

# **Let me Decide and Thrive**

Global discrimination and exclusion of girls and young women  
with disabilities

Plan International, November 2017

## Acknowledgments

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***“Girls and young women with disabilities have the right to make decisions over their own bodies and live free from violence and fear”***

## Forward

Girls and young women with disabilities have the right to make decisions over their own bodies and live free from violence and fear. Yet, on a global level, they are the people least likely to enjoy their sexual and reproductive health and rights (SRHR). Compelled by this reality, Plan International and the Office of the UN Special Rapporteur on the Rights of Persons with Disabilities have joined forces to ensure young women and girls with disabilities can exercise choice and have control over their bodies. The *Let Me Decide and Thrive* initiative is supported by in-depth, critical field and desk research and aims to empower girls and young women with disabilities, raise awareness of their plight among stakeholders, and work to secure their sexual and reproductive health and rights.

Our research found that the barriers to SRHR confronted by girls and young women with disabilities are overwhelming: infantilisation and disempowerment; forced sterilisation, abortion, and contraception; disproportionate suffering from all forms of violence; substantial barriers in accessing justice; discriminatory attitudes, norms, and behaviours rendering them invisible; and a lack of accessible and appropriate SRHR information and services.

States have largely failed in their duty to respect, protect, and fulfil the sexual and reproductive health and rights of girls and young women with disabilities; and families and communities continue to be bound by stigma and taboos. International mobilisation is crucial to remedy the glaring void of recognition and care for vulnerable and excluded girls and young women with disabilities.

Plan International's new global strategy *100 Million Reasons* commits us to strive for a just world that advances children's rights and equality for girls. Girls and young women with disabilities are an integral part of this strategy. One of the main goals of *Let Me Decide and Thrive* is to highlight the specific

challenges faced by girls and young women with disabilities in realising their sexual and reproductive health and rights.

*Let Me Decide and Thrive* is an urgent call to action for states, policy and change makers, and service providers of the sexual reproductive health and rights of girls and young women with disabilities. In this current, challenging political climate, the risk of attacks on their SRHR may be greater than ever. Failing to act is no longer an option. There is no time to wait!

Anne-Birgitte Albrechtsen  
Chief Executive Officer Plan International

Catalina Devandas Aguilar  
UN Special Rapporteur on the Rights of Persons with  
Disabilities

## Recognising the Most Disempowered

Girls and young women with disabilities are the least likely to enjoy their sexual and reproductive health and rights (SRHR). Families and communities continue to be bound by discriminatory social norms, putting this group at greater risk of exclusion. Plan International seeks to raise awareness of the underlying issues and challenges faced by girls and young women with disabilities, offering examples of good practices in this area, as well as calling stakeholders to action to advance the recognition and realisation of their sexual and reproductive health and rights.

Girls and young women with disabilities have the same sexual and reproductive health and rights as other girls and young women, as recognised in the *Convention on the Rights of the Child (CRC)*, the *Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW)*, and the *Convention on the Rights of Persons with Disabilities (CRPD)*, as well as in other international policy documents, including the *Programme of Action of the International Conference on Population Development*. Therefore, a human rights and gender equality framework, guided by international treaties and development commitments such as the 2030 Agenda for Sustainable Development, must guide all future work. Medical and charity models need to be replaced by human rights based models that position the SRHR of girls and young women with disabilities at the centre of any strategy, ensuring that they are able to make informed choices free from coercion, violence, discrimination, and abuse.

Due to the stigma and negative social norms associated with the SRHR of girls and young women with disabilities, they are often discriminated against, left behind and become invisible in society. The discriminatory hurdles posed by either gender, youth, or disability alone can be great, but when all three come together, they intensify the negative effects of exclusion. When the intersection of these three characteristics is further

compounded by belonging to other groups that have been systematically disadvantaged or discriminated against, such as indigenous peoples, religious and ethnic minorities, poor or rural populations, migrants and refugees, and lesbian, gay, bisexual, transgender, intersex or questioning persons (LGBTIQ), the effects can be exponentially worse. Therefore, an intersectional approach is critical to an in depth understanding of the problem, and to creating effective solutions.

***“Girls with disabilities are last in the priority list for scarce resources” – District Chief in Africa***

The barriers that girls and young women with disabilities face to fulfilling their sexual and reproductive health and rights are further compounded by the variety and intensity of their disabilities – the more severe the disability, the greater the risk of exclusion and abuse. Each type of disability creates specific needs around which SRHR services and information must be tailored, meaning there is no one-size-fits-all approach to guaranteeing the realisation of their SRHR. However, attention to these particular needs is rare, rendering the entire spectrum of sexual and reproductive health services inaccessible to girls and young women with disabilities.

## **Violence and Lack of Agency**

Girls and young women with disabilities encounter significant barriers that lead to grave violations of their sexual and reproductive health and rights. This section outlines some of the most shocking barriers.

### **Lack of agency and violence**

Girls and young women with disabilities are often infantilised, disempowered, and robbed of the agency they need to make decisions about their own bodies, sexuality, and lives. Forcing them to undergo sterilisation, abortion, or use contraception are extreme measures, which might result in lifelong and irrevocable consequences, but are all too common crimes against their sexual integrity and sexual and reproductive health and rights. The most common justification given by family members, or other care takers who make these decisions on their behalf, is that the forced practice will protect them from harm. However, such beliefs are often also motivated by underlying factors, including facilitating menstrual management, pregnancy prevention, and even eugenics. There are numerous clear examples of families and other caretakers, including in institutional settings, putting their own needs and convenience above the realisation of the SRHR of girls and young women with disabilities.<sup>1</sup>

***“They [parents] do not allow us to have children because they think we are not normal”- Young African woman with a disability.***

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<sup>1</sup>For examples see; Franklin & Smeaton, (2017); Healy, McGuire, Evans & Carley, (2009); Kef & Bos, (2006); Löfgren-Mårtenson, (2004); Maia, (2016); McConkey & Ryan, (2001); McKenzie & Swartz, (2011); Rohleder & Swartz, (2009); Wilkinson, Theodore & Raczka, (2015). Referenced in Stine Hellum Braathen, Poul Rohleder & Gloria Azalde.(2017) “Sexual and reproductive health and rights of girls with disabilities. A review of literature.” (UEL & SINTEF), p. 22.

In this context of disempowerment, girls and young women with disabilities are disproportionately affected by violence. The World Health Organization (WHO) reports that children with disabilities are almost four times more likely to experience violence than non-disabled children.<sup>2</sup> The Special Rapporteur on the Rights of Persons with Disabilities has stated that “the risk is consistently higher in the case of deaf, blind and autistic girls, girls with psychosocial and intellectual disabilities, and girls with multiple impairments”.<sup>3</sup> The many taboos surrounding disabilities can lead them to accept partners who mistreat them, or refrain from reporting abuse and violence out of fear of institutionalisation, loss of assistive devices and other supports, or abandonment. Furthermore, girls with disabilities are at a heightened risk of child marriage and human trafficking.<sup>4</sup>

***“A man told me that he loved me and wanted to take me away, but I screamed for help from passers-by” – Young African women with a disability***

The effects of this shocking level of abuse are further compounded by the substantial barriers that girls and young women with disabilities face in accessing justice. They often fail to report incidents of abuse due to fears of retribution, abandonment, single parenthood and losing custody of their children, as well as doubts about whether they will be believed. The legislative and court systems regularly fail to acknowledge

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<sup>2</sup> [The World Health Organisation](#) (2017): Disabilities and rehabilitation: violence against adults and children with disabilities.

<sup>3</sup> UNGA, Report of the Special Rapporteur on the Rights of Persons with Disabilities. *Sexual and reproductive health and rights of girls and young women with disabilities*. 14 July 2017. (A/72/133).

<sup>4</sup> UNGA, Report of the Special Rapporteur on the rights of persons with disabilities. *Sexual and reproductive health and rights of girls and young women with disabilities*. 14 July 2017. (A/72/133).

them as competent witnesses. This is especially true for girls and young women with intellectual disabilities.<sup>5</sup> Physical and communication barriers in the justice system further hinder their ability to seek and obtain redress. These include a lack of accessibility and other procedural accommodations, such as sign language interpretation, alternative forms of communication, and support services that are age and gender-sensitive.

### **Discriminatory attitudes, norms and behaviours**

Systematic forms of exclusion stem from discriminatory attitudes, norms, and behaviours that drive profound prejudice and stigma, often making girls and young women with disabilities invisible within society and more vulnerable to harmful practices. Stigma can lead to seclusion and isolation, either because of misconceptions about what causes disabilities, or because of deeply held prejudice about the capacity of girls and young women with disabilities to contribute to society. Girls and young women with disabilities are still widely perceived as merely recipients of care, and are consistently undervalued.

Discrimination is often so widespread that stigma may be deeply internalised by girls and young women themselves. This can lead them to feel ashamed of their own bodies and to accept ill treatment from others. For example, girls and young women with disabilities have reported hiding their disability from a potential partner for fear of rejection<sup>6</sup>, or that they may be

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<sup>5</sup> B. L. Bottoms, K. L. Nysse-Carris, T. Harris and K. Tyda, (April 2003) "Jurors' perceptions of adolescent sexual assault victims who have intellectual disabilities", *Law and Human Behavior*, vol. 27, No. 2.

<sup>6</sup> Chappell, (2014) "How Zulu-speaking youth with physical and visual disabilities understand love and relationships in constructing their sexual identities", *Culture, Health and Sexuality*, vol. 16, No. 9.

willing to have unprotected sex because the need to be loved and accepted is more important to them than their own safety.<sup>7</sup>

***“I have a lot of questions related to this topic, but I do not dare to ask and do not know who to ask” – Young Asian woman with a disability***

Girls and young women with disabilities have the same concerns and needs with regard to sexuality, relationships and identity as their peers, and share similar patterns of sexual behaviour. However, there are prevalent and competing assumptions that portray girls and young women with disabilities as either asexual or hypersexual. Both misconceptions present a distorted image of their reality and challenge the realisation of their sexual and reproductive health and rights. Within this distorted view, young women with disabilities who identify as LGBTIQ face additional barriers to their right to assert their own sexual orientation and gender identity.

***“Just because we have a disability doesn’t mean we don’t comprehend or understand. Our development is the same” – Young woman with a disability in Latin America***

### **Lack of reliable data and statistics**

There is only a rough global estimate of the prevalence of children and young people with disabilities. There is between 93 and 150 million children with disabilities<sup>8</sup> and, between 180

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<sup>7</sup> Wazakili, M., Mpofu, R., & Devlieger, P., (2006). Experiences and perceptions of sexuality and HIV/AIDS among young people with physical disabilities in a South African township: A case study. *Sexuality and Disability*, 24(2), 77-88.

<sup>8</sup> WHO and World Bank, (2011) *World Report on Disability*, p. 36.

and 220 million young people with disabilities.<sup>9</sup> Furthermore, national census data is generally not disaggregated by gender, age, or type of disability, resulting in a lack of reliable statistics and data, which consistently underestimates the number of girls and young women with disabilities. The stigma of disability often leads to a reporting bias among census respondents, resulting in an ‘invisible’ population of people with disabilities, and providing a justification for the low level of resources allocated.

For some countries, national census figures indicate that persons with disabilities comprise just 2% of the population, while international estimates or other national measurements for the same countries often show numbers 8-10 times higher.<sup>10</sup> Gender bias in the design of instruments and collection methods is another major source of flaws in the quality of data. There is also no consistent data on sexual and reproductive health for children under 15, as the reproductive age used in national surveys is generally 15-49.

***“I went to the gynaecologist once but she would not talk to me because she said she doesn’t work with ‘abnormal’ people” – Young woman with a disability in Latin America***

### **Lack of availability and accessibility of SRHR information and services**

Provision of accessible sexual and reproductive health and rights information and services for girls and young women with disabilities is largely non-existent, with service providers in health centres, schools, and institutions that house them ill-

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<sup>9</sup> UNDESA, (2012) *Building a Better Tomorrow: The voices of young people with disabilities*. New York: Department of Economic and Social Affairs.

<sup>10</sup> Plan International, (2017) *Let Me Decide and Thrive: Research Project on Sexual and Reproductive Health and Rights of Girls and Young women with Disabilities*. (International Solutions Group).

prepared to handle their specific needs. Common barriers they face in accessing services include negative and hostile attitudes among service providers, lack of accessible buildings, equipment, and transportation, affordability of services, and isolation in institutions, camps, family homes, or group homes. The lack of accessible comprehensive sexuality education (CSE) for girls and young women with disabilities is an enormous hindrance to their SRHR, and as a result they rarely have the tools or skills to protect themselves from disease, abuse, or unwanted pregnancy. Caregivers and duty bearers often assume that they do not need nor desire sexual education or experience. This is a form of oppression that keeps them in the dark about the many dangers they face, thereby compounding those risks.

***“We want more information (on SRHR) so that nothing will surprise us” – Young Asian woman with a disability***

### **Menstruation and menstrual hygiene**

In many societies, taboos and social norms around menstruation and menstrual hygiene affect the autonomy of all women and girls, and have particularly debilitating effects on the realisation of SRHR of girls and young women with disabilities. For example, the absence of appropriate sanitation facilities in schools, including separate, accessible, and sheltered toilets, in addition to the lack of education, resources, and support for menstrual hygiene, compromise their ability to properly manage their hygiene, and make them especially prone to diseases. This often leads to girls and young women with disabilities staying at home or being sent to special schools. It can also lead to grave violations of rights such as forced hysterectomies or forced use of contraception that can eliminate or reduce menstruation.

***“We want more information so that we can plan when to have children” – Young Asian woman with a disability***

## Building on Existing Good Practices

There is little precedent for the inter-sectoral collaboration needed to support the realisation of the sexual and reproductive health and rights of girls and young women with disabilities. The lack of communication and sharing of expertise between the protection systems for children, young women and persons with disabilities has left them exposed to heightened risk of exclusion. Fortunately, there are examples of promising practices and strategies that can be built on – some are highlighted below.

- Effective strategies include the integration of attention to both SRHR and disability into existing programmes and initiatives. For example, several North American NGOs have developed sexual and reproductive health materials in alternative formats for rape crisis centres, disability service agencies, and self advocates that include guidance for prevention education programmes and picture guides about sexual assault exams and sexual violence victim's/ survivor's rights.<sup>11</sup> The Women's Refugee Commission developed a toolkit aimed at disability inclusion within Gender- Based Violence (GBV) Programming that facilitates engagement and participation by people with disabilities and their caregivers, and offers tools for facilitating group discussions and individual interviews, training modules for GBV practitioners, guidance on communicating with people with disabilities, and general principles for obtaining informed consent from people with disabilities.<sup>12</sup>
- Providing services that specifically target girls and young women with disabilities can offer essential resources where they are most needed. The Straight Talk

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<sup>11</sup> For example; [Illinois Images](#).

<sup>12</sup> Women's Refugee Commission, (2015) ["\*I See that it is Possible\*": Gender-Based Violence Disability Toolkit](#).

Foundation in Uganda set up mobile clinics with trained multidisciplinary teams. Training girls and young women with disabilities as educators or community health workers has improved access to SRHR services in rural or otherwise isolated areas.

- [Profamilia](#), an organisation in Colombia, developed mobile health brigades and adolescent-led community education programmes, which have allowed them to bring SRHR information and services to crisis affected adolescents in some of the communities most impacted by conflict and displacement.<sup>13</sup>
- The [National Union of Women with Disabilities in Uganda](#) is one example of working towards breaking down and overcoming barriers to access to the justice system. This group is training individuals to become paralegals to assist girls and young women with disabilities to navigate the justice system and overcome access barriers. These women who have been fully informed about SRHR and GBV, have become community role models, offering peer-to-peer support in reporting violations, conducting the necessary follow-up to ensure justice was achieved, and advocating for systemic change.<sup>14</sup>
- In Nepal, the [Karuna Foundation](#)<sup>15</sup> helps to strengthen inclusive reproductive health services via its *Inspire2Care*

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<sup>13</sup> <https://profamilia.org.co/>

<sup>14</sup> Women Enabled International, (2017), Submission to OHCHR: *Comments for Report on Access to Justice for Persons with Disabilities*. (citing [National Union of Women with Disabilities of Uganda](#), *Uganda case: Model of paralegal: empowering women and girls with disabilities to be champions of change*.)

<sup>15</sup> <http://www.karunafoundation.nl/en/> - Good practice example taken from the Dutch Coalition on Disability and Development (DCDD), (2017) *Everybody Matters*.

programme by training Community Based Rehabilitation (CBR) facilitators in disability inclusion and the importance of healthy pregnancies and safe deliveries in order to prevent disability and diseases. Female community health volunteers are trained and then work closely with the Nepalese Government in each community and ward to distribute medicine and raise awareness on reproductive health and vaccines. They go from home to home and play a crucial role in bridging the gap between community members and the often distant local health post.

- Utilising social media, cell phones, and other technology can promote access to information on SRHR for young women and girls with disabilities. For example, with the support of UNFPA three Latin American countries ran a successful campaign for deaf youth, which included posters with barcodes giving them access to videos in sign language addressing sexuality, gender equality, body development, and other CSE topics.<sup>16</sup> The accessible blog, [Sexuality and Disability](http://www.sexualityanddisability.org/), empowers individuals with disabilities toward positive sexuality, answering questions on a range of issues related to sexual health and sexuality for women and girls with disabilities, including relationships, sex, violence, parenthood, and knowing one's own body.<sup>17</sup>

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<sup>16</sup> <http://decimeloami.com/web/quienes-somos/>

<sup>17</sup> <http://www.sexualityanddisability.org/>

## **No Time to Wait**

Girls and young women with disabilities have the right to make decisions about their bodies and live free from discrimination, fear and violence. Yet, as a group, they remain largely in the dark about their rights entitlements, and are seldom thought of as rights holders. A combined lack of political will, entrenched taboos and harmful social norms have resulted in girls and young women with disabilities being the group least likely to enjoy sexual and reproductive health and rights.

There is no time to wait to tackle the profound discrimination and invisibility of girls and young women with disabilities. States must take the lead in ensuring that their rights are respected, protected and fulfilled. However, success can only be achieved through collaboration with other stakeholders in the SRHR, girls and women's rights, and disabilities sectors, as well as with girls and young women with disabilities themselves.

Plan International is therefore calling on States, policy makers, civil society actors and SRHR service providers to implement the following recommendations to tackle the systematic exclusion of girls and young women with disabilities, and ensure the full realisation of their sexual and reproductive health and rights.

### **Legal and policy frameworks, data and accountability**

1. Remove all legal barriers that prevent girls and young women with disabilities from accessing sexual and reproductive health and rights information, goods and services, including legislation related to guardianship that limits their legal capacity and their right to make their own decisions.
2. Criminalise harmful and forced practices related to SRHR, including forced sterilisation, forced abortion, and forced use of contraception, as well as ensure the prosecution of offenders.

3. States must ratify and fully implement core conventions and agreements relating to sexual and reproductive health and rights of women and girls with disabilities, particularly the CRC, CEDAW and the CRPD, and withdraw any reservations that they have expressed about these instruments.
4. Prioritise the collection and use of accurate information, including statistical and research data, on the SRHR of girls and young women with disabilities, including data on harmful practices and all forms of violence, and ensure disaggregation by sex, age and disability at a minimum.

### **SRHR information and services**

5. Ensure the availability, accessibility, and high quality of SRHR information, goods, and services for girls and young women with disabilities, making sure to address gender-based violence and access to justice.
6. Take specific actions to ensure, in both formal and non-formal educational settings, the availability and accessibility of comprehensive sexuality education for all girls and young women with disabilities, which is gender responsive, rights based, and adolescent and youth friendly.
7. Parents and educators should be trained to support girls and young women with disabilities to learn about their bodies, relationships, and sexuality from early childhood through to adulthood.
8. Girls and young women with disabilities are given the opportunity to learn about their rights, particularly their SRHR as a means to increase their agency and to make decisions for themselves and thrive in all stages of life.

9. Ensure the meaningful and safe participation of girls and young women with disabilities in all processes of public and private decision-making including those related to SRHR.

### **Norms, attitudes and behaviours**

10. Expose and counteract the harmful social norms, stigma and discrimination that prevent the full realisation of the SRHR of girls and young women with disabilities.
11. Support the empowerment of girls and young women with disabilities to become advocates and agents of change in their communities and at national and global levels.
12. Support partnerships between Disabled Persons Organisations and girls and women's rights organisations, so that together they can raise awareness and advocate for the SRHR of girls and young women with disabilities.

## Photo credits

p.1 - Cover photo: Girl who has difficulty walking attends a Plan International supported school, Sierra Leone © Plan International / Erin Johnson, Room3

p.2 Girl with special needs with her friends at a Plan International supported school, Indonesia © Plan International

p.5 Girl with physical disability in her lower legs can walk to school thanks to her ankle brace, Nepal © Plan International / Rajesh Rai

p.7 Girl in a wheelchair wants to become a lawyer to support children with disabilities, Sierra Leone © Plan International / Erin Johnson, Room3

p.9 Girl with physical disability plans to continue her education and become a teacher, Guatemala © Plan International

p.11 Girl received physiotherapy and a leg brace to help with her mobility, and enjoys school and playing with her friends, Togo © Plan International / Akintunde Akinleye

p.13 Girl with hearing impairment is helped to learn with specially trained teacher, Indonesia © Plan International / Erin Johnson, Room3

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p.17 , Girl with a disability attends one of the safe schools with her friends built as part of the earthquake response in Nepal © Plan International / Max Greenstein

Note: The information within this report is derived from research in three countries in Asia, Latin America, and Africa, from a comprehensive literature review completed by UEL/ SINTEF, as well as the Special Rapporteur's report to the United Nations General Assembly of 14 July 2017 (A/72/133).