COMMENTARY

SRHM SEXUAL AND REPRODUCTIVE HEALTH MATTERS
MORE THAN A JOURNAL

Actions, not words: progress since ICPD on disability and SRHR

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Introduction

It is welcome to see how prominent disability issues were in the International Conference on Population and Development (ICPD). This inclusion was prescient, given that the human rights of persons with disabilities would only grow in significance in the intervening years, as evidenced by the Convention on the Rights of Persons with Disabilities (CRPD), with its specific reference to sexual and reproductive health in Article 25 (Health). The ICPD recognised persons with disabilities as a significant minority in society – now known to be one billion people worldwide, 15% of the global population – and called for awareness and knowledge of disability issues around sexual and reproductive health, and actions to promote shared caring responsibilities, together with continued action to achieve the goals of full participation and equality for persons with disabilities.

What has changed since 1994

Since 1994, the ageing of the population has continued in low, middle and high income countries. This demographic transition is relevant to disability policy in two ways: persons with disabilities are living into older age, and need continuing support and inclusion, plus an increasing number of older persons are also disabled persons, due to effects of stroke, dementia, macular degeneration and other health problems.

Whereas the ICPD highlighted prevention and rehabilitation, as well as participation and equality, since the CRPD, 2006, the emphasis is less on health and care, and more on removal of social barriers to participation, both in domains such as education and employment, but also across society. In Article 23 (Home and Family) and Article 25 (Health), the CRPD does emphasise access to sexual and reproductive healthcare on an equal basis with others, as well as recognising the right of children and adults with disability to family life. Importantly, Article 12 (Legal capacity) highlights how supported decision making is preferable to substitute decision making, because the latter is implicated in forced abortion and sterilisation of women with intellectual disabilities. Since the CRPD, there has been a renewed understanding of the human rights of persons with disabilities, and periodic review of progress. The Committee on the Rights of Persons with Disabilities has published General Comment 3 about women and girls with disabilities, which discussed sexual and reproductive rights and particularly violence against women. However, the Committee has been criticised for its narrow and protective framing of sexual and reproductive health,[1] which can be related back to the role of conservative member states in affirming marriage and parenthood, rather than sexuality and sexual pleasure, in drafting the CRPD.

Within the CRPD, and in the practices of bilateral and multilateral donors, there has been an emphasis on a twin track strategy – both mainstreaming disability in all actions, but also specific work targeted at disabled persons. The mainstreaming approach, which has been adopted by World Bank, UK Department for International Development, World Health Organization and other actors, requires programmes to be fully accessible. This entails attention to physical premises, provision of accessible information, removal of any other barriers, and training to ensure equitable treatment from all staff. Conceptually, mainstreaming is intended both to reduce costs – saving on expensive targeted provision, to be in line with the principle of Universal Health

Care, and to promote inclusion so that anyone affected by disability has a right to exactly the same services as anyone else. However, there is a danger that mainstreaming may translate into neglect of specific needs of persons with disabilities, if discriminatory attitudes remain unchanged.

What has not changed since 1994

The lack of access to SRH services for persons with disabilities is evident in all settings, as are contributing factors that range from inaccessible facilities, to lack of appropriate equipment, to communication barriers, to negative attitudes and violence.[2] Increasing focus on rights-based research has elevated the discourse to also reflect mistreatment[3] and failure to recognise sexual and reproductive aspirations among persons with disabilities.[4]

Positive attitudes and awareness among service providers have been known to improve access,[5,6] and repeated appeals have been made to strengthen training of health professionals[4] – similar suggestions were made in 1997.[7] That these findings and recommendations have not changed much since 1994 indicates persistence of these barriers in service delivery and a lack of progress in addressing them.

We have strong descriptive data, presenting the need for SRHR for persons with disabilities, and identifying barriers to their inclusion,[5,6] but we lack impact evaluations of actual interventions to improve provision. If we are to translate our knowledge into action, the health system needs to prioritise efforts to remove barriers, to train personnel, to improve physical access, to address financial constraints, and to change attitudes in society to respond positively to the sexual aspirations of persons with disabilities.

In particular, we need more examples of genuinely participatory research where persons with disabilities are involved in reviewing and evaluating SRH services – not forgetting that any interventions and any research need to reflect intersectionality. "Vulnerable families" (p.41)[8] who might be poor, displaced, affected by AIDS or domestic violence or LGBT, may also include persons with disabilities. This needs to be reflected in more data and evidence.

The elements for the integrated definition of SRHR in the Guttmacher-Lancet Commission report[9] include, for example, control over marriage choice and fertility, freedom from violence, and safe and pleasurable sexual experiences. If persons with disabilities are unable to achieve these elements for themselves, it is hard to talk about progress and inclusion.

Ways forward

The movement for universal health coverage (UHC) might be expected to do something for universal access to sexual and reproductive health and rights, to include persons with disabilities. However, it is alarming that the forthcoming UN High-Level Meeting on UHC does not mention disability, and nor does Sustainable Development Goal 3 on healthy lives and well-being. The WHO Global Disability Action Plan 2014–2021 aims at "Better health for all people with disability", and if the recommended actions were implemented by member states, this would go a long way towards equitable SRHR, such as adopting national accessibility standards and ensuring compliance within mainstream health settings.

While SRHR may now be more visible on main political agendas globally, regionally, and nationally, if only in terms of reproductive health, there appears to have been little meaningful implementation regarding inclusion of persons with disabilities. Now is the time to address the shocking exclusion of the sexual rights and aspirations of persons with disabilities in all dimensions of sexual and reproductive health services, from comprehensive sexuality education, to contraception and abortion, and to maternal health care.

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