Liliane Fonds

open the world for a child with a disability

Sexual and Reproductive Health and Rights

Table of Contents

Foreword

Sexual and Reproductive Health and Rights (SRHR) are presently recognised as a determining factor in human well-being and as an essential element of human rights. Yet despite the issue's high profile today, and the widespread attention it is receiving in international policies and funding opportunities, the sexual and reproductive needs and desires of people with disabilities are rarely addressed.

Instead, people with disabilities are treated as not having sexual and reproductive desires and needs, or as not engaging in the active fulfilment thereof.[1] Due to these misunderstandings and to social prejudices, people with disabilities are excluded from information and from access to SRHR-related services and care such as sexuality education, HIV/AIDS testing or maternal health services. It should be recognised that children and young people with disabilities have the same sexual needs as their non-disabled peers, and thus the same need for information and access to related services. Moreover, people with disabilities are more vulnerable to violence and harmful practices such as forced sterilisations, abortions and forced marriages. Women and girls with a disability face double discrimination on the grounds of both their gender and their impairments.[2]

Sexuality as an expression of love is not recognised for people who have been stigmatised in society. Viewing sex from a biological viewpoint, with sex solely for the purpose of reproduction, and then solely the reproduction of the 'fittest', means that people with disabilities are excluded. The additional socio-cultural point of view that sees sex as a source of danger, adds to the need to protect people with disabilities. From a human-rights based perspective, the Liliane Foundation believes that it is important for people with a disability to have control over their own lives, including achieving the highest possible degree of bodily autonomy.[3] By not discussing sexual pleasure and human rights, the Liliane Foundation would perpetuate the asexual and victimisation status of people with disabilities.[4]

This paper presents the vision and position of the Liliane Foundation with regard to SRHR, and has been written for the international development community, government officials and Non-Governmental Organisations (NGOs) both in the Netherlands and the global South. Our vision and position is based on our and our partners' experience with SRHR and with the issues that are frequently encountered and discussed in the countries where the Liliane Foundation works. Including children and young people with disabilities requires the attention and effort of all stakeholders: governments, Civil Society Organisations (CSOs), parents, teachers and communities. This implies removing barriers in terms of availability, accessibility and acceptability, and the provision of SRHR information in a reliable and comprehensive way, based on evidence. This report calls on NGOs and decision makers not to leave children and young people with disabilities behind when investing in SRHR, and to remind NGOs that strive for the inclusion of people with disabilities that SRHR is also an important aspect of human development.

There are one billion people in the world living with a disability. This is an estimated 15% of the world's population.[5] People with disabilities are overrepresented among those living in extreme poverty, as 80% live in developing countries.[6] An estimated 20% are between the age of 10 and 24.[7]

PHOTO: BEYOND BORDERS

Getting the global perspective

1.

Children and youth with disabilities are like all other youth: they have dreams, ambitions and hopes for the future, including education, a decent job, a partner and a family. People with disabilities, however, face social injustice as a consequence of stigma, prejudices and discrimination.

Gender inequality is a significant contributor to unmet SRH needs worldwide. Harmful gender norms and attitudes influence men's and women's health and well-being

An introduction to SRHR

SRHR are seen as a set of rights that apply to all people in the world, regardless of religion, ethnicity, culture, gender, age or impairment. It is about the ability to make your own, well-informed choices and decisions when it comes to sexuality and reproduction, but also to respect the choices of others and to practice sexuality and reproduction in a healthy way.[8] It is about the 'ability' to reproduce and to regulate your fertility, but also the right to enjoy sexual relationships and to choose with whom, if and when you want to marry, start a family and have children.[9] When sexual and reproductive rights are violated, it means that the affected people lack control over their own bodies in terms of fertility, sexuality and relationships and that individuals are not allowed to make their own choices and decisions, because these are made for them by others, for example by family, laws, or the norms and values of society. It is important to realise that SRHR not only entail the absence of reproductive or sexual illness, but also the full enjoyment and well-being of sexual health.[10] Gender inequality is a significant contributor to unmet SRH needs worldwide. Harmful gender norms and attitudes influence men's and women's health and well-being, and shape behaviours in ways that have a direct impact on the SRHR of their partners, families and themselves. At the same time, SRH and family planning issues are often treated solely as a woman's responsibility.[11]

SRHR and legal frameworks

SRHR combines four distinct but connected concepts: sexual health, reproductive health, sexual rights and reproductive rights.

SEXUAL HEALTH

The World Health Organisation (WHO)[12] defines sexual health as "a state of physical, emotional, mental and social well-being related to sexuality: not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled".

SEXUAL RIGHTS

Sexual rights are a part of the universal declaration of human rights and consist of the right of all persons - including those with disabilities – free of discrimination, coercion, or violence, to seek and receive information related to sexuality, have their bodily integrity respected and to decide whether to be sexually active and to engage in consensual sexual relationships.

REPRODUCTIVE HEALTH

Reproductive health is, complementary to sexual health, "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes" according to the United Nations (2017).[13] In order to make these decisions freely and responsibly, it is necessary that people receive accurate information about their reproductive system. The reproductive system not only includes managing fertility with access to safe, effective, affordable and acceptable contraceptive methods, it also includes preventing and managing sexually transmitted diseases, including HIV/AIDS and to manage menstruation in a hygienic way, in privacy and with dignity[14].

REPRODUCTIVE RIGHTS

Reproductive rights include the right of all individuals to attain the highest standard of reproductive health possible and to decide the number, spacing, and timing of their children. In order to do so, they have the right to receive scientifically accurate and reliable information, free of discrimination, coercion or violence.

Figure 1: What is SRHR?

SRHR, as a part of human rights, follow the rights-based principles as outlined by UNFPA:

- **Universality:** They are, without exception, equally applicable to every individual.
- **Inalienability:** You can never lose your rights; you are born with them.
- **Indivisibility:** No right is more important than another right, they are all connected and you can't have one without the other. If one aspect is denied, it influences the enjoyment of other rights
- **Interdependency and interrelation:** The fulfilment of one right may depend in part or in whole on the fulfilment of other rights.

Leave no one behind: the Sustainable Development Goals (SDGs) and legal frameworks

The main principle of the SDGs is to leave no one behind. This means that the most excluded groups have the highest priority, including people with disabilities. This applies all over the world, but especially in the world's poorest places. Five out of 17 of the Goals are related to areas of SRHR, and there are five goals that have targets that specifically mention people with disabilities as a key population in their targets. Only one of the goal touches upon both disability and SRHR.

SDGS THAT INCLUDE DISABILITY	SDGS RELATED TO SRHR
4: Quality Education	3: Good Health and Well-being
8: Decent Work and Economic Growth	**4: Quality Education**
10: Reduced Inequalities	5: Gender Equality
11: Sustainable Cities and Communities	6: Clean Water and Sanitation
17: Partnerships for the Goals	16: Peace, Justice and Strong Institutions

Figure 2: Overview SDGs in relation to both Disability Inclusion and SRHR

In SDG 4, Quality Education, which includes comprehensive sexuality education, commitments are made to educating people with disabilities. However, no other goal related to SRHR pays attention to people with disabilities. This is despite people with disabilities being more vulnerable to sexual abuse and gender-based violence than people without disabilities.

Additionally, there are a number of international legal agreements that address sexual and reproductive health and rights. The following are considered in this report:

1948	The Universal Declaration of Human Rights* (art. 25.1)
1979	Convention on the Elimination of all forms of Discrimination Against Women (CEDAW)*
1989	**UN Convention on the Rights of the Child* (art. 17, 23-25 and 27)** **The CRC has three optional protocols, of which two are related to SRHR. First, the prohibition of the sale of children, child prostitution and child pornography, and second, the right of children to file complaints when their rights have been violated.**
1994	American Convention to Prevent, Punish and Eradicate Violence against Women – "Convention of Belém do Pará"
1995	International Conference on Women in Beijing
2000	Millennium Development Goals 2, 3, 4, 5 & 6
2006	**International Convention on the Rights of Persons with Disabilities* (art. 9, 12, 16, 22-23, 25 & 32)** **The CRPD includes articles that promote the inclusion of disabled people in SRHR, and stipulates that governments should guarantee access to SRHS and should protect the rights of people with disabilities in this regard.[15]**
2015	Sustainable Development Goals 3, 4, 5, 6 & 16

* legally binding texts

The global reality: SRHR for people with disabilities

People with disabilities are found in all key and vulnerable sectors of society when it comes to SRHR and therefore cannot be seen as a separate target group. These sectors of society include sex workers, people who are lesbian, gay, bisexual and transgender, children out of school, women and girls, and young people and migrants. Due to misguided beliefs and social prejudices, people with disabilities are excluded and denied information and access to SRHR-related services and care, leaving them among the most marginalised groups when it comes to SRHR.[16] The image of people with disabilities as being dependent, in need of protection, or as individuals that will never marry or have children, is obstructing a discussion of the combination of disability and sex. Consequently, children with disabilities grow up with this image.[17] In most contexts where the Liliane Foundation works, sex and sexuality solely serve reproduction and are only appropriate within marriage.

Feelings of love, intimacy and nurturing contacts form the basis of children's sexual development and their feeling of safety in the world. Children with disabilities, however, have fewer opportunities to experience caring and nurturing behaviour such as cuddling and caressing, or to explore their bodies, because parents are often ashamed of their child, feel guilty, or simply because most physical contact occurs because of health care needs.[18] Consequently, children with disabilities are less able to form healthy and nurturing relationships with

PHOTO: MARIEKE VIERGEVER

those close to them, and may have the feeling their bodies belong to other people. Social or sexuality education only occurs at an informal and reactive level, for example when a challenge occurs. As parents also lack knowledge or information, and the topic is ignored until it becomes a challenge, the challenge is handled in a negative manner. Instead of focusing on constructive learning, sexual activity is often approached by saying no, or treated as something unhealthy or disgusting.[19] These negative messages about sexuality and people with disabilities fuel negative attitudes and misguided beliefs about their sexual potential, and take their toll on self-esteem. This, when combined with physical limitations or diminished sensation, may make sex and sexual relationships seem pointless, reaffirm unexpressed beliefs of asexuality, and tend to lead to the conclusion of 'why bother'.[20]

Having a disability increases the risk of being trafficked for sexual or other forced labour, and of experiencing sexual abuse

Child maltreatment and SRHR

Children with disabilities are more vulnerable to abuse. Violence against people with disabilities is compounded by the fact that they are often physically and/or financially dependent on those who abuse them. This is also related to the fact that violence against children with disabilities is tolerated and seen as an appropriate way of controlling and disciplining behaviour. A study by UNICEF (2017) showed that nearly 25% of all caregivers believed that physical punishment is necessary to control inappropriate behaviour.[21]

Having a disability increases the risk of being trafficked for sexual or other forced labour, and of experiencing sexual abuse. To protect young women and girls from an unintended pregnancy as a result of sexual abuse, parents and service providers often pursue sterilisation.[22] However, in practice sterilisation increases the vulnerability to sexual abuse as it makes the abuse more difficult to detect. Since half of children with a disability are out of school, and are often socially isolated, they do not become aware of what is acceptable behaviour by others and what is not. This causes emotionally needy behaviour, and a desperate necessity to make friends for children and young people with disabilities. Consequently, they are easily manipulated, and often tolerate abusive behaviour in their intimate relationships.[23]

The Liliane Foundation is investing in child protection, and training its partners in preventing, recognising and reporting abusive situations. Child maltreatment and the role of child protection is an integral part of SRHR. A further explanation is given in Chapter 2.3 about Acceptability.

SRHR can be considered an ingredient that is central to the development of a child or adolescent with a disability

The importance of SRHR for young people with disabilities

As the Liliane Foundation works with a vulnerable and marginalised group of children, SRHR is an important theme in its strategic policies and plans. Although SRHR is linked to interventions on, for example, education, rehabilitation and child protection, it was not yet an integral part of the organisation's work. However, field visits to partners have shown the importance of the theme. SRHR can be considered an ingredient that is central to the development of a child or adolescent with a disability. There are several other reasons to include children and young people with disabilities in SRHR policies and practices:

SRHR is central to young people's development. All young people – including children and young people with disabilities – have the fundamental right to decide on sexuality and reproductive issues, in order to live a healthy life and to make informed choices that govern their bodies and affect their lives and futures. These decisions should be made based on accurate and evidence-based information, free of stigma, discrimination and coercion. Information about SRHR should be available, accessible and affordable to all individuals who need it, regardless of their age, marital status, socioeconomic status, sexual orientation or ability. In order to achieve this, it is necessary to take action beyond the health sector, so that social norms, laws and policies can be changed.[24]

Evidence shows that access to sexual and reproductive health services (SRHS) saves lives, improves health and well-being, promotes gender equality, increases productivity and household income and has multi-generational benefits by improving children's health and well-being.[25]

SRHR contributes to the personal empowerment of children and young people with disabilities as it helps to preserve their integrity, their freedom of choice, and the nurturing of their own bodies and needs.

Children and young people with disabilities are part of every population and have a higher prevalence when it comes to STIs and experiences of abuse. It is therefore a matter of urgency for the Liliane Foundation to advocate for the inclusion of children and young people in SRHR-related policies and programmes.

SRHR is a key part of achieving gender equality and the empowerment of girls and women. Ensuring universal access to SRHR brings positive gains to the health and well-being of women and girls, reduces cases of gender-based violence[26], and it makes women better able to participate in the economy when they can plan their families.[27]

PHOTO: LILIANE FONDS

Our approach to disability inclusive SRHR

2.

The policy of the Liliane Foundation to promote SRHR is based on two approaches. Firstly, it is based on the human rights-based approach. There are several international conventions that emphasise SRHR for people with disabilities, the most important being the UNCRPD. Articles 25b, the right to health and 23, the right to family planning, are the most explicit ones. The UNCRC furthermore emphasises the right to child protection in Article 19. The right to health is the economic, social and cultural right to which all individuals are entitled to ensure a universal health standard. According to the WHO, this right is as broad as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity".[28]

The human rights based approach to the right to health is made operational in a framework of Availability, Accessibility, Acceptability and Quality of services*:

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Availability
Availability pertains to the functioning of public health and its facilities, goods and services.

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Accessibility
Accessibility promotes non-discrimination, physical accessibility, economic accessibility (affordability of services) and the accessibility of information.

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Acceptability
Acceptability pertains to respectful and medical ethics and sensitivity to age, gender and disability.

Q

Quality
Quality means that the information provided is scientifically and medically appropriate, and should include trained service providers.

*The human rights based approach to health is derived from article 12 of the International Covenant on Economic, Social and Cultural Rights and explains that Availability, Accessibility, Acceptability and Quality (AAAQ) are essential to the enjoyment of the right to health by all.

The second approach is the community-based rehabilitation (CBR) and community-based inclusive development (CBID) framework.

CBR and CBID are aimed at improving the functionality and participation of children and young people with disabilities in their family and community setting, in sectors of health/rehabilitation, education, livelihood and other relevant areas, by supporting the work of those responsible in both communities and service delivery. For the Liliane Foundation, this means that all services that are provided in the area of SRH need to be based as much as possible within the families and in the communities in which the children and young people are living and thriving. They need to be further contextualized, to be culturally sensitive, and to be reconcilable with the specific cultural and ethical norms of the communities in which the SRH is provided. The services and the interventions also need to be provided in a tailored way for the children, by encouraging them and their parents to participate in the process of making decisions for their development and their future prospects. The Liliane Foundation believes that a bottom-up and child-centred approach will increase the likelihood of creating more resilient families and more empowered children and young people with disabilities.

The two approaches are connected by using the twin-track approach. The Liliane Foundation pursues a twin-track approach by actively supporting its Strategic Partner Organisations (SPOs) to collaborate with governments and mainstream SRHR organisations, to ensure that the needs and interests of young people with disabilities are met by including children and young people with disabilities in the laws, policies, and through programmes that are related to the promotion of SRHR.

All services that are provided in the area of SRH need to be based as much as possible within the families and in the communities in which the children and young people are living and thriving

PHOTO: LILIANE FONDS

Availability

Challenges

In many places around the world, SRH such as emergency contraception or safe abortions are not available to anyone to begin with.[29] They are illegal or simply not available. Services such as prenatal care or testing for STIs may be largely available, but only rarely for young people, and especially not for those with disabilities. Small scale studies, for example the one in Ethiopia, found that 52% of all young people with disabilities stated that SRHS were not available to them.[30] Young people with disabilities often do not know where and when the services are provided and they are not tailored to their needs. The same goes for legal services. Although these are generally available, they are not accessible. Challenges related to the accessibility of available services will be discussed in the next chapter. Additionally, some of the countries where the Liliane Foundation works have or are making CSE curricula available in schools. A further point is that NGOs working on SRHR are often not equipped to reach people with disabilities in their programme, while NGOs working on the inclusion of people with disabilities often neglect (aspects of) SRHR in their programmes. For example, materials are not available in a format required for those needing braille, large print or sign language.[31] For disability organisations, there are obstacles to supporting the sexual expression of people with disabilities because of a lack of availability of training materials and contextual and culturally appropriate information.

Health and rehabilitation workers are sensitised to pay attention to the SRH of children and young people with disabilities as part of their overall health and well-being.

PHOTO: RONNIE DANKELMAN

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Besides having a disability, there are other factors that intersect with and influence the availability of SRHS. People with disabilities are, for example, overrepresented among those affected by natural disasters and emergency situations because they live in unsafe conditions or because evacuation facilities and information are not available to them. This has implications for the availability of family planning services in general, and the physical structure of camps and settlements often make it even more difficult, or even impossible, for people with disabilities to reach out to health services.[32] The lack of availability of SRHS in emergency settings is aggravated by the fact that the level of (sexual) violence increases dramatically in these situations, with women and girls with disabilities being especially vulnerable. Not only is rape seen as a means of humiliating and dominating, protection systems also collapse during natural disasters and conflicts.[33] All these factors result in the fact that overall, young people with disabilities have low levels of SRH awareness and knowledge. This leads to risky behaviours and has implications for the accessibility of the services, which are addressed in the next chapter, 2.2 Accessibility.

Liliane Foundation's position on availability of SRHR

The Liliane Foundation, together with its partners, invests in raising awareness about the importance of health services being available to both young people and people with disabilities. The Liliane Foundation is focusing on adding the SRH aspect to the overall health services for children and young people with disabilities. This is being done by sensitising health and rehabilitation workers to pay attention to the SRH of children and young people with disabilities as part of their overall health and well-being. The SRHR projects of the SPOs in Bangladesh (DRRA) and Indonesia (NLR) are partly focusing on training and sensitising health care providers, among other stakeholders, to make their services accessible to young people with disabilities. These projects also simultaneously educate (D)POs by training them on the importance and need of SRHR for people with disabilities. Furthermore, the Liliane Foundation, together with its partners, is working with SRHR organisations to mainstream children with disabilities into their own programmes, and to take their needs into account from a disability perspective. These SRHR organisations often need support and knowledge about how to make their programmes and interventions more disability-friendly, by making sure: (1) that they have appropriate tools for communication with children and young people with disabilities, (2) that their services are physically accessible and that they also cater for specific disability needs within the SRH service. By tapping into existing structures and systems and strengthening them with both SRHR and disability knowledge and skills, the SRH services can become more available for children and young people with disabilities. The Liliane Foundation and its partners are conducting studies to gather data about the current level of knowledge and support for people with disabilities. For example, the SPOs in Zimbabwe, Zambia and Ghana joined forces to conduct research on the accessibility of family planning services for girls with disabilities in the three countries. CSE curricula are additionally made available in collaboration with knowledge institutes on SRHR, for example Rutgers in Indonesia. Furthermore, campaigns are established to raise awareness about the lack of available SRHR services in schools and health care centres.

Accessibility

Challenges

An essential part of SRH is that all people have access to, for example, counselling and care related to sexuality, sexual identity and sexual relationships, and also services for the prevention and treatment of STIs. Issues surrounding healthy sexual development, sexual fulfilment and freedom from illness, violence, and harmful practices related to sexuality are also included. Although little is known about young people with disabilities in general[34], because only limited disaggregated data are available, people with disabilities generally tend to have greater unmet health care needs and poorer levels of health than the general population, mainly because they have difficulties accessing even primary health care. The accessibility of services can be divided into different levels. Within the Liliane Foundation, we divide access into physical accessibility, attitudinal accessibility and institutional accessibility.

SRHS are often physically inaccessible to people with disabilities. The physical barriers vary from lack of ramps, the fact that services are too far away, to the lack of adapted examination tables and lack of adapted communication materials. A small study in Senegal found that services were only accessible to people with disabilities if they were accompanied by another person, a situation which reduces confidentiality and the right to privacy.[35] Lack of information in general[36], or lack of information in specific formats, are also factors that affect accessibility for people with disabilities. Even when services are physically accessible, they may not be tailored to the needs of young people with disabilities. For example, IEC materials are not available in braille or large print and pictures, and services lack sign language interpreters.

The low uptake of health care is related to negative attitudes and the lack of skills among health care providers. These attitudes are shaped by discrimination and stigma in society. This is worsened by the general belief within society – including teachers, parents or caregivers – that people with disabilities are asexual, hyper-sexual, or not capable of feeling love and sexual desire. Consequently, it is believed that people with disabilities do not need information on their SRHR. This barrier is discussed further in Chapter 2.3 about Acceptability.

Just over half of people with disabilities cannot afford health care services, compared to nearly one-third of people without disabilities

Institutional accessibility can be divided into legal accessibility (access to justice) and economic accessibility, or affordability of services. Legal accessibility is related to restrictive laws and policies that are linked to SRHR in general, or lack of implementation of proper SRHR policies. Marital status is also often a key determinant of whether young women are sexually active and whether they receive information about family planning or sexuality education. For example, midwives and free governance family planning services are only accessible for

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PHOTO: HELDERGROEN

Gender stereotypes, together with the incorrect association of disability with inability, reinforce the low social status of disabled women and girls when it comes to marriage and child-bearing prospects

married women. Since people with disabilities are not seen as eligible marriage partners[37], due to beliefs regarding people with disabilities being infertile, or because of the belief that having a disability is contagious, they cannot access these services. Gender stereotypes, together with the incorrect association of disability with inability, reinforce the low social status of disabled women and girls when it comes to marriage and child-bearing prospects[38], and also puts them at risk of unstable relationships.[39] Furthermore, people with disabilities are often denied access to fair and equal treatment in courts, making it more difficult to claim their rights. Children and young people with disabilities are often unaware of the violation of their rights, but when they do recognise the violation and want to come forward to report it, the medical, legal and social service systems are often unresponsive and inaccessible.

Economic accessibility is another barrier caused by lack of funding, including a lack of health-care insurance, which makes health care unaffordable for people with disabilities. According to the World Report on Disability, just over half of people with disabilities cannot afford health care services, compared to nearly one-third of people without disabilities.[40] Even if they have some basic package of health insurance, this often does not cover SRH services, such as visits to a midwifery practice.

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Liliane Foundation's position on accessibility of SRHR

The Liliane Foundation, together with its partners, works on improving the physical access to SRH services for children and young people with disabilities. This is often done as an advocacy intervention towards local government institutions, to improve their health care services and make them physically more accessible for children and young people with disabilities, by building ramps, providing assistive devices when necessary, and creating disability and SRHR-appropriate communication tools for children and young people with disabilities. With regard to legal accessibility and to protecting children from sexual abuse, the Liliane Foundation supports its partners in awareness and prevention training on how to recognise abusive situations and what to do in case of abuse in terms of both reporting and support. Partners are encouraged to lobby and advocate for more inclusive and accessible justice systems that are more child and disability sensitive. A project in Nicaragua, for example, is focusing on the establishment and strengthening of a policy on how to manage and deal with sexual violence at the community level.

With regard to economic accessibility, the Liliane Foundation strives to promote affordable SRH services that are already included in the general health care package of children and young people with disabilities as a part of integrated services. Furthermore, it supports the Community Based Distributors (CBD) who can conduct counselling with clients and distribute short-term contraception, condoms and emergency contraception. Typically living in the communities that they serve, CBDs are available for free and 'on-demand' counselling and services and are therefore the first line in access to information and prevention of mistimed pregnancy.[41] As part of our contribution, we seek to train SPOs, POs and local communities in the importance of SRHR and accessible health services.

The Liliane Foundation supports its partners in awareness and prevention training on how to recognise abusive situations and what to do in case of abuse in terms of both reporting and support

PHOTO: LILIANE FONDS

In Indonesia, staff from partner organisations and health providers learn more about sexual and reproductive health and rights so they can support children and youth with disabilities.

PHOTO: JAN JOSEPH STOK

Global/Regional facts:

People with disabilities are three to four times as likely to experience physical, sexual and emotional abuse than people without disabilities.[42]

Young people with disabilities were, on average, 12% less likely to self-report violence at home. For both girls in general and all young people living in rural settings, this proportion was 17%.[43]

As 50% of children with disabilities do not go to school, they miss out on important information such as sex education, and also suffer illiteracy, which means that they do not have access to the information that is provided in health centres or via the media.

Nicaragua: In 2010, 40% of domestic violence cases were filed against women with disabilities and of the total of 57 femicides (gender-based murders) reported, 21 (36%) were women with disabilities.[48]

Ethiopia: In Ethiopia, 52% of young people with disabilities reported that sexual and reproductive health services were not available to them.[45]

Nepal: In Nepal, 50% of girls with disabilities were not aware of the changes that occur during puberty. In comparison to boys, of whom 25% were aware of these changes, they were less likely to learn from friends, school or the media due to prejudice and lack of access to education.[47]

Sub-Saharan Africa:
In a large study in five sub-Saharan African countries, 37% of the respondents between the ages of 14- 17 living with a disability reported having experienced forced sexual intercourse. Children were at even more risk of sexual violence.[44]

Rwanda: While the national incidence of HIV stands at 3% in Rwanda, the incidence among people with disabilities is 3.5%.[46]

Acceptability

Challenges

The acceptability of health services is related to non-discrimination, which means that health services must be accessible to all, especially the most vulnerable or marginalised groups, such as people with disabilities. These groups should be respected according to medical ethics, in a way that is culturally appropriate to gender, age, and type of impairment. SRHR programmes can only be effective when it is believed that these individuals have the same basic social and sexual rights and responsibilities as anyone else. This belief starts within the family, through parents and caregivers. An acceptable direct environment is important, as this influences the (sexual) development of children and their self-esteem, and also their ideas about what constitutes love and healthy relationships. Unfortunately, people with disabilities have to deal with stigma and discrimination in all societies, but in some parts of Africa and Asia, this discrimination can be oppressive.[49] People with disabilities are often considered by their communities to be weak, worthless or even sub-human.[50] As mentioned earlier, perpetrators of violence see people with disabilities as easy targets[51], and there are areas in Africa where it is believed that sexual intercourse with people with disabilities can cure HIV.[52]

There are also specific myths that make the experience of SRHR for people with disabilities a taboo topic. SRHR service providers, but also parents and teachers, fail to provide information to children and young people with disabilities because of the following stereotypical beliefs[53]:

SRHR programmes can only be effective when it is believed that these individuals have the same basic social and sexual rights and responsibilities as anyone else

- People with disabilities are dependent and childlike, and thus need to be protected from information;
- People with disabilities are either asexual or oversexed and have uncontrollable urges;
- Disability breeds disability;
- People with disabilities should stay with and marry other people with disabilities;
- If a person with a disability has a sexual problem, it is always due to the disability;
- People with disabilities cannot raise children, and they will be an extra burden for the parents;
- Parents of children with disabilities do not want their children to receive sexuality education.

A study has shown that parents, teachers and health care providers feel anxious and untrained, and lack the confidence to discuss sexuality with children and young people with disabilities, leaving them with a lack of social confidence and sexual self-esteem.[54] Moreover, health services may be provided in such a way

PHOTO: RONNIE DANKELMAN

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Parents, teachers and health care providers feel anxious and untrained, and lack the confidence to discuss sexuality with children and young people with disabilities

that young people do not feel comfortable obtaining them, even if this would otherwise be possible. Additionally, there is the fear that health workers will not maintain confidentiality, or will put them through unpleasant and unnecessary procedures.[55] Health care providers also face difficulties. When providing information, they face family opposition, or feel confused over the legality of their support. Therefore, the physiological needs of a person – such as food, water and shelter – are placed ahead of aspects such as a natural exploration of sexuality and sexual expression. This is seen more as an expression of self-actualisation, self-esteem, love and a feeling of belonging, safety and security, which is not considered a normal right for people with disabilities. They are not given support to understand their sexual rights, nor the opportunity or the education to explore their bodies.[56]

Another aspect is that the quality of training for CBR workers varies greatly, and issues of sexuality and relationships are often not adequately covered.[57] They do not receive training themselves about pleasure in general, or SRHR, as being an integral part of a good quality of life. People with disabilities are reliant on others when it comes to advising and educating them on their rights and what they mean in practice. When it comes to sex and sexuality, however, CBR workers, health workers and parents may believe that their own rights, values and beliefs are paramount.[58] It is not easy to find out more about problems with, and questions, about sexuality. The service providers therefore have to take the initiative. From childhood onward, this subject needs to be a topic of discussion with the child and parents of the rehabilitation expert and social workers.[59]

Liliane Foundation's position on acceptability of SRHR

The Liliane Foundation believes that families should be the first to accept their children as human beings with sexual and reproductive needs, as an intrinsic part of their overall personal development. Coming to acceptance is a life-long process. There are vulnerable periods when special care and additional support are needed, for example at big developmental milestones such as reaching preschool/school age. An accepting family is able to give love to the child, with no feelings of rejection or over-protection. This also includes accepting the child as an individual who can live on equal terms with others, including the ability to have relationships, get married and start a family. For example, our SPO ACAI in Bolivia supports parents with special parent support training, and one of the sessions is devoted to ***'Sexuality in adolescence with intellectual disability'***. Inclusion must first begin in the family, and then develop to the community level, which includes schools, health services and ultimately, a work environment.

The Liliane Foundation promotes aspects of SRHR, such as family planning and the use of contraception, without disrespecting or trying to change cultural and religious narratives

Capacity development for health care providers in approaches appropriate for young and disabled people is also particularly important, because health care providers are frequently the first people children and young people with disabilities turn to in case of abuse, or when having questions about their SRHR. CBR workers and people who regularly work with the rehabilitation of children and young people with disabilities also need information about the importance of SRHR. The Liliane Foundation therefore actively encourages its partners to see SRHR as an integral part of CBR, rather than a separate thematic area.

The Liliane Foundation also invests in child protection because of the high vulnerability of children and young people with disabilities and the risk of becoming victims of trafficking for sexual or forced labour, including child

Education about disability rights in the Phillippines, including the right to health and education without discrimination.

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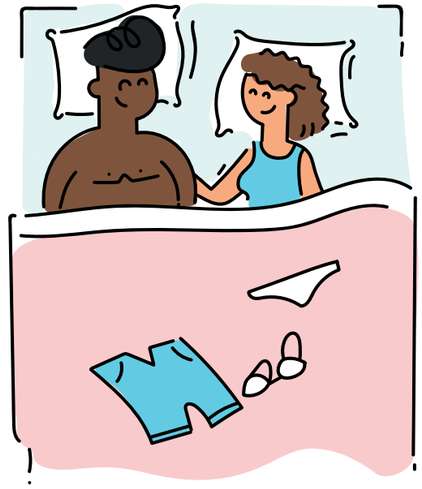

marriage, sexual abuse and other forms of abuse. Child protection not only means responding adequately to cases of abuse, but also helping partners to prevent abuse through proper training, awareness-raising sessions and monitoring mechanisms. All partners are required to establish and implement a child protection policy to monitor and respond to child abuse. Care, support and protection for children and young people with disabilities that have been subjected to violence must be an essential component of the organisation's strategy. When highlighting the risks of unhealthy relationships, bodily autonomy and self-protection skills, healthy relationships and how to achieve them cannot be overlooked.[60] This not only includes relationships with others, but also the relationship someone has with themselves and their body. Every human being is a sexual being, regardless of their limitations. It is therefore important for children and young people with disabilities, and their parents, to include intimacy, their own sexuality, and the forming of relationships as an obvious and natural topic in conversations about development.[61]

The Liliane Foundation promotes aspects of SRHR, such as family planning and the use of contraception, without disrespecting or trying to change cultural and religious narratives. However, safeguarding the quality of, for example, sexuality education and the human rights framework remains a high priority. Aspects of SRHR are promoted within the human rights framework, guaranteeing the ability of children and young people to make decisions about their own bodies, futures and lives. Programmes and policies should not be the same the world over, but societal norms and beliefs should be considered before opening discussions about contraception and family planning. When talking about comprehensive sexuality education, it is important to reframe the issue away from 'teaching children how to have sex' to a methodology that provides a structured opportunity for young people to gain knowledge and skills. The aim should be to develop skills and knowledge about their bodies and minds, to explore their attitudes and values and to practice the decision making and other life skills necessary for making healthy and informed choices about their sex lives.

Quality

Challenges

In many of the countries where the Liliane Foundation works, sexuality education is not part of the general curriculum to begin with, even for young people without disabilities. This is often due to the prevalent socio-cultural norms and values. For example, family planning information is not offered until someone is married, as it is assumed that people will not use it before marriage. Too many young people receive information about relationships and sex that is confusing and conflicting. This has consequences for their transition from childhood to adulthood.

Additionally, young people often receive information that only entails how to avoid contracting reproductive or sexual illnesses. Cultural and religious beliefs force young people to believe that sexuality is exclusively tied to reproduction. Issues of sexual pleasure, autonomy and the full enjoyment of sexual well-being and health are controversial topics.[62] It is therefore important that all young people receive reliable information, in order to prepare them for safe, productive and fulfilling lives.[63] When SRHR intersects with disability it is even harder to receive good quality and scientifically correct information, because – besides the myths and beliefs surrounding sexuality – it is assumed that people with disabilities are not sexually active at all, never get married, or are 'oversexed'.[64]

Not being able to express choices, wishes or desires in (sexual) relationships affects well-being and ultimately undermines political, social and economic empowerment

Evidence shows that young people with disabilities tend to have low levels of SRH knowledge.[65] Everything from cleaning their teeth to understanding public and private spaces is taught to people with disabilities, but organisations also need to invest in routinely teaching people how to have healthy and intimate relationships.[66] Not being able to express choices, wishes or desires in (sexual) relationships affects well-being and ultimately undermines political, social and economic empowerment.[67]

There are different types of sexuality education. UNESCO takes a comprehensive approach to sexuality education with their ***Technical Guidance on Sexuality Education***[68]. This starts from the principle that sexuality is a fundamental aspect of every human life, having physical, psychological, social, spiritual and cultural dimensions.[69] Everyone needs sexuality education, including young people with disabilities. Effective sexuality education is a vital part of the prevention of STIs, including HIV/AIDS, and reduces the risks of unintended pregnancies and abusive sexual activity. However, most projects, policies and programmes – especially those for people with disabilities – focus on the prevention of pregnancy and promote abstinence as the best way forward.

It is important to recognise that young people with disabilities are sexually active and may engage in behaviours that put them at risk of contracting HIV and other STIs, because they have little knowledge about HIV and sexuality. Five out of ten children that do not attend school are children with disabilities.[70] This means they are excluded from vital SRH education which is often provided in school settings. Those who are at school may lack access to comprehensive sexuality education, as their educators and peers often hold negative beliefs about their need for sexuality education, or lack the skills and tools to accommodate people with diverse learning needs. Very often, educators avoid discussing sexuality or use an abstinence-driven teaching approach.[71]

There is a need for disability-specific information. For example, children with cerebral palsy need information on the influence of spasticity or tension on sexual intercourse

Although young people with disabilities do not necessarily need other information than their peers without a disability, there is a need for disability-specific information. For example, children with cerebral palsy need information on the influence of spasticity or tension on sexual intercourse. Or they need advice on suitable ways of showing intimacy, apart from intercourse. The absence of quality in sexuality education for people with disabilities, combined with learning about sex solely from conversations with others, or through sexual intercourse, leads to sexuality that is cognitively focused on a perfect performance. It is therefore important to invest in a twin-track approach towards SRHR, with both qualitative and scientifically accurate information, combined with disability-specific approaches towards issues such as sexuality.

Liliane Foundation's position on quality of SRHR

When considering the issue of access to education, all children and young people with disabilities should have access to an SRHR curriculum in special and regular education settings, at all levels of education. The Liliane Foundation empowers its partners to pay attention to this aspect of the curriculum in all school settings. More attention should also be paid to wider aspects of SRHR, and not only to reproductive body parts – such as relationship building, intimacy, sexual and reproductive development.

The Liliane Foundation is in favour of comprehensive sexuality education (CSE). CSE covers a broad range of topics that are related to the physical and biological aspects of sexuality as well as to the emotional and social aspects. All these topics should provide age-appropriate, culturally relevant and scientifically accurate information.[72] The information that is provided, and the way it is provided, develops young people's knowledge and improves their skills, attitudes and values on SRHR. It is not about encouraging young people to engage in sexual relationships, nor teaching them how to have sex.

To ensure that children and young people with disabilities have access to CSE, it is important – besides mainstreaming disability into CSE programmes implemented

In Indonesia, youth learn what body parts may be touched and which parts are private.

within formal school settings – to also provide CSE programmes in informal school settings. CSE can be used as a preventive measure in child protection and, if implemented in an appropriate manner, it can mitigate potentially risky situations in which many children and young people with disabilities can find themselves. Furthermore, CSE can contribute towards the empowerment of children and young people with disabilities, making them aware of their sexuality as a natural aspect of their personal development as well as of their reproductive health and rights, which are just as important as any other rights which they are fully entitled to exercise in their lives.

To be comprehensive, sexuality education should not only focus on sex and sexuality, or the prevention of ill health, but should also emphasise sexuality with a positive approach

Although the Liliane Foundation has a preference for teaching sexuality education according to a comprehensive approach, it will not always be appropriate for the local context in which the educational activities take place, especially not when abstinence is the only message. It is important to note that abstinence is also included in the CSE curriculum, as it incorporates a range of prevention strategies on contraception to prevent STIs and unwanted pregnancy, and it highlights the importance of safe sexual practice.[73] This means that, while one way to prevent pregnancy and STIs is to stay away from sex, other forms of contraception are also explained. In fact, programmes that promote abstinence as the only option have proved to be ineffective while programmes that combine a focus on delaying sexual activity complemented with other comprehensive content has proved to be effective.[74] The use of mobile technologies, peer groups, sports, community and youth centres where topics and problems can be discussed openly should be considered.

To be comprehensive, sexuality education should not only focus on sex and sexuality, or the prevention of ill health, but should also emphasise sexuality with a positive approach by paying attention to values such as respect, inclusion, equality, non-discrimination, responsibility and reciprocity.[75] Additionally, young people should gain self-esteem and should learn how to protect their emotional and physical well-being.[76] The inclusion of a comprehensive approach to

pleasurable sex and healthy relationships serves to empower young people with disabilities to become agents, entitled to pleasure and therefore responsible for their own sexuality.[77]

There are critics who say that the more information you provide to children and young people (with and without disabilities) about sex, the more it will encourage them to experiment. However, research has shown that children and young people who are informed are better able to make the right choices to protect themselves, and can help delay sexual initiation[78], and that CSE is the most effective teaching method for young people. Programmes that promote abstinence as being the only option for sexuality education have been found to be ineffective when it comes to delaying sexual activity, or to reducing the frequency of sex or the number of sexual partners.[79]

Research has shown that children and young people who are informed are better able to make the right choices to protect themselves

Good examples where the methodology of CSE is implemented, while not advocating explicitly for sexual activity, is the programme My Body Is Mine that is implemented in Indonesia as a combined effort by NLR Indonesia and Rutgers, and the project in Nicaragua in collaboration with UNFPA. While implementing comprehensive activities, the project is framed as one that will teach children with disabilities to protect themselves from abuse, and to have respect for their bodies and (the bodies of) others – including the transitions that they go through in life, gender roles and stereotypes and setting boundaries.

PHOTO: LILIANE FONDS

3. Steps towards disability-inclusive SRHR

PHOTO: JAN-JOSEPH STOK

The Liliane Foundation believes that children and young people with disabilities living in poor families and communities are entitled to be included in society and to enjoy the highest attainable quality of life, including SRHR. The following focus areas and principles are crucial to achieving disability-inclusive SRHR. The Liliane Foundation is devoted to this goal, but the following activities require coordination and collaboration with other parties.

Building knowledge and expertise on SRHR for children and young people with disabilities
Considering the lack of data and materials available on the topic, knowledge needs to be built at all levels. The Liliane Foundation invests in new opportunities for collaboration and research to gather data, gain new insights and to build a permanently growing portfolio. In order to do so, collaboration between the Liliane Foundation, (SRHR) research and knowledge institutes and the partners of the Liliane Foundation is essential. The Liliane Foundation and its partners need to stay up to date with the latest insights on SRHR for children and young people with disabilities in diverse contexts, and to consider how these can be incorporated into their policy and programme cycles. The Liliane Foundation should also strengthen the capacities of its SPOs by sharing and providing information, training and materials on disability and SRHR, and by empowering families to support their children in exercising their SRHR.

Pioneering on the topic of disability-inclusive SRHR
The Liliane Foundation is committed to supporting partners with innovative projects on SRHR for children and young people with disabilities and encourages them to collaborate with organisations that specifically work on SRHR. The Liliane Foundation and its partners are committed to jointly developing new and innovative projects that include youth with disabilities together with others. By providing partners with disability expertise, disability can be mainstreamed into SRHR policies, systems and services and access is better assured. Additionally, implementing good projects and extracting lessons from them can contribute towards best practices and a solid track record.

Lobbying and advocacy for disability-inclusive SRHR
By working together with like-minded disability organisations, rehabilitation experts and SRHR organisations, alliances and networks focused on disability inclusion can be initiated. These alliances should be formed at the local, national, regional and international levels in order to further lobby and advocate for better SRHR policies and services for people with disabilities within their communities and society at large.

Promoting SRHR as a cross cutting issue
Cross-sectoral linkages between SRHR and other issues such as child protection, rehabilitation, education, labour, transport and communication and disaster risk management, need to be sought and further explored, including how these topics interrelate and influence each other. In this way, the interventions in the services provided will be of better quality and have a more sustainable and positive effect on children and young people with disabilities.

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Abbreviations

AAAQ	Availability, Accessibility, Acceptability, Quality
CBD	Community Based Distributors
CBID	Community Based Inclusive Development
CBR	Community Based Rehabilitation
CSE	Comprehensive Sexuality Education
CSO	Civil Society Organisations
IEC	Information Education and Communication
NGOs	Non-Governmental Organisations
SPO	Strategic Partner Organisation
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health and Rights
SRHS	Sexual and Reproductive Health Services
STI	Sexually Transmitted Infection
UNCRC	United Nations Convention on the Rights of the Child
UNCRPD	United Nations Convention on the Rights of People with Disabilities
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNFPA	United Nations Family Planning Association
UNICEF	United Nations Children's Fund
WHO	World Health Organisation

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Making children with disabilities stronger

At least 40 million children with a disability live in the poorest areas of Africa, Asia and Latin-America. They are often left behind and frequently victims of neglect, abuse and violence. This is contrary to their rights: they should be able to participate equally and fully, at home and in their communities - and to live a life to the highest possible standard.

Our dream for the future is that children with disabilities are equal and participate as fully as possible in their homes and their communities. Their lives have the highest possible quality.

To make that dream come true the Liliane Foundation contributes to a world that is open to everyone and in which children with disabilities in poor resource areas can develop and use all their talents. Together with local organisations in Africa, Asia and Latin America, we make children stronger and their environment more accessible.

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