

**Submission to the Special Rapporteur on Rights of Persons with Disabilities  
Sexual Rights Initiative  
March 2018**

1. This submission is made by Sexual Rights Initiative.<sup>1</sup> The Sexual Rights Initiative (SRI) is a coalition of organizations from Canada, Poland, India, Egypt, Argentina and South Africa, that work together to advance human rights related to sexuality at the United Nations.

2. According to the World Health Organisation, more than a billion people or about 15% of the world's population are estimated to live with some form of disability.<sup>2</sup> A world health survey found that people with disabilities were twice as likely to find health-care provider skills and equipment inadequate to meet their needs, three times as likely to be denied care, and four times as likely to be treated badly as non-disabled people. They were also 50% more likely to experience catastrophic health expenditure.<sup>3</sup> The burden of this health expenditure exacerbates for persons with disabilities, when the public health system is neither fully functional nor catered to addressing the requirements of persons with disabilities. While in theory, public health systems are supposed to provide universal health care, the real access to such universal health care is very rare. No country has ensured that everybody has immediate access to all health care services. In the poorest countries only the most basic services may be available. In many low-income countries less than 1% of health budgets are spent on mental health care, with countries relying on out-of-pocket payments as the primary financing mechanisms.<sup>4</sup> Restrictions in public health sector expenditure are resulting in an inadequate supply of services and a significant increase in the proportion of out-of-pocket expenditure by households. This increases significantly for persons with disabilities where health systems are not catered to the specific needs of persons with disabilities. For instance, according to the World Federation of the Deaf, in 2017, only 41 countries of the 193 member states of the United Nations were estimated to legally recognise sign language in their countries.<sup>5</sup> Research in the states of Uttar Pradesh and Tamil Nadu in India found that cost (70.5%), lack of services in the area (52.3%), and transportation (20.5%) were the top three barriers to using health facilities for persons with disabilities.<sup>6</sup> Similar findings were found in Southern Africa that identified cost, distance, and lack of transport as reasons for not using services, along with services no longer being helpful or the individual not being satisfied by the services.<sup>7</sup> In the rhetoric on health, persons with disabilities are generally excluded and

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<sup>1</sup> <http://www.sexualrightsinitiative.com/>

<sup>2</sup> World Health Organisation, The World Bank: World Disability Report at [http://www.who.int/disabilities/world\\_report/2011/report.pdf](http://www.who.int/disabilities/world_report/2011/report.pdf)

<sup>3</sup> World Health Organisation, The World Bank: World Disability Report at [http://www.who.int/disabilities/world\\_report/2011/report.pdf](http://www.who.int/disabilities/world_report/2011/report.pdf)

<sup>4</sup> World Health Organisation, The World Bank: World Disability Report at [http://www.who.int/disabilities/world\\_report/2011/report.pdf](http://www.who.int/disabilities/world_report/2011/report.pdf)

<sup>5</sup> Dulamsuren Jigjid, Removing Communications Barriers: Accessing Comprehensive Reproductive Health Services for Deaf Women and Girls, Arrow For Change, Vol 23, no 3, 2017 at [http://arrow.org.my/wp-content/uploads/2017/10/AFC\\_23\\_3\\_2017.pdf](http://arrow.org.my/wp-content/uploads/2017/10/AFC_23_3_2017.pdf)

<sup>6</sup> World Health Organisation, The World Bank: World Disability Report at [http://www.who.int/disabilities/world\\_report/2011/report.pdf](http://www.who.int/disabilities/world_report/2011/report.pdf)

<sup>7</sup> World Health Organisation, The World Bank: World Disability Report at

there is a higher burden to access affordable and acceptable health care for persons with disabilities. However, this is exacerbated when sexual and reproductive health and rights of persons with disabilities.

### **Persons with Disabilities and SRHR**

3. 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, their sexual and reproductive health and rights (SRHR) continue to be contested and/or not prioritised by health systems. Hence, persons with disabilities often face additional barriers to care and information about SRHR, gender based violence and other violence and abuse. Where access to health in general is restricted, sexual and reproductive health is almost negligible.

### **Need for SRHR for persons with disabilities**

4. WHO defined sexuality as; "...a central aspect of being human throughout life 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. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors."<sup>8</sup> Sexuality is a basic human need, however, awareness and knowledge about sexuality are shaped through a range of contextually specific sociocultural and religious ideas and practices. People with disabilities whose sexuality is stigmatised and denied are systematically denied access to knowledge about sexuality, sexual behaviour and services leading to their sexual marginalisation.<sup>9</sup>

5. At the core of sexuality and sexual rights, is the question of autonomy and the right to decide for one's own body and life. The stigma with respect to persons with disabilities and their sexuality has the effect of denying this essential aspect of life to persons with disabilities. This is made worse for women with disabilities whose sexual rights are often considered superfluous at best, and a complete non-issue at worst. Discussions around the sexuality of women with disabilities are often negative, and revolve around stopping an "abnormal" person from having the "normal" experience of sex and intimacy.<sup>10</sup> This denial of autonomy, choice and control leads to multiple violations including forced and coerced sterilisation; denial of maternity and parenting rights; denial of legal capacity and decision-making; and a lack of access to sexual and reproductive health services, programmes, information and

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[http://www.who.int/disabilities/world\\_report/2011/report.pdf](http://www.who.int/disabilities/world_report/2011/report.pdf)

<sup>8</sup> [http://www.who.int/reproductivehealth/topics/sexual\\_health/sh\\_definitions/en/](http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/)

<sup>9</sup> Renu Addlakha, Janet Price & Shirin Heidari (2017) Disability and sexuality: claiming sexual and reproductive rights, *Reproductive Health Matters*, 25:50, 4-9, DOI: 10.1080/09688080.2017.1336375

<sup>10</sup> Nidhi Goyal (2017) Denial of sexual rights: insights from lives of women with visual impairment in India, *Reproductive Health Matters*, 25:50, 138-146, DOI: 10.1080/09688080.2017.1338492

education<sup>11</sup>. Women with disabilities are also more likely to experience physical and sexual abuse than women without disability<sup>12</sup> and have high unmet needs and demands for their sexual and reproductive health; they lack awareness on contraceptives, abortion rights, STIs and STDs, adolescents' health, and reproductive rights.<sup>13</sup>

6. Often for women, disability means exclusion from a life of femininity, partnership, active sexuality and denial of opportunities for motherhood.<sup>14</sup> This is also because decisions about the right to parent for those with disabilities take place in childhood (at the time of puberty) often as part of a series of protectionist measures and can often take the extreme form such as sterilisation and hysterectomy. In its more benign form it manifests in the way families, caregivers, and other institutions “permanently” infantilise women with disabilities and accord no recognition to their evolving sexuality.<sup>15</sup> This can be seen in policies and programmes as well, which concentrate on the prevention of pregnancy but ignore the fact that many persons with disabilities will eventually have children of their own. Hence, forced sterilization and forced abortion often have been imposed on persons with disabilities. The idea that a woman with a disability cannot be a “good mother” and caregiver remains strongly entrenched as a societal norm. Families and caregivers deploy a raft of protectionist measures, from the more benign confinement within the home to the more extreme hysterectomy and sterilization, based on a belief that women with disabilities are incapable of providing consent and pregnancy can only be the result of non-consensual sex, an act of violence. It is worth pointing out that this can vary depending on the type of disability.<sup>16</sup>

### **Barriers to access to SRHR**

7. SRHR services are often inaccessible to persons with disabilities for many reasons, including physical barriers, the lack of disability-related clinical services, and stigma and discrimination. In many situations barriers to health services include<sup>17</sup>:

- lack of physical access, including transportation and/or proximity to clinics and, within clinics, lack of ramps, adapted examination tables, and the like;

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<sup>11</sup> Alexandra Devine, Raquel Ignacio, Krystle Prenter, Lauren Temminghoff, Liz Gill-Atkinson, Jerome Zayas, Ma Jesusa Marco & Cathy Vaughan (2017) “Freedom to go where I want”: improving access to sexual and reproductive health for women with disabilities in the Philippines, *Reproductive Health Matters*, 25:50, 55-65, DOI: 10.1080/09688080.2017.1319732

<sup>12</sup> Alexandra Devine, Raquel Ignacio, Krystle Prenter, Lauren Temminghoff, Liz Gill-Atkinson, Jerome Zayas, Ma Jesusa Marco & Cathy Vaughan (2017) “Freedom to go where I want”: improving access to sexual and reproductive health for women with disabilities in the Philippines, *Reproductive Health Matters*, 25:50, 55-65, DOI: 10.1080/09688080.2017.1319732

<sup>13</sup> Rashid Mehmood Khan, *Addressing SRHR Concerns Faced by Persons with Disabilities in Pakistan*, Arrow For Change, Vol 23, no 3, 2017 at [http://arrow.org.my/wp-content/uploads/2017/10/AFC\\_23\\_3\\_2017.pdf](http://arrow.org.my/wp-content/uploads/2017/10/AFC_23_3_2017.pdf)

<sup>14</sup> Renu Addlakha, Janet Price & Shirin Heidari (2017) *Disability and sexuality: claiming sexual and reproductive rights*, *Reproductive Health Matters*, 25:50, 4-9, DOI: 10.1080/09688080.2017.1336375

<sup>15</sup> Rupsa Mallik, *Women with Disabilities: Parenting and Reproduction*, Arrow For Change, Vol 23, no 3, 2017 at [http://arrow.org.my/wp-content/uploads/2017/10/AFC\\_23\\_3\\_2017.pdf](http://arrow.org.my/wp-content/uploads/2017/10/AFC_23_3_2017.pdf)

<sup>16</sup> Rupsa Mallik, *Women with Disabilities: Parenting and Reproduction*, Arrow For Change, Vol 23, no 3, 2017 at [http://arrow.org.my/wp-content/uploads/2017/10/AFC\\_23\\_3\\_2017.pdf](http://arrow.org.my/wp-content/uploads/2017/10/AFC_23_3_2017.pdf)

<sup>17</sup> Promoting sexual and reproductive health for persons with disabilities WHO/UNFPA guidance note

- lack of information and communication materials (e.g. lack of materials in Braille, large print, simple language, and pictures; lack of sign language interpreters);
- health-care providers' negative attitudes;
- providers' lack of knowledge and skills about persons with disabilities;
- lack of coordination among health care providers;
- lack of funding, including lack of health-care insurance

8. In Nepal, for example, the infrastructure in health service centres is not accessible to women with disability. There are no, inter alia, ramps, lifts, disabled friendly toilets and birthing beds, etc. In many cases, access to basic health services itself is a challenge. Furthermore, when women with disabilities do manage to physically access hospitals, there is complete disregard to their right to privacy and confidentiality. The health centres are extremely unhygienic and unsanitary with a risk of infections for those women with disabilities who have bed sores and open wounds. Hospital and health care setting have no sign language interpreters, thus for someone with hearing impairment, it becomes challenging to explain their health issue as she would have to either find a sign language interpreter to accompany her or use natural sign language, which is often not sufficient for communication. Women with physical disabilities have shared that they are anxious accessing sexual and reproductive health related services, and have faced discrimination and are mistreated when accessing these services. Further, health professionals in general are not aware about needs of women with disabilities making it even more complicated when women with disabilities seek health services and especially those services related to their sexual and reproductive health. In addition, unmarried women face further discrimination or are not taken seriously when they visit health centres for sexual and reproductive health services. The health professionals are often insensitive, behaving inappropriately because they do not understand conditions and challenges of women with disabilities<sup>18</sup>.

9. Similarly in Kenya, there is a general lack of disability mainstreaming within public healthcare institutions as there are inaccessible beds, toilets and washrooms, lack of Sign language interpretation, inaccessible gender based violence recovery centres, a lack of privacy and confidentiality and a general lack of awareness on the needs of women with disabilities. The lack of accessible infrastructure brings about poor sanitation especially for women and girls with physical disabilities because most toilets in public institutions are pit latrines and inaccessible therefore posing a health risk for girls with physical/multiple disabilities getting in contact with the dirty floor of the latrine as they are forced to crawl<sup>19</sup>.

10. While analysing barriers to the access to SRHR information and services, it is imperative to consider the many intersecting marginalisation's faced by persons with disabilities, including poverty, age, gender and sexual orientation. These factors will further impede the access to SRHR. A study in Senegal highlighted the importance of analysing the social identities that intersect with culture as well as access to resources in health systems and

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<sup>18</sup> Supplementary report submitted by the Women with Disabilities Network, Nepal to the 19th CRPD Session

<sup>19</sup> Shadow Report submitted by the Kenyan Network Advocating for the Rights of Women & Girls with disabilities to the 68th CEDAW Session

broader support for young people with disabilities. Low utilisation of contraception is also reinforced by norms related to gender roles and sexuality, extramarital sex, and the use of contraception inside and outside of marriage.<sup>20</sup> So access to health services was not only influenced by disability and age but also the cultural taboos on sexuality.

11. One of the main barriers, as stated above is the frequent assumption that persons with disabilities are not sexually active and therefore do not need SRH services. Many people, including clinicians, feel uncomfortable discussing sexual matters, discomfort which may increase in the context of disability. It has been reported that physically disabled women accessing family planning were treated as if they were asexual by clinicians, who berated them for being sexually active.<sup>21</sup> For instance it has been documented there are greater unmet needs for women with physical disabilities trying to access reproductive healthcare services, and contraception.<sup>22</sup>

12. Further, health-care providers often are of the opinion that people with intellectual disabilities or other disabilities should not have a sexual life, reproduce or look after children, and therefore should not need sexual and reproductive health services<sup>23</sup>. Health care providers may also lack the skills to communicate with the persons with disabilities. Several studies have found that health professionals exhibited ignorance and misunderstanding of the unique communication needs of deaf people. It has been observed that deaf adolescents, in particular, have difficulty accessing information on SRH issues due to communication barriers with health professionals. It has been documented that disabled persons have received little attention in SRH policies, research, and programmes in Ghana.<sup>24</sup> This limited capacity of service providers to provide inclusive services further magnifies these barriers for women with disabilities, and they continue to experience violations of their human rights, especially in relation to sexual and reproductive health and exposure to violence<sup>25</sup>

13. In addition, health-care settings may be physically inaccessible and health information may be unavailable in different format. In resource-poor settings in particular, sexual and

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<sup>20</sup> Eva Burke, Fatou Kébé, Ilse Flink, Miranda van Reeuwijk & Alex le May (2017) A qualitative study to explore the barriers and enablers for young people with disabilities to access sexual and reproductive health services in Senegal, *Reproductive Health Matters*, 25:50, 43-54, DOI: 10.1080/09688080.2017.1329607

<sup>21</sup> Sumaya Mall, Leslie Swartz; *Sexuality, disability and human rights: Strengthening healthcare for disabled people*, *South Africal Medical Journal*, Vol 102, No 10 (2012)

<sup>22</sup> Xanthe Hunt, Mark T Carew, Stine Hellum Braathen, Leslie Swartz, Mussa Chiwaula & Poul Rohleder (2017) The sexual and reproductive rights and benefit derived from sexual and reproductive health services of people with physical disabilities in South Africa: beliefs of non-disabled people, *Reproductive Health Matters*, 25:50, 66-79, DOI: 10.1080/09688080.2017.1332949

<sup>23</sup> World Health Organisation, The World Bank: *World Disability Report* at [http://www.who.int/disabilities/world\\_report/2011/report.pdf](http://www.who.int/disabilities/world_report/2011/report.pdf)

<sup>24</sup> Wisdom Kwadwo Mprah, Patricia Anafi & Paul Yaw Addai Yeaboah (2017) Exploring misinformation of family planning practices and methods among deaf people in Ghana, *Reproductive Health Matters*, 25:50, 20-30, <https://doi.org/10.1080/09688080.2017.1332450>

<sup>25</sup> Alexandra Devine, Raquel Ignacio, Krystle Prenter, Lauren Temminghoff, Liz Gill-Atkinson, Jerome Zayas, Ma Jesusa Marco & Cathy Vaughan (2017) "Freedom to go where I want": improving access to sexual and reproductive health for women with disabilities in the Philippines, *Reproductive Health Matters*, 25:50, 55-65, DOI: 10.1080/09688080.2017.1319732

reproductive health programming often inadvertently excludes women with disabilities. Limited context specific data on the experiences and needs of women with disabilities undermines the development of disability inclusive policy and programming. There is also limited evidence and capacity on how best to address barriers to inclusion in sexual and reproductive health programmes.<sup>26</sup>

14. One of the most common problems faced by people with disabilities and especially women with disabilities is the lack of access to comprehensive sexuality education. There is general shyness when it comes to talking about SRHR because cultural norms have deemed it a taboo subject, consequently restricting people’s choices on SRHR issues. In Nepal, though parents and teachers of girls with autism, intellectual disability and down syndrome have expressed the need to provide their children with knowledge and information on sexual and reproductive health and rights is extremely important, they do not have enough materials and the tools to address these issues. In fact, parents are themselves unaware about sexual and reproductive health and rights concerns of their daughters, especially when it comes to managing their menstruation. Girls with disabilities still miss out on schools during menstruation, mostly because of the lack of support in schools. Women with severe physical disabilities think it’s a burden to have menstruation every month because they need someone else to take care of them. It is difficult for girls and women with disabilities to exercise autonomy when it comes to making informed decisions about their own bodies and to negotiate safer sex.<sup>27</sup> Women with physical disabilities, have greater unmet health needs than women without disability, and reduced access to health information, screening, prevention, and care services in the realm of sexual and reproductive health.<sup>28</sup> Interviews with women with disabilities in Philippines highlighted numerous barriers to sexual and reproductive health including limited availability of accessible services; women’s limited awareness about sexual and reproductive health and when and how to access appropriate information and services; negative attitudes of service providers and communities in relation to disability and sexual and reproductive health; and experiences of violence and abuse. Women with disabilities also wanted more information about sexual and reproductive health and greater access to services.<sup>29</sup> As people with physical disabilities are taken to lack sexuality,

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<sup>26</sup> Alexandra Devine, Raquel Ignacio, Krystle Prenter, Lauren Temminghoff, Liz Gill-Atkinson, Jerome Zayas, Ma Jesusa Marco & Cathy Vaughan (2017) “Freedom to go where I want”: improving access to sexual and reproductive health for women with disabilities in the Philippines, *Reproductive Health Matters*, 25:50, 55-65, DOI: 10.1080/09688080.2017.1319732

<sup>27</sup> Rashid Mehmood Khan, *Addressing SRHR Concerns Faced by Persons with Disabilities in Pakistan*, Arrow For Change, Vol 23, no 3, 2017 at [http://arrow.org.my/wp-content/uploads/2017/10/AFC\\_23\\_3\\_2017.pdf](http://arrow.org.my/wp-content/uploads/2017/10/AFC_23_3_2017.pdf)

<sup>28</sup> Xanthe Hunt, Mark T Carew, Stine Hellum Braathen, Leslie Swartz, Mussa Chiwaula & Poul Rohleder (2017) The sexual and reproductive rights and benefit derived from sexual and reproductive health services of people with physical disabilities in South Africa: beliefs of non-disabled people, *Reproductive Health Matters*, 25:50, 66-79, DOI: 10.1080/09688080.2017.1332949

<sup>29</sup> Alexandra Devine, Raquel Ignacio, Krystle Prenter, Lauren Temminghoff, Liz Gill-Atkinson, Jerome Zayas, Ma Jesusa Marco & Cathy Vaughan (2017) “Freedom to go where I want”: improving access to sexual and reproductive health for women with disabilities in the Philippines, *Reproductive Health Matters*, 25:50, 55-65, DOI: 10.1080/09688080.2017.1319732

the need for sex education, and sexual and reproductive healthcare services for people with physical disabilities, is overlooked.<sup>30</sup>

## **Recommendations**

15. Comprehensive sexuality education should be mandatory in formal and informal settings and should be disability friendly. All persons including women and girls with disabilities should be provided with the comprehensive, scientific and non-judgmental information on their sexuality in order for them express their sexuality without stigma.

16. One of the major barriers in accessing health care and information is the preconceptions of gatekeepers of information including doctors and teachers. Their lack of awareness and bias perpetuates the stigma faced by for women with disabilities. It is imperative that training courses for such gatekeepers, who are the one of the primary sites of contact for information should be inclusive and holistic.

17. Laws and policies which deny women with disabilities autonomy over their own bodies including any laws that directly or indirectly condone, forced sterilization and/or abortion should be revised and reformed. Any change in these laws and policies should be made in consultation with and meaningful participation of women and girls with disabilities.

18. Strengthening public health systems to ensure universal access to health services including sexual and reproductive health services is essential. Every person has the right to accessible, affordable and acceptable quality health care service and information including sexual and reproductive health and rights. This means that health care services should be affordable for all and accessible and disability friendly. All states must revised their public health policies in consultation with and meaning participation of persons with disabilities.

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<sup>30</sup> Xanthe Hunt, Mark T Carew, Stine Hellum Braathen, Leslie Swartz, Mussa Chiwaula & Poul Rohleder (2017) The sexual and reproductive rights and benefit derived from sexual and reproductive health services of people with physical disabilities in South Africa: beliefs of non-disabled people, *Reproductive Health Matters*, 25:50, 66-79, DOI: 10.1080/09688080.2017.1332949