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Summary

The subject of sexual rights and disability is a largely underdeveloped sphere in relation to African rights discourse. This subject becomes even more contested and unacceptable when discussing access in relation to sexual expression or relationships amongst adolescents with disabilities. Most commonly, adolescents with disabilities are often denied their sexual autonomy and are generally depicted as being non-sexual and incapable of sexual agency. In view of this, while adolescents with disabilities continue to gain recognition as citizens with the same equal opportunities as their non-disabled peers, they have not as yet truly emerged as sexual citizens within the African context.

This article aims to (re)position discourses of sexual access in relation to adolescents with disabilities in South Africa. In particular, the article outlines the importance of supporting and nurturing the sexual autonomy of adolescents with disabilities. The article also outlines the way in which international rights conventions and national legislation may impact sexual encounters amongst adolescents with disabilities and what this means for significant adults working with adolescents with disabilities.

1 Introduction

Since the country's first democratic elections in 1994 and the ending of apartheid, South Africa has introduced several advancements in terms of

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its socio-political context, Constitution and legislation. One of the most significant advancements has been the promotion of basic human rights, which has had a particular bearing on young people with disabilities who, for the first time, were recognised as having a substantive role in the country's new Constitution.¹ In this context, South Africa is recognised as having some of the most comprehensive legislation and policies in the world that protect and promote the rights of all people with disabilities.²

At the basis of this rights legislation is the discourse of accessibility. For instance, in accordance with the basic principles of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), accessibility is recognised as a crucial component in the realisation of disability rights, and enabling people with disabilities to 'participate fully in all aspects of life ... on an equal basis with others'.³ Moreover, the discourse of accessibility is often used by the disability movement as a gauge in which to measure the lived experiences of people with disabilities within an ableist world.

In terms of children and adolescents with disabilities, much attention has been given to their rights of access in relation to inclusive education⁴ and to ending their discrimination and oppression in South Africa.⁵ Likewise, increasing attention has been given to children and adolescents with disabilities in relation to accessing HIV and AIDS services⁶ and the judicial system following sexual abuse.⁷ Despite this, very little attention has been given to access in relation to sexual expression and relationships. This becomes evident from the apparent invisibility in the CRPD of adolescents with disabilities, and the growing number of youth sexuality studies in South Africa.⁸ In view of this, while adolescents with disabilities continue to gain recognition as citizens with the same equal rights and opportunities as their non-disabled peers, they have not as yet truly emerged as autonomous sexual citizens.

1 CS Howell et al 'A history of the disability rights movement in South Africa' in B Watermeyer et al (eds) *Disability and social change: A South African agenda* (2006) 46-84.

2 AK Dube 'The role and effectiveness of disability legislation in South Africa: Disability and Knowledge Research Programme' http://www.dfid.gov.uk/r4d/PDF/Outputs/Disability/PolicyProject_legislation_sa_ex.pdf (accessed 6 December 2012).

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

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

5 Howell et al (n 1 above) 46.

6 J Hanass-Hancock 'A systematic review of literature on disability and HIV and AIDS in Africa' (2009) 12 *Journal of the International AIDS Society* 34.

7 B Dickman et al 'How could she possibly manage in court? An intervention programme assisting complainants with intellectual disabilities in sexual assault cases in the Western Cape' in Watermeyer et al (n 1 above) 116.

8 P Chappell 'Troubling the socialisation of the sexual identities of youth with disabilities: Lessons for sexuality and HIV pedagogy' in D Francis (ed) *Sexuality, society and pedagogy* (2013) 111.

In accordance with the World Health Organisation (WHO) and United Nations Population Fund (UNFPA), adolescence is defined as being between the ages of 10 and 19 years.⁹ This critical period is marked as a time of great physical and psycho-social change as individuals transition from childhood to adulthood. Regardless of this age range, the article will focus on adolescents between the ages of 12 and 19 years. The reason for focusing on adolescents over 12 years of age is guided by national legislation, mainly the Children's Act 38 of 2005. Although the Act does not directly discuss sexuality, it does allude to sexual access and the ability of adolescents over the age of 12 years to consent to HIV testing¹⁰ and to access condoms and other contraceptives¹¹ without the consent of parents or caregivers. Notwithstanding legislation, another reason for concentrating on this age group is because of the high levels of reported sexual risk-taking amongst this age group.¹² In addition, recent data on sexuality and HIV prevalence demonstrates that AIDS-related deaths have tripled since 2000 and that AIDS is now the leading cause of death among adolescents in Africa.¹³ The United Nations Children's Fund (UNICEF) also reports that over 70 per cent of adolescents aged 12 to 19 years in sub-Saharan Africa lack comprehensive knowledge about HIV or their sexual and reproductive rights.¹⁴

Against this background, the article aims at critically exploring constructions of disabled sexualities and rights discourse in relation to sexual access and adolescents with disabilities in the South African context. In particular, the article outlines the importance of supporting and nurturing the sexual expression of adolescents with disabilities. The article also outlines how international rights conventions and national legislation may impact sexual expression and encounters among adolescents with disabilities, and what this means for parents and other adults working with adolescents with disabilities. By addressing the issue of sexual access for adolescents with disabilities, the article ultimately aims to politicise what has, until now, remained an invisible and, at times, controversial topic.

After defining the concepts of disability, sexuality and sexual access, the article proceeds to explore commonly-held constructs of disabled sexualities and the invisibility of sexuality within the rhetoric of the disability rights movement in South Africa. The article then critically explores how sexuality and disability have been addressed in international rights conventions and declarations, including the CRPD, and their links

9 K Mitchell *Adolescent sexual and reproductive health toolkit for humanitarian settings* (2009) 5.

10 Sec 130(2)(a).

11 Sec 134(1)(a)-(b).

12 A Pettifor et al 'Early coital debut and associated HIV risk factors among young women and men in South Africa' (2015) 35 *International Perspectives on Sexual and Reproductive Health* 2.

13 UNICEF 'Children and AIDS 2015 Statistical Update' <http://www.childrenand aids.org/situation> (accessed 29 January 2016).

14 As above.

to national sexuality legislation. Following this, the article discusses the way in which these social and legislative constructs impact sexual access for adolescents with disabilities. Drawing from national legislation and international rights conventions and treaties that include issues of sexuality, the article then attempts to (re)position sexual access for adolescents with disabilities in South Africa, and concludes with recommendations for future practice and research.

1.1 Defining disability, sexuality and sexual access

The construct of disability in South Africa has been the subject of much historical debate, ranging from a biomedical discourse to that of a social and human rights perspective.¹⁵ For purposes of the article, disability is situated as a social construct and draws upon the CRPD, which defines disability as

an evolving concept that results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full participation in society on an equal basis with others.¹⁶

For purposes of the article, the focus will be on adolescents with sensory, physical, communication, and mild to moderate intellectual or psychosocial disabilities.¹⁷

In terms of sexuality, it is also recognised as being more than just a biological or psychological construct, and includes other significant factors such as gender, identity, desirability, love and forming meaningful relationships. In view of this, the article adopts the World Health Organisation (WHO) definition, which describes sexuality as

a central aspect of human life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.¹⁸

In acknowledgment of the WHO definition of sexuality, it is clear that when defining sexual access, it goes beyond merely sexual intercourse, and includes 'access to the psychological, social and cultural contexts and

15 Howell (n 1 above) 46.

16 CRPD Preamble (e).

17 Young persons with severe intellectual or psychosocial impairments have been excluded at this time due to ongoing debates surrounding their ability to consent to sexual practices.

18 WHO 'Defining sexual health: Report of a technical consultation on sexual health' 28-31 January 2002 http://www.who.int/reproductivehealth/publications/sexual_health/defining_sexual_health.pdf (accessed 23 May 2014).

supports that acknowledge, nurture and promote sexuality in general'.¹⁹ Therefore, the article draws upon the work of Kanguade, who categorises sexual access within two principle domains. According to Kanguade,²⁰ the first domain of sexual access acknowledges the importance of supporting and nurturing sexual expression, and covers issues such as comprehensive sexuality education and sexual autonomy. The second domain focuses upon opportunities for sexual encounters. In relation to disability, opportunities for sexual encounters stir up controversies and emotive discussions around such issues as facilitated sex, sexual surrogacy, and the use of sex workers.²¹ Although discussions surrounding access to sexual surrogates and sex workers are an important issue, they go beyond the scope of this article. Likewise, in discussing sexual encounters, the article does not promote sexual activity amongst adolescents with disabilities who lack sexual maturity.

2 Social constructions of disabled sexualities

Before discussing rights legislation in terms of adolescents with disabilities and sexuality, it is important to provide a critical overview of how disabled sexualities have emerged in social discourse. As put forward by Shildrick,²² social constructs of disabled sexuality and rights policies are 'mutually constitutive' in shaping each other and an individual's perception of their own sexual identity and practice.

The discourse on disabled sexualities has been subjected to similar a historical and apolitical disregard as that on African sexualities. For instance, popular notions about disabled sexuality have usually focused around biomedical discourses that construct people with disabilities in terms of 'deviance, lack and tragedy', and as victims of impairment.²³ As a result, ableist communities have made stereotypically incorrect assumptions about the sexualities of people with disabilities, their desirability, and their abilities to exercise agency in negotiating intimate relationships. When these assumptions intersect with other oppressions, such as the severity of the impairment, gender, age, sexual orientation,

19 R Shuttleworth & L Mona 'Disability and sexual access: Toward a focus on sexual access' (2002) 22 *Disability Studies Quarterly* 4.

20 G Kanguade 'Advancing sexual health for persons with disabilities through sexual rights' in R Shuttleworth & T Sanders (eds) *Sex and disability: Politics, identity and access* (2011) 206.

21 Kanguade (n 20 above) 207.

22 M Shildrick 'Silencing sexuality: The regulation of the disabled body' in J Carabine (ed) *Sexualities, personal lives and social policy* (2004) 143.

23 M Corker & T Shakespeare 'Mapping the terrain' in M Corker & T Shakespeare (eds) *Disability/Postmodernity: Embodiment disability theory* (2002) 2.

race and socio-economic status, it further complicates the discourse on disabled sexualities and how it is captured within rights legislation.²⁴

In most societies, prominent socio-medical discourses construct people with physical or sensory impairments as incapable of experiencing sex or intimate relationships. As portrayed by Morris, those with physical impairments are deemed 'non-sexual, or at best sexually inadequate; that they cannot ovulate, menstruate, conceive or give birth, have orgasms, erections, ejaculations or impregnate'.²⁵ This notion of being non-sexual is clearly emphasised in a study conducted amongst boys with physical impairments in Lesotho.²⁶ The boys reported that their non-disabled peers would often tease them, believing them to be incapable of having the same sexual fantasies or feelings. In essence, the boys were rejected because of their perceived incapability of performing normative constructs of sexuality and masculinity due to their physical impairments.

Besides being deemed non-sexual, those with psycho-social or intellectual impairments are often 'infantilised'²⁷ and depicted as lacking the capacity to engage in responsible sexual relationships. On the other hand, commonly-held public perceptions view those with psycho-social and intellectual impairments as over-sexed with limited social judgment to control their sexual desires.²⁸

Notwithstanding these differences in sexual abilities, the article contends that these hegemonic discourses of disabled sexuality are largely formulated through the discourse of heteronormativity. Understood in this context, it is widely accepted that heteronormativity is responsible for governing and regulating our gender roles, our sexual behaviour and, to a large extent, sexuality rights legislation.²⁹ In doing so, heteronormativity privileges narrow constructs of phallogentric (mainly that of penile-vaginal) sexuality and notions of compulsory able-bodiedness that uphold beliefs of health and fertility as normal sexuality.³⁰ As a result, those who do not embody these dominant socio-sexual norms are often marginalised and relegated as non-normative or even perverse. Quintessentially,

24 R Shuttleworth 'Disability and sexuality: Toward a constructionist focus on access and the inclusion of disabled people in the sexual rights movement' in N Teunis & G Herdt (eds) *Sexual inequalities and social justice* (2007) 174.

25 J Morris *Pride against prejudice* (1991) 20.

26 KM Motalingoane-Khau "'I never thought they do it too ...!'" Sexuality and the disabled body' (2006) Understanding Human Sexuality Seminar Series, Durban: Africa Regional Sexuality Resource Centre.

27 A Craft 'Mental handicap and sexuality: Issues for individuals with a mental handicap, their parents and professionals' in A Craft (ed) *Mental handicap and sexuality: Issues and perspectives* (1987) 14.

28 M Milligan & A Neufeldt 'The myth of asexuality: A survey of social and empirical evidence' (2001) 19 *Sexuality and Disability* 2.

29 RP Cheng 'Sociological theories of disability, gender, and sexuality: A review of the literature' (2009) 19 *Journal of Human Behaviour in the Social Environment* 1.

30 R McRuer *Crip theory: Cultural signs of queerness and disability* (2006).

heteronormative constructs of sexuality and desirability ultimately question the suitability of all people with disabilities as sexual partners.³¹

2.1 South African disability rights movement and sexuality

The medicalised and apolitical focus on disabled sexuality has drawn attention away from the rights of sexual access of people with disabilities, and fails to recognise the experiences of multiple barriers to sexual expression and relationships.³² What is more, this apolitical approach to sexuality has been inadvertently reinforced by the disability rights movement, both in South Africa and globally. For instance, although the disability rights movement in South Africa has played an influential role in terms of addressing the exclusion of people with disabilities from public issues, such as education, employment and poverty reduction strategies, the private lives of people with disabilities, that is, sexuality and identity, are not seen as equally worthy of concern.³³ This is evident in the South African country progress report to the UN General Assembly on the implementation of the CRPD.³⁴ For instance, the report highlights varying changes in terms of physical and social disability indicators, but does not include anything about sexual access. By failing to engage with sexual access as a rights-based issue, the disability rights movement in South Africa perpetuates the marginalisation of disabled sexualities. Finger, a disabled feminist activist, poignantly sums this up by suggesting:

The disability rights movement has certainly not put sexual rights at the forefront of its agenda. Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about – and formulate strategies for changing – discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction.³⁵

The continual absence of sexuality on the disability rights agenda impelled disabled feminists and disability scholars to call for the politicisation of sexuality within the disability rights movement, particularly in the Western world.³⁶ In so doing, they aimed to draw attention to the notion that the sexual socialisation of people with disabilities did not exclusively revolve around pathologised bodies, but also the structures within social communities. As portrayed by Shakespeare:

31 T Shakespeare 'Disabled sexuality: Toward rights and recognition' (2000) 18 *Sexuality and disability* 3.

32 Shuttleworth & Mona (n 9 above) 4.

33 Shakespeare (n 31 above) 159.

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

35 A Finger 'Forbidden fruit: Why shouldn't disabled people have sex or become parents?' (1992) *New Internationalist* 233 <http://www.newint.org/issue233/fruit.htm> (accessed 28 June 2009).

36 Shakespeare (n 31 above) 159.

The solution is not more prosthetics, or more Viagra, or any other physical or clinical intervention ... The barriers to the sexual expression of disabled people are primarily to do with the society in which we live, not the bodies with which we are endowed with.³⁷

The politicisation of disabled sexualities as a rights-based issue is still in its infancy in the context of Africa and the global south. Moreover, much of African disability scholarship on sexuality is primarily focused upon the rights to protection from sexual exploitation and abuse. This protection discourse may be largely influenced by the reported high incidence of sexual abuse among people with disabilities,³⁸ but also international rights treaties.

3 Disability and sexual rights in international conventions and national legislation

Before discussing the way in which international rights conventions³⁹ address disabled sexualities, it is important to give some background on how the discourse of sexuality has emerged within international conventions and treaties. According to Petchesky,⁴⁰ the terms 'sexual' and 'sexuality' did not appear in international conventions until after 1993. Prior to this, sexuality was only discussed in relation to reproductive health rights. The only exception was the UN Convention on the Rights of the Child (CRC) in 1989, which addressed protection from sexual exploitation. Sexuality-related rights only started to emerge following efforts by transnational women's advocacy groups at the International Conference on Population and Development in Cairo in 1994, and the International Conference on Women in Beijing in 1995.⁴¹ Their efforts resulted in the UN incorporating reproductive health with freedom from sexual violence and equality between men and women in relationships.

Reflecting critically on sexuality rights in UN conventions and treaties, although discussions surrounding sexuality rights have been extended to include sexual orientation and the sexual rights of minors, sexuality rights still predominantly relate to health, protection and public morals. To date, UN conventions have not included regulation on sexual behaviour or access.⁴² As far as South Africa is concerned, the notion of international regulation on sexual access could be a bitter pill to swallow, especially

37 Shakespeare (n 31 above) 161.

38 Hanass-Hancock (n 6 above) 5.

39 For the purpose of this article, this mainly focuses on the CRPD.

40 R Petchesky 'Sexual rights: Inventing a concept, mapping an international practice' in R Parker (ed) *Framing the sexual subject: The politics of gender, sexuality and power* (2000) 81.

41 M Schaff 'Negotiating sexuality in the Convention on the Rights of Persons with Disabilities' (2011) 8 *International Journal of Human Rights* 14.

42 A Miller 'Sexuality and human rights: discussion paper' (2009) Geneva: International Council on Human Rights Policy http://www.ichrp.org/files/reports/47/137_web.pdf (accessed 5 February 2016).

given previous colonial and apartheid racial legislation regarding sexual behaviour in the country.⁴³

3.1 Sexuality and disability in the Convention on the Rights of Persons with Disabilities

In terms of disability, the CRPD clearly recognises the full and equal participation of all people with disabilities in all aspects of life. Included in this are several rights pertaining to sexuality. These include the rights to freedom from exploitation, violence and abuse;⁴⁴ respect for the home and family;⁴⁵ and the right to health.⁴⁶ Besides protection from abuse and sexual violence, these specific articles highlight the right to reproductive health information and the right to marry and have children. Reflecting critically on these sexuality-related rights, although they do acknowledge people with disabilities as sexual agents, and also issues of gender, reproduction, and protection from abuse, the CRPD, like other UN conventions and treaties, fails to explicitly mention sexual access, and ultimately continues to promote a heteronormative gaze. As a result, issues surrounding sexual diversity, promoting positive sexual identity development, sexual expression, and sexuality education remain invisible within the international disability rights discourse.⁴⁷

However, this has not always been the case. For instance, the United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, which informed the backdrop of the CRPD and national disability legislation, clearly call for the politicisation of disabled sexualities in Rule 9(2), which unequivocally states:

Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. Persons with disabilities must also have the same access as others to family planning methods, as well as to information in accessible form on the sexual functioning of their bodies.⁴⁸

In addition to this, Rule 9(3) states:

43 For further reading on previous sexual legislation in South Africa, refer to P Delius & C Glaser 'Sexual socialisation in South Africa: A historical perspective' (2002) 61 *African Studies* 1.

44 Art 16(2) of the CRPD.

45 Art 23(b) of the CRPD.

46 Art 25(a) of the CRPD.

47 D Higgins 'Sexuality, human rights and safety for people with disabilities: The challenge of intersecting identities' (2010) 25 *Sexual and Relationship Therapy* 3.

48 UN General Assembly, Standard Rules on the Equalisation of Opportunities for Persons with Disabilities: Resolution adopted by the General Assembly, 20 December 1993, A/RES/48/96.

States should promote measures to change negative attitudes towards marriage, sexuality and parenthood of persons with disabilities, especially of girls and women with disabilities, which still prevail in society.⁴⁹

According to Schaaf, the failure to explicitly include sexual access in the CRPD was not only due to pressure from the Vatican and other religious states to limit sexual rights, but also because of widespread concerns about eugenic practices and the 'centrality of the body in conceptions of disability'.⁵⁰ Moreover, reflecting on both the CRPD and Standard Rules, both fail to address the needs of adolescents with disabilities. Given the invisibility of sexual access and disabled adolescents in the CRPD and other UN conventions and treaties, it may provide a reason as to why national states and the disability rights movement in South Africa have not readily politicised the issue of disabled sexualities within their own legislation. In this regard, concepts of disabled sexual rights remain inadequate, with what Miller describes as 'troublesome but predictable disjunctures [that] constrain the evolution of coherent and progressive policy positions in this area [of disabled sexual rights]'.⁵¹

3.2 Sexuality and disability in national legislation

As outlined earlier in this article, South Africa is recognised for its comprehensive legislation and policy development in relation to disability rights. However, similar to the CRPD and other UN conventions, rights in relation to sexual access and disability are minimal; however, rights in terms of protection from abuse appear strongly in national sexuality-related legislation. An example is the Criminal Law (Sexual Offences and Related Matters) Amendment Act 5 of 2015, which includes two parts related to 'sexual offences against children, and persons who are mentally disabled'.⁵² In summary, the Act states that youths and adults who are 'mentally disabled' (either intellectually or psycho-socially) are unable to consent to sex and, therefore, any attempt at a sexual act is deemed an offence.

In a first reading of the Act, it is often misunderstood that the Act is applicable to everyone with an intellectual or psychosocial disability, and is often used as a means of preventing sexual encounters amongst adolescents with varying intellectual disabilities. However, on closer reflection, in particular the definitions in Chapter 1, the Act defines 'persons who are mentally disabled' as any person who, as a result of a disorder or disability of the mind, is:

49 Standard Rules (n 48 above) Rule 9 relates to family life and personal integrity.

50 Schaaf (n 41 above) 119.

51 Miller (n 42 above) 1.

52 Ch 7, Part 1 & 2 of Criminal Law (Sexual Offences and Related Matters) Amendment Act, 2015.

- (a) not able to understand the nature and outcomes of the sexual act;
- (b) able to understand the sexual act but unable to make a proper decision based on this understanding;
- (c) unable to resist the sexual act; or
- (d) unable to show that she does not want to take part in the sexual act.⁵³

Given this context, it is evident that the Act does not prevent sexual encounters amongst adolescents with disabilities (including those with intellectual or psycho-social impairments) who can understand the nature and outcome of a sexual act, and who are able to consent to sexual acts.

4 Sexual silence of adolescents with disabilities

The continual subjugation of disabled sexualities and the silence surrounding adolescents with disabilities within the CRPD has played a significant role in the understanding of sexual access in relation to adolescents with disabilities in South Africa. This is made evident by the fact that adolescents with disabilities are generally discouraged by their parents or caregivers and other significant adults from discussions around sexuality, and are often inhibited from expressing their sexuality. For instance, in a study in the Northern Cape, Sait et al⁵⁴ found that the mothers of girls with intellectual disabilities ignored their daughters' attempts to talk about issues of a sexual nature. What is more, the majority of the mothers perceived sexuality education as consisting only of discussing the sex act, which they believed was inappropriate for their disabled daughters. Similar findings were reported among parents of adolescents with physical disabilities in the Western Cape, who limited sexual discussions with their disabled offspring, believing them to be non-sexual and not in need of sexuality education.⁵⁵ Similarly, it was found that Xhosa-speaking parents of disabled youth in the Eastern Cape were reluctant to talk about issues of sexuality because of doubts about the sexual and reproductive capacities of youths with disabilities.⁵⁶ As a result, the youths with disabilities who took part in the same study indicated that their non-disabled siblings were reportedly more valued as reproductive family members, leaving the disabled siblings feeling rejected. Contrary to these studies, a study amongst Zulu-speaking adolescents with disabilities in KwaZulu-Natal revealed that their lack of sexual communication with their parents or caregivers was no different from that of their non-disabled

53 Centre for Applied Legal Studies & Tshwaranang Legal Advocacy Centre *A summary of the Criminal Law Sexual Offences Amendment Act 32 of 2007* (2008) 13.

54 W Sait et al 'Sexuality, gender and disability in South Africa' in S Tamale (ed) *African sexualities: A reader* (2011) 50.

55 M Wazakili et al 'Experiences and perceptions of sexuality and HIV/AIDS among young people with physical disabilities in a South African township: A case study' (2006) *Sexuality and Disability* 24.

56 J McKenzie 'Disabled people in rural South Africa talk about sexuality' (2013) 15 *Culture, Health and Sexuality* 3.

siblings. Instead, the young participants attributed this lack of sexual communication to cultural practices and the inability of parents or caregivers to talk about sexuality.⁵⁷

4.1 Sexuality education in schools

With the reported inability of parents and caregivers to discuss sexuality, and their apparent lack of awareness surrounding sexuality rights, more emphasis has been placed on educators to provide moral (sexual) guidance. However, given the fact that nearly half a million children and adolescents with disabilities in South Africa do not attend school,⁵⁸ it is clear that they are exempt from these efforts to provide sexuality education. Nevertheless, those adolescents with disabilities who do attend school are often exempt from efforts at sexuality education.⁵⁹ It is reported that some educators in South Africa believe that discussing sexuality would only encourage adolescents with disabilities to go ahead and practise sexual activities.⁶⁰ Contrary to this, however, some educators working in special education did recognise the importance of providing sexuality education to learners with disabilities, but the way in which it was delivered differed between schools and educators.⁶¹ Furthermore, as indicated by De Reus, educators of learners with intellectual disabilities were less inclined to discuss sexuality in detail, as they assumed that the learners would not understand.⁶²

These differences in terms of the provision of sexuality education are exacerbated by a reported lack of skills and resources on the part of educators in terms of conveying sexuality messages in accessible and understandable format to learners with disabilities.⁶³ Moreover, with the invisibility of disabled sexuality in initial teacher education and national guidelines in teaching sexuality education, educators also reported tensions between the discourses on human rights and the restriction of sexual behaviour of adolescents with disabilities.⁶⁴ This conflict between rights and sexual access will be discussed below.

57 P Chappell 'Secret languages of sex: Disabled youth's experiences of sexual and HIV communication with their parents/caregivers in KwaZulu-Natal, South Africa' (2015) 16 *Sex Education* 405.

58 Human Rights Watch (n 4 above) 1.

59 N Groce 'Adolescents and youth with disability: Issues and challenges' (2004) 15 *Asia Pacific Disability and Rehabilitation Journal* 2.

60 P Rohleder & 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* 4.

61 L De Reus et al 'Challenges in providing HIV and sexuality education to learners with disabilities in South Africa: The voice of educators' (2015) 15 *Sex Education* 333.

62 As above.

63 P Rohleder et al 'Challenges to providing HIV prevention education to youth with disabilities in South Africa' (2012) 34 *Disability and Rehabilitation* 8.

64 Rohleder & Swartz (n 60 above) 605.

Apart from a reluctance on the part of adults to discuss sexuality issues, attempts at sexual expression or sexual encounters are often also chastised or prevented. This is particularly evident amongst adolescents with intellectual disabilities living in institutional care or educational settings. For example, studies in New Zealand⁶⁵ and Canada⁶⁶ demonstrate how a lack of privacy, combined with negative attitudes of caregivers and support staff, reduced opportunities for the development of intimate relationships in institutional care settings. Moreover, attempts at sexual acts by young residents with intellectual disabilities were generally classified as problematic behaviour rather than as expressions of love and intimacy.⁶⁷ In addition to attitudes towards sexuality and disability, issues of morality and religion also play an integral role in preventing sexual encounters. This was revealed in a study conducted amongst educators and support staff in a Christian residential organisation for adolescents and young adults with intellectual disabilities in the Western Cape. Some educators identified a conflict between their Christian beliefs and the promotion of sexual rights, as identified in the following extract:

If an organisation were to recognise the sexual rights of persons with learning disabilities, and provide condoms to residents, there will be a perceived condoning of sexual relationships occurring outside of marriage.⁶⁸

To overcome this moral dilemma and to manage sexual behaviour, educators would make it difficult for the residences to access condoms, and did not provide private spaces in which couples could meet.⁶⁹ Critically analysing this situation, the lack of privacy and access to condoms not only goes against the Children's Act, but would undoubtedly not deter curious adolescents with disabilities from having sexual encounters. If anything, this situation may perpetuate risky sexual behaviour and heighten risks of unplanned pregnancies, rape and HIV infection.

Separate from the doubts concerning the sexual capacities of adolescents with disabilities, Milligan and Neufeldt⁷⁰ contend that the reluctance of both parents, caregivers and educators to engage with the discourse of sexual access may be further attributed to their efforts to protect adolescents with disabilities from future rejection and vulnerability to sexual abuse. These concerns about abuse also intersect in the control of reproduction and use of forced or coerced sterilisation to protect young disabled women from pregnancy following sexual abuse.⁷¹ This is of

65 CA Hamilton "Now I'd like to sleep with Rachael" – Researching sexuality support in a service agency group home' (2009) 24 *Disability and Society* 3.

66 A Saxe & T Flanagan 'Factors that impact support workers' perceptions of the sexuality of adults with developmental disabilities: A quantitative analysis' (2014) 32 *Journal of Sexuality and Disability* 45.

67 Hamilton (n 65 above) 304.

68 Rohleder & Swartz (n 60 above) 606.

69 As above.

70 Milligan & Neufeldt (n 28 above) 93.

71 Schaff (n 41 above) 14.

particular relevance in the South African context, where sexual and gender-based violence is rife and where children and youths with disabilities are two to five times more likely to experience sexual abuse than their non-disabled peers.⁷²

A closer reflection on the various attitudes of parents/caregivers and educators towards the sexuality of adolescents with disabilities clearly reveals that sexuality is presented as a dangerous and risky discourse. These notions of sexuality as 'dangerous' or 'risky' are not unique to the disability discourse, but also feature prominently in South African sexuality discourse and national legislation.⁷³ Given this perspective, instead of recognising the sexual agency of adolescents with disabilities, parents/caregivers and educators have tended to focus on the construct of adolescents with disabilities as innocent and, therefore, in need of protection. Although not denying the importance of protection from harm, it is argued that the discourse of innocence 'constructs young [disabled] people as un-knowledgeable about sexuality, sexual practice and their own bodies, and inherently creates young [disabled] people as pure'.⁷⁴

Although the discourses of innocence and purity are also related to non-disabled adolescents,⁷⁵ it is more pronounced amongst adolescents with disabilities as it is believed that sex will never form a part of their lives. This continual silence surrounding sexuality and adolescents with disabilities demonstrates not only adultist constructs of adolescence, but ableist constructs of disabled sexuality. Quintessentially, it also demonstrates a general disregard for recognising the sexual agency and rights of adolescents with disabilities. As argued by Coppock, the discourses of silence and protectionism does nothing more than 'skilfully disguise a fundamental distrust in young [disabled] peoples' competence'.⁷⁶ Moreover, the silence surrounding sexual access and adolescents with disabilities reflects a powerful discourse that ultimately culminates in the regulation of young disabled sexual identities.

4.2 Sexual self-esteem and adolescents with disabilities

As a result of the silence and invisibility of adolescents with disabilities in terms of sexual access, many disabled adolescents may lack the confidence to find out how to discuss matters of sex, love and relationships.⁷⁷ This, for example, was identified in a qualitative study in the United Kingdom,

72 Hanass-Hancock (n 6 above) 5.

73 Posel (n 43 above) 1.

74 C Mitchell et al 'Visualising the politics of innocence in the age of AIDS' (2004) 4 *Sex education: Sexuality, society and learning* 36.

75 V Coppock 'Children as peer researchers: Reflections on a journey of mutual discovery' (2010) 25 *Children and Society* 6.

76 Coppock (n 75 above) 439.

77 Shakespeare (n 31 above) 3.

which sought to understand disabled sexuality amongst 44 disabled persons in the UK.⁷⁸ The study found that, although respondents were able to talk in general about their lives and issues of identity and barriers, they had difficulty talking about relationships and sexuality. As a consequence of not being able to speak openly about sexuality, it could in turn increase the vulnerability of adolescents with disabilities to abusive relationships and continue to privilege hegemonic notions of non-sexuality.

Similarly, in the South African context, as children and youths with disabilities are often 'hidden' away, either in their own homes or distant schools or institutions, it is argued that adolescents with disabilities may experience a different sexual identity development process than their non-disabled peers, as the knowledge that they are 'different' is always present.⁷⁹ Consequently, in the absence of positive role models and because of their need to 'fit in' with their peers, some adolescents with disabilities may try to overcompensate for their physical and psycho-social differences.⁸⁰ This became evident in a study amongst Zulu-speaking older adolescents with visual and physical disabilities in KwaZulu-Natal, where it was reported that, in an effort to overcompensate for their differences and fit in with their non-disabled peers, some disabled adolescents displayed behaviour that put them at high risk of sexual exploitation, abuse and HIV infection, all in an attempt to prove their self-worth.⁸¹

5 Sexual rights versus the need for protection: (Re)positioning adolescents with disabilities

Reflecting on the various studies, the CRPD and other legislation discussed in the article, it is clear that the sexuality of adolescents with disabilities in South Africa is constructed as a danger both to themselves and others and, at times, is perceived as socially unacceptable. As a result, any attempt at sexual communication or sexual expression is deemed undesirable and in need of adult and state intervention. Understood in this way, the notion of sexual access for adolescents with disabilities is manipulated and contrived in social and legislative contexts by important adults who are generally perceived as having more power. In the context of adolescents with disabilities, these important adults are the parents or caregivers, educators and government departments, who through their given positionality are able to enforce certain vocabularies and values and

78 T Shakespeare et al *The sexual politics of disability* (1994).

79 Sait et al (n 54 above) 50.

80 C Johnstone 'Disability and identity: Personalised constructions and formalised supports' (2004) 24 *Disability Studies Quarterly* 4.

81 P Chappell 'The social construction of the sexual identities of Zulu-speaking youth with disabilities in KwaZulu-Natal, South Africa, in the context of the HIV pandemic' unpublished PhD thesis, University of KwaZulu-Natal, 2013 180.

in effect control and protect the discourse of sexuality amongst adolescents with disabilities.

As far as South Africa is concerned, the need for control over and protection of adolescents with disabilities has been justified because of the current climate where issues such as HIV and AIDS, gender-based violence and sexual exploitation of children and youths with disabilities are rife. However, in critically analysing this protectionist approach, it not only constructs sexuality as a dangerous and risky discourse, but also renders adolescents with disabilities as void of sexual agency. This undoubtedly has a two-fold effect on disabled adolescents. First, it marginalises the (sexual) voices of adolescents with disabilities and, second, it may also impact on the individual and their perceptions of their own sexual identity, desirability and, possibly, their perceptions regarding the risk of HIV. In this regard, it is argued that by taking a solely protectionist approach to sexual access, it can be a potentially 'disempowering act', which fails to recognise the sexual rights of adolescents with disabilities.⁸²

Although not denying the significance of protection, the article calls for a more balanced, holistic approach between the need for protection and recognition of the rights of adolescents with disabilities to access their sexualities. However, in order to achieve this balance, it is necessary to recognise the fluidity of power and that adolescents with disabilities also have the potential to exercise agency and trouble constructions of their sexual identities and notions of sexual access. In adopting this approach, we need to (re)position adolescents with disabilities as sexual beings who, in line with Marr and Malone's concept of the 'agentic child', are 'capable and competent agent(s) who replicate and appropriate aspects of their culture through their talk and interaction with others, thereby actively participating in the construction of their own social situations'.⁸³ Given this perspective, adolescents with disabilities are positioned as 'knowers' or experts in their own lives.⁸⁴ The notion of adolescents with disabilities as 'knowers' troubles constructs of innocence and encourages adults to take cognisance of the knowledge and experiences disabled adolescents already have regarding sexuality.

To some extent, this approach has been acknowledged within the recent Department of Social Development's national adolescent sexual and reproductive health and rights framework strategy, 2014-2019.⁸⁵ In

82 D Francis et al 'Deconstructing participatory research in an HIV/AIDS context' (2006) 38 *Journal of Education* 141.

83 P Marr & K Malone 'What about me? Children as co-researchers' <http://www.aare.edu.au/data/publications/2007/mar07118.pdf> (accessed 5 February 2016).

84 D Francis 'Sexuality education in South Africa: Three essential questions' (2010) 30 *International Journal of Educational Development* 3.

85 Department of Social Development *National adolescent sexual and reproductive health and rights strategy framework, 2014-2019* (2015).

the milieu of South Africa's growing youth population, the aim of the strategy is to address some of the gaps in the provision of sexual and reproductive health care for adolescents (defined between the ages of 10 to 19 years) and to call for

the development of an inclusive agenda that intends to promote the quality of life and the right to choose whether and when to have children; the right to exercise sexuality free of violence and coercion; the right to seek pleasure with respect for other people's rights; the right to protect fertility; and the right to access modern techniques for the prevention, diagnosis and treatment of sexually transmitted infections.⁸⁶

As part of its commitment to developing an 'inclusive agenda', the strategy framework acknowledges adolescents with disabilities. Furthermore, reflecting on the five key priorities in the strategy framework, it attempts to ensure that the (sexual) voices of adolescents are heard, and that parents/caregivers and other significant adults are trained in the sexual and reproductive health rights of adolescents with disabilities. In taking a rights-based approach, although the strategy does not include any indicators, it does, however, start to positively acknowledge both the sexual agency of adolescents with disabilities, and their rights to sexual access.

6 Recommendations

To conclude the article, the following recommendations are put forward:

- There is a need to develop a draft sexuality rights policy within the disability sector, which aims at creating optimal and safe conditions for adolescents with disabilities to experience positive relationships, sexuality and sexual health.
- Further research is required amongst adolescents with disabilities in South Africa to gain a better understanding of their experiences of sexual access and sexuality rights. In line with the concept of adolescents with disabilities as experts in their own lives, research efforts should engage adolescents with disabilities as co-researchers. The findings from this research may contribute to developing comprehensive indicators in relation to disabled adolescents and the national adolescent sexual and reproductive health and rights framework strategy.
- Comprehensive sexuality educational programmes that use a rights-based approach are needed for parents/caregivers and educators of adolescents with disabilities. From the outset, these educational programmes must recognise adolescents with disabilities as 'capable social agents' and not merely innocent vessels when it comes to sexuality and HIV.

86 Department of Social Development (n 85 above) 6.