

Поддержка сексуальной идентичности, благополучия и безопасности молодых людей с ограниченными возможностями







"Disabled People Are Sexual Citizens Too": Supporting Sexual Identity, Well-being, and Safety for Disabled Young People

Sonali Shah*

Centre for Disability Research, Institute of Health and Wellbeing, University of Glasgow, Glasgow, United Kingdom

Disabled young people are sexual beings, and deserve equal rights and opportunities to have control over, choices about, and access to their sexuality, sexual expression, and fulfilling relationships throughout their lives. This is critical to their overall physical, emotional, and social health and well-being. However, societal misconceptions of disabled bodies being non-normative, other, or deviant has somewhat shaped how the sexuality of disabled people has been constructed as problematic under the public gaze. The pervasive belief that disabled people are asexual creates barriers to sexual citizenship for disabled young people, thereby causing them to have lower levels of sexual knowledge and inadequate sex education compared to their non-disabled peers. As a consequence, they are more vulnerable to "bad sex" - relationships, which are considered to be exploitative and disempowering in different ways. Access to good sex and relationships education for disabled young people is, therefore, not only important for them to learn about sexual rights, sexual identity, and sexual expression but also about how to ensure their sexual safety. In so doing, it will contribute to the empowerment and societal recognition of disabled people as sexual beings, and also help them resist and report sexual violence. Therefore, it is critical that parents, educationalists, and health and social care professionals are aware and appropriately equipped with knowledge and resources to formally educate disabled young people about sexuality and well-being on par to their non-disabled peers.

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*Correspondence:

Sonali Shah sonali.shah@glasgow.ac.uk

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INTRODUCTION AND BACKGROUND

1

Disabled young people are sexual beings, and deserve equal rights and opportunities to have control over, choices about, and access to their sexuality, sexual expression, and fulfilling relationships throughout their lives. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006) guarantees disabled people the right to "enjoy legal capacity on an equal basis to others in all aspects of their lives." Although not explicit in the Article, such aspects include those pertaining to sex and relationships. Sexuality and sexual relationships are fundamental parts of every human life, and are critical to overall physical, emotional, and social health and well-being. As pointed out by the World Health Organization (2012), sexuality is a global

issue, central to human development and thus "... 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." Armed with knowledge about sexual rights, and differences between "healthy" and "risky" sexual choices and exchanges, disabled people are also better positioned to resist sexual violence and abuse (SVA) in different social spaces.

In the Convention for the Protection of Human Rights and Fundamental Freedoms, Article 8, everyone has the fundamental right to a private life, family life, personal development and right to develop healthy relationships with others (European Human Rights Convention, 1953). Within "private life" includes the right to a sexual life, and to engage in relationships of their choice with others as long as it did not involve hurting others. Although sexuality is conceived as a "private" matter, it is highly regulated by institutional and individually directed normative values. Sexual citizenship is about ascertaining legal and social rights for a sexual identity (Bacchi and Beasley, 2002). However, it can be argued that as disabled bodies are constructed as nonnormative, the sexuality of disabled people is not accepted but seen as problematic under the public gaze. As Shildrick (2013), p. 3, put it "both sex and disability threaten to breach certain bodily boundaries that are essential to categorical certainty and, as such, they provoke widespread anxiety."

Disabled young people have historically been excluded from dominant processes of socialization and learning that prepare people for love, sex, and reproduction (Shakespeare et al., 1996; Davis, 2000). Parents, educationalists, and health professionals often feel uncomfortable or unprepared to discuss issues around sexuality with disabled young people (East and Orchard, 2014). As discussed above, this could be attributed to the exclusion of disabled people from normative definitions of sexuality coupled with the pervasive societal devaluation of disability and the cultural scripts that portray disabled people as asexual beings (Payne et al., 2016). For instance, D. H. Lawrence's publication, Lady Chatterley's Lover, does not condemn the act of an extramarital affair of a woman married to a disabled man, fueling a widespread assumption that disabled people are incapable of sexual relations (Battye, 1966; Shah et al., 2015). Even twentyfirst century on-screen portrayals of the sexual body are focused on the non-disabled body. One example is Dove Company's "Campaign for Real Beauty," which failed to include disabled women (Heiss, 2011).

The invisibility and oppression of disabled people's sexual lives in public spaces contributes to disabled young people's low levels sexual knowledge and inadequate sex education compared to their non-disabled peers. As a consequence, they are more vulnerable to "bad sex" (Shakespeare et al., 1996), ranging from areas such as prostitution and pornography, to sexual violence, unplanned pregnancies, and sexually transmitted diseases. Although these are distinct areas, they all involve relationships which are considered to be exploitative and disempowering in different ways.

The stigma, limited communication, and inadequate resources in relation to sexuality and disability can have detrimental effects on the physical and psychological health and

well-being of disabled young people. It can lead to confusion about their sexual identity, reduced self-esteem, and self-doubt about their status as a sexual being. This, coupled with high levels of dependency on non-disabled adults for personal care, introduces risk to young people, thereby potentially increasing their exposure to violence (Shakespeare et al., 1996; Nosek et al., 2001; Mandl et al., 2014; Shah et al., 2016a,b), and other "bad sex" highlighted above. Access to good sex and relationships education for disabled young people is, therefore, not only important to learn about sexual rights and sexual expression but also about sexual safety.

SEXUAL VIOLENCE AND CHILD PROTECTION

The UNCRPD states that disabled people should be protected from violence, exploitation and abuse (Article 16), inhuman and degrading treatment, and punishment (Article 15). However, national and international evidence indicates that disabled children are at greater risk of SVA than non-disabled children (Sullivan and Knutson, 2000; Jones et al., 2012). The risk of SVA toward disabled children during their lifetime is three to four times greater than toward non-disabled children. It starts in early childhood, is more severe, and may be connected to the prevailing disablism in society, which views disabled children and young people as inferior to their non-disabled contemporaries. Furthermore, the type of violence experienced can be connected to having a particular impairment, and can be perpetrated by individuals and result from institutional practices that are part of disabled children's everyday life (Shah et al., 2016a,b). Indicators of abuse are often misdiagnosed as related to individual impairment and not recognized as violence by professionals or the victims themselves. First-hand accounts of the experiences and consequences of sexual violence in the childhoods of disabled people are just beginning to emerge (Jones et al., 2012; Taylor et al., 2015; Shah et al., 2016a,b).

Official definitions of childhood abuse used within mainstream child protection fail to grasp the full range of maltreatment experienced by disabled children, which often goes beyond that experienced by many non-disabled children. Hernon et al.'s (Hernon et al., 2015) review reveals how disabled children are largely excluded from mainstream child protection policies due to societal disablism which create barriers to disclosure and support. This includes professionals' views toward abuse against disabled and non-disabled children. Kennedy (1996), and more recently, Taylor et al. (2015) argue that there is a notion, among professionals, that abuse toward disabled children is more acceptable than when directed toward non-disabled children. They revealed how this was due to practitioners over-empathizing with parent/carer-perpetrators who were seen to be under increasing stress with caring for a disabled child. The differential perceptions of violence toward disabled children and non-disabled children are not new. In the early 90s by Marchant (1991) and Kennedy (1992), revealed views such as "sexual abuse of disabled children is OK, or at least not as harmful as sexual abuse of other children" (Marchant, 1991: p. 22) or "these children won't understand what's

happened, therefore won't be damaged by it" (Kennedy, 1992: p. 186). However, these do influence the extent to which disabled children are listened to and believed when attempting to disclose.

In addition, diagnostic overshadowing by health service providers (i.e., the tendency to attribute signs of violence to the person's impairment) is likely to mask child protection concerns (Murray and Osborne, 2009; Jones et al., 2012). Westcott and Cross (1996) argue that little account is taken of disabled children's communication and information requirements. Where they cannot use traditional communication methods, they are forced to remain silent or depend on proxies, who may be the perpetrators. Even where assistive communication tools are used, these do not always include vocabulary to describe intimate and inappropriate acts toward them and interpreters may also be perpetrators. In terms of information, materials developed for "prevention programmes" are not always sensitive to the needs of children with different learning and communication styles.

Disabled children are likely to encounter potentially risky actions and practices, specific to being disabled. For instance, their use of segregated services and institutional facilities, and dependency on adults without impairments for basic personal and social needs will place them in potentially vulnerable situations and increase their risk to SVA. However, as such practices are a normalized part of the everyday life of a disabled child, they are unlikely to be considered as unsafe. Drawing on the social relational interpretation of disability (Thomas, 2004), it is important to stress that it is not a child's impairment that provokes abuse, but rather the institutional context in which they are placed and the practices they are coerced to endure-all of which are constructed by adults with a non-impairment status, a status deemed relatively powerful. Therefore, listening to and understanding the perspectives of disabled victim-survivors of childhood violence is essential to improve relationships across the ecological spectrum and highlight practices that oppress and infringe their human rights (HM, 2011).

Disabled child victim-survivors may not always recognize signs of violence, nor realize when they are being abused. Cossar et al. (2013) suggest how recognition is often gradual and operates along a spectrum from "no recognition" to "clear recognition." Barriers to recognition include disabled children's limited access to social networks and opportunities to compare life stories with friends and family; inadequate formal learning about sexual relationships and sexual health, and exclusion from informal social spaces where sexual exchanges and boundaries are explored (Watson et al., 2000; Nosek et al., 2001). Thus, it is critical for schools to provide the sex and relationship education to disabled children on the same level as to non-disabled children, with learning materials and resources accessible to the individual needs of the child.

POLICES, RIGHTS, AND EDUCATION ON SEXUALITY

Sexual identity is a basic human right and an essential aspect of healthy development. Rule 9.2 of the UN Standard Rules on the Equalization of Persons with Disabilities argues that disabled people have a right to "...experience sexuality, have sexual relationships...information in accessible form on the sexual functioning of their bodies." (United Nations, 1993: 9.2). The UNCRPD (United Nations, 2006) reinforces the rights of disabled children and adults, including their rights to express their views and have an opinion (Article 7, Article 21); to have access to justice (Article 13) information (Article 21) and education (Article 24) on the same level as their non-disabled peers. The United Nations Convention on the Rights of the Child (United Nations, 1989) outlines states' responsibilities to respect and ensure children's rights to protection (Article 19); to express their views and to have these views taken seriously (Article 12); and to be provided with support, including to aid recovery from abuse (Article 36).

However, unlike discrimination in education or employment, access to sexuality and relationships does not get priority status on the equality agenda even though it is a basic human right and an essential aspect of health and development. As the American sociologist and disabled woman, Finger (1992), p. 9, puts it:

Sexuality is often the source of our deepest oppression; it is 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.

Even in popular culture—film, TV sitcoms, and novels—disabled people are rarely portrayed as sexually attractive or active. While their public lives in public spaces are accepted as valid topics for public discussion, their private lives (sexuality and emotional desires and needs) are perceived as taboo and excluded from public discussions about the everyday (Lamb and Layzell, 1994). The negative messages relating to disabled people as sexual beings in popular culture inevitably shapes both public attitudes and disabled people's own understandings of their potential to be sexual beings and engage in romantic relationships.

Not only are these sexual representations of disabled people absent in the cultural scripts disabled children are exposed to growing up but also such knowledge does not feature in their formal and informal education. Disabled children and young people's exclusion from certain social spaces impacts their exposure to sexual knowledge and sexual opportunities during this crucial period of development. Shah (2005) and Morris (1997) suggest that disabled children are excluded from important social processes and childhood socialization by differential mechanisms of surveillance and segregation, and are consequently prevented from developing their sexuality and exploring their sexual identity and body at the same level as non-disabled children.

Formal sex education has been, at best severely truncated and watered down, or at worst absent from the lives of physically disabled students (East and Orchard, 2014). This is generally related to the perception that disabled people are eternal children "innocent, naïve, and asexual" (p. 336) and incapable in any form of sexual expression and exchange. Further educators, parents, and health professionals are unprepared and lack the appropriate knowledge and resources to teach disabled young people about

such matters. Therefore, further research is important and necessary to address such a dearth in knowledge.

CONCLUDING COMMENT

Exploring the views and concerns of health professionals, educators, parents, and disabled young people in relation to issues of sexuality and disability is important to inform the development of inclusive resources for disabled young people to learn about sexual health and sexual safety in different spaces. Such knowledge will also contribute to micro, meso, and macro level social changes in relation to the sexual citizenship of disabled people.

AUTHOR NOTES

SS is a senior research fellow in disability equality and human rights. Her work adopts qualitative methods to explore the social

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inclusion and social equity for disabled people across the life course and intersectional identities—ages, genders, and ethnicities. A key concern of her research is to ensure the voices of historically marginalized and oppressed populations are listened to and included in policies and practices that affect their well-being and participation in society. She is the author of Career Success of Disabled High-Flyers (Shah, 2005), Young Disabled People: Aspirations, Choices and Constraints (Shah, 2008) and co-author of Disability and Social Change—Private Lives and Public Policies (Shah and Priestley, 2011). She has also published in high-quality journals the areas of disability and violence, educational policy, and qualitative methods.

AUTHOR CONTRIBUTIONS

The author confirms being the sole contributor of this work and approved it for publication.

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