best victim', highlighting the particular vulnerability to abuse of people with communication difficulties.⁴² Yet, even with functional communication, children and adults with intellectual disabilities are effectively silenced by withholding information about appropriate and inappropriate sexual behaviour and training them to be compliant. Children with intellectual disabilities are estimated three to eight times more likely to be abused than non-disabled children⁴³ and adults, particularly women⁴⁴ with intellectual disabilities, remain at increased risk of sexual violence and abuse.⁴⁵ A lack of sexuality education results in low levels of knowledge about sexual behaviour and is a factor that increases vulnerability to sexual violence,⁴⁶ increasing the risk of sexually-transmitted infections (STIs), including HIV,⁴⁷ as well as mental health problems more common in people with intellectual

39 Perlin & Lynch (n 10 above); C Capri & C Buckle 'We have to be satisfied with the scraps: South African nurses' experiences of care on adult psychiatric intellectual disability in patient wards' (2015) 28 *Journal of Applied Research in Intellectual Disabilities* 167.

40 Adnams (n 20 above).

41 D Papalia & R Feldman R *Experience human development* (2012).

42 J Bornman 'Join the fight as we pave a new way forward: A view from South Africa' in DN Bryen & J Bornman (eds) *Stop violence against people with disabilities. An international resource* (2014).

43 Save the Children *Out from the shadows: Sexual violence against children with disabilities* (2011).

44 E Barger et al 'Sexual assault prevention for women with intellectual disabilities: A critical review of the evidence' (2009) 47 *Intellectual and Developmental Disabilities* 249.

45 D Sobsey 'Sexual abuse of individuals with intellectual disabilities' in A Craft *Practice issues in sexuality and learning disabilities* (1994) 94.

46 'UN Thematic study on the issue of violence against women and girls and disability' *Report of the Office of the United Nations High Commissioner for Human Rights* (2012) 7; Barger (n 44 above) 251.

47 P Chirawu et al 'Protect or enable? Teachers' beliefs and practices regarding provision of sexuality education to learners with disability in KwaZulu-Natal, South Africa' (2014) 32 *Sex and Disability* 259.

disabilities.⁴⁸ Furthermore, people with intellectual disabilities have a poor understanding of their rights and the law, further increasing their vulnerability.

For many young people, friends are a source of sexual information, especially if parents are resistant to providing information, but young people with intellectual disabilities will struggle to 'share information and knowledge with one another'.⁴⁹ Additionally, people with intellectual disabilities are more likely to have low self-efficacy in relation to sexual decision making and negotiating skills in relation to condoms,⁵⁰ as they often lack social and educational opportunities to build skills related to setting boundaries or understanding their basic rights to consent.

South Africa continues to be one of the most highly HIV-affected countries in the world.⁵¹ Yet, people with disabilities are less informed about HIV, and have less access to testing and treatment despite their increased risk.⁵² Learners with intellectual disabilities show low levels of HIV knowledge,⁵³ reflecting a lack of accessible HIV education, the inability to access written information about HIV and the likelihood that television or radio information aimed at the general population is too complex for them to comprehend.

5 A rights-based framework

A rights-based framework, underpinned by international conventions and their respective monitoring bodies, offers a powerful tool to engage professionals, community leaders, parents and wider communities, as well as people with intellectual disabilities themselves, with the right to comprehensive sexuality education. These instruments provide an opportunity to legitimise and, thus, to challenge attitudinal barriers toward providing sexuality education for children and adults with intellectual disabilities, to shape policy, as well as examine the predominant discourse within any sexuality education programme. African-based human rights 'instruments' offer an additional tool to support the right to comprehensive sexuality education in an African context.

48 D Shaafsma et al 'Identifying effective methods for teaching sex education to individuals with intellectual disabilities: A systematic review' (2014) *Journal of Sex Research* doi 10.1080/00224499.2014.919373.

49 Lofgren-Martenson (n 4 above).

50 Aderemi (n 5 above).

51 P Rohleder et al 'HIV/AIDS and disability in Southern Africa: A review of relevant literature' (2009) 31 *Disability and Rehabilitation* 51.

52 J Hanass-Hancock 'Interweaving conceptualisations of gender and disability in the context of vulnerability to HIV/AIDS in KwaZulu-Natal, South Africa' (2009) 2 *Sex and Disability* 35.

53 T Aderemi et al 'Differences in HIV knowledge and sexual practices of learners with intellectual disabilities and non-disabled learners in Nigeria' (2013) 16 *Journal of the International AIDS Society* 1.

5.1 An international human rights framework on sexuality

5.1.1 Right to equality and non-discrimination

Perlin and Lynch⁵⁴ argue that the CRPD has the potential to challenge longstanding discrimination in the area of sexuality and people with intellectual disabilities. Rights concerning sexuality cannot be separated from other 'equal inalienable rights'⁵⁵ and the need for these to be enjoyed 'without discrimination'.⁵⁶ The UN Committee on Economic, Social and Cultural Rights (ESCR Committee)⁵⁷ acknowledges that people with disabilities may experience legal, practical and social barriers in accessing sexual health, and affirms that all individuals or groups have the right to enjoy the same range and standard of sexual health services and information as others. Article 23(1) of the CRPD, 'Respect for Home and Family', calls for the elimination of discrimination 'relating to marriage, family, parenthood and relationships'.⁵⁸ Rule 9 of The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities,⁵⁹ which predated the CRPD, took a more overt tone by stating that persons with disabilities 'must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood'.⁶⁰ Schaaf⁶¹ documents the difficult process of negotiating sexuality within the CRPD, illustrating the tension between a conservative versus a sexual rights-based discourse and the resulting dominance of heteronormative values through the positioning of sexuality within the conservative framework of marriage, the family and health.⁶² The Convention on the Rights of The Child (CRC)⁶³ prioritises non-discrimination and emphasises the fact that these rights apply to all children, no matter their abilities or circumstances. Article 23 addresses the rights of children with disabilities to special support to live full and independent lives. The equality of children with disabilities with other children is also supported by article 7(1) of the CRPD.

54 Perlin & Lynch (n 10 above).

55 CRPD, Preamble, para (a).

56 CRPD, Preamble, para (c).

57 UN Committee on Economic, Social and Cultural Rights (ESCR Committee) 'The right to sexual and reproductive health' General Comment 22, DOC E/C/12/2016/ 2 para 2.

58 Art 23(1) CRPD.

59 UN Standard Rules on the Equalisation of Opportunities for Person's with Disabilities Rule 9; Family Life and Personal Integrity (1993) <http://www.un.org/esa/socdev/enable/dissre00.htm> (accessed 18 June 2016).

60 UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (n 59 above).

61 Schaaf (n 9 above).

62 As above.

63 UN Convention on the Rights of the Child (CRC) (1990) <http://www.ohchr.org/esa/socdev/enable/dissre00.htm> (accessed 18 June 2016).

5.1.2 Right to education

The right to education is fundamental to conventions such as the CRC,⁶⁴ CRPD,⁶⁵ and deserving of the ongoing scrutiny by treaty-monitoring bodies, such as the UN Committee on the Elimination of Discrimination Against Women (CEDAW Committee) and ESCR Committee. Article 17 of the CRC states that all children have the right to information important to their wellbeing, and article 28 enshrines the right of all children to free primary education. Article 24 of the CRPD affirms the rights of children and adults with disabilities to equal education, including reasonable accommodation to facilitate their learning needs. The recognition of life-long learning without discrimination⁶⁶ is relevant to adults with intellectual disabilities who remain capable of continued learning and development once they have left school.⁶⁷ The right to inclusive education⁶⁸ is seen as integral to ending the discrimination experienced by people with disabilities.⁶⁹

Comprehensive sexuality education forms part of the right to education⁷⁰ and underpins other human rights, such as the right to health, information, non-discrimination, freedom from violence, and sexual reproductive autonomy for all.⁷¹ The UN CRC Committee argues that adolescents have the right to adequate information regarding their health, which includes information on sexual behaviour.⁷² Article 10 of CEDAW urges states to provide women with equal educational opportunities, including information on family planning. The CEDAW Committee further identifies the rights of girls and boys to age-appropriate and comprehensive sexuality education as part of the primary and secondary school curriculum.⁷³ The ESCR Committee cites the right to sexual and reproductive health combined with the right to education, and affirm a right to sexuality education that is 'comprehensive, non-discriminatory, evidence-based and age-appropriate'.⁷⁴ The ESCR Committee states that

64 Art 28 CRC.

65 Art 24 CRPD.

66 Art 24(5) CRPD.

67 O Coetzee & R Johns 'Development and the child with intellectual disability' in Johns & Adnams (n 20 above) 21.

68 Art 24(1) CRPD.

69 International Disability Alliance (IDA) and Centre for Reproductive Rights Comments to the Committee on the Rights of Persons with Disabilities on Draft General Comment 4, on the Right to Inclusive Education (art 24) 22 December 2015 <http://www.ohchr.org/documents/HRBodies/CRPD/GC./CentreReproductiveRights.doc> (accessed 18 June 2016).

70 IDA (n 69 above).

71 As above.

72 UN Committee on the Rights of the Child, General Comment 4: Adolescent health and development in the context of the Convention of the Rights of the Child (2004) in UNESCO (n 8 above) 30.

73 Committee on the Elimination of Discrimination against Women (CEDAW Committee) Concluding Observations: Ghana para 33 UN Doc CEDAW/C/GHA/CO/6-7 (2014).

74 ESCR Committee (n 57 above) 3.

information must be accessible to the needs of the individual and includes disability as a factor that must be taken into consideration.⁷⁵ The Centre for Reproductive Rights argues that comprehensive sexuality education forms part of inclusive education for people with disabilities, and argues that this position is supported by the Special Rapporteur on the Right to Education and enshrined by article 24(1) of the CRPD. This indicates that comprehensive sexuality education for persons with disabilities should occur from a young age, alongside reasonable accommodation and appropriate teacher training.⁷⁶

With regard to the increased risk of abuse experienced by people with disabilities, and especially women and children with disabilities, article 16 of the CRPD, 'Freedom from Exploitation, Violence and Abuse', recognises the need for information and education on how to avoid and report instances of exploitation and abuse.

5.1.3 Right to health

The right to health is indispensable to other human rights and, according to article 12(b) of the ESCR Committee⁷⁷ which asserts that health services may not discriminate against people with disabilities. The ESCR Committee in General Comment 22 argues that sexual health is intrinsic to the right to health.⁷⁸ Article 25 of the CRPD states that people with disabilities should have equal access to health services and programmes, including on sexual and reproductive health. This is further supported by the CEDAW Committee in that states may not 'censor or withhold sexual and reproductive health information', and that everyone has the right to 'comprehensive, unbiased and scientifically accurate sexuality education'.⁷⁹

The ESCR Committee distinguishes between sexual health as defined by WHO (described above) and reproductive health which 'concerns the capability to reproduce and the freedom to make informed, free and responsible decisions'.⁸⁰ Article 23 of the CRPD recognises 'the rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education'. This is of crucial relevance to sexual decision making and sexual health

75 ESCR Committee 5.

76 IDA (n 69 above) 5.

77 ESCR Committee (n 57 above). Substantive issues arising in the implementation of the International Covenant on Economic, Social and Cultural Rights, art 12, General Comment 14 (2000).

78 ESCR Committee (n 57 above) 1.

79 Centre for Reproductive Rights *Breaking ground 2015: Treaty-monitoring bodies on reproductive rights* (2015) 6.

80 ESCR Committee (n 57 above) 2.

interventions. Women and girls (as well as men and boys)⁸¹ with intellectual disabilities are frequently the recipients of medicalised sexual health interventions, often with little explanation or process of informed consent.⁸² The higher rates of forced sterilisations and abortions experienced by women with disabilities remain in violation of their human rights.⁸³ Article 25 of the CRPD requires health professionals to provide equal treatment on 'the basis of free and informed consent',⁸⁴ and this is further emphasised by the CEDAW Committee in the need to train health workers to improve support for women with disabilities concerning their reproductive health decisions.⁸⁵ Again, accessible and comprehensive sexuality education is integral to any possibility of autonomy in this area. Additionally, article 12 of the CRPD addresses equal recognition under the law and equal capacity. People with intellectual disabilities are often poorly informed of their rights regarding all aspects of their lives.

5.1.4 African instruments supportive of the right to sexuality education

The right to sexual and reproductive health is addressed by the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (African Women's Protocol).⁸⁶ The Women's Protocol articulates the rights of African women and girls, such as the right to dignity (article 3); the right to life, integrity and security of the person (article 4); and the right to equality before the law (article 8). Article 14 addresses 'the right to self-protection and to be protected'⁸⁷ regarding STIs, including HIV, and recognises the need for states to provide accessible health services and information. Article 23 recognises the need to ensure the protection of women with disabilities, and ensure their freedom from violence, discrimination and sexual abuse.⁸⁸ However, Murungi and Durojaye observe that the Protocol fails to support a more positive

81 In the author's experience of training educators and health professionals, anecdotal reports indicate that boys and men with intellectual disabilities in the Western Cape, South Africa are given the female contraceptive injection, Depo Provera, as anti-libidinal medication to manage what is perceived as 'difficult' sexual behaviour, such as public masturbation or inappropriate sexual behaviour towards others. This is despite the lack of standard guidelines or evidence-based research to support this approach.

82 W Holness 'Informed consent for sterilisation for women and girls in the light of the Convention of the Rights of Persons with Disabilities' (2013) 27 *Agenda* 35.

83 Centre for Reproductive Rights (n 79 above) 22; Human Rights Watch 'Sterilisation of women and girls with disabilities: A briefing paper' (2011) <https://www.hrw.org/news/2011/11/10/sterilization-women-and-girls-disabilities>, (accessed 18 June 2016).

84 Art 25(d) CRPD.

85 Centre for Reproductive Rights (n 79 above).

86 Adopted in Maputo, Mozambique on 11 July 2003; entered into force on 25 November 2005; reprinted in C Heyns & M Killander (eds) *Compendium of key human rights documents of the African Union* (2016) 65.

87 Arts 14(1)(d) & 2(a) African Women's Protocol (n 86 above).

88 Art 23(b) African Women's Protocol.

discourse of sexuality, particularly for women with disabilities.⁸⁹ This is addressed in part by General Comments on article 14 of the African Women's Protocol,⁹⁰ where the African Commission emphasises that states must

guarantee information and education on sex, sexuality, HIV, sexual and reproductive rights. The content must be evidence based, facts based, rights based, non-judgmental and understandable in content and language.⁹¹

This expands the focus of the Women's Protocol's from the prevention of HIV and sexual disease toward a more a rights-based framework toward sexual health.

The African Charter on the Rights and Welfare of the Child (African Children's Charter)⁹² specifies the right of children with physical or mental disabilities to protection and measures to ensure dignity, self-reliance and active participation in the community.⁹³ Additional support is provided by the Ministerial Commitment on Comprehensive Sexuality Education and Sexual and Reproductive Health Services for Adolescents and Young People in Eastern and Southern Africa 2013.⁹⁴ These instruments are important in challenging views that comprehensive sexuality education is contrary to African cultural values.

5.2 Legal framework on sexuality education and persons with disabilities in South Africa

5.2.1 Right to information

The South African Constitution⁹⁵ is the overarching legal instrument that infers support for the right to inclusive and comprehensive sexuality education for persons with disabilities, including those with intellectual disabilities, through the following rights: The state may not unfairly discriminate against anyone on the grounds of disability (article 9(3)); every child has the right to be protected against abuse (article 28(d)); everyone has the right to a basic education including adult education (article 29(a)); and everyone has the right to bodily and psychological integrity, which includes the right to make decisions about reproduction and to have control over their body (articles 12(2)(a) and (b)).

89 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* 1.

90 General Comments on art 14(1)(d) and (e) of the African Women's Protocol.

91 Art 26 Africa Women's Protocol.

92 OAU Doc CAB/LEG/24.9/49 (1990); reprinted in C Heyns & M Killander (eds) *Compendium of key human rights documents of the African Union* (2016) 80.

93 Art 13 African Children's Charter (n 92 above).

94 UNFPA (n 14 above) 8.

95 Secs 9(1) & 10 South African Constitution.

The National Health Care Act⁹⁶ states that all health users have the right to accessible information and to participate in health decisions even without the capacity to consent.⁹⁷ Additionally, the Children's Act⁹⁸ states that all children have the right to access information on health promotion and prevention and treatment of ill-health and disease, sexuality and reproduction, and to be given information in an accessible way that considers their age, literacy and any special needs.⁹⁹

The White Paper on the Rights of Persons with Disabilities (WPRPD), approved in 2015, further strengthens South Africa's commitment to the CRPD. Of particular relevance is the importance of life-long education and training;¹⁰⁰ the vulnerability of women and girls to sexual violence;¹⁰¹ and the need for persons with disabilities to access all HIV education programmes, and that these must include 'family planning, sexuality/sex education programmes' through services that are accessible and disability specific.¹⁰² However, the influence of the WPRPD is somewhat undermined by the opening disclaimer that it does 'not introduce a policy shift, nor does it replace any sector specific policies on disability'.¹⁰³

5.2.2 Right to protection

The high rate of sexual abuse in South Africa leads to heightened awareness of the need to protect children and adults with intellectual disabilities in recognition of their increased vulnerability.¹⁰⁴ The Sexual Offences Amendment Act¹⁰⁵ acknowledges CEDAW, CRC and the Constitution as underpinning its objective to protect vulnerable people.¹⁰⁶ However, sections 15 and 16, which define the statutory rape and statutory sexual assault of children, were challenged as unconstitutional in criminalising normative developmental and consensual sexual acts between children, and seen to 'infringe on children's constitutional rights to dignity, privacy and bodily and psychological integrity'.¹⁰⁷

Adults with intellectual disabilities are protected from unconsensual sexual acts, such as sexual exploitation, sexual grooming and exposure to

96 National Health Act 61 of 2003.

97 Secs 6, 7 & 8 Act 61 (n 96 above).

98 Children's Act 38 of 2005

99 Secs 13(1) & (2) Children's Act.

100 White Paper on the Rights of Persons with Disabilities (WPRPD) (2015) sec 6.4.1.2.

101 WPRPD (n 100 above) sec 6.2.1.4.

102 WPRPD (n 100 above).

103 WPRPD (n 100 above) Overview.

104 TN Phasha & LD Myaka 'Sexuality and sexual abuse involving teenagers with intellectual disability: Community conceptions in a rural village of KwaZulu-Natal South Africa' (2014) 32 *Sexuality and Disability* 153.

105 Act 32 of 2007 (n 31 above)

106 Act 32 of 2007 Preamble.

107 *Teddy Bear Clinic for Abused Children & RAPCAN v The Minister of Justice and Constitutional Development & The National Director of Prosecutions* 2013 12/13 35 (CC)

pornography.¹⁰⁸ The mandate for protection is further emphasised by stating that someone with a ‘mental disability’ is incapable of consenting to a sexual act.¹⁰⁹ In this context, the term ‘mental disability’ is not defined as a diagnosis, or a particular level of intellectual disability, but as the person’s inability to consent to sexual behaviour at the time when the offence is committed.¹¹⁰ This dynamic is easily overlooked and encourages caregivers or parents to react to all sexual acts as abusive without examination. It could be argued that the misinterpretation of ‘mental disability’ in relation to the capacity to consent infringes the constitutional rights of adults with intellectual disabilities. The possibility of misinterpreting all consensual sexual acts as abusive is heightened in the context of the duty to report¹¹¹ sexual offences against people with ‘mental disability’ and the fear of committing an imprisonable offence if any suspicion of abuse goes unreported. The misperception that people with intellectual disabilities are unable to consent to sexual behaviour may compound the fear that sexuality education that addresses sexual behaviour is unnecessary or even against the law. Current thinking around the capacity to consent as a dynamic construct¹¹² that varies from individual to individual in each circumstance needs to be addressed in the training of legal, health and education professionals, alongside the provision of comprehensive sexuality education for people with intellectual disabilities to address the topics needed to facilitate any possibility of capacity.¹¹³

6 Barriers to providing sexuality education for persons with intellectual disabilities

In Southern Africa, the need for comprehensive sexuality education is unequivocal in the face of the continuing high rates of HIV, endemic sexual abuse,¹¹⁴ teenage pregnancy and sexual violence.¹¹⁵ This need is no different for people with intellectual disabilities, who remain disadvantaged by negative attitudes toward their sexuality and a lack of accessible information. Educators commonly feel inhibited by ‘social norms’ that prevent them from providing information about sexual

108 Ch 4 Act 32 of 2007 (n 31 above).

109 Sec 57(2) Act 32 of 2007.

110 Ch 1 Act 32 of 2007 (n 31 above).

111 Ch 7 & 54 Act 32 of 2007.

112 J Rose & M Rennie ‘Managing the risks associated with sexual activity’ in L Walker-Hirsch *The facts of life and more: Sexuality and intimacy for people with intellectual disabilities* (2007) 202.

113 M Lyden ‘Capacity issues related to the health care proxy’ in M Lyden ‘Assessment of sexual consent capacity’ (2007) 25 *Sex and Disability* 8.

114 BJ Dickman & AJ Roux ‘Complainants with learning disabilities in sexual abuse cases: A 10-year review of a psycho-legal project in Cape Town, South Africa’ (2005) 33 *British Journal of Learning Disabilities* 138.

115 UNESCO (n 3 above).

behaviour.¹¹⁶ Yet, these barriers are significantly increased in relation to children and adults with intellectual disabilities due to negative beliefs about their sexuality

6.1 Ambivalence and negative attitudes

Negative beliefs concerning the sexuality of people with intellectual disabilities are pervasive worldwide.¹¹⁷ The myth of asexuality 'strengthens the belief that people with intellectual disability should not be exposed to sexuality education'.¹¹⁸ The myth of hypersexuality strengthens the fear that teaching about sexuality will increase indiscriminate sexual behaviour.¹¹⁹ This, combined with the belief that young persons with intellectual disabilities are incapable of reciprocal relationships,¹²⁰ alongside low expectations about their ability to understand the topic, means that educators, parents and caregivers feel uncertain about providing sexuality education to children or adults with intellectual disabilities,¹²¹ and are concerned about how much information is appropriate. Some parents may also avoid the topic for fear of giving their child expectations in the area of relationships that they assume are not possible.¹²²

Although the need for protection is unequivocal, this may take the form of limiting opportunities for socialising and relationships, further reducing normative opportunities for social learning and decreasing the person's self-protection skills. Misconceptions concerning the ability to consent, as discussed above, may strengthen resistance to providing information about sexual behaviour.

People with intellectual disabilities may internalise these negative attitudes about their sexuality.¹²³ The denial of sexuality as an acceptable part of the self may result in low sexual self-esteem, and exacerbate challenging behaviour, depression, inappropriate sexual attraction,

116 As above.

117 A Swango-Wilson 'Caregiver perceptions and implications for sex education for individuals with intellectual and developmental disabilities' (2008) 26 *Sexuality and Disability* 167.

118 Aderemi (n 5 above) 248.

119 As above.

120 As above

121 P Rohelder & L Swartz 'Challenges to providing HIV prevention education to youth with disabilities in South Africa' (2012) 34 *Disability and Rehabilitation* 619.

122 C Kahonde 'A grounded theory study of family caregivers responses to sexuality issues of young adults with intellectual disabilities' unpublished PhD thesis, University of Cape Town Disability Studies Programme, Department of Health and Rehabilitation Sciences (2015).

123 E Healy et al 'Sexuality and personal relationships for people with an intellectual disability. Part 1: Service user perspectives (1998) 53 *Journal of Intellectual Disability Research* 905; A Swango-Wilson 'Caregiver perceptions and implications for sex education for individuals with intellectual and developmental disabilities' (2008) 26 *Sexuality and Disability* 167.

inappropriate sexual behaviour or secretive sexual experiences.¹²⁴ There is no evidence to support fears that teaching about sexuality increases sexual behaviour in mainstream youth¹²⁵ or in youth with intellectual disabilities; rather, evidence points to sexuality education improving positive decision-making skills in people with intellectual disabilities related to sexual behaviour.¹²⁶

Another common area of resistance is in acknowledging and, thus, including respectful information about same-sex relationships in sexuality education. The Constitution states that no one should be discriminated against on the basis of their sexual orientation.¹²⁷ However, for many educators this issue remains uncomfortable and, therefore, is most likely avoided. A study on identifying effective sexuality education methods,¹²⁸ based in developed countries, suggested low levels of knowledge and negative attitudes about same-sex relationships contributes to the isolation experienced by homosexual individuals.¹²⁹ In the South African context, negative attitudes may contribute to the low visibility of homosexual individuals with intellectual disabilities.

6.2 Lack of curriculum and leadership

School-based programmes are an important platform to deliver sexuality and HIV education to learners,¹³⁰ yet messages associated with sexuality education tend to be 'negative and based in fear'.¹³¹ The new draft Department of Education policy on HIV, sexually-transmitted infections and tuberculosis presents a disease-focused intervention.¹³² This draft policy commits access to male and female condoms as well as information on their use to all learners in the basic education sector.¹³³ The draft policy also commits to increased educator training and support in the teaching of sexual and reproductive health education.¹³⁴ In the authors' experience of training educators, it is disturbing how many educators lack basic information about the sexual reproductive system and sexual development. Lack of information and mistaken beliefs prevent them from

124 L Walker-Hirsch *The facts of life ... and more. Sexuality and intimacy for people with intellectual disabilities* (2007) 58.

125 D Kirby et al 'School-based programmes to reduce sexual risk behaviours: A review of effectiveness' (1994) 109 *Public Health Reports* 339.

126 Healy et al (n 123 above).

127 Sec 9(3) Constitution (n 95 above).

128 Shaafsma et al (n 48 above).

129 As above.

130 Kirby et al (n 125 above); L de Reus et al 'Challenges in providing HIV education to learners with disabilities in South Africa: The voice of educators' in *Sex education: Sexuality, society and learning* (2015) doi: 10.1080/14681811.2015.1023283.

131 UNESCO (n 3 above) 22.

132 Department of Basic Education National Policy on HIV, STI's and TB (2015) 6.2.6.1.

133 Department of Basic Education National Policy (n 132 above) 6.2.2.4.

134 Department of Basic Education National Policy 6.2.7.

imparting accurate information or having the confidence to even begin a discussion with learners.

A recent South African study based in special schools found that educators were supportive about the need to provide sexuality education, but tended to focus on information related to personal hygiene, body development, self-respect, abstinence and the need to use condoms, but avoided topics such as sexual behaviour, contraception, sexual orientation and how to use condoms.¹³⁵ Information about sexual behaviour is most likely to be provided reactively in response to problems rather than as a tool to prevent problems.¹³⁶ Educators who are supportive of sexuality education may lack the confidence, skills or resources to present the information in an accessible format,¹³⁷ especially because the concepts are so abstract.¹³⁸ In identifying reasons to provide sexuality education, educators¹³⁹ first prioritise protection against sexual abuse and sexually-transmitted infections and, second, sexually-appropriate behaviour, such as what is public and private. These priorities reflect real concerns about the sexual risk in South Africa, as well as the real stigma associated with sexually-inappropriate behaviour. However, a supportive framework¹⁴⁰ that acknowledges pleasurable sexual experiences, alone and with others, is much less likely to be communicated, if at all.¹⁴¹ Additionally, there may be disagreement among staff about providing sexuality education to learners¹⁴² or beliefs that parents will disapprove, especially considering the taboo in many South African cultures associated with talking about sexuality.¹⁴³

Sexuality and HIV education is a compulsory part of the national curriculum¹⁴⁴ for all learners, regardless of their ability. Yet, an adapted curriculum for learners with intellectual disabilities attending LSEN schools or ordinary schools to date is lacking.¹⁴⁵ A draft skills and vocational curriculum statement for Grade R to Grade 9, to include learners with intellectual disabilities, is currently in process and is expected to be released to schools in 2017/2018.¹⁴⁶ In residential and work settings

135 De Reus et al (n 130 above).

136 Schaafsma (n 48 above); Rohelder & Swartz (n 5 above).

137 Aderemi (n 5 above); Rohelda & Swartz (n 121 above).

138 Rohelder & Swartz (n 121 above).

139 In the authors' experience of training educators.

140 L Haroian 'Child sexual development' (2000) 3 *Electronic Journal of Human Sexuality*.

141 Swango-Wilson (n 123 above).

142 Rohelder & Swartz (n 121 above).

143 De Reus et al (n 130 above).

144 The Life Orientation curriculum covers the foundation, intermediate and senior phase and can be downloaded as Curriculum Assessment Policy Statements (CAPS). <http://www.kzneducation.gov.za> (accessed 17 June 2016).

145 The new curriculum for learners with severe intellectual disability currently in process (n 35 above).

146 Basic education on development of vocational learning programme' South African government <http://www.gov.za/basic-education-development-vocational-learning-programme> (accessed 17 June 2016).

for adults, participation in sexuality education is dependent on the individual outlook and policy of each centre, leading to different approaches to or the total absence of programmes.

A more positive attitude toward sexuality education by educators is difficult, if not impossible, to maintain without a whole school approach. There is an urgent need for increased leadership from principals and the education department to prioritise and formalise sexuality education for learners with intellectual disabilities with regard to their rights expressed in the CRPD, South African law and not least due to the unacceptable levels of sexual abuse and HIV risk in South Africa.

7 Developing a sexuality education programme

Although sexuality education programmes for people with intellectual disabilities have been available in Europe and America since the 1990s,¹⁴⁷ in South Africa there are few available resources or programmes. Those available, and in use, reflect the commitment of individuals within small-scale organisations, often non-governmental organisations (NGOs), who have identified the need for this work in a 'bottom-up' approach rather than directed from above by national policy.¹⁴⁸

In advocating for the rights of people with intellectual disabilities, the Western Cape Forum for Intellectual Disability (WCFID) has developed sexuality and education programmes and resources. 'All About Me' is a group-based programme facilitated by educators and aimed at learners with intellectual disabilities from the foundation to senior phase.¹⁴⁹ This programme will be discussed in the context of a rights-based framework, identifying core components of effective sexuality education and accommodations for people with intellectual disabilities.

7.1 A rights-based curriculum

7.1.1 From foundation to senior phase and beyond

Treaty-monitoring bodies urge that sexuality education be introduced as

147 L Walker-Hirsch & MP Champagne *'Circles, level 2: Intimacy and relationships'* (2005); A Craft *Living your life* (1991); L Scott & L Kerr-Edwards *'Talking together about growing up: A workbook for parents of children with learning disabilities'* (1999); M McCarthy & D Thompson *Sex and the 3R's* (2007).

148 See Cape Mental Health Sexuality Awareness Training Programme, <http://www.capementalhealth.co.za/sexuality.html> (accessed 18 June 2016). See R Johns et al *Breaking the silence and closing the gap: Accommodating young people with disabilities in sexuality education* (2014).

149 Johns (n 11 above).

part of the primary phase, to continue throughout secondary education.¹⁵⁰ The need for sexuality education to reach children before puberty and before sexual debut¹⁵¹ is recommended to improve their sexual health outcomes.¹⁵² Children with intellectual disabilities have an equal right to accurate and age-appropriate information in preparation for puberty and the social and emotional changes of adolescence.¹⁵³ Additionally, their increased difficulty to learn through observation and to generalise and internalise information means that comprehensive sexuality education is conditional to achieving their basic rights. The All About Me programme is organised into nine modules, designed to be repeated, and extended in response to the age and learning needs of participants: modules 1-5 foundation phase; modules 1-6 intermediate phase; modules 1-8 senior phase; and modules 1-9 upper senior phase and beyond.

7.1.2 Balancing a rights and risk discourse

The tension between a rights and risk discourse in relation to the sexuality education of people with intellectual disabilities is well recognised.¹⁵⁴ The increased risk of sexual abuse, combined with conceptualising the sexuality of people with intellectual disabilities as problematic, skews content toward fear based and restrictive messages. This may have unintended consequences, as discussed above, such as reinforcing secretive sexual behaviour or maintaining low sexual self-esteem.

The need to balance messages is achieved in the All About Me programme through using social stories, pictures and activities that balance and, thus, integrates a rights and risk perspective.¹⁵⁵ Positive relationship experiences in relation to family and friends or sexual relationships can be interrogated in the context of equality, consent, autonomy and respect, alongside related feelings of joy and wellbeing. The possibility of harmful relationship experiences engendering hurt, anxiety, fear, anger and sadness can more easily be understood in relation to that which is positive.

The programme provides matter-of-fact and age-appropriate information about sexual development, sexual body functions and reproduction that normalise sexual development. Learners need to discriminate between public and private places, body parts and behaviour. Ignorance about these matters increases the likelihood of making sexual

150 CEDAW Committee Concluding Observations: Ghana para 33, UN Doc CEDAW/C/GHA/CO/6-7 (2014).

151 UNESCO (n 3 above) 24.

152 UNESCO 25.

153 Centre for Reproductive Rights (n 79 above) 5.

154 Rohelder & Swartz (n 5 above). R Johns 'Rights versus risk: Balancing perspectives in a sexuality programme for learners with moderate intellectual disabilities' unpublished MEd thesis, University of the Western Cape, 2004.

155 Johns (n 11 above)

mistakes, such as masturbation in public, and so perpetuates stigma and discrimination against people with intellectual disabilities. The tendency to treat adults with intellectual disabilities like children is a form of discrimination that impacts self-concept, behaviour and wellbeing. The 'right to grow up and be treated with the respect and dignity accorded to adults'¹⁵⁶ means that sexual development, sexual feelings and safer sexual behaviour must be acknowledged and taught in a way that is accessible and affirming.

The values in the All About Me programme reflect the 'core universal values of human rights' identified by the UNFPA as an essential component of comprehensive sexuality education.¹⁵⁷ The UNFPA argues that 'even younger learners can grasp concepts of fairness, respect, equal treatment, protection of bodily integrity and freedom from stigma and violence'.¹⁵⁸ This assertion is equally relevant to learners and adults with intellectual disabilities if their learning needs can be accommodated.

7.2 Methodology; accommodation of learning needs

7.2.1 Visual resources

There is limited research identifying evidence-based practice and efficacy of methods for this population group.¹⁵⁹ Studies are limited by small sample sizes, a lack of detail concerning goals and methods as well as the difficulty of evaluating behavioural outcomes due to the private nature of sexuality.¹⁶⁰ Schaafsma et al begin to address the knowledge gap concerning sexuality education and people with intellectual disabilities, and identify three components of an effective programme: information and instruction; modelling and rehearsing; and testing and generalising skills.¹⁶¹

The All About Me programme uses participatory group-based activities and specially-developed visual resources. These support the more concrete learning needs of people with intellectual disabilities¹⁶² and methods that do not rely on reading, writing skills or verbal skills.¹⁶³

156 A Craft & H 'Brown Personal relationships and sexuality: The staff role' in A Craft *Practice issues in sexuality and learning disabilities* (1994) 3.

157 UNFPA (n 14 as above) 10.

158 As above.

159 Schaafsma et al (n 48 above) 6.

160 As above.

161 As above.

162 L Lomofsky & M Skuy 'Educational needs related to intellectual and cognitive difference' in P Engelbrecht & L Green *Promoting learner development: Preventing and working with barriers to learning* (2001) 188.

163 De Reus et al (n 130 above).

Placing pictures into categories, that is, showing consensual and non-consensual touch,¹⁶⁴ or different kinds of relationships,¹⁶⁵ allows learners to indicate their understanding even without expressive verbal communication.

Large body outlines allow learners to draw the private body parts¹⁶⁶ or, for those who struggle with fine motor control, to stick on cut-out body parts. Fake bodily fluids made from tea, water, tomato sauce, water-based lubricant and shampoo provide concrete information about sexual bodily functions and how bodily fluids transmit STIs.¹⁶⁷ A penis made from clay illustrates ejaculation and demonstrates how condoms act as a barrier to prevent the transmission of bodily fluids.¹⁶⁸ Visual resources and interactive methods enable information and instruction to be accessible and memorable and are particularly relevant, as children and adults with intellectual disabilities often have difficulties with short-term memory.¹⁶⁹

7.2.2 Participatory methods

The UNFPA identifies participatory methods as a core component of effective sexuality education in developing 'communication, negotiation and decision-making skills'.¹⁷⁰ The UNESCO report on sexuality education in Southern Africa asserts that participatory teaching methods are a significant skills gap for teachers that need to be addressed in the delivery of comprehensive sexuality education.¹⁷¹ Participatory methods in the All About Me programme provide an opportunity for modelling and rehearsing social skills, engendering a new and shared understanding of appropriate sexual behaviour and sexual rights. Games, social stories and role play can be repeated to assess and improve learners' understanding and to offer significant opportunities for social learning, especially considering the reduced opportunities for social learning experienced by many people with intellectual disabilities. Methodology developed for learners with intellectual disabilities is relevant to an inclusive setting and the need for participatory methods that meet different learning needs.¹⁷²

The ability to generalise behaviour relies on social reasoning or the ability to learn rules and apply them repeatedly in different contexts.¹⁷³ The skill of generalising is difficult for people with intellectual disabilities. Topics taught in sexuality education need to be reinforced in other

164 Johns (n 11 above).

165 Johns (n 11 above) 62.

166 Johns (n 11 above) 71.

167 Johns (n 11 above) 89.

168 Johns (n 11 above) 127.

169 Walker-Hirsch (n 124 above) 58.

170 UNFPA (n 14 above) 13.

171 UNESCO (n 3 above) 23.

172 UNESCO (n 3 above).

173 Walker-Hirsch (n 169 above) 64.

contexts, such as the home, emphasising the importance of parental involvement. This aspect, namely, what happens outside of the programme, is the most difficult to evaluate. Interviewing participants may not reveal accurate information because of the participant wanting to provide socially-desirable answers,¹⁷⁴ or having difficulties with understanding questions or expressing themselves.

7.2.3 Involving the youth

One component of effective comprehensive sexuality education is strengthening youth advocacy, and some research shows the benefit of peer-led education programmes.¹⁷⁵ The involvement of youth in programmes facilitates personal agency, empowerment and leadership. Negative perceptions about the learning capabilities of learners with intellectual disabilities, especially in relation to sexuality education, forecloses their ability to disseminate this information. However, this perception is currently being challenged by a peer educator-led sexuality education programme in an LSEN school for learners with intellectual disabilities using the All About Me curriculum and programme.¹⁷⁶

8 Conclusion

The silence surrounding the sexuality of persons with intellectual disabilities has the result that most educators, caregivers, parents and health professionals struggle to engage with the topic,¹⁷⁷ whilst having few, if any, opportunities to re-examine their beliefs. A rights-based framework used in policy development, training and awareness campaigns can support engagement with the need for comprehensive sexuality education and an opportunity to re-examine the way in which negative beliefs impact the life experiences of persons with intellectual disabilities.

The importance of equal access to information and the right to informed consent is integral to international human rights conventions and South African law. These principles present an argument in favour of sexuality education as a human right. The denial of this right could be viewed as simultaneously negligent and directly harmful, especially in the context of South Africa, where the rate of sexual abuse and HIV infection is soaring. The denial of sexuality education is well researched as a factor increasing sexual risk and the vulnerability of people with intellectual disabilities. The lack of comprehensive sexuality education denies persons with intellectual disabilities their constitutional and legal rights, as the

174 Shaafsma et al (n 48 above).

175 UNFPA (n 14 above) 14; UNESCO (n 8 above) 24.

176 Afrikka Tikkun 'Peer educator delivery of a comprehensive health and wellness course' 4th Afrikka Tikkun Child Protection Dialogue 2016.

177 Perlin & Lynch (n 10 above).

denial of accessible information prevents any possibility of informed consent or self-protection.¹⁷⁸

For many learners and adults with intellectual disabilities, relationships are forbidden and information about sexuality and sexual behaviour remains taboo. Perceptions that people with intellectual disabilities cannot consent and, therefore, do not need sexuality education may be further entrenched by the Sexual Offences Amendment Act.¹⁷⁹ There is an urgent need to understand how the definition of mental disability in this Act impacts the sexual experiences of people with intellectual disabilities.

There is also a need for more evidence-based research into which kind of sexuality education is effective for people with intellectual disabilities to guide the development of curriculum, methods and resources.¹⁸⁰ The growing research in this area worldwide and in Southern Africa reflects an increasing engagement with the sexual rights of people with intellectual disabilities. Advocates of sexuality education programmes believe that it is possible to teach the abstract and sensitive concepts needed in sexuality education through participatory-based methods. Concurrent to this belief is the fact that learners and adults with intellectual disabilities are capable of life-long learning and development if their learning needs are appropriately accommodated.

Presently, sexuality education for people with intellectual disabilities in South Africa is driven by a small number of NGOs, individual educators and health professionals who remain passionate about the rights of persons with intellectual disabilities. The Department of Education is required to address, with increased urgency, educator training, an appropriate curriculum, the methodology and visual resources appropriate to the learning needs of learners with intellectual disabilities. Methodology suitable for learners with intellectual disabilities is conducive to an inclusive approach and may benefit learners with a wide range of learning needs.

Attitudes that sexuality education causes indiscriminate sexual behaviour leads to denying support and information about sexuality. Avoidance increases the risk of secretive, ignorant or abusive sexual experiences alongside mental health problems so common in people with intellectual disabilities. In South Africa, the long journey to acknowledge the autonomy of people with intellectual disabilities and their rights to be sexual beings, whether in a relationship or not, remains in its early stages. The provision of comprehensive sexuality education is a step in the right direction.

178 Art 14 African Women's Protocol (n 86 above).

179 Act 32 2007 (n 31 above).

180 Schaafsma et al (n 48 above) 8.