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Disability and sexuality: claiming sexual and reproductive rights

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Introduction

More than 15% of the world's population are affected by disability, including physical and sensory impairments, developmental and intellectual disability and psychosocial disability.¹ While it goes without saying that people with disability have equal rights to sexual and reproductive desires and hopes as non-disabled people, society has disregarded their sexuality and reproductive concerns, aspirations and human rights. People with disabilities are infantilised and held to be asexual (or in some cases, hypersexual), incapable of reproduction and unfit sexual/marriage partners or parents. The sexual and reproductive health and rights (SRHR) of people with disabilities continue to be contested, and there are particular concerns in relation to women with disabilities. For women, disability often means exclusion from a life of femininity, partnership, active sexuality and denial of opportunities for motherhood.^{2,3}

Analysis of the United Nation Convention on the Rights of Persons with Disabilities negotiations at the beginning of the twenty-first century demonstrates how sexual rights were downgraded to focus on family life, resulting in no mentions of sexuality, sexual agency or non-hetero-patriarchal identities.⁴ However, activism has resulted in positive changes at regional level. For instance, the ASEAN Incheon Protocol proposes strong advocacy for SRHR. In negotiating the Sustainable Development Goals, activism achieved limited impact. Whilst disability is listed within some articles: education, growth and employment, inequality, physical accessibility, data collection and monitoring, they leave out any specific article on disability itself.⁵

For a long time SRHR have been largely overlooked, including by the disability rights movement, and neglected in policy, planning and service delivery by social, health and welfare services. This follows an initial long silence in the early days of disability activism, where SRHRs were seen as lying

within the private sphere. Debates and campaigns addressing the SRHR of people with disabilities are now increasingly common and of public relevance. They are frequently fronted by statements that imply a commonality of global experience for people with disabilities in the failure of society to recognise them as sexual beings.⁶

Nevertheless, societies are moving at different rates in recognising SRHR of people with disabilities, with organisations in countries as diverse as India and Australia pushing the debate forward. As people with disabilities gain increasing agency and control in other areas of their lives, like education and employment, it is essential to better understand the context and outcomes of demands for choice and agency over sexuality and relationships. Debates and campaigns are emerging, recognising people with disabilities as sexual beings with equal rights to aspirations for sexual pleasure, intimacy, love, friendship, relationships and sexual and reproductive choices. Inter-movement coalitions and alliances between gender and disability rights activism are playing an important role in making these issues visible. Feminist and sexual rights organisations are actively promoting this inter-movement dialogue and collaboration in their advocacy and research work.

While disability, sexuality and reproductive rights have gained significant visibility in research, policy and activist discourses in the high-income regions of the world, it is only now taking shape in public debates in many low- and middle-income countries. This is in part due to the small-scale action research funded and led by organisations in high-income countries. Much of this action research combines exploratory research with pilot interventions focussing on changing perceptions, raising awareness and sensitising key stakeholders in the community. Often, such efforts are guided by key questions such as: how are sexuality and reproduction of people with disabilities understood at the local level by people with disabilities

themselves and by non-disabled members? What barriers do people, especially women with disabilities, experience in accessing SRH services, particularly in the health sector? What context-specific strategies should be developed to facilitate recognition of the sexuality and reproductive rights of people with disabilities, particularly women with disabilities? How can appropriate SRH services be made available to people with disabilities in their communities?

This issue of Reproductive Health Matters contains original research, analytic pieces and commentaries, personal accounts, poetry and book reviews that address the current situation and future direction of SRHR of people with disabilities. Given the predominance of this concern among adolescents and youth, a number of papers focus on this age group. The gendered inequities, in most if not all domains of life, also warrant the greater focus on women. The issue includes papers on the sexual experiences, aspirations and rights of people, particularly women, with disabilities in the context of prevailing inequitable material, ideological and institutional structures that hinder access to SRHR services. Whilst the majority of the papers present perspectives and findings from low- and middle-income countries, covering contexts ranging from Senegal and Zimbabwe to Cambodia and Philippines, many of the research papers are funded and led by individuals and organisations in high-income countries. These are complemented by a judicious mix of research, research-cum-advocacy, and a number of commentaries and personal narratives around the core themes; some of the latter are individual authored endeavours. The issue also addresses diverse categories of disability, including blindness, deafness and intellectual disability; nonetheless, the complex heterogeneity of disabilities is not adequately captured. For instance, there were no submissions engaging with the complex issues around sexuality in the context of psychosocial disability. At the same time, other forms of sexual disability, such as that associated with female genital mutilation (FGM), are featured. However, it must be noted that the exclusions, prejudices and discrimination are similar in form, if not in context, across the different disabilities when it comes to sexuality.

Disability, sexuality and experience

How do people with disabilities conceptualise, experience and engage with themselves as sexual

beings? In addition to the specific constraints imposed by a particular disability, such experiences crystallise within the broad rubrics of culture, socialisation, socio-economic class, gender, caste and other specific locations that contribute to particular configurations of gendered sexual identities at the individual level. Poverty, stigma, discrimination and a host of other external factors shape personal experiences of shame, sexual desire and desirability or lack thereof, sexual confidence and esteem. In most cultures, the pleasure associated with sexual intimacy is both decried and denied. Additionally, apart from legally defined acts like rape and molestation, the violence associated with both normative sexual life and the absence of any acknowledged sexual relationship are strategically enveloped in a veil of silence. While sexual violence towards people with disabilities is moderately well documented, and human rights violations in this regard are well recognised, crucial analysis of personal context and gender/sexual dynamics, are limited. Using this issue as a springboard for this discussion, we ask: how do individuals whose sexuality is depicted in popular understanding as lying somewhere around the extremes of the non-sexual and hypersexual constitute their sexual subjectivity?

Personal accounts provide the sharpest insights into experience. In her narrative, Karimu provides an account of her own ideas and prevailing general perceptions about sexuality in the context of a blind school she attended as child in the 1980s in Ghana. The paper highlights the challenges that adolescent girls and women with visual impairment confront in trying to address their sexuality and the consequences that such attempts may bring upon their lives.

While one may concede that sexuality is a basic human need, awareness and knowledge about sexuality are shaped through a range of contextually specific sociocultural and religious ideas and practices. People with disabilities are systematically denied access to knowledge about sexuality, sexual behaviour and services leading to their sexual marginalisation. Several papers in this issue dwell further on these gaps in different parts of the world. In their paper on the violations experienced by women with disabilities in the Philippines, Devine and colleagues highlight inadequate disability inclusion within SRH policy and programming, and the limited disability awareness of service providers. A similar study by Burke et al in Senegal shows low utilisation of

SRH services among people with disabilities. In addition to financial barriers and provider attitudes, other disability-specific barriers included relying on a known person, often a family member, to attend health clinics, which infringed their privacy and confidentiality. In this study, multiple cases of rape were reported, particularly amongst women with hearing impairment. This pattern is reflected again in the high rates of sexual violence and exclusion from health promotion activities and health services for young disabled adolescents in Uganda, linked to rising rates of HIV, as cited by Nampewo. The paper offers a broader resolution of sexual health through a proposal to mainstream disability into the national HIV response in Uganda. Enabling disability to be advanced at the national level in all development processes, alongside HIV, would lead not only to young disabled people but also to non-disabled people receiving improved access to sexual health information, protection and treatment. Linking programmes can lead to increased awareness of rights owed to disabled people through initiatives implemented by government, international actors and civil society.

Mprah et al report on the violence against deaf people in Ghana and highlight how risky sexual behaviour leads to pregnancy, abortions, high levels of STIs and emotional trauma, which is shown to be related to the low levels of literacy amongst people with disabilities, in particular deaf people. The paper reiterates that full realisation of the SRHR of young people with disabilities requires policies and interventions based on an understanding of the local intersections of youth, disability and gender, along with poverty, unemployment and other factors that influence not only their sexuality and actions, but also health care responses and staff attitudes.

In contrast, Peta and colleagues focus on the childbearing aspirations and experiences of women with disabilities in Zimbabwe. Using the Biographic Narrative Interpretive Method, they generate data to gain insight into how women's disability impacts their desires, choices and practical usage of services. Participants recounted their satisfaction with having their own biological children, albeit registering frustration over the discrimination they often face. Participants without children reported their aspiration to have their own biological children. Women's negative experiences in clinical contexts point to the need to address not only discrimination but the underlying

staff disinterest that excludes women with disabilities from the childbearing and reproductive health arena.

Gartrell presents a qualitative study on SRHR of women with disabilities in rural Cambodia and puts forward a holistic agenda to ameliorate their status. The strategy, which aims to make SRH services and polices inclusive for disabled people, combines: efforts to improve disabled women's livelihoods; to engage women with disabilities to provide inputs into health service decision-making, planning and delivery; and to ensure health centre staff have access to communication resources to strengthen their skills. This approach would not only increase access of women with disabilities to SRHR services, but would also transform the understanding and attitudes of health staff to engage with this population group.

Indeed, research findings indicate that staff, usually non-disabled persons, are often disinterested, fail to promote inclusiveness, and lack awareness and understanding about disability. Hunt and colleagues in South Africa offer concrete evidence of the misperceptions and attitudes of non-disabled people towards those with disabilities. They found that non-disabled people perceive people with physical disabilities as having fewer sexual and reproductive rights and deriving less benefit from SRH services than the population without disability. The researchers argue that these findings evince a negation of the SRH needs and capacity of people with physical disabilities.

Intersectionality

One of our hopes with this journal issue is to assist in the reframing of sexuality in disability away from the negative. One major angle for enquiry within the broad spread of heteronormative societies is the ways in which (negative) views of disability affect how the individual's gender and sexuality are perceived. Further, context interacts with the disability-sexuality nexus to alter the individual's experience and ways of becoming. A common view is that disabled people's sexuality is rarely significantly influenced by any factor that is not primarily related to disability. This holds whether it be prejudice and discrimination they face or the effect of the impaired, broken body. This medical perspective neglects other influential factors such as gender, economic status, particularly employment, education and urban-rural

residence. In some settings, beyond the individual, it is the family and community that are crucial in offering a route map for the lifeworld including the sexual terrain. The family institution is usually a heteropatriarchal realm of gendered power, organisation and control, which suffers severe disruption when a disabled person, especially a disabled female, joins it. She forces a re-reading of the values and norms of gender/sexuality, shifting not only the day-to-day material factors but also influential symbolic and cultural norms.

Goyal shares her experience of running a series of workshops across India on sexuality and sexual health for blind people, predominantly women and older girls. Drawing together a wealth of knowledge gained during the often intimate exchanges that occur, she offers us insight into the difficulties of blind adolescence and womanhood. Myths and superstition play a large role in creating the gendered shame of disability, which acts to limit families as well as individuals, and decreases the overall value and desirability of siblings of blind girls in the marriage market. Although disabled boys are also affected, their gender serves to balance many of the negativities carried by the girls that limit their dreams.

Disabled people are rarely asked to express their dreams, their sensual or sexual desires, as the standard belief is that they have none. Alexander and Taylor Gomez in UK and Australia, running workshops for people with intellectual disabilities, highlight how the dreams and pleasures of this group's lives are frequently neglected. They face restrictions by patriarchal power and by the disciplinary "activities of daily living" arranged through care organisations. In contrast to shame, non-disabled people respond to disability with powerful emotions of anxiety, vulnerability and fear and provoke some of the double standards that proliferate within service provision.

In contrast to a focus on exploring desire and pleasure, Owojuyigbe demonstrates the restriction of pleasure, addressing the sexual experiences of women disabled by FGM in Southwest Nigeria. The consequences of this patriarchal cultural practice, intended to help maintain the highly prized status of virginity before marriage, shift the research focus to the intimate, interactional, sexual and emotional space of marriage itself. Faced with disabling consequences from FGM that are largely sexual in nature, couples, particularly women, experience reduced pleasure, physical and emotional trauma and difficulties in

developing a fulfilling relationship. Further, as the FGM will be known about by her family and local community, any complaint by a woman about it will lead to her own shaming, particularly by other women around her, as unable to bear the suffering.

The articles included within this issue of RHM raise the question of what understanding of sexuality underlies the claim to rights advocated by many of the authors in support of the UN Convention for Rights of Persons with Disabilities? Although they advocate the social model of disability, the persistent, if irregular, framing of gender and sexuality through a medical lens rather than a social one, questions the political potential of this Convention.

Ruiz explores how disability, gender and sexuality are shaped within the context of rights through his examination of five years of the Concluding Observations of the Committee on the Rights of Persons with Disabilities. These are offered in response to State reports on progress with implementation of the Convention by governments who have signed it. Ruiz tracks the observations, analysing the emergence of a persistent essentialist naturalisation of gender and sexuality, where women are presented as victims of violence and heterosexual men depicted as aggressors. This heterosexual matrix renders invisible the disabled man, as one who both experiences high levels of sexual violence and whose masculinity and sexuality are constituted differently. Only in 2016 was there mention in the Observations of lesbian, gay, bisexual, trans or intersex disabled people. Gender and sexuality emerge as fixed, constrained concepts, hedged in by anxieties and in need of correction and protection. Ruiz argues that political action incorporating more fluid notions of gender and sexuality requires the recognition of the wide intersectional scope of the lives of disabled people and support for their agency, choice and desires.

The review by Tataryn of the Sins Invalid document on Disability Justice, *Skin, Tooth, Bone*, addresses how political actions can be taken forward, addressing the development of QueerCrip activism, disability justice and the necessity to incorporate thinking not simply around gender, disability and sexuality alone, but also race, class and post-colonialism. A treatise for political action, it sits in support of essays such as that by Goyal which, in its assertion of the value of uncovering the dreams and desires of blind people and

insistence on their rights not only to dream but to live them, offers hope for the sexual future of people with disabilities.

The expression of dreams and longing for freedom of disabled people is seen further in the poetry of Breckenridge which depicts not only the damage done, the psychosocial disability that people live with, but also the possibility of escape. She captures some of the healing power of touch and of the natural world, of the desires that people hope to follow, using a lyrical tone that offers a very different insight on disability and sexuality.

The activism of Sins Invalid itself places a strong emphasis on stimulating the creativity of disabled people, of using Arts such as poetry as a force for change. Whilst interactions and alliances around disability and sexuality justice are growing, there is a lack of synergy more widely across disability, feminist and sexual/gender rights movements which are failing to come together to address the sexuality of disabled people in all its complexity. For instance, many of the research projects, even where participatory, do not appear to create space for disabled people to lay claim to other than a hetero- and gender-normative identity. There needs to be an increased awareness and cooperation amongst activists, civil society groups, research colleagues and healthcare professionals. State-level actors must take the initiative to mainstream the issue of disability and sexuality in laws, policies and programmes, thus providing the backdrop for collaborative multi-sectoral engagement. But this requires the activism mapped out in *Skin, Tooth, Bone*. The emergence of coalitions, courses and research developed transversally and in various regions, some illustrated in this issue, suggests that there is a burgeoning activism. This can both drive and grow further from policy and research, leading to the firm establishment of disabled people's sexual and reproductive justice and rights within societies globally.

Further themes

This issue addresses surrogacy through two approaches in relation to aspects of disability and sexuality that have been considered unimportant. Pleasure and sexual satisfaction is viewed as irrelevant because disabled people are meant to feel no desire, yet Shapiro writes of the personal journey he has followed, as a disabled man, to recognise his own sexuality. He undertook training as a sexual surrogate, someone who can support others to identify their own desires, build body

confidence and make choices around intimacy. Shapiro works through touch-based exercises that deal as much with people's "touch hunger" as they do with specific sensual engagements.

A second approach is the more common one of reproductive surrogacy, which meets the desire to mother of disabled women with no capacity to bear children. Rothler addresses the legal issues raised by the case of a disabled woman in Israel whose sister agreed to carry a pregnancy for her. Litigation addressing the legality of a surrogacy undertaken outside Israel decided against the disabled protagonist and the child was adopted elsewhere. Rothler raises a profound and troubling question: what weight did disability play in the court's decisions? The silence about disability did not remove it from the courtroom or from the discursive framing of disabled people's sexuality. Rather, its exclusion heightened the constitution of disabled women as "not-mother" – that they should not, by any means, become mothers.⁷

Final thoughts

There is a silence within society that pervades many areas of disability and sexuality resulting in the views of disabled people being rendered absent. It has been possible to address some of these silences in this issue of RHM: the desire of women (and men) with disability to bear and raise a child; sexual assistance to disabled people; the treatment of disabled people by SRH services. But there are other areas of this silencing not addressed here: the day-to-day experience of raising a disabled child; women acting to maintain or abort pregnancies with an anomalous foetus (connected to the ability to screen for genetic differences), and the linkage to wider questions about the impact of eugenics on reproductive technologies; disabled people who identify as or want to explore queer and non-hetero- and non-gender-normative identities and desires; people living with psychosocial disability and the impact on their sexuality. These silences are ones that, as joint editors, we were concerned pervaded this journal issue. The articles included here serve to offer a better understanding and awareness of perspectives that can inform disabled and non-disabled people's sexuality, women, men, trans or gender-fluid, and empower them in the social and sexual choices they make. But to truly empower all disabled people it is vital to act to end the remaining silences. And journals such as RHM have a crucial role to play in this.

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