

Everybody matters

Good practices for inclusion of people with disabilities in sexual and reproductive health and rights programmes



Every**body** matters

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and reproductive health and rights
programmes

Colofon

A production of the Dutch Coalition on Disability and Development (DCDD) and Share-Net International, the knowledge platform on sexual and reproductive health and rights.

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In the Dutch Coalition on Disability and Development (DCDD), individual experts and development organisations have joined forces to promote the inclusion of people with disabilities in development cooperation. DCDD's main focus is on advocacy towards the Dutch Parliament and Ministry of Foreign Affairs, development NGOs and the private sector.

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Share-Net International, the knowledge platform on sexual and reproductive health and rights, combines the expertise and strengths of Dutch organisations, Southern partners and key international actors working in the area of sexual and reproductive health and rights (SRHR) to achieve the SRHR and HIV related Sustainable Development Goals (SDGs).

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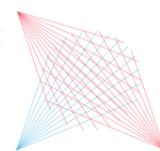


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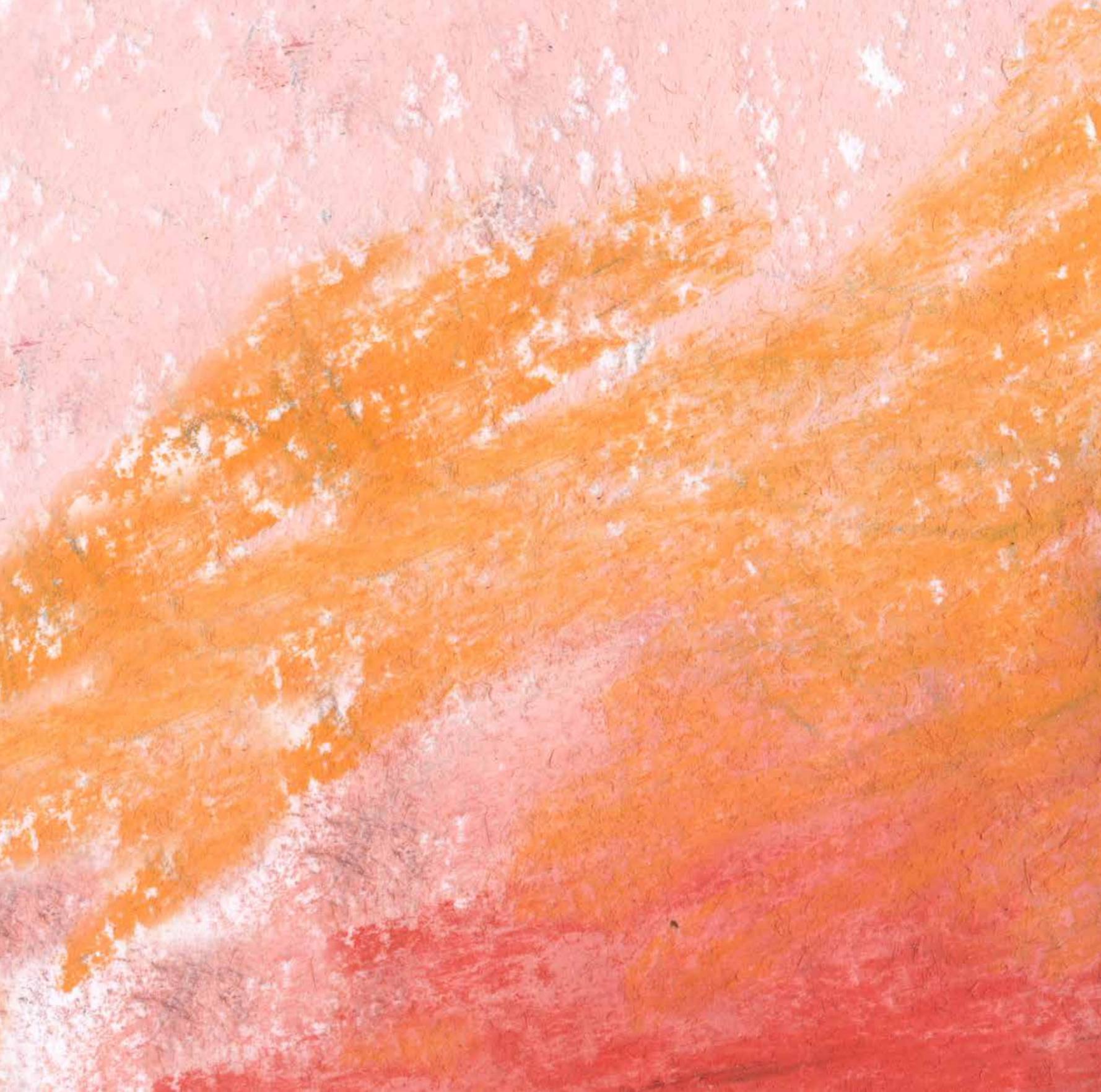
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Foreword

by Catalina Devandas

'Everybody matters' addresses important issues related to the sexual and reproductive health and rights of persons with disabilities from a legal, policy and practical perspective. It shares with the reader the lived experiences of persons with disabilities, introducing them as individuals and equal right holders.

The book exposes the damaging misconceptions and deeply ingrained prejudices around disability and sexuality and calls attention to the atrocious human rights violations disproportionately affecting girls and women with disabilities around the world. It challenges specific forms of gender based violence, such as forced sterilisation or involuntary contraception, which, in spite of being unanimously condemned, are still perceived as acceptable when it comes to girls and women with disabilities. It reveals the struggles and barriers which render access to justice out of reach for many people with disabilities.

Beyond its profound sensitisation impact, the publication is a valuable resource book aimed at supporting decision-makers, globally, in their efforts to provide legal protection against all forms of discrimination and non-consensual practices infringing on the sexual and reproductive integrity of persons with disabilities. It helps policy makers understand how to frame policies aimed at increasing autonomy, choice and control in the exercise of sexual and reproductive health and rights by persons with disabilities. It serves to guide disability rights advocates and other stakeholders on how to influence the way in which sexual and reproductive health and rights services are shaped.

The rights of girls and women with disabilities have always been at the forefront of my work as Special Rapporteur on the rights of person with disabilities. I am therefore honoured to introduce this important publication which draws on some of the much valuable work conducted by women with disabilities that are leading the way towards positive change.



Introduction

To be human is to be sexual

Just like all human beings, people with a disability are sexual. Those with disabilities are, first and foremost, people: they have the same rights, feelings, sexual desires, needs and possibly family dreams as anybody else. A positive body image and healthy self-esteem helps in pursuing and celebrating a pleasurable and healthy sexual and family life. At the same time, it is necessary to know how to set boundaries and how to protect against sexually transmitted diseases, unwanted pregnancy and in the worst case, sexual violence. In other words: all people – both male and female – with or without disabilities have

the same needs in terms of access to and information about 'sexual and reproductive health and rights': SRHR, so that they can celebrate satisfying sex and having a family if, when, and with whom they want.

However, the SRHR needs of people with disabilities often remain unmet. A profound worldwide misconception exists, that suggests people with disabilities are either asexual or hypersexual (without inhibitions)⁹. In terms of love, relationships and having children, it is thought to be best if men and women with disabilities do not venture into these areas, for their own sake and that of society. With the imposition of such negative ideas, and telling them they are undesirable and not worthy of desires, it is likely that the self-esteem of people with disabilities is suppressed. As a result, they might not seek access to SRHR services of their own accord¹⁰.

Not only disability, but sexuality too is unmentionable in many cultures and is often shrouded in shame. In various (traditional) societies, it is taboo to openly discuss issues like menstruation,

*"Some people misunderstood our relationship, and thought of him as being my caregiver instead of my partner"*⁴

*"I get the feeling people think that because I am in a [wheel]chair there is just a blank space down there."*³

*"I am blind, and so is love. Get over it!"*¹

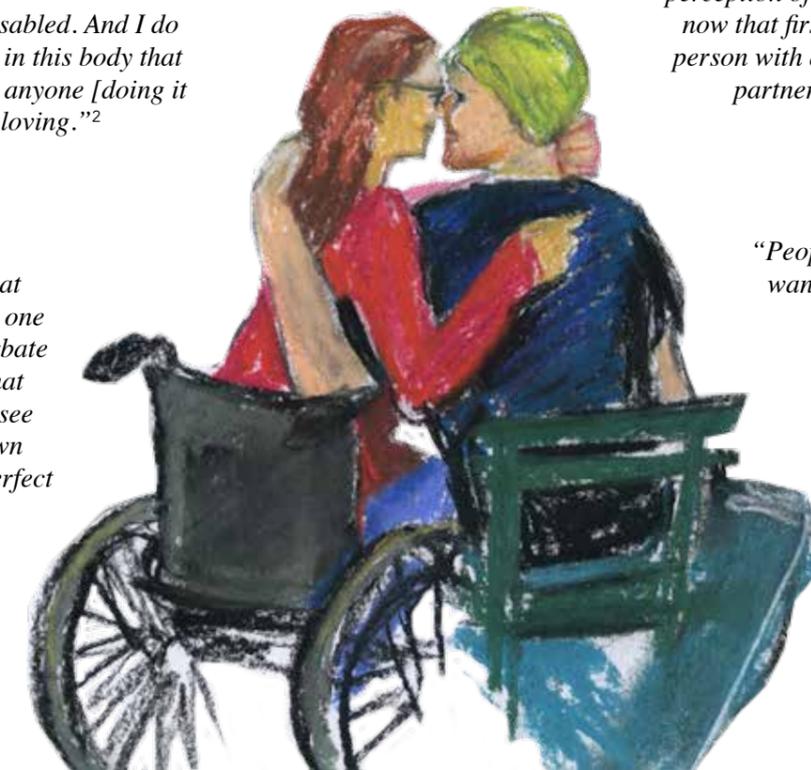
*"I'm here. I'm disabled. And I do it. Yes, I do. Even in this body that you can't imagine anyone [doing it with] and loving."*²

*"The [sexuality] course influenced my perception of my own sexuality. I understand now that first I am a woman and second a person with a disability. I deserve to have a partner, children and a family."*⁷

*"Why do we think that someone who only has one hand would not masturbate with the other? Or that someone who cannot see does not paint her own mental images of the perfect lover?"*⁶

*"People would say to me: 'Why would you want to be tested [for HIV], as if you're able to have sex?'"*⁵

*"Sexuality is not just physical – it is also socio-cultural, spiritual, and psychological. Everyone has the right to sex education that encompasses all of these aspects."*⁸



relationships, sexual diversity, safe and pleasurable sex and family planning^{11/12}. This is even more so when it comes to sexual exploitation and abuse, let alone when people who have a disability are involved.

Due to the above-mentioned negative perceptions, people with disabilities are more likely to experience the downside, rather than the upside, of sexuality and family life than others. Whilst more research and data are needed, the figures below highlight some of the key issues from recent studies related to SRHR and disability:

- » People with disabilities are as sexually active as their non-disabled peers¹³;
- » People with disabilities are twice as likely to be on the receiving end of inadequately skilled healthcare providers at improper facilities. They are three times more likely to be denied healthcare and four times more likely to be treated badly by healthcare systems¹⁴;
- » People with a disability are three times more likely to become a victim of sexual, emotional and physical violence. People with intellectual and mental disabilities are the most vulnerable¹⁵;
- » Children with a disability are almost three times more likely to experience sexual violence than their peers without disabilities, and for children with an intellectual disability this is even higher: 4.6 times¹⁵;
- » Between 40 and 68 percent of young women with disabilities and 16 to 30 percent of young men with disabilities experience sexual violence before the age of eighteen¹⁶;
- » Forced sterilisation of women and girls with disabilities happens up to three times more often than amongst their peers¹⁷.
- » All risk factors associated with HIV (poverty, lack of education, lack of SRHR information, higher risk of violence and rape) are higher for individuals with a disability¹³;

What is SRHR?

Sexual and reproductive health and rights (SRHR) refers to the rights of all human beings to receive comprehensive sexuality education, choose their partner, have respect for bodily integrity, decide to be sexually active or not, have consensual sexual relationships and marriages, decide whether and when to have children or not and to pursue a satisfying, safe and pleasurable sexual life. Sexual and reproductive health (SRH) services include¹⁸:

- » Maternal and newborn care;
- » Contraceptive information and services;
- » Prevention and appropriate treatment of infertility;
- » Safe abortion and post-abortion care;
- » Combatting HIV/AIDS and other sexually transmitted diseases;
- » Prevention of gender based violence, care for victims and information, education and counselling on sexual violence;
- » Actions to eliminate harmful traditional practices such as female genital mutilation and early and forced marriage;
- » Comprehensive sexuality education and youth friendly services.

Comprehensive sexuality education, according to UNFPA¹⁹, is a rights-based and gender-focused approach, that includes scientifically accurate information about human development, anatomy and reproductive health, contraception, childbirth and sexually transmitted infections (including HIV). It goes beyond information, helping young people to explore their bodies in a positive way, discusses family life, relationships, culture and gender roles.

What is disability?

More than one billion people in the world (15%) live with some form of disability, of which approximately 200 million (2%) experience significant functional difficulties. 80% of all people with a disability live in developing countries²¹. Whilst stereotypical views of disability might emphasise wheelchair users, impairments come in many different forms: physical, sensory, intellectual or psychosocial, or a combination of any of these. People with different impairments face different kinds of obstacles in their own environment. The World Health Organisation

(WHO) promotes a social perspective on disability²¹, whereby the person or their impairment is not viewed as 'the problem', but understand disability as a result of the barriers they face in society. The challenges are therefore not necessarily due to having an impairment in itself, but rather reflect a lack of social attention, legal protection, understanding and support¹⁵.

The UN Convention on the Rights of People with Disabilities (CRPD)²⁰, states that:

People with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"

The following articles relate to sexual and reproductive health and rights¹⁵:

- Article 9: Accessibility
- Article 16: Freedom from exploitation and abuse
- Article 22: Respect for privacy
- Article 23: Respect for home and the family
- Article 25: Health

Everybody Matters

Working towards inclusion is not necessarily difficult. On the contrary, existing services can be easily adapted to suit people with disabilities¹⁵.

Good practices, whereby SRHR and disability inclusion come together, do exist but are rarely documented. This book aims to bring these practices to the forefront, so that barriers can be broken down and bridges can be built between the worlds of SRHR and disability.

To Leave No One Behind – an overarching theme in the Sustainable Development Goals²³ (SDGs) - in addressing sexual and reproductive health and rights, all stakeholders, including governments, SRH service providers, NGOs, activists, people with disabilities and their parents have an important contribution to make.

This can be done most effectively when stakeholders link up with each other and work alongside each other. Together, we can work towards ensuring that the sexual and reproductive health and rights of people with disabilities are fully recognised and addressed, in turn, empowering people with disabilities to make their own decisions about their sexual and family lives.

Twin track approach for disability inclusion

This book underlines the importance of the twin track approach²². This means, aiming for the full inclusion and participation of people with disabilities in society and development programmes, at the same time as providing time specific attention and support for people with disabilities to empower them in participating on an equal basis with others. In short: track 1 represents disability inclusion in 'mainstream' initiatives; track 2 represents disability-specific initiatives.

About this book

This book is a collaboration between the Dutch Coalition on Disability and Development (DCDD) and Share-Net International, the knowledge platform on SRHR.

In the following chapters, we meet activists, Toyin Aderemi and Nidhi Goyal, who both work tirelessly to create better opportunities for people with disabilities in their parts of the world – Nigeria and India.

Subsequently, drawing from our international networks, we exhibit the challenges that organisations worldwide have encountered whilst improving the access to and knowledge of sexual and reproductive health and rights for people with disabilities. We look at the ways in which they managed to find solutions to address this topic and review the results they have achieved. Some cases show us the importance of a more personal approach whilst others emphasise the advantage of changing systems and policies. Some cases have shared their challenges and others put forward personal stories or showcase programme components. Different regions, types of disabilities and various SRHR-topics are reflected in these stories. All cases provide lessons learnt that contribute to a set of recommendations for improved responses.

The closing chapter highlights the challenges, solutions, and ambitions that are presented and lead up to a concise overview of recommendations, which enable people living with a disability to embrace their sexual and reproductive health and rights.

This book was written in the hope that these stories and practical lessons will inspire you as a policy maker, decision maker, development worker or health professional to embark on similar journeys.

'Only awareness triggers change'

About tireless activism

by Caroline van Slobbe

As long as the sexual and reproductive health and rights of people with disabilities are insufficiently addressed in policies and programmes throughout the world, we will need many more experts and activists on disability and sexuality who can guide and inspire us. Experts like Dr. Toyin Aderemi, for example, who works tirelessly to create better opportunities for people with disabilities in the African countries where she has been working: Nigeria, Ethiopia and South Sudan. With a PhD in Behavioural Medicine and a post-doctoral in sexuality education of learners with disabilities, she is one of the few experts on this topic in Nigeria. What can we learn from her?



"I became interested in disability inclusion mainly because of my own experience as a woman with a disability. During my Master in Public Health, I was doing an internship at a national NGO working on sexual and reproductive health. I loved what the NGO was doing, especially for women. But at one point, I realised, being a woman with a disability myself, I could not get access to their services if I should need them. When I asked the programme manager why women and girls with disabilities were not included, she was not interested and said: 'this is not our area of work.'" It was during this internship that Aderemi's motivation to work in the field of SRHR and people with disabilities developed.

Toyin Aderemi (46) was born and raised in Ibadan, in the southwestern part of Nigeria, and now lives in the country's capital Abuja. She has worked as a pharmacist in Nigeria for twelve years, but then decided to pursue her Masters in Public Health. She knows first-hand that there was a need that was not being met regarding issues of sexuality. "The way in which people perceived me, thought of me as not sexual, or that I should not be sexual. It is... unpalatable. All this sparked my interest in specialising in that topic."

"Many girls with intellectual disabilities were able to demonstrate that they were in love and they wanted to have sexual relationships"

The strength of conversations

When she started her PhD in 2007, the experiences of young women with disabilities were not documented when it came to HIV and sexuality. Aderemi was curious to know: what do women with intellectual disabilities in Nigeria know about sexuality and HIV? And what are the consequences of this? For her PhD-research she held numerous in-depth conversations with them, in order to compare the knowledge of learners with intellectual disabilities with the knowledge of their non-disabled peers²⁴.

"They knew less than nothing about sexuality. They did not know what a condom is, let alone how to use it. Teachers would not teach girls with disabilities about this, as they believe that these girls do not have a real attachment to any man, that they just want to have sex. Do not let them be promiscuous, let a sleeping dog lie, was their idea. However, many girls were able to demonstrate to me that they were in love and they wanted to have sexual relationships. The opposite idea is widespread. One of my graduate friends even once shared that she

would not expect me to be involved in a relationship because of my disability. And that was a highly educated person!"

Another finding of Aderemi's extensive research was that the rate of sexual abuse among girls with intellectual disabilities was almost five times higher than amongst girls without disabilities. "They are 'easy victims': they are perceived as naïve or unable to seek justice."

"Data collection is the very first step in colouring the advocacy strategy"

Through talking with the young women, she found out that most of the perpetrators are people very close to them – husbands, brothers, fathers, neighbours: people they are dependent on. "There is a system of justice in Nigeria, but it is not very effective, particularly when it comes to victims with a disability. Worse still, traditional religious leaders play a large role in this, arguing that in cases of domestic violence, women and girls with disabilities should simply be happy that they have a man at all. They say: 'For you to have gotten this man is a blessing in itself.'"

People who have experienced sexual abuse are often unwilling to talk about it. What approach can we use with women and girls with intellectual disabilities that will encourage them to talk about their trauma? "There are certain methods that you have to learn. You use very simple language, pictorials, and you have to repeat your sentences to be sure they understand, to be able to really interact with them."

How does change happen?

After her PhD, Aderemi started to work for Handicap International in Ethiopia as an HIV and disability advisor. When she came back to Nigeria, she could not find a job with any national or international NGO. "Despite my PhD-research and years of experience, they thought I would not be able to work, because of my disability." She then decided to return to South Africa for a post-doctorate in the Health Economics and HIV/AIDS Research Division (HEARD).

Later, she worked as a programme manager at Light For The World within the complex context of conflict in South Sudan, and her current title is that of country representative at CBM in Nigeria. Both are international NGOs striving towards a disability inclusive society.

According to Aderemi, lobby and advocacy at the national government is the first crucial focal point to make positive change happen. "I think it is problematic that priorities like SRHR of people with disabilities are only set by donor funds.



The government rarely allocates funds for programmes like this as they do not see disability inclusion as a priority. But if we remain dependent on donors, it will never be sustainable. That is why we should focus, first of all, on lobby and advocacy with the national government. For that, first and foremost, they need to know about the topic."

Data collection is the very first step in colouring the advocacy strategy, she argues. Without data and statistics, government officials will not be convinced that there is a problem. "We need to review existing laws and policies to find where the gaps are regarding SRHR and disability, and steer the government in that direction," advises Aderemi. "Additionally, gather and document the stories and experiences of people with disabilities, families, and other stakeholders. When an implementing partner of us [CBM] was lobbying on SRHR and disability, they hired a consultant to draw up how the policy should be designed, partnering with the Federal Ministry of Health and other stakeholders. The Nigerian government has finally approved a new SRH policy for women and girls with disabilities! It is a breakthrough, but adequate implementation is still key."

In South Sudan, where she worked for Light For The World, everything was different. "It was an area of conflict where people were displaced and humanitarian response was the largest issue. There were many people with disabilities who were sexually abused as well, and

were trying to cope with huge traumas. We worked on the inclusion of people with disabilities in humanitarian relief, emergency aid and trauma counselling, as well as in health services. There was no particular SRHR programme, and we partnered with different organisations, including UNICEF, UNESCO and UNFPA. In terms of lobbying, it was a big advantage that it was a new country, where policies were being set up from scratch: we could influence them from the outset – and it worked.” Amongst other things, Light For The World co-developed the first South Sudanese sign language dictionary.

“People with disabilities open up when they see another person with a disability, standing firm, working on this topic”

In both lobby and advocacy, and also in establishing grassroots programmes for inclusive SRHR, sensitising stakeholders should be the very first action. Afterwards you can build an intervention plan together with them. “People are eager to work for disability inclusion, but before sensitising them, many are completely ignorant. Any organisation that is aiming to reach marginalised people will not succeed if they do not target people with disabilities, too.”

“NGO workers often think that it is too difficult because they do not have disability-specific expertise. But it is not necessarily difficult if you are willing to work on it. You can always find organisations with the right expertise for advice and technical support. Networking with the disability community is also highly recommended. I noticed, when doing research myself, that people with disabilities open up when they see another person with a disability, standing firm, working on this topic. It empowers them. Only when people with disabilities are involved in programming, policy-making and implementation, can real inclusion take place.”

Dr. Toyin Aderemi
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Activism, feminism and comedy

At the intersection of the women’s movement and disability rights

by Caroline van Slobbe

A trainer, writer, researcher and advocate, from the grassroots to the international level: Nidhi Goyal does it all. Meet the feminist and disability rights activist from Mumbai, India, who raises her voice in all possible ways to promote disability rights and gender justice. On top of all her serious work, she performs in her own comedy shows, using the art to perform issue based comedy and raise awareness on disability, gender and sexuality.



“I am Nidhi Goyal and I am blind. Yes, I am blind and so is love: get over it.” That is how this powerful lady starts her show in a comedy club in Mumbai¹. In her show, she also shares the reaction of a man who had seen her profile on matrimonial site Shaadi.com. “I remember this one educated, progressive man who called to say I would be perfect for his son, but from what he was saying, I guessed he had not read about my disability. I clarified this with him because it had happened too many times by then. He paused. People generally go into shock, because they do not believe that someone who’s disabled will even be on the website. They can’t connect the picture they’ve conjured up of the well-educated, outgoing girl from the profile with someone who is also visually impaired. So after a few moments of silence, the man said, ‘Really?’ So I repeated myself: ‘Yes, I cannot see. I am blind. Is that okay?’ He said, ‘Yes, no, no, uh, I think uh... ya... good luck,’ before he hung up. That is when I learned disability is indeed contagious: I said I am visually impaired, he became speech impaired!”

“...that is when I learned disability is indeed contagious: I said I am visually impaired, he became speech impaired!”

Challenging misconceptions

Her shows are about her daily experiences and that of her friends who have a disability, mostly in interaction with non-disabled people. Her performance reveals different layers of how people think about those with disabilities and dating, relationships, sexuality or having children. “It is the small daily conversations that show how deeply prejudice and stigma are entrenched in society. The misconceptions are not only on asexuality or hypersexuality, but also, for example, that disability breeds disability.”

With comedy, Goyal wants people to just sit, listen and enjoy. To listen and learn is easier like this, she thinks, because the audience does not feel targeted directly. After her debut, she received mixed reactions. “One woman came up to me and said: ‘I laughed a lot, but I was also cringing and thinking, oh, yes, I have these misconceptions too.’ She said that it had opened her eyes. On the other hand, I noticed that apparently it is indigestible that a woman with a disability is standing on stage, talking about sexuality. It is a shock for people, as we do not expect that someone with a disability would be funny and could laugh at her disability experiences. When they do not laugh, it is fine, you change your jokes, talk to them: eventually they get it. As I always say, we, people with disabilities, are laughing at the silly,

ignorant and prejudiced behaviour that society exhibits. If you do not get it, the ultimate joke is on you.”

Fighting at all levels

When Goyal was 15 years old, she was diagnosed with retinitis pigmentosa, a an incurable irreversible degenerative eye disorder. Within a few years, she would slowly turn blind. Initially then, Goyal had to make some quick career choices since she had dreamt of becoming a portrait painter. Her visual impairment and the gradual loss of eye sight layered her education opportunities, her navigation of an inaccessible city, and social barriers. Her eyesight also began making the difference in interaction with her classmates and college friends. “I was lucky that my parents were very understanding and strong. My father was advised to hide my disability and get me married as soon as I turned 18, because ‘of course’ I would not be able to find someone once I was completely blind, that was the assumption. My father rejected this. This is when I realised how strong the stigma is in society is.

Today, she is fighting against this stigma. Alongside her comedy show, which she performs in India and globally, the spectrum of work that Nidhi Goyal exercises is tremendous. “After my Mass Media studies, I worked as a journalist, writing about women, disabled women in particular, but at one point I decided that this was not enough, I needed to do more. That is how I entered the development sector and the broader field of activism.”

“It is not only a question of sexuality as sex, but also about what you want to wear, who you want to be, how you want others to see you, and how you express yourself”

Nidhi Goyal works with a range of women’s rights and human rights organisations. She is the program director of the Sexuality and Disability Program at a Mumbai based non-profit, Point of View, where she has researched and co-authored the online platform www.sexualityanddisability.org. This website discusses the sexual rights of women with disabilities, their bodies, sexuality, relationships, marriage, parenting, violence and abuse. Under this program she also conducts trainings for people with disabilities on these topics. Moreover, she is a consultant researcher with Human Rights Watch and has consulted with the feminist human rights organisation CREA on disability policy

and international human rights mechanisms. She writes in books, academic journals, news platforms and blogs about her experiences and opinions to raise awareness on issues faced by girls and women with disabilities. Finally, she is on the civil society advisory group of the UN Women's Executive Director, and takes place in the advisory board of the innovative grant facility VOICE (initiated by the Dutch Ministry of Foreign Affairs).

"The interaction with so many people with disability, knowing their stories and contexts, that is what I like the most. I love that I can stand with them, embrace their struggles and fight and raise my voice, and can advocate. I'm very conscious of the privilege that I have in accessing and working with the grassroots as well as the national and international policy arenas. I think I gained this access because I learnt early on in my disability that there are alternate realities, and because I really like to work with people within their context. I know it may not be a good idea to go into the interiors of an underdeveloped or developing country to tell people: look, CRPD²⁰ gives you these rights. That makes no sense: who is CRPD? For a woman with a disability living in rural India who faces isolation, stigma, non-acceptance, and abandonment – in her context, she does not care about human rights or mechanisms. That is a conversation for the policy level."

Having no dreams is impossible

"Whilst working with a lot of women and girls with disabilities, I have seen that many of them have strongly internalised almost all gendered prejudices including the idea imposed on them by others that they do not have desires, that they do not have the right to dream, and that they are undesirable. They are convinced that no one would ever be with them and that they should be happy with anyone who might 'want them'. That is what they have heard their entire lives. That is why the first step is to empower them so that they can begin challenging this stigma around them and inside them. During our trainings with Point of View, we realised that women with disabilities are rarely asked to dream. They do not dare to have ambitions in their personal lives. One of the girls said: 'I have no dreams.' And I said 'that is impossible. As a simple example, do you not feel like dressing differently, do you not love a sari?'

'I would love to wear a sari.'

'What is stopping you?'

'Well, because I'm disabled.'

'But what is the connection?'

'I do not have functioning body parts from my waist downwards, why would you wear a sari when you have no legs?'

You see, it is not only a question of sexuality as sex, but also about

what you want to wear, who you want to be, how you want others to see you, how to express yourself."

How does change happen?

"I think the best way to positively change this issue of disability and sexuality, is to work on raising awareness and to make sure people with disabilities are visible in public spaces in order to get rid of the prevalent stigma. What would also help is positive or 'normal' representations in mainstream media including advertisements, films, television, etcetera. At the same time, we must empower people with disabilities to become self-confident and live full lives like anyone else."



According to Goyal, one of the gaps to be filled by NGOs and governments is the lack of documentation. "We are invisible because numbers are invisible, our issues are invisible, and research is, to a large extent, invisible. That starts a cycle of invisibility and suppression and a neglect of rights. Disability inclusion should be measured at many different levels: in accessibility, in comprehensive sexuality education, and in health services."

The purpose is not to stick to disability related spaces, or research journals, for a one-time engagement. "Disability should be seen as a cross-cutting issue with many other identities and issues. So, for example, if a sexual rights or health journal comes out with one special issue on disability and encourages research it would be a great first step. But in the long run, disability research needs to become a part of health, reproductive rights, sexual rights researches and discourses. We need to open up spaces and make them more inclusive rather than, for example, having that one panel of marginalised voices in a women's rights or sexual rights conference. Similarly, all plans, policies and programs at national or global levels need to consider and include disability rather than only having a separate law or policy for people with disabilities. That would be real inclusion."

"All plans, policies and programs at national or global need to consider and include disability rather than only having a separate law / policy for persons with disabilities. That would be real inclusion"

Is there already progress? Yes, "Small efforts are already going well. However, they are not yet visible enough and the various 'efforts' are not working together or in synchronicity. Organisations with different expertise, engaged in disability rights and sexuality rights, should join forces. Disability rights groups may not have a clear understanding of sexuality and what it means. They have often internalised the stigma around sexuality and certainly around gender. They need to talk with sexuality rights groups. They need to open up and talk and start a movement or a collective of some sort, to engage in and gain an understanding of what sexuality is. In conservative regions in particular, it will be important to first change the prevalent misconceptions of sexuality in the disability-rights groups and coalitions themselves. At the same time, the issues of girls and women with disabilities should be led by disabled women and not by their male counterparts. Similarly,

organisations working on sexual and reproductive health and rights should deal with their prejudices and work together with disability groups to be sensitised and to eventually become inclusive."

"Disability-rights groups may not have a clear understanding of sexuality and what it means. They have also internalised that stigma around sexuality and gender"

A rising flame

Although Goyal is mostly working with women and girls with disabilities, men and boys face difficulties and stigma, too. "For men and boys, their masculinity and power is automatically assumed by patriarchal society, but for those males with a disability, this is not necessarily the case: often, their masculinity and power is threatened and they are perceived as 'not man enough'. Therefore, in trainings, advocacy or campaigns on disability and sexuality we cannot leave out gender and identity."

Goyal is now expanding her work. In September 2017, she launched her organisation 'Rising Flame'. "I want people with disabilities to find their voice, rise for their rights, become self-advocates and leaders who embody the change they want to see. Through our various programs we will use technology, arts, networks, mentoring and social access and support to build an inclusive world where diverse bodies and minds can live with dignity."

"My dream is that intersectionality becomes a concept that people and societies understand effortlessly, where multiple power structures are broken down, where all the movements are converging and working with each other: the women's movement and the disability movement. In the meantime, I keep working on the intersection of these, negotiating, pushing, and rising for my rights and rights of people with disabilities."

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Common challenges

On the way to obtain pleasurable and healthy sexual and family lives, people with disabilities – both male and female – encounter different barriers: from negative attitudes in the community to the inaccessibility of services, information and communication. Although challenges for people with disabilities in finding access to and information about sexual and reproductive health and rights might differ for each individual, influenced by gender, age, context and type of disability, there are some general barriers that need to be overcome¹⁵. The following challenges are partially intertwined and are witnessed in most, if not all stories presented hereafter in this book. The review of literature also yielded results which are in line with the challenges described in the stories of this book.

Knowledge and awareness

There is a prevalent assumption that people with disabilities do not (or should not) have sexual lives and thus do not need sexual and reproductive health services^{15/17}. Yet, research of the World Bank shows that people with and without disabilities are just as sexually active¹³. Taboo and stigma as a result of a lack of knowledge and awareness translates into negative attitudes of service providers and, as such, the denial of health services^{26/27/28}.

Accessibility of services and communication

Service providers reportedly refuse to help clients with a disability^{29/30/31}. Accordingly, health, justice and other services are not made accessible for everyone. Barriers to access services also include physical accessibility, as well as communication skills and materials in braille, sign language, plain language, audio and video formats and pictograms.

“When a deaf person comes to the police station, she is often ignored by the officers in this station, because of communication barriers”

Police officer in Kenya²⁵

Comprehensive sexuality education

Children and adolescents with disabilities are largely excluded from (regular) education²¹ and therefore miss out on essential comprehensive sexuality education, if given at all in schools. Special schools, if available, often neglect to give comprehensive sexuality education because of the belief that their pupils do not need information about sexuality.

Protection against violence

In some contexts there is a belief that sex with a virgin or person with a (specific) disability is a cure for HIV or other diseases¹³. In most cases they are seen as an ‘easy victim’. Adults and children, male and female, with disabilities who became a victim of sexual and gender based violence, are often held back by shame and stigma to report this. If they do seek justice, the communication barrier mentioned above might be a large obstacle.

“They say that if you are infected with HIV and you have sex with a woman with Albinism, that you get cured!”

Woman with albinism from Uganda³²

Decision-making and autonomy

With the right support, people with disabilities can express and pursue their own needs and desires. But there is often the tendency of ‘overprotection’: family members and professionals tend to make decisions for them. This can result in forced sterilisation, forced abortion, forced marriage and the denial of comprehensive sexuality education.

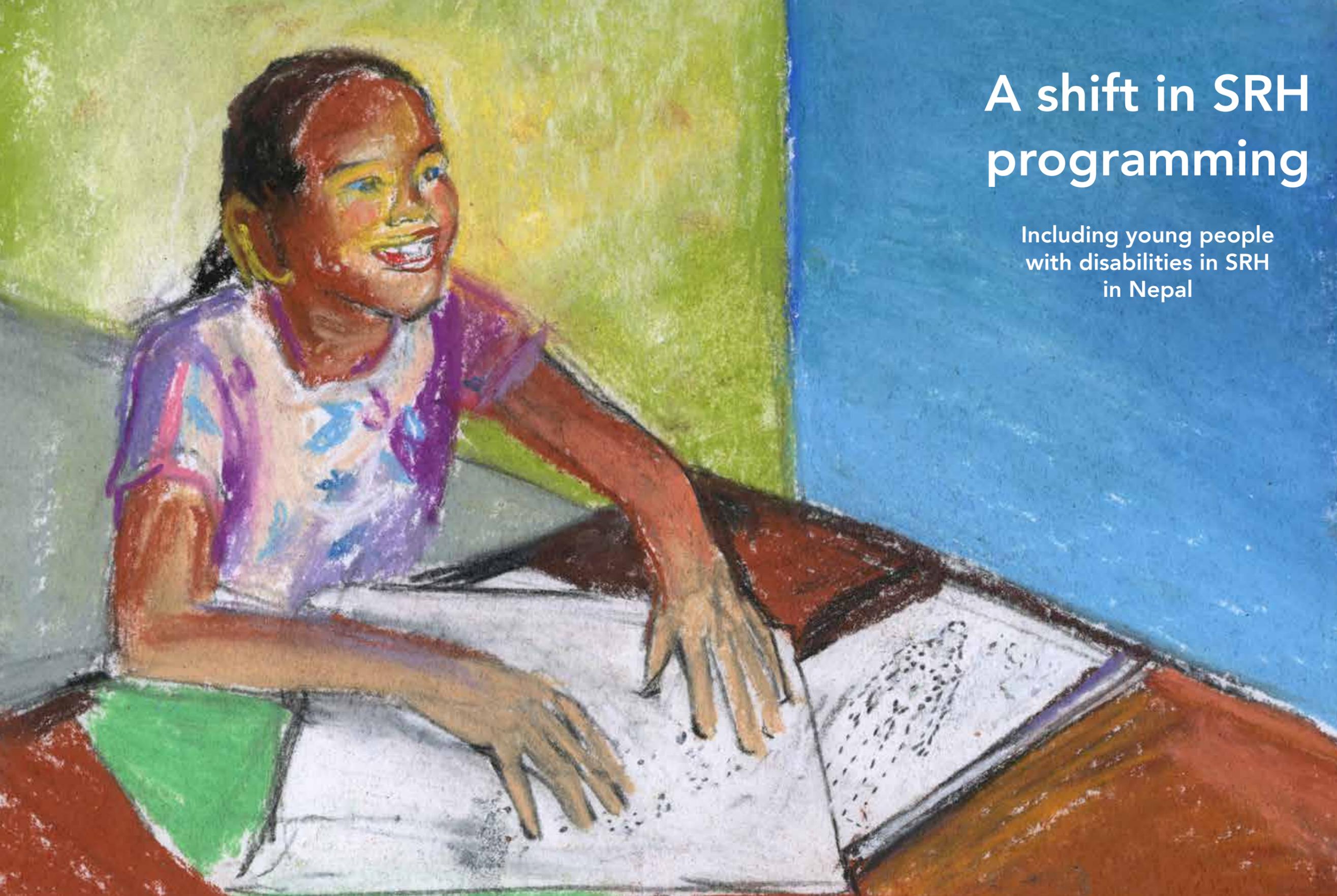
“Oh, your daughter is blind? I know this boy who’s also blind. Let’s get them married!”

Nidhi Goyal¹

Good practices

The good practices, i.e. personal stories, good examples, solutions for common challenges, described in this chapter are from different organisations all over the world, mostly NGOs. Some of the NGOs have their main focus on disability inclusion and incorporated SRHR into their programmes, whilst others originate in the field of SRHR and have made their programmes inclusive or specifically began to target people with disabilities. A few of the story tellers have mixed backgrounds, such as an alliance of four different NGOs in Colombia and a socially engaged dance group called ‘Dance into Space’. Finally, there is also an inspiring story about an individual case from Argentina, which has wider implications for everyone working on this topic, as it deals with issues of autonomy and setting boundaries.

Out of 26 submissions, 11 good practices were selected, covering different regions, age groups, types of disabilities, various SRHR components, and approaches. All the cases were written by representatives of the organisations themselves, drawing from their extensive experience and observations in their own contexts. Thus, in the following section, ‘we’ characterises the representative of the organisation sharing their story with us.



A shift in SRH programming

Including young people with disabilities in SRH in Nepal

By Nilima Raut, Satyajit Pradhan and Sabitri Sapkota
A programme by Marie Stopes Nepal

To address the unmet need for contraception among the youth in Nepal, the government is implementing an adolescent-friendly sexual and reproductive health and rights (SRHR) programme³³. However, the SRHR needs of young people with disabilities are largely ignored.

Marie Stopes Nepal has been working in the field of SRH, mainly on contraception and safe abortion and post-abortion care for more than twenty years. Between 2014 and 2016, we implemented a youth project to increase access to SRH information and services among adolescents and youth in four districts.

As part of this project, we conducted a study³⁴ to understand the use of SRH services by young people with disabilities, including the social context, awareness and barriers to accessing information and services. Amongst other things, the study revealed that more than 90% of the young people with disabilities were unaware of all modern methods of contraception. Based on the study findings, we implemented several activities for disability inclusion.

The practice: a multi-pronged approach to achieve inclusive SRH

The Marie Stopes project management team, service providers, youth volunteers and counsellors from contact centres (helplines) were trained in disability sensitisation, after which disability inclusion activities were organised. Information, education and communication (IEC) materials were produced in braille, large font and sign language and subtitles were incorporated into IEC videos. Partnerships with Disabled People's Organisations (DPO's) were formed to reach young people with disabilities at the community level. We organised targeted programs to reach people living with disabilities. We provided mobile SRH information and services accommodating the target group's needs in schools, colleges, and communities in coordination with DPOs. For example, if we had deaf students then we organised the program in coordination with the deaf association. Young people with disabilities were recruited as youth volunteers to optimise disability inclusion activities guided by peers. Wheelchair ramps were purchased to organise accessible SRH services. Health management information systems were updated to record disability-disaggregated service data. We also included the short set of Washington Group questions³⁵ (a set of questions designed to identify people with a disability) in our annual client exit interview survey to accurately measure the prevalence of disability amongst our clients seeking SRH information and services. Findings were disseminated among government stakeholders, DPOs, youth organisations and organisations working in different sectors.

As a result of this multi-pronged approach, in 2016 Marie Stopes Nepal reached 816 young people with SRH services, as compared to only 4 of them in 2015. Likewise, in the same year, 57 young people with disabilities were provided with personalised counselling through our client contact centre.

Lessons learnt: start with documentation

We experienced a few challenges in implementing disability inclusion activities. Overall, disability sensitisation training on youth-friendly SRH services helped service providers and youth volunteers create a disability-friendly approach. Furthermore, it is highly recommended that the social and cultural context is studied beforehand, and that adolescents with disabilities themselves are involved in disability-inclusive SRH programme design. Other specific lessons we learnt are:



Data collection

Disability-disaggregated service-use data should be collected, ideally using the Washington Group short-set of questions. This can be included in regular exit interviews or ad-hoc surveys of clients. While simple questions can be integrated into health management information systems, they are not recommended because without the correct questioning approach, they may underestimate disability prevalence without the correct questioning approach.

A challenge was that disability segregated data had to be recorded manually as there was no systematic data recording system for disability focused information. Although this process of recording consumed a lot of time, the data we obtained was limited to understanding disability types. Therefore we could not provide a better estimation than one per cent of disability prevalence among the clients we served with SRH services.

Accessibility

Making disability-friendly physical infrastructures is the biggest challenge as all our service centres are on the first floor and modifications appeared not to be possible in some centres, partly because these centres are rented, not owned.

Additionally, disability-friendly or -specific IEC materials such as braille, large font, and videos with sign language were preferred by the target group as a resource to access information without other's help. Blind people specifically expressed a preference for IEC's in audio format over IEC's in braille. IEC materials should therefore be reviewed preferably by the beneficiaries themselves and revised accordingly so as to reach them in an effective way.

Marie Stopes' helpline, m-health push messages, and social and digital media were also used by adolescents with disabilities to access SRH information. One of the challenges here is that there are many technical terminologies that have no direct translation into sign language. An SRH-specific sign and braille dictionary should probably be developed.

Young people with disabilities as volunteers

Recruiting young people with disabilities as youth volunteers made the team disability-inclusive and it helped facilitate the coordination with DPOs and those beneficiaries with disabilities.

Partnerships with disabled people's organisations (DPO's)

Partnerships with DPOs were effective in reaching out to our target group, as these organisations have the necessary data and contact with people with disabilities in the community.

Outreach services

The use of new media and technology – for instance, audio messages and a helpline for blind people and live chat with a counsellor for deaf people – can be used as communication tools to reach young people with disabilities with SRH information. Outreach services offered to young people with disabilities close to their own communities will help to address geographical challenges

Advocacy

Advocacy to address the SRH issue of young people with disabilities at the policy level is important, as policies can hinder the implementation of disability-friendly and inclusive SRH services.

Sharing lessons

We always work closely together with Marie Stopes International on this specific topic. Alongside Marie Stopes Nepal, Marie Stopes Tanzania and Marie Stopes Timor Leste are working on disability-friendly or

inclusive SRHR services. All our learnings are documented and shared with all stakeholders within the country and internally with all other Marie Stopes country offices. As a result, Marie Stopes Nepal has developed a guideline for disability inclusion³⁶.

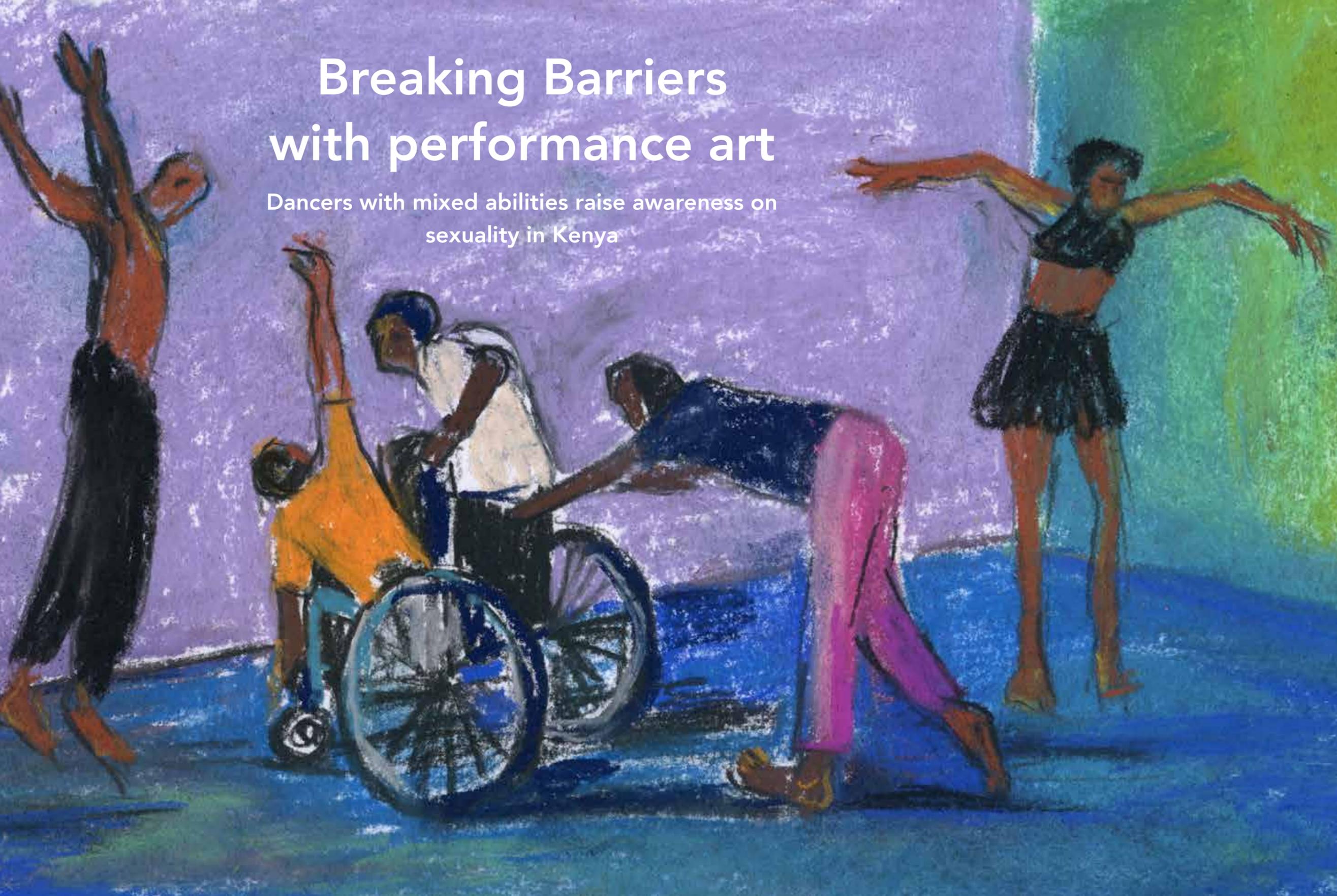


Marie Stopes Nepal is an SRHR-organisation focusing on safe abortion, post-abortion care and contraception.

Programme highlights:

- » A twin track approach
- » Disability sensitisation of project team, health staff, counsellors and volunteers
- » Research and documentation, using Washington Group questions
- » Accessible services and materials
- » Volunteers with disabilities who participate in programme design

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Breaking Barriers with performance art

Dancers with mixed abilities raise awareness on
sexuality in Kenya

By Ondiege Matthew
A programme by Dance Into Space
Partner of AmplifyChange

Siaya County in the southwest of Kenya has one of the highest HIV prevalence rates in Kenya, at 24.8%, nearly 4.2 times higher than the national rate³⁷. People with disabilities in Siaya, the majority being physically challenged by polio in their childhood, are disadvantaged on almost all fronts, including in sexual and reproductive health and rights services.

Therefore, Dance Into Space, a group of performance artists, designed the Breaking Barriers Project. This is an innovative, inspiring and revolutionary mixed-ability contemporary dance theatre addressing sexual and reproductive rights and HIV of people with disabilities, together with performing artists both with and without (physical) disabilities³⁸.

The practice: dance to empower and create awareness

Our Breaking Barriers programme is both experiential and experimental. The creative process preceding the dance performances draws from real and personal experiences of sexual and reproductive health and rights of participants with disabilities. Personal experiences are deconstructed, creatively re-imagined, improvised and reconstructed and then presented in open-air community forums. With this process, we aim to break down cultural barriers, superstition, taboos and stigma surrounding people with disabilities and their sexuality. Other goals include the following.

Empowerment

We are empowering people with disabilities through expressive contemporary dance and performance skills for advocacy on SRHR. Amongst other things, the participants are taught choreography and other exercises and games that enhance concentration, team work, leadership qualities and self-confidence. This enables participants to overcome their individual and cultural inhibitions that would ordinarily hinder them from expressing themselves fully.

“Dance, music and theatre processes liberate the participants to express themselves freely and share their true stories devoid of any inhibitions.”

Disability rights advocates

Through discussions, reflections and dialogues around rights and advocacy in broader contexts, participants with disabilities are empowered to become self-advocates who can speak out against oppression and claim their rights regarding SRH. The management of the health clinic specifically involved the trained advocates in regular health talks at the clinic to address community stigma and service provision to people with disability.

Create alternative sexual narratives

With our dance performances, we provide a platform for engagement to debunk the myths around disabilities and sexuality, targeting people with disabilities themselves, their care givers and the community. We show alternative sexual narratives that recognise the sexual needs of people with disabilities and promote their rights to access those needs.

HIV knowledge and testing

We encourage people with disabilities to know their HIV status and to use methods of protection. The project has partnered with service providers who carried out HIV counselling and testing during the performance presentations. It is still too early to tell whether people with disabilities in the community can now buy or access these commodities with ease, or for the project to have data on the knowledge of their status as a result of the performances.

Access to reproductive health services

We promote reproductive health service delivery to people with a disability within the county. By targeting and reaching those in the community who come to the presentations in the county, the performances create awareness of the existence of RH services within this county.

Lessons learnt: the power of the arts in addressing sensitive topics

Performing arts work specifically well in addressing sensitive topics like SRHR and disability, primarily because a disability is only a 'disability' in relation to a person's environment. For example, a visual impairment is not a disability for a musician and a hearing impairment is not a disability for a dancer. Dance, music and theatre processes liberate the participants to express themselves freely and share their true stories devoid of any inhibitions.

After the programme, we observed that people with disabilities were now included in the community's sexual and reproductive health and rights agenda. Against a hitherto culturally stigmatised environment, community members confessed that the captivating work

had enlightened them and changed their perceptions of disability and sex.

Delve into the local context

Planning early and factoring-in time for preparation is crucial because it will allow for more thorough research into and with the community. This will also enable you to experience the magnitude of the social problems first hand and identify smooth entry points into the community i.e. engaging 'gate keepers', local authorities and influential people.



Partner with the community and other organisations

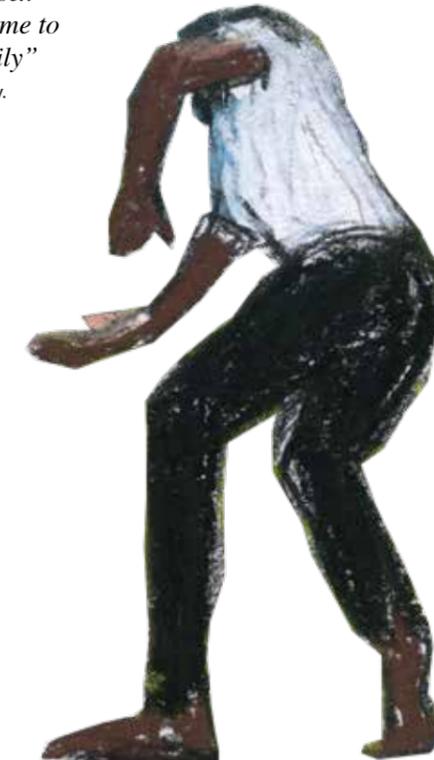
Partnering with the community, other organisation and existing structures on the ground, in order for the community to own the project, ensures sustainability. Other like-minded partners we worked with include the Ministry of Health, community based rehabilitation organisations, local disabled people's organisations and SRHR-organisations. Incorporating the community and using participatory means helped us to engage participants with a disability in the programme.

Increasing self-confidence

We learnt that empowerment is a slow process. At the beginning, the art director introduces some of the company's past works to motivate the people with disabilities to participate as performers. This slowly increases their self-confidence. The mixed display of people with and without a disability in performance helps in this.

"This dance performance and sex education process has motivated me to find a woman and start my family"

A dance participant with a disability.



Accessing services

Health service providers averred that since the advent of the project, a significant increase in people with disabilities seeking reproductive health services at the clinic had been recorded. The resident doctor at the health clinic in Siaya county remarked that it was the first time in general that a condom demonstration was done in public, as it has always been done in private to one client at a time.

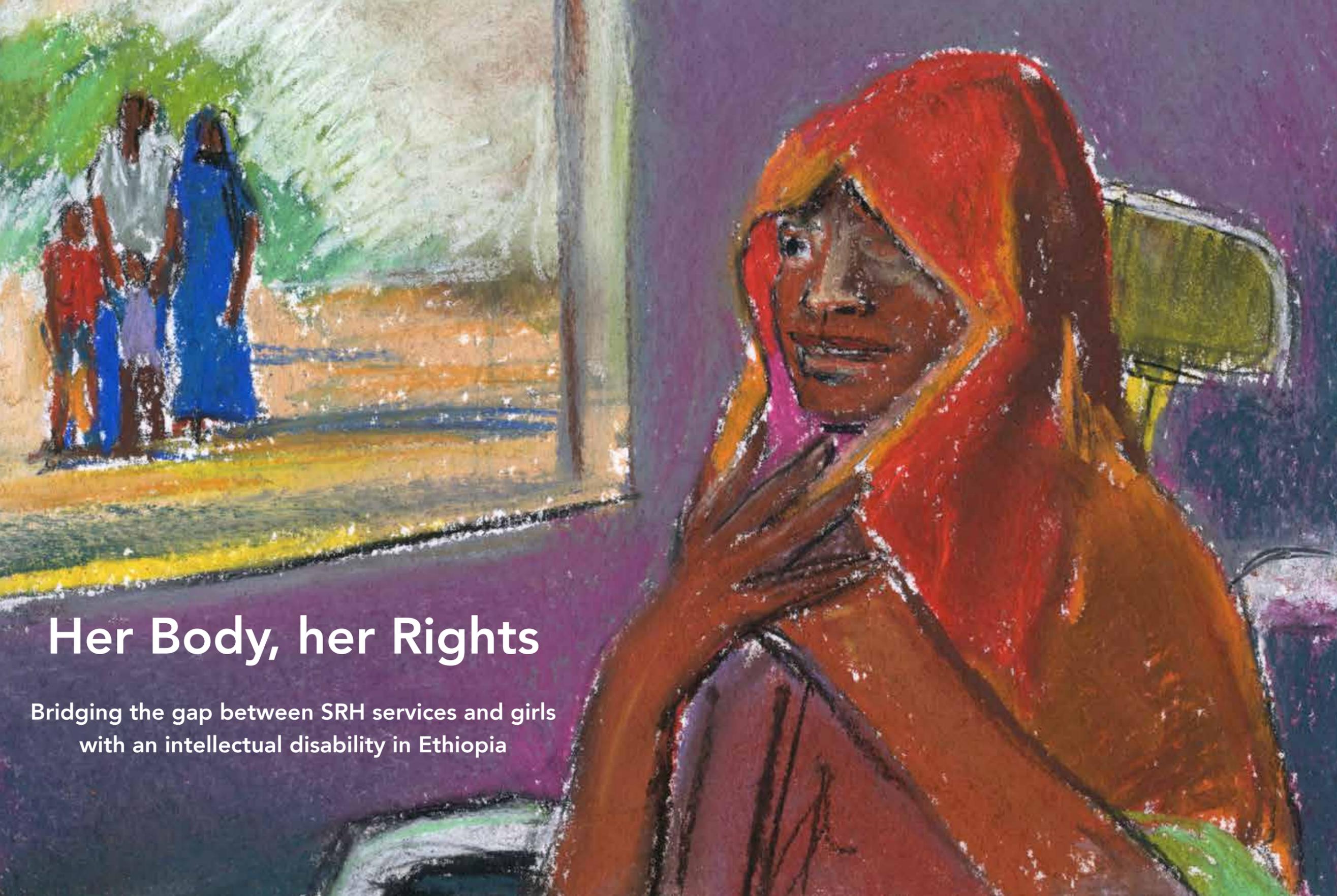
We hope that in the near future the initiative will not only be expanded, but be replicated in other villages, communities, and counties in Kenya.

Dance Into Space is a group of socially engaged performance artists.

Programme highlights:

- » Contemporary dance theatre, using personal stories and participatory methods
- » Teaching dance and empowering people with mixed abilities
- » Raising awareness on SRHR and enhancing HIV knowledge and testing
- » Strengthening self-advocacy
- » Strong community engagement and involvement of all stakeholders

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Her Body, her Rights

Bridging the gap between SRH services and girls with an intellectual disability in Ethiopia

By Marieke Boersma

A pilot project by Light For The World and CBR Network Ethiopia

Worke is an 18 year old girl with an intellectual disability. Her mother, Beletu, has never discussed reproductive health issues with her daughter. "It has never crossed my mind. Since Worke has started getting her periods, I am only worried that someone will trick her into having sex, and she will bring another burden to the family."

In Ethiopia, particularly in the rural areas, the Community Based Rehabilitation (CBR) NGOs have the most contact with people with disabilities. CBR workers go from home to home to support people with intellectual disabilities and their parents in learning how to go about the basic daily activities. Yet, they are not addressing topics such as understanding sexuality, menstrual hygiene, and preventing unwanted sex or pregnancy.

Furthermore, Ethiopia has a nation-wide health extension workers programme, implemented by the government, to provide health information to the community. However, besides the taboos associated with disability and sexuality, their information materials and way of communication are not suitable for people with disabilities.

This gap between CBR workers and government health extension workers leaves the sexual and reproductive health needs of women and girls with disabilities unheard and unmet. This is especially true for women and girls with intellectual disabilities.

In 2015, Light For The World partnered with the Community Based Rehabilitation Network Ethiopia (CBR-NE) to implement a pilot programme, learning how best to provide CBR professionals, service providers and parents the skills to reach, teach, inform and discuss the topic of sexuality with girls with intellectual disabilities.

"Worke is not shy in letting us know she wants to have a boyfriend and a child. I scold her whenever she raises this issue. I keep telling her that she will never get married."

Mother of Worke (18), who has an intellectual disability

The practice: bridging the service gap

We developed a training programme for CBR-NE members. CBR workers attended a three day sensitisation workshop conducted by external experts, where they discussed the need and possible methodologies to address the sexual and reproductive health needs of women with intellectual disabilities, as well as the SRH services

available. After a call for proposals, CBR-NE invited two member organisations to implement a pilot project, through which they were able to experiment with various activities to reach and teach the young women and their families. They collaborated with the government's health extension workers on the issue.

As a result of this project, government health workers learnt that it is part of their role, and that they are able to support women and girls with intellectual disabilities to receive sexual and reproductive health services. CBR workers learnt how to approach the topic of reproductive health during their day-to-day work. Parents became less scared of the topic, and learnt that their girls are able to take care of themselves during their periods, and make informed decisions about their sexual lives.

And most importantly, the girls with intellectual disabilities were proud of what they had learnt: that they could take care of themselves, and protect themselves when needed.

Lessons learnt: relief for all stakeholders

The publication *Her Body Her Rights*³⁹ presents the key lessons we learnt on how CBR workers and family members can best support and

empower young women with intellectual disabilities when it comes to their sexual and reproductive health. When the pilots ended, these lessons were shared amongst all members of the CBR Network Ethiopia.

Breaking taboos

The taboos around the sexuality of girls with intellectual disabilities needed to be broken, in order to be able to work on the project with all the different stakeholders. Many of the CBR fieldworkers were concerned that discussing sexuality would 'awaken something dormant within the girls'. The parents of the girls also thought this way. It is not easy to change this: it takes a lot of time, many discussions and hard work.

Bridging the service gap

With neither CBR workers nor health extension workers comprehending both disability and reproductive health, no one feels responsible or knows how to reach the young women with intellectual disabilities. Bringing them together in one training session, meant that the two parties were both aware of the issue, and of each other's roles. They jointly developed information materials and methods on this topic that

were accessible for the girls and learnt a lot from each other in the process.

Provide reproductive health information in an accessible way

The different organisations used a variety of methodologies to reach the girls with intellectual disabilities in order to help them understand and accept the sexual and reproductive health messages. Considering the huge variation within intellectual disability, there are large differences in how the girls take-in, process and retain information. It is therefore crucial that messages and modes of communication are tailored to each specific need.

Moreover, people with intellectual disabilities require repetition to ensure that their new insights stick, so the girls needed follow up visits and conversations with CBR workers and their family in order to reinforce the message.

Involve family members

In general, many parents in Ethiopia refrain from discussing sexuality with any of their children due to cultural barriers, and those family members who said they were willing to do discuss sexuality with their children, said they simply had no idea what to do. Holding expert sessions with service providers gave parents of young women with disabilities the opportunity to learn how to discuss and handle sexual and reproductive health issues with their children.

Focus on both men and women

Whereas this pilot project focused only on girls and women, it is equally important to provide information and services to boys and men with an intellectual disability, not only because the boys and girls meet each other within the CBR programmes (meaning that the boys felt left out for not being allowed to attend a training like the girls), but boys with intellectual disabilities are also vulnerable to abuse. They are just as much in need of positive information regarding their sexuality and reproductive health and deserve more attention in future endeavours. This project, albeit small, showed clearly that all parties were relieved to receive more knowledge and skills on how to organise sexual and reproductive health

While Worke now has a much better understanding of what happens to her body, her mother Beletu is also now in a position to better understand that her daughter's sexual needs and desires will not go away by ignoring them. She is relieved to know that her daughter can learn how to make decisions about her sexuality and has the capacity to protect herself from unwanted sex, sexual diseases and pregnancy. services for women and adolescents with intellectual disabilities.

"I regret not having started speaking to Worke about her sexuality years ago. As a family, we have now decided to support Worke, and allow her to choose for herself if and when she wants to make use of services regarding her sexuality."

Mother of Worke (18)

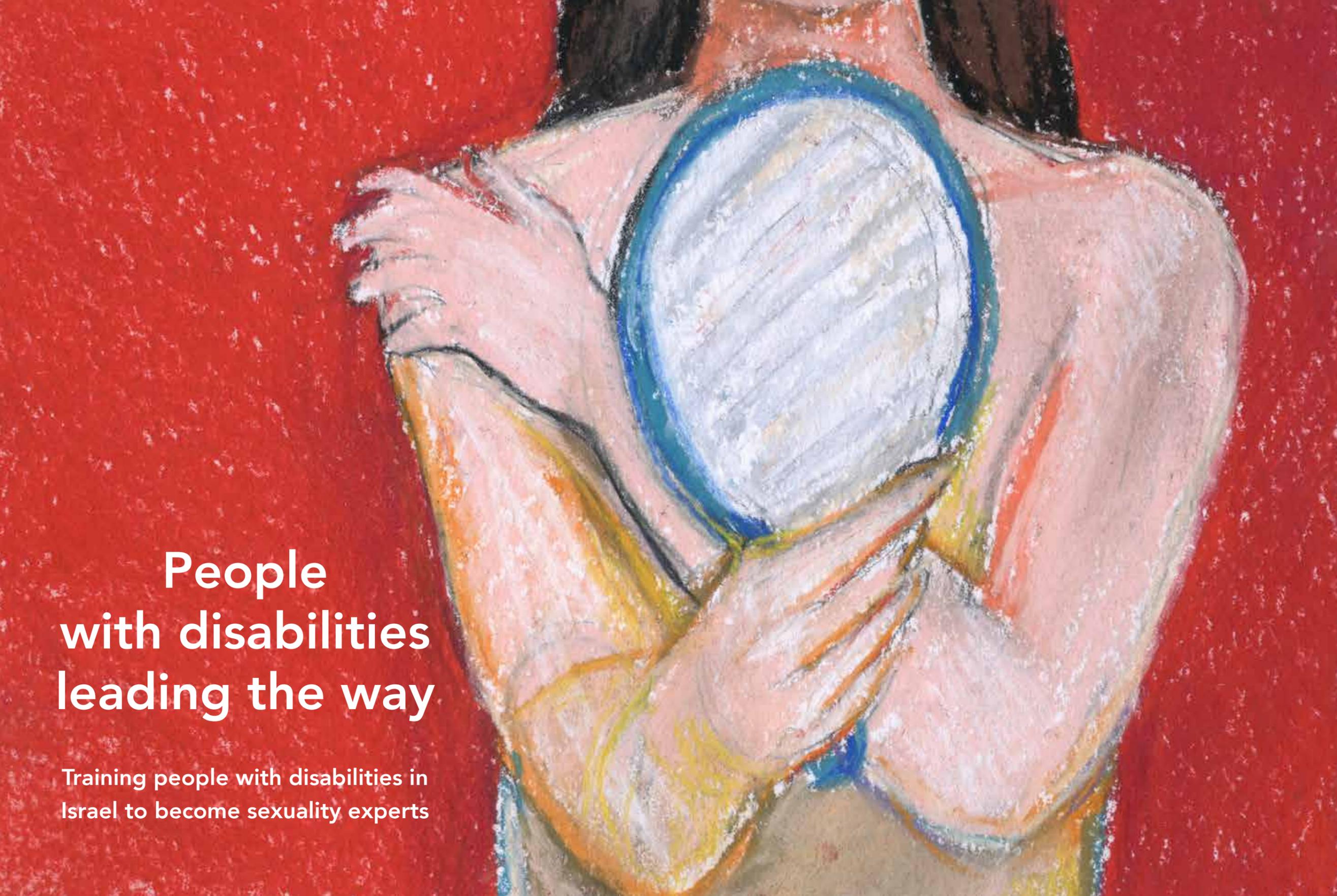
Light for the World is an international disability inclusion organisation.

Programme highlights:

- » Joining forces to address SRHR in disability programmes
- » SRH sensitisation for CBR workers
- » Disability sensitisation for government health extension workers
- » A pilot project targeting women and girls with intellectual disabilities
- » Breaking taboos by involving all stakeholders
- » Making communication materials accessible

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People with disabilities leading the way

Training people with disabilities in
Israel to become sexuality experts

By Sharon Cherkasky

A program by Israel Family Planning Association (IFPA)
Partner of the International Planned Parenthood Federation (IPPF)

In Israel, 20% of the population lives with a moderate to severe form of disability. The sexual and reproductive health and rights of people with disabilities are often ignored or overlooked. By focusing on the sexual health and rights of people with disabilities⁴⁰, the Israel Family Planning Association (IFPA) explores an area that is often neglected. IFPA's three year Innovation Fund project supports people with disabilities to make responsible choices regarding their sexuality and sexual and reproductive health and rights. Our programme was the first of its kind in Israel. We used a three-pronged approach of sexuality education, service delivery and advocacy.

The practice: peer sexuality education

15 people with a physical disability and 17 with a sensory disability were invited to complete a comprehensive sexuality education course. From the course, participants graduated as trained sexuality educators, going on to deliver sexuality education workshops for youth with and without disabilities. All graduates conducted workshops and lectures to both groups of young people with disabilities as well as other groups (parents, professionals and young people without disabilities). Some of them also provided counselling and workshops, giving lectures and interviews in the media, and some are part of the Nothing about us without us - advocacy group.

The graduates carried out over fifty introductory workshops and lectures throughout the course of the program, with hundreds of participants: adolescents, parents and professionals.

The project has had a profound impact on many of the graduated sexuality educators, not only in relation to their knowledge of sexual health but also in other, more subtle ways, with many of them stating that it was the first time ever that their sexuality had been taken seriously.

“The course influenced how I see my own sexuality. I understand that first I am a woman and second a person who has a disability. I deserve to have a partner, children and a family.”

Project participant

Understanding their own sexuality

Our project has significantly improved the well-being and emotional health of those involved who were able, sometimes for the first time, to understand their own sexuality. For many, the programme gave them a vocation and provided an important source of independence and empowerment. It has increased the capacity and skills of the participants, and has increased awareness of the importance of sexuality and disability for participants and the wider community

Involvement in the education programme has significantly improved participants' overall well-being. Some had previously thought of themselves as being non-sexual and without the same sexual rights as people without disabilities. Now they understand and recognise their own sexuality and that sexual rights are not a privilege.

A positive body image

Many linked their new understanding and acceptance of their sexuality to an increased confidence in themselves. For some, the project had an effect on their external appearance.

Participation in the project has changed the way people with disabilities communicate with others, which has impacted their relationships with family and friends.

The programme resulted in a change in participants' attitudes towards their own disabilities. As well as accepting their sexuality, it also helped them to accept their disability. The programme required them to draw on their own personal experiences, and for some, this meant relating to their disability in a way they had not done before.

Some participants also noted a change in their attitude towards other people with disabilities. Prior to the project, a lot of them did not know many other people with disabilities. Taking part in the training programme gave them the opportunity to get to know others that had disabilities different from their own. This helped to broaden their understanding and acceptance of a range of disabilities.

Knowledge on sexual health and rights

The education programme led to increased knowledge and understanding of a range of subjects and issues relating to sexuality, sexual health and sexual rights. The training contributed to improved technical knowledge, as well as a marked improvement in the participants' communication skills. This was a significant outcome. The people with disabilities found they were able to apply their new skills to all aspects of their lives, particularly when talking about sexuality related issues.

Breaking taboos

Another important achievement of the project was the increased

profile and attention given to the issue of sexuality and disability. A highly taboo topic, this subject had previously been little discussed in the public or private arenas in Israel. Both project staff and project beneficiaries perceived a noticeable change in the amount of interest this issue was generating on a national level.

Lessons learnt: taking time for change and people with disabilities as experts

Since this was the first project of its kind in Israel there were issues that had not been thought of and a great many lessons learned. The main challenge the project faced was the attitude and ignorance of parents, teachers and health professionals towards sexuality and disability related issues. Additionally, some participants held negative attitudes towards other sensitive issues such as homosexuality, domestic violence and sexual abuse. Some people remarked that they were not comfortable discussing these topics, and would therefore not address them.

Change does not happen overnight

One major lesson is to ensure adequate time for implementation and to not expect changes overnight, as sexuality education is a slow process. An IFPA project staff member explained: "To start talking about sexuality straight away can be distressing and intrusive. Going and doing just one session is like an assault, it should not happen that way."

Involvement and leadership of people with disabilities

Training people with disabilities to be sexuality educators who then have the skills and knowledge to talk with authority on this issue on a professional level at conferences and workshops was an innovative and crucial part of this process. Care should therefore be taken to ensure that the appropriate candidates are recruited for the programme, rather than simply filling the available spaces. Likewise, having a supportive instructor who helps the group to bond is an important part of the learning process. Almost all participants mentioned group sessions as a highlight of the course.

Organisational issues

The trainees were recruited from a wide geographical area and some had to make long journeys to the training venue, meaning that the education programme required a significant investment of time from the participants. Some of the trainees felt that the course was too short or that there was not enough time to discuss issues in depth. The group composition in the course was mixed in terms of age groups, sex and

types of disabilities. Whilst some saw this as a positive, others thought it slowed down the pace of learning. Some participants also expressed feelings of segregation from the other training courses that IFPA conducts for people without disabilities, feeling that there should have been more overlap between these trainings.

Overall, this project successfully highlighted the linkages between disability and sexuality issues.

"I thought I am not sexual, I looked different. I used to hide my body. But now I feel sexual. I have changed my appearance and the way I dress. Today, I feel feminine, beautiful and attractive."

Project participant



IFPA is an SRHR-organisation focusing on family planning.

Programme highlights:

- » Training people with physical and sensory disabilities as leaders in sexuality education
- » Improving emotional well-being and positive body images
- » Facilitating peer-to-peer education on SRH
- » Breaking taboos amongst programme staff and beneficiaries

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Best Wishes for safe motherhood

Towards inclusive
reproductive healthcare in
Nepal

By Samridhi Rana Thapa
A programme of Karuna Foundation Nepal

In a remote village in the hilly Ilam district in eastern Nepal, lives Mallika with her family. Since the age of 3, Mallika has lived with a physical disability. She is married and recently delivered her first baby. To ensure her child was born in good health and that she is in safe hands, she had made all the necessary preparations. Before the estimated delivery date, Mallika and her husband made a trip to the hospital, a two hour drive away by public transport.

Mallika's efforts are not common in Nepal, where women with and without disabilities often do not attend antenatal check-ups and deliver their babies at home, mostly due to a lack of knowledge on reproductive health.

For ten years, Karuna Foundation Nepal has been working on improving maternal and young children's healthcare as a component of our Inspire2Care model. On the one hand, this model aims to achieve inclusive societies and an improved quality of life for children with disabilities, and on the other hand, the prevention of avoidable disabilities and diseases, through improving maternal and child healthcare. Since 2015, our prevention work has been packaged in the Best Wishes programme, an SRH programme targeting and tracking pregnant women with and without disabilities.

The practice: providing inclusive reproductive health services

Unlike many women with disabilities in Nepal, Mallika knows about the importance of adequate maternal and child healthcare and of disability inclusion, as she works for the Inspire2Care programme in her village as a Community Based Rehabilitation (CBR) facilitator. For that, Mallika was trained in disability inclusion and the importance of healthy pregnancies and safe deliveries for the prevention of disabilities and diseases. She is a role model for other people with disabilities, as she spreads her knowledge and positive attitude.

Our Inspire2Care model is fully planned, implemented and evaluated with and by the communities, involving people with disabilities themselves. The allocation of financial resources from local government and community ensures sustainability of services in the future. This combination makes inclusive reproductive health, maternal and child (health)care possible.

Sensitising health staff on disability

As part of the Inspire2Care programme, we aim to increase the quality of and access to family planning and maternal and child healthcare services for both women with and without disabilities.



Hence, we have trained and sensitised health staff and female community health volunteers on disability-related issues, including sexual and reproductive health needs of women with disabilities. Female community health volunteers are appointed by the Nepalese government in each community and ward to distribute medicine, information and 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.

Tracking pregnant women for adequate care

The female community health volunteers advise pregnant women on healthy nutrition, medicine, antenatal check-ups and professionally guided delivery. To increase the number of pregnant women who attend antenatal check-ups, the volunteers keep track of them. Initially, the most common method to track them was by word of mouth.

Since 2017, pregnant women are registered through a mobile

tracking system. This has made inclusion of women with disabilities easier, as they were tracked separately and could be given extra attention. The mobile system works as follows:

In the first meeting at the health post, the woman's name and number of weeks of pregnancy is documented by sending a mobile SMS to the district public health office. It automatically registers and generates a reminder SMS to the nominated female community health volunteer when it is time for each pregnant mother to visit health facilities for antenatal care, institutional delivery and postnatal check-ups. This is the moment the volunteer calls or visits the expectant mothers to advise them that on certain dates they should make a visit for specific health check-ups. The volunteer can also assist women with disabilities when going to the health facility.

A Best Wishes card to improve knowledge on safe motherhood

Upon the pregnant woman's first visit to the health facility, she is also

issued a Best Wishes card giving information about a safe pregnancy and delivery. This card highlights in both images and text the importance of a healthy diet, the role of folic acid, correct birth spacing, important vaccinations, routine antenatal and postnatal check-ups, and delivery preparation. The volunteers also provide information regarding contraception as well as distribute free condoms.

“If the Inspire2Care Program had not come to my village I would not have known where or how to get antenatal check-ups or that institutional delivery really is the safest option. The most important thing I wanted was for my child to be healthy.”

Mallika, community based rehabilitation facilitator living with a disability

Lessons learnt: accessible formats and comprehensive training

It is likely that some women with disabilities have not yet been reached, partly because of the hilly geography and remote location of isolated houses in large parts of Nepal. Since April 2017, the moment the inclusive tracking system was fully operational, we have documented five women with disabilities who have had healthy deliveries and one who is currently pregnant. In total, in our current programme area, there are 503 women with disabilities, of whom 52% are married. The integral community-based and disability-inclusive approach of Karuna ensures that health staff are able to reach people with disabilities in their communities. However, we expect that with even greater effort, awareness and disaggregated mobile registration, the communities will reach out to more pregnant women with disabilities through Best Wishes, which has reached 3744 pregnant women over the last 2 years.

Accessible information on reproductive health

The Best Wishes card is currently being developed to become accessible for people with different disabilities. By using braille, pictograms, easy language and other accessible formats, many more people, including people with disabilities, may be intrigued to go through it.

A new SRH training for CBR facilitators

Our SRH approach was initially incorporated into the prevention of disabilities component of our Inspire2Care programme. Karuna Nepal is currently working to include SRHR more comprehensively in the CBR

component of the programme. We have recently included SRHR in our regular trainings for CBR facilitators, like Mallika. In total, 13 women and 4 men who work directly with children and adults with disabilities and their families were trained and sensitised by external SRHR-experts. Even whilst being a disability focused organisation like Karuna, we realised that additional effort is required to ensure disability inclusion in SRHR. Moreover, we need to segregate data of pregnant women with a disability, in order to be more sensitive and to be sure that, together with the communities, we reach them all and leave no one behind. The process of sensitisation never stops.



“I felt comfortable to participate in the training but I could see that my unmarried friends were blushing and shy. I am now using the knowledge gained in the training to counsel people with disability and their families based on their situations and context.”

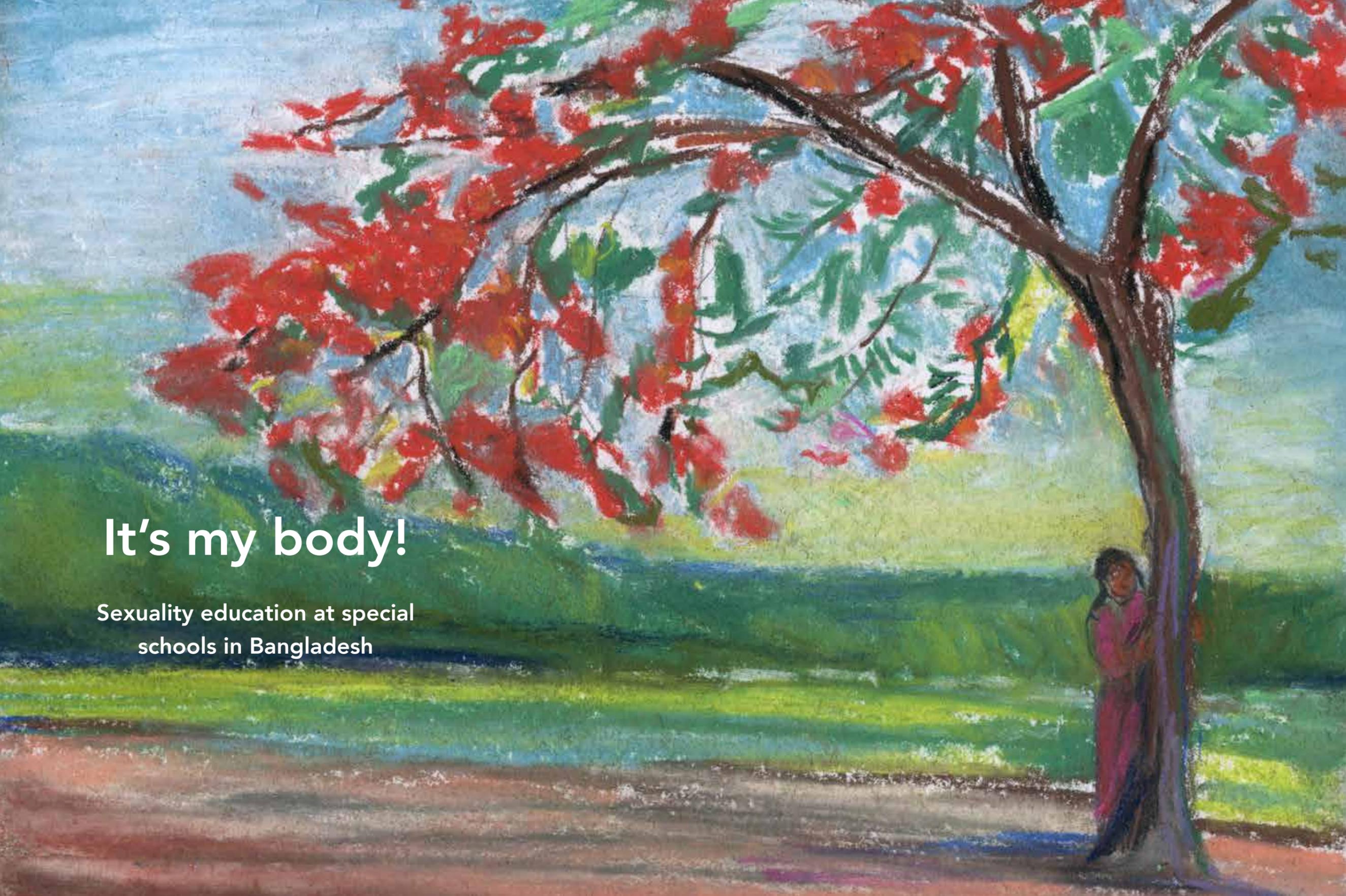
Nirmala, CBR facilitator

Karuna Foundation Nepal is an entrepreneurial disability organisation focusing on inclusion of children with a disability and prevention of avoidable disabilities.

Programme highlights:

- » Strengthening the existing maternal and child healthcare
- » Sensitising health staff on disability
- » Ensuring accessible health services
- » Tracking pregnant women with and without disabilities with a mobile service
- » Training community based rehabilitation facilitators
- » Equal partnering with the community and local government

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It's my body!

Sexuality education at special schools in Bangladesh

By Antoinette Termoshuizen
A programme of Niketan Foundation

A 14-year-old girl from Bangladesh with mental and hearing disabilities tells her story, agitated but cheerily. She uses dolls (often used in sexuality education) to better explain what she means by pointing to specific body parts. She has been touched and abused twice by a boy who lives nearby in her village. Another girl, with autism, reveals that her father sleeps with her, fondles her breasts and has sexual intercourse with her.

In conversations with twenty girls with disabilities before Niketan's Right to Decide-programme, eighteen girls shared negative sexual experiences. There were two recurring themes: firstly, the young girls do not really grasp the offensiveness of the sexual abuse, and secondly, their families and the village communities blame the girls themselves for those acts rather than consider them as victims.

Niketan Foundation helps both male and female adolescents with disabilities to remove barriers to their participation in society and to create equal opportunities. Niketan supports early childhood programmes, special schools, vocational training centres, community based rehabilitation programmes and a provides a residential place for children and adolescents with complex disabilities.

The practice: breaking taboos about sexuality among disability-experts

In 2017, in order to empower young women and men with a complex (intellectual) disability and teach them about their sexual and reproductive health, Niketan started with the course 'It's my body!'. The course is designed for adolescents between the ages of 13 and 25 and includes subjects such as knowing your own body, personal hygiene, social relations, friendship and abuse.

Step one: training teachers of special schools on SRHR

We partnered with the SRHR-organisation Rutgers Foundation to develop the training outline and toolkit. Prior to this, Rutgers had trained local SRHR-consultants.

These consultants 'trained the trainers': teachers and caregivers of the target group – disability-experts at the grassroots level who already had close working relationships with the adolescents.

The Training of Trainers (ToT) focused on the existing psychological, social and cultural barriers leading to the negation of the rights, privileges and liberties surrounding the sexual life of people with multiple disabilities. This was quite a challenge in itself given that in Bangladesh openly talking about sexuality is considered taboo.

“I found many misconceptions in the minds of the participants, such as, ‘people with disabilities have higher sexual urges than others’ or ‘disability is a curse!’

It was a hectic journey to make them aware that sexual and reproductive health and rights are the same for all human beings.

SRHR-trainer and consultant

We started work to break the taboos about sexuality, for both people with and without disabilities, in 2013. We tried to bring teachers, management and caregivers working at special schools together to talk about sexuality and disability. In the first meetings, the participants were too shy or simply too reluctant to talk. Gradually, they got used to the idea and meetings with parents of adolescents with a disability convinced them that we could not keep ignoring the subject indefinitely.

The 8-day training course in 2016 was an eye-opener for the trainees. For them to be able to teach the adolescents with a disability about sexuality, they first needed to learn how to openly share their own thoughts, experiences and beliefs on sexuality. Their values were based on myths and beliefs, which were reflected in their attitude. Breaking these and teaching them rights-based values was the biggest challenge. By the end, the trainees were extremely grateful and relieved to be able to talk about this, as they had never had the opportunity to broach the subject before. They were now equipped to start teaching their student, some of whom had complex or multiple (intellectual) disabilities.

Step two: sexuality education at special schools for adolescents with disabilities

The pilot course, ‘It’s my body!’, was targeted at twenty female and twelve male adolescents, mostly with intellectual disabilities, from special schools in three cities. The course methodology was specifically tailored to the students’ level, for example making use of a family of

“Sometimes they cannot avoid some giggling but they are not afraid anymore to participate in the discussions”



instruction dolls and using posters that depicted the development of the body.

The adolescents listened attentively and eagerly to the trainer. There were times when they could not help giggling but they are no longer afraid to participate in the discussions. The safe and supportive environment, with sign and body language as supportive communication tools, helps the students to open up. They openly use the names of the private body parts, which in the past they only referred to as ‘down below’.

Lessons learnt: a balancing act

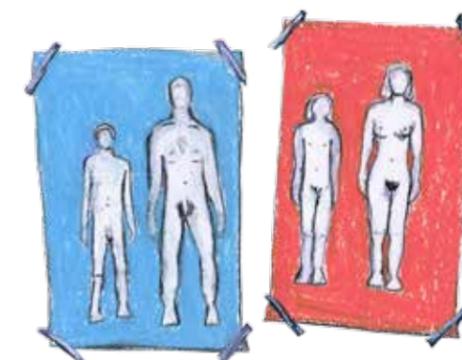
Both teachers and adolescents with disabilities showed an eagerness to learn more and to share the lessons with their families. The attitude of the teachers has changed dramatically: one year before the programme began, the subject was strictly taboo, but today they teach the class without any apparent embarrassment and speak with confidence about reproductive health and rights. The adolescents now know about their private body parts, about relationships and sex, and they know how to set boundaries (It’s my body!). The benefits of the course were not limited to these adolescents alone, but transcended to their family members as well.

Breaking taboos whilst keeping parents on track

We currently face two major challenges. The first is the deeply rooted taboo around sexuality in Bangladesh, particularly for young children. Although sexuality education would benefit children both with and without disabilities under the age of 13, this is not yet accepted in Bangladesh. This made the use of posters depicting naked bodies and private parts somewhat tricky. We had to find the right balance between breaking taboos and keeping parents on board. In order to obtain their consent, we had to make sure images were not too explicit. Eventually we agreed on using drawings of naked bodies, because it was the only way our target group would understand.

Tailoring communication to people with (severe) intellectual disabilities

The biggest challenge remains customising the information to fit the targeted adolescents, often with complex (intellectual) disabilities, who attend the special schools. The risk of confusion or misinterpretation, potentially resulting in problematic sexual behaviour, remains a subject of constant concern. It thus requires positive and clear feedback on desirable behaviour. For example, telling adolescents in a ‘negative’ way that masturbation is not allowed in public might be problematic for adolescents with (severe) intellectual disabilities, who often do not understand the word ‘not’. They might understand ‘masturbation is



allowed in public’. It would therefore be recommended to rephrase this to say that they can masturbate in their bathroom or bedroom.

The whole exercise feels like a balancing act. Niketan is strongly aware of the need to continuously monitor and evaluate the impact of the course with the assistance of external local and international SRHR-consultants, not only during the training, but also after completion of the course.

Niketan is a disability-organisation focusing on participation of children and youngsters with complex disabilities in Bangladesh.

Programme highlights:

- » Training disability-experts on SRHR at special schools, who can then:
- » Educate young people with complex (intellectual) disabilities on SRHR
- » Accessible information, education and communication, including instruction dolls
- » Breaking taboos about sexuality among disability-experts

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Calling a spade a spade

Sexuality education at special schools in the Netherlands

By Sanna Maris
A programme of Rutgers

In the Netherlands, the topic of people with disabilities and sexuality has been overlooked and underreported for a long time. However, negative beliefs towards disability and sexuality are slowly changing, firstly due to a policy shift in 2012 when key goals for sexuality education for children and adolescents with a disability were formulated, and secondly, due to a rise in video documentaries and tv-programmes on the subject.

Rutgers is an international centre of expertise on sexual and reproductive health and rights based in the Netherlands. Both special schools and regular schools throughout the Netherlands participate in our annual national project week 'Spring Fever'⁴¹; a week focusing on the importance of sexuality education for children between the ages of 4 and 12. The Van Koetsveld School in Amsterdam, a school for pupils with severe learning disabilities and additional challenges, is one of the participating schools. Since 2010, the school has been providing sexuality education to pupils from 4 to 12 years old, in collaboration with Rutgers.

The practice: adapting SRHR materials for children with disabilities

Together with special schools for children with disabilities, such as the Van Koetsveld School, we developed special learning materials on sexuality issues. In essence, the information is the same for children without disabilities, but it is simplified further, repeated more often and made accessible in different formats for children with different types of disabilities. We worked together with many experts and the CED group on forming learning objectives and didactics for children with disabilities, related to a suitable developmental level.

In addition, the whole team of teachers at the Van Koetsveld School was given an awareness training on how to give training in SRHR, including answering questions such as: 'How do you ensure that you will not freeze up in front of the class?'

Developing a special learning path on SRHR

Rutgers and the CED group developed a learning path⁴² for children with disabilities aged from 4 to 20. Within the Dutch special school system, there are four clusters for children with different types of disabilities. The pupils in the Van Koetsveld school vary in IQ from 35 to 65 with additional challenges such as Attention Deficit Hyperactivity Disorder (ADHD) or Autism Spectrum Disorder (ASD).

There is a difference between the calendar age and the social age of children with intellectual disabilities. For example, at some point

the social age can be that of a young child, whilst physically the child has already developed the body of an adolescent. Nevertheless, the knowledge of how a baby is born is given to children with the calendar age of 10 to 12, even though their social age may be lower, because biologically they may be ready and should be prepared accordingly. For this, teachers can use a guideline to determine the suitable information for each developmental level, which they can adapt as needed, since they know their individual pupils, their needs and skills the best.



“The pupils really enjoy the lessons. In the final group, the pupils could also discuss romantic feelings and sexual diversity. It is very unusual that pupils with severe learning disabilities can raise these issues themselves”

Teacher at the Van Koetsveld School

Four SRHR components in primary education

Basically, four themes are discussed throughout the years in primary education, which are the same for children with and without disabilities. The first is on knowledge and awareness of body development and positive body- and self-image; What does the body look like? Which body part are you proud of? The second is on relational development and sexual diversity; What do you feel when you're in love? What is the difference between a friend and a lover? And who can love who? The third is about (online) sexual behaviour and resilience; What are social boundaries? What is usually private and what is covered? Who can touch you, and who not? We teach the very young to express this verbally (No!). Within this theme, gender stereotypes are also discussed and discouraged. The fourth theme is reproduction: basically this is a biology class about how babies are born. In high school, a fifth topic on safe sex and sexually transmitted diseases is added.

Lessons learnt: the difference between regular and special schools

We noticed that it is recommendable for the developers of the learning path to take teachers by the hand, to inform them about when (at which calendar age) a certain topic is appropriate. The teachers can then convert this into the right social age of children with intellectual disabilities themselves.

The teaching team at the Van Koetsveld School is now able to discuss the theme much more easily. A teacher shares: “We have agreed on ‘calling a spade a spade’. How else does one encourage body awareness? We no longer evade questions on this topic - we simply answer them. It is clear that the pupils are also benefitting from this. There is usually a lot of physical contact from our students. They often touch each other and their teachers; some would like to sit on their teachers’ laps or cuddle all day. We noticed positive changes: pupils have learnt how to set boundaries.”

Avoiding misinterpretation

The lessons are a challenge for groups with severe intellectual disability, but these pupils also receive lessons. If we find a teaching objective at a higher level very important for a specific pupil, we just simplify the teaching material e.g. with pictograms; in this way, pupils of all abilities are given lessons.

Both the awareness and ease of the teacher in openly discussing the topic can help avoid misinterpretations by children with disabilities. For example, after a condom use demonstration with a banana, one student proudly announced that he had fully understood and practiced the right behaviour: before having sex, he put a condom on a banana and put the banana next to the bed.

Involving parents

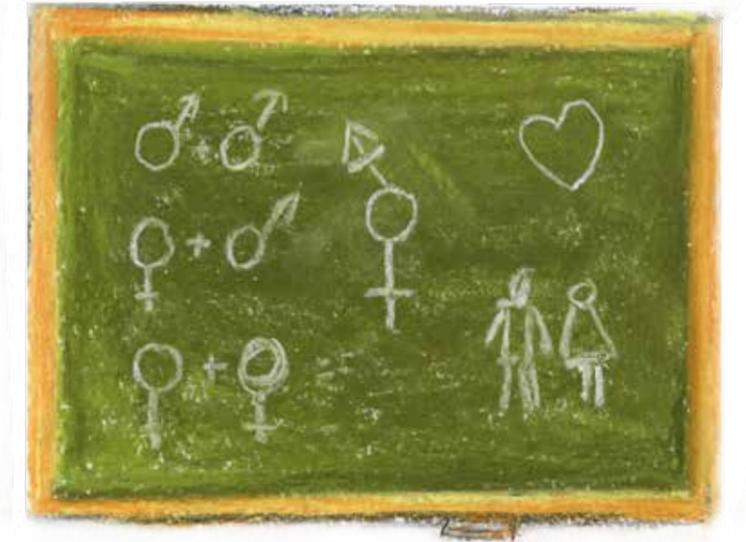
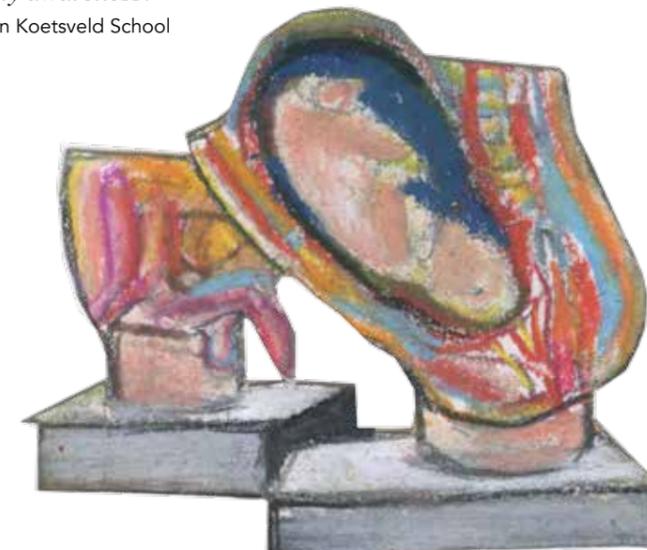
Rutgers encouraged the Van Koetsveld school to involve parents in this topic, just as they would in others. A teacher explains: “We describe what we do and why. For each lesson (and specific module) we also hand out information to the parents on a sheet of paper. We explain to the parents which topic we are going to cover in this lesson and we suggest little books and films to use at home. During the year we also organise parent evenings and run short films of the lessons. This is always much appreciated by the parents.

“The lessons are not demanding for the teachers, but they are part of the social skills lessons. Indeed, sexuality education and empowerment are social skills!”

Sonja Brilman, specialist in severe learning difficulties at the Van Koetsveld School

“We agreed on ‘calling a spade a spade’. How else does one encourage body awareness?”

Teacher at the Van Koetsveld School



Rutgers is an international centre of expertise on SRHR based in the Netherlands.

Programme highlights:

- » Developing a SRHR learning path for children from 4 to 20 with (severe) learning difficulties in special schools
- » Making the formats of existing SRHR-information, -education and -communication accessible
- » Training teachers at special schools in knowledge and awareness on sexuality
- » Including a guideline for suitable information depending on the developmental level of a child
- » Involving parents in the course

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Four joining forces

A Colombian alliance promoting inclusive SRHR

By Natalia Acevedo Guerrero

A collaborated programme by Profamilia, ASDOWN, LICA and PAIS, Partners of Handicap International

People with disabilities in Colombia are subject to serious forms of discrimination and violence in the exercise of their sexual and reproductive rights. This became visible in research conducted before the start of our programme. One of the main human rights violations is that people with disabilities are exposed to involuntary treatments, including forced sterilisation.

Since 2012, four organisations have been working together on ensuring and promoting the sexual and reproductive rights of people with a disability. Profamilia is an NGO with fifty years of experience in providing SRHR services; Colombian League of Autism (LICA) is an NGO working for the rights and improvement of the quality of life of people with autism and their families; Colombian Association of Down Syndrome (ASDOWN) is a family association which promotes the inclusion of people with intellectual disabilities; and Action Program for Equality and Social Inclusion (PAIS) is a human rights program of the University of the Andes. Partnering with four different organisations has been key to the project, as it amplified our different areas of expertise.

The practice: mainstreaming disability in a SRHR programme

Our collaborated project has four objectives, which are captured in all our activities. Firstly, we aim to raise awareness of stereotypes related to people with disabilities and their sexuality. Secondly, we train young people (from 15 to 21) with intellectual or psychosocial disabilities on their sexual and reproductive rights, who become multipliers, going on to share what they have learnt with others. Thirdly, we train and raise awareness with families and decision-makers regarding international standards and the legal framework for the rights of people with disabilities. And finally, we strengthen advocacy actions before judicial and administrative authorities for the elimination of the violations of sexual and reproductive rights of people with disabilities, specifically against forced sterilisation. These objectives are translated into the following activities:

Accessible SRHR services

Profamilia has been working with a youth network since the 1990s, providing young people with sexuality education and promoting activities to make them more aware of their sexual and reproductive rights. In 2013, the other three partner organisations adapted Profamilia's curriculum to make it more accessible for people with disabilities, and designed new activities.

The adjustments included the use of accessible information, pictograms, a virtual course and didactic methodologies to ensure maximum comprehension of all the topics. This was the first time that Profamilia's psychologist and professionals worked on educational activities with people with disabilities, so it was a learning process for all the partner organisations. Since 2016, the project has continued to focus on the accessibility of Profamilia's other SRH-services to people with a disability.

Sensitising SRHR-professionals on disability inclusion

The three organisations have also sensitised and trained Profamilia's health professionals and administrative staff in different cities, including on the Convention of the Rights of People with Disabilities of the United Nations, the models of disabilities in history and the model of supported decisions and the legal framework for the sterilisation of people with disabilities and the implementation of this guide. Currently, all staff are trained in disability inclusion and the 28 Profamilia clinics provide accessible SRH services for people with disabilities, which take into account their needs and any supports and adjustments that may be required.

Empowering young leaders

To overcome the Colombian discriminatory context of SRHR and disability, the project has developed strategies to empower young leaders with disabilities and to push for transformation from health providers and in the current legislation and judicial standards. Overall, the project trained eight groups: 120 leaders in four cities, all of them young people with disabilities. The process lasted forty hours in total and included topics such as decision making, sexual and reproductive rights, self-esteem, prevention of sexual abuse, contraception, etc. Today, these leaders provide peer multiplication and actively participate in debates on the topic.

Tools

The basic guide, 'Support in Decision Making in Sexual and Reproductive Health,' is a tool to provide support through images, attitudes and actions that health professionals can use to support people with disabilities in making decisions about contraceptive methods, abortion, sterilisation, detection of violence, etc. This tool was aimed at supporting young people and adults with intellectual and psychosocial disabilities. The organisations are currently sharing their experience in this and the assessment tool with other health providers.

Lessons learnt: consent of parents

One challenge was that it was difficult to convince parents and families of young people with disabilities to allow their children to take a course that includes topics such as sexuality and reproductive rights. In many cases, parents refused to allow their children to take the course. Taking the time to talk with parents was crucial in changing their minds.

During a new phase, which started in September 2017, the project seeks to train the leaders in the use of strategic communication and advocacy skills. This is in order to empower them to be part of the decision-making process where their sexual and reproductive rights are being discussed.

A milestone: successful lobby against forced sterilisation

Apart from our daily activities, as four organisations we have been engaged in the wider discussion in society about the standards in decision-making and sterilisation consent of people with disabilities. As a result, the organisations have actively participated in several judicial debates on rulings by the Constitutional Court of Colombia.

In 2016, the Constitutional Court ordered the Ministry of Health to regulate the accessibility of sexual and reproductive health services. In a participatory scenario, the Ministry convened organisations of people with disabilities and those which defended the rights of people with disabilities to come up with new regulations on the topic. Thus, the four organizations of this project actively participated in the construction of the administrative regulation Resolución 1904 of 2017⁴³. The decision-making assessment tool carried out by the project was used as an example for the creation of the legal standard on the subject.

With this new regulation the Ministry of Health prohibited all procedures of sterilisation without consent of the person with disability. Also, it makes the use of reasonable accommodation, safeguards and supported decision-making mechanisms mandatory for all hospitals, clinics and insurance companies. This regulation is a victory for the sexual and reproductive rights of people with disabilities in Colombia, and the project organisations will keep working and advocating for its implementation.

“Contrary to most students, I knew about contraceptive methods and voluntary termination of pregnancy, because of the training I received”

A young woman with a disability

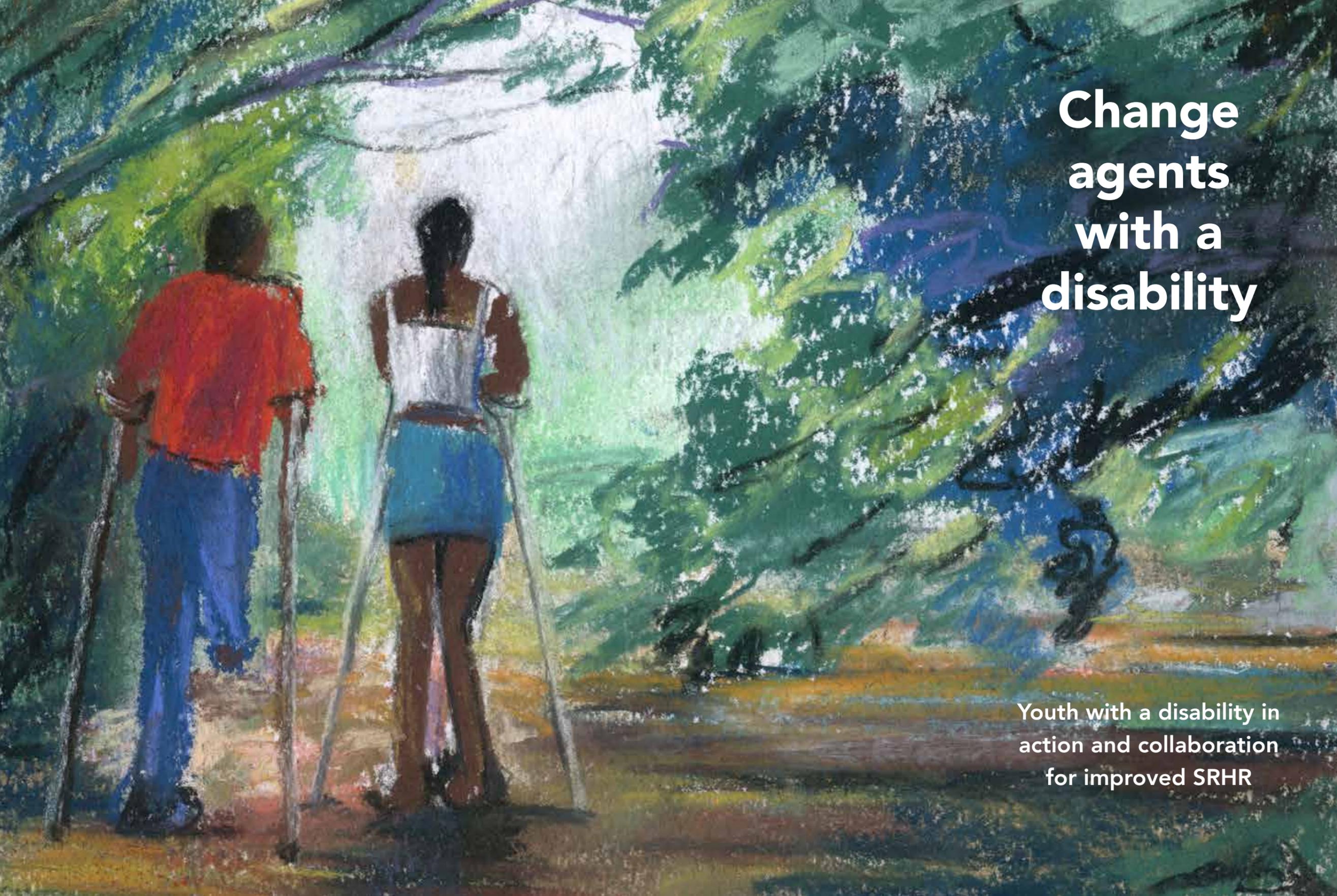


Four different organisations in one alliance, focusing on SRHR (Profamilia), people with disabilities and their parents (ASDOWN and LICA), and human rights and equality (PAIS).

Programme highlights:
» Organisations with different expertise working together

» Mainstreaming disability in an SRHR programme
» Disability-sensitisation for SRH experts and service providers
» Empowering young leaders with disabilities
» Successful lobby and advocacy against forced sterilisation

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Change agents with a disability

Youth with a disability in action and collaboration for improved SRHR

By Greaterman Chivandire
A project of Leonard Cheshire Disability Zimbabwe
Partner of Liliane Foundation

In Zimbabwe, the prevalence of disability is estimated to be 7%⁴⁴. Adolescents' sexual and reproductive health is particularly topical in Zimbabwe's fight against HIV. The first national strategy to address this topic was developed in 2011, emphasizing the need to reach out to marginalised people. However, very few children and youth with a disability have been reached.

To improve the sexual and reproductive health status of youth with a disability in both rural and urban areas, in 2015, Leonard Cheshire Disability Zimbabwe (LCDZ) implemented an SRHR project called Youth Action for Better Health. The purpose of our project was to enhance accessible and inclusive SRHR information and services by youths with a disability to their peers.

Leonard Cheshire Disability Zimbabwe is a non-profit organisation that works with children and youth with a disability in creating and improving awareness, access, participation and inclusion in their communities.

The practice: peer-to-peer training and complementary activities

The project is aimed at engaging SRHR and HIV issues in disability-specific programmes and approaches. The project involved a variety of activities: training for adolescents with a disability, peer education, safe spaces, school activities and providing information in accessible formats. All activities reinforce and complement each other, covering a wide range of disabilities, including physical, intellectual, visual and hearing impairments.

We involved 21 local partner organisations working for people with a disability throughout the country: special schools, health centres, disability service organisations, and community based rehabilitation partners. Those disability-specific organisations were linked to SRHR- and HIV-specific organisations for collaboration. Additionally, regular schools, policy makers, parents and caregivers were also involved. The project targeted young men and women equally, ensuring a sound interaction between gender and disability. The following components were executed:

Sexuality education for change agents with a disability

We partnered with HIV/AIDS organisations to give comprehensive training on SRHR to 357 adolescents with a disability. The aim of the training was to empower them to become change agents. As such, apart from SRHR, they also learnt about effective lobbying and

advocacy. The disability-customised training package was drawn from the Standard National Adolescent Sexual and Reproductive Health (ASRH) Training Manual⁴⁷ with emphasis on the Life Skills Approach.

Peer education

The 357 trained change agents became peer-to-peer trainers in SRHR for other adolescents with a disability. Some youth became treatment buddies for their peers whilst HIV-positive young women with a disability became community based female facilitators, meeting periodically with peers to discuss issues such as SRHR, HIV/AIDS, sexual violence and child marriage. Peer-to-peer education had a multiplying effect.

“I am now confident enough to talk about HIV and AIDS and I can teach others about transmission and protection”

Young woman with a physical disability,
peer educator

Awareness campaigns and lobbying

Through meetings, flyers, pamphlets, a video documentary and a radio programme, our campaign on raising awareness of SRHR and disability at the community and service provision level. In addition, we held panel discussions and dialogues with the National Aids Council (NAC) and government bodies to address the SRHR needs of people with a disability in national HIV programming.

As a result, there was an improved government responsiveness to sexual and reproductive health and rights of adolescents with a disability, especially towards women who are infected with and affected by HIV/AIDS. The current Zimbabwe National HIV/AIDS Strategy Plan (ZNASP) III now recognises disability and the National Aids Council is allocating support to people with a disability through various partners.

Safe spaces

Safe spaces in schools acted as meeting points for youth with and without a disability, where issues of sex and sexuality could be openly discussed. This has proven to be particularly useful in reaching girls with information and services on SRHR

Sexuality education at special schools

The project built on the use of existing school curricula to give further SRHR information to youth with a disability. In collaboration with special schools and institutions, we developed and adapted information,

education and communication materials in braille, sign language and other formats. Teachers explained that learning materials with graphic illustrations were the best kind of learning aids for youth with an intellectual disability. Youth with a visual impairment preferred to touch contraceptive items. Information was tailored to suit the level of comprehension specifically for children and youth with an intellectual disability, using repetitive learning and methods such as drama, role-play, visualisation, art forms and field trips.

Additionally, some schools held percussion and traditional dance competitions at which information on sexual and reproductive health and rights was disseminated. The competitions were also part of further raising awareness about the SRHR needs of people with a disability.

One of the teachers noted that sexuality education helped youths to protect themselves and improved their attitudes and behaviour towards SRHR issues. He reported that, unlike in previous years, in the year of implementation, there had not been a single case of (unwanted) pregnancy among pupils with a disability.

“During the training, I was asked: ‘Is it true that if you are HIV-positive, and you sleep with a person with a disability, you will be healed?’ I was able to explain that this is a myth”

Young woman with a physical disability, peer educator

Lessons learnt: involving youth with a disability and their parents is essential

All our activities helped in mainstreaming SRHR/HIV in the existing programmes of disability-specific partner organisations. As a result, we noted a reduction in teenage pregnancies in some instances, as well as a lower number of cases of sexually transmitted diseases, which indicates improved autonomy and use of contraception. Youth with a disability reported that they now practice abstinence or use contraceptives.

We also saw improved access to treatment information, knowledge and awareness for youth with a disability infected by HIV/AIDS. Special counselling teachers played an essential role in addressing SRHR issues and partner disability-organisations established collaborations with centres specialising in HIV counselling, testing and treatment. Consequently, adolescents with a disability are frequently tested and treatment is initiated in the case of infection.

Furthermore, lobby and (self-) advocacy turned out to be essential. For this, SRHR and HIV organisations must be involved, as they have

the resources and experience which can benefit people with a disability, provided that the services and information are accessible and disability friendly.

Whilst the project scored highly on educating youth with a disability about what constitutes sexual abuse and how to protect themselves from it, perpetrators of the crime could often still escape prosecution and conviction. In view of this, we recommend partnerships with justice service providers in SRHR programming. The lack of skilled personnel in SRHR for people with a disability was

Through Leonard Cheshire, I have managed to go to America to represent Zimbabwe on sexual and reproductive rights and HIV and AIDS. That was quite an experience for me!”

Young man with cerebral palsy, peer educator



a challenge. Training SRHR service providers in disability inclusion was indirectly part of the project through the trainer-to-trainer activity. However, negative attitudes towards people with a disability and their sexuality were sometimes very severe and difficult to tackle. Attention therefore needs to be paid to enabling factors. The involvement of youth with a disability and their parents from the beginning of the project affected the outcomes positively.

Leonard Cheshire Disability Zimbabwe is a disability organisation focusing on equal opportunities and choices.

Programme highlights:

- » Training youngsters with disabilities in SRHR to educate their peers
- » Partnering with special schools, local disability-organisations, and SRH and HIV service providers
- » Awareness campaigns and lobbying together with all stakeholders
- » Sexuality education in special schools using adapted formats

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Tito's privacy and rights

A personal story from Argentina about setting boundaries

By María del Carmen Malbrán

A case story of The Federation of Entities for Attention to Persons with Intellectual Disabilities (FENDIM)

Tito comes from a typical middle-class Argentinian home in La Plata, close to Buenos Aires. He lived with his mother and a maid in a large, comfortable house. Tito has a profound intellectual disability. He does not speak and does not understand verbal language. Orders and comments must be made by accompanying words with movements and gestures. He continuously walks around the room. He can feed himself but the food must be cut into small pieces.

All of a sudden, he began to compulsively masturbate in the presence of others. The caregivers were unable to stop the behaviour with physical or verbal orders. Sometimes he would pull down his pants. The classmates at the day centre beat or insulted him: 'You're a pig!' As a result of this behaviour, initially the family began to avoid social gatherings and invitations. They decided to feed Tito alone, always fearing that the inappropriate behaviour might reoccur. However, his mother, then an old lady, did consider masturbation to be a right and a private issue. She attributed Tito's problem on a lack of inhibitory controls and an inability to discriminate between places and situations.

Although the sexual and reproductive rights of people with disabilities are regulated by law in Argentina, in practice, they are often denied, especially when it comes to people with intellectual disabilities. This case story reflects a rights-based and personal approach to the sexual needs of a young man with a severe intellectual disability.

I encountered Tito when I worked as a consultant for The Federation of Entities for Attention to Persons with Intellectual Disabilities (FENDIM), an Argentinian NGO and member of Inclusion International, which supports (associations of) parents of people with mental disabilities. FENDIM's members are mainly formed by parents and have local representatives all over the country.

One of FENDIM's members provides services for young children with intellectual disabilities, counselling for families, special schools, a sheltered workshop and a day-care centre for (young) adults. The latter is where I met Tito.

The practice: a personal and rights-based approach

To teach Tito about appropriate sexual behaviour, his family, therapists and caregivers all agreed on the following plan. If the behaviour happened in the day-care centre, Tito would be gently led to an empty room and left alone for some time. If the behaviour occurred at home, his mother would lead him to his own room. It was a time out-

strategy. Once he finished, he was allowed to return to the main room. The procedure was repeated whenever the inappropriate behaviour occurred.

During the course of the intervention, a kind of warning reaction seemed to take place when Tito began to stare, as if trying to say 'lead me to the other room'. He began to go to the other room, closing the door and coming back, by himself. Sometimes, an anticipatory reaction could be observed, as if he felt an urge or a sign. At such times, he went to the other room without anyone else involved. Since the intervention, Tito has not repeated masturbation in the presence of others.

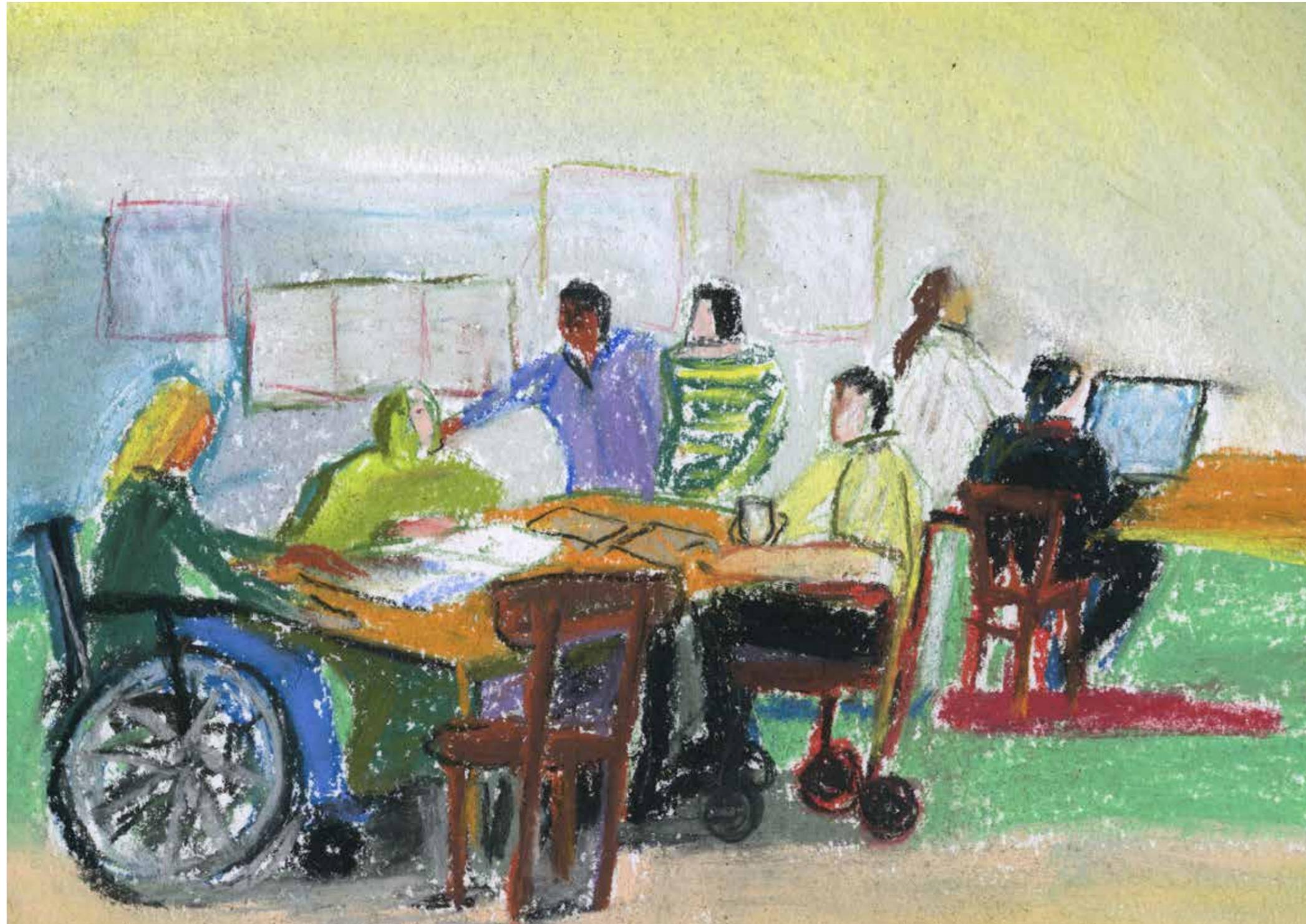
This intervention has modified the place and the presence of other people but not the frequency and intensity of the behaviour, which is in itself not problematic. The awareness that people with disabilities have the same sexual and reproductive needs, desires and rights, including masturbation, as anyone else, should become more widespread.

Lessons learnt: adapting to an individual's needs

What does this case tell us? A relatively simple intervention has improved the quality of relationships with the family, other caregivers and peers at the day-care centre. In such an approach, it is important that family, caregivers and disability-experts work together on a personal plan that ensures and promotes the individual's sexual rights – including masturbation – and allows them to make decisions themselves, whilst ensuring their privacy and a safe space.

When using this (type of) strategy with people with (intellectual) disabilities who exhibit inappropriate sexual behaviours, it should be noted that the approach should fit the individual's specific needs and level of communication. An obstacle to also be considered is the frequent change of caregivers in such day-care centres.

This case serves as an illustration of the importance of cooperation between the family, the therapists and the caregivers in improving social relationships with Tito, and between him and his peers, including him in everyday life at home and in his immediate surroundings.



María del Carmen Malbrán is a member of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASIDD). She worked as a consultant for FENDIM when she encountered Tito.

Story highlights:
» A personal approach to the sexual needs of a person with a severe intellectual disability
» Creating a safe place for masturbation, respecting rights and protecting privacy
» Working closely together with family members, caregivers and therapists

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Sign language for service providers

And empowerment
of deaf women against
violence in Kenya

By Aska Josephine Odera
A project of FEDWEN Kenya
Partner of AmplifyChange

12-year-old Wanjiru, who is deaf, was rushed to hospital after she was brutally raped. She needed treatment. At this young age, in sixth grade at school, the rape left her pregnant; she dropped out of school and gave birth to her daughter, Emily. With the help of her grandmother, Wanjiru raised her daughter through petty jobs. In the course of her daily endeavours to earn a living, she was sexually abused again, by a driver who was well known to her. Due to a lack of support for Wanjiru, who lacked awareness on her sexual and reproductive health and rights, the incident went unreported and she conceived again. Following the birth of a second daughter, Joy, Wanjiru was left highly traumatised and faced stigma every day. Her family did not have the means to protect her from abuse. They felt shamed by the community, were pained with the incident and forced sterilisation on her.

Deaf and hard of hearing people in Kenya face numerous challenges in seeking services and inclusion in society, and never more so than when it comes to their sexual and reproductive health and rights, prevention of and response to sexual abuse.

The Federation for Deaf Women Empowerment Network - Kenya (FEDWEN-K) has implemented a project, funded by the international SRHR organisation AmplifyChange, entitled 'Listening to the voice of the voiceless' in Kenya. It was implemented in four counties for a period of eight months. Through the project, we targeted deaf women, youth, children and their parents, law enforcers and health service providers.

The practice: empowerment and sign language provision

FEDWEN-K has integrated various strategies to create awareness on SRHR. We have designed and formulated information, education and communication materials accessible to deaf people and basic Kenyan sign language pamphlets for the community and service providers. Sign language training has been offered to service providers, including, but not limited to law enforcers and health service providers in all four counties. To empower deaf women and provide knowledge on SRHR, we used various methods: community interactive sessions in safe spaces; awareness creation for women, youth and children with disabilities, parents of deaf children, law enforcers and health service providers; the formation of self-support groups; and the provision of referrals and legal help.

Empowered through sharing experiences

Wanjiru shared her experience in an interactive safe space. Just like her, most of the deaf women attending the safe spaces were sharing their stories for the first time in their lives. From humiliation and discrimination to sexual abuse, all stories were heard. Some women even perceived what had happened to them as 'normal', or they felt guilty. Through the project, they became aware of their rights and learnt that their rights had been violated. By opening up to each other, these women felt empowered and determined to protect themselves.

The biggest challenge has always been getting sexual and gender-based violence survivors to open up and just talk. Through the project, Wanjiru gained self-confidence and awareness of her sexual and reproductive health rights. Whereas she felt alone and isolated after what happened to her, she has now gained confidence and feels stronger because of the connections she has made with other deaf women, and knowing that she is not alone.

Sign language to get justice after sexual violence

Elizabeth is a deaf lady with a rough life, introduced to us by well-wishers. She had lost four legal cases before she came to us: gender-based violence towards her; attempted murder by her husband; the burning of her house; and domestic violence. All these cases failed due to the lack of a sign language interpreter. For recording statements at the police, it would have to be the husband to help her write. However, he was the offender. Since the police could not communicate with her, the case could not proceed to court.

With the help of FEDWEN-K and her two children, Elizabeth's last case was pushed through. We were present in the court to make sure that, unlike the previous times, the interpretation was accurate. A lot of information had previously been distorted or lost as there were no professional sign language interpreters present during the court sessions. Eventually, a ruling was given; she retained her property and the husband was imprisoned.



The case of Elizabeth highlights the importance of professional sign language interpreters. We provided police and medical officers with training in basic sign language as well as training on disability inclusion. This raised awareness amongst these professionals of the need to involve a qualified interpreter. The training could be used as leverage to gain promotion, which increased the staff's motivation to participate.

Lessons learnt: attention to lobby and awareness raising

Our project, 'Listening to the voices of the voiceless', has certainly shown results worth mentioning. For example, Kenyan sign language pamphlets have been shared in the community and amongst service providers. Additionally, the sign language training offered to service providers was well received by them. Through active advocacy on SRHR and gender-based violence, a deaf person has been chosen as a representative of people with disabilities on the Nyeri County Government Health Committee. Finally, law enforcers in Murang'a, Kirinyaga and Nyeri counties have formed a policy that requires all their front office personnel to learn basic sign language. This is the most remarkable outcome, and the one of which we are the most proud.

We would emphasise the importance of mapping out all stakeholders for more targeted interventions, and, having safe spaces or forums for sharing experiences and success. It is essential to engage with the media to bring the topic of disability and sexuality to the fore. Furthermore, knowledge is power. Many deaf people and other people with disabilities have been kept in the dark about their SRHR, which has often resulted in a lack of power to better protect themselves and self-advocate. Simple community interaction and awareness sessions serve as eye openers for many different groups and individuals. We therefore pride ourselves in bridging the gap and creating an enabling environment for people with disabilities.



Federation for Deaf Women Empowerment Network

(FEDWEN) Kenya is a disability organisation focusing on deaf women and girls

Programme highlights:

- » Creating safe spaces for deaf women and girls, where they can share their (negative) experiences with sexuality
- » Legal support for deaf women and girls who have faced sexual violence
- » Providing basic sign language and disability sensitisation training for police officers
- » Raising awareness and lobby and advocacy against disability and gender-based violence

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Ways forward

Everybody Matters: Reflection

This book has explored the harsh realities, strong ambitions and practical lessons learnt encompassing the theme of disability and sexuality, and more specifically, has considered the sexual and reproductive health and rights (SRHR) of people with a disability.

Activists Toyin Aderemi and Nidhi Goyal took us along their determined and ongoing journey of listening thoroughly to the stories of people with disabilities, of tirelessly raising one's voice against taboos and stigmas that exist everywhere in the world, and of bridging gaps between people and organisations. Subsequently, eleven good practices took us deeper into the question of how best to address this topic.

Before we present concrete recommendations, we would like to reflect on the ambitions, challenges and solutions described in the various sections of both this book and other literature.

Visibility, knowledge and awareness

The organisations and experts who have contributed to this book all conveyed the strong message that lack of knowledge and awareness is an overarching challenge that reinforces all other barriers.

Insufficient knowledge and awareness about disability causes stigma, taboo and discrimination, which can lead to the exclusion and invisibility of people with disabilities in society in general¹⁵. The idea that people with disabilities do not (or should not) have sexual lives⁹ and do not need SRHR services is fairly common worldwide and applicable in almost all cases presented in this book.

The respective suppressed self-esteem and negative body image as a result of discrimination and stigma, made most, if not all organisations presented in this book decide to emphasise the empowerment of people with a disability: children, adolescents and adults, male and female. Part of this means involving people with a disability in the programme, which makes them visible either as peer educators (Leonard Cheshire Disability Zimbabwe; Israel Family

Planning Association), role models (Dance Into Space Kenya; Karuna Foundation Nepal; the Colombian alliance) or as co-programme developers (Marie Stopes Nepal).

Whilst comprehensive sexuality education for adolescents with disabilities might be perceived as 'awakening the dormant within', as depicted for example in the cases of Light For The World (Ethiopia), Leonard Cheshire Disability (Zimbabwe) and Niketan (Bangladesh), the organisations' work included the provision of comprehensive sexuality education in accessible formats. Even where negative attitudes about disability are not as profound, such as in the case of Rutgers (The Netherlands), disability experts lack the specific knowledge and confidence to deal with SRHR. Rutgers in this case filled the gap by giving teachers on special schools SRHR-knowledge.

It should be noted, however, that this lack of knowledge and awareness is twofold: both disability and sexuality in general are taboos in many societies, as we have seen in Ethiopia, India, Bangladesh and Nepal throughout this book. Several actors use creative means like stand-up comedy (Nidhi Goyal) or dance theatres (Dance Into Space), to break down taboos in the community: in this way, people feel more comfortable with the issue and open up more easily.

Accessibility of services and information

Lack of knowledge and awareness, leading to taboo, stigma and discrimination, can lead to a negative attitude of health and justice service providers. This often results in the denial of services to help clients with a disability¹⁵. Another consequence is that health, justice and other services are not made accessible for people with different types of disabilities. For example: descriptions on medicine packaging may not be accessible for people with visual impairments, or not understandable for people with intellectual disabilities; health centres may have steps or examination benches that are inaccessible for people with physical impairments; and there may not be any staff with sign language skills to communicate with people who are deaf¹⁷.

Achieving accessibility for all is relatively easy. However, it should be kept in mind that accessibility is not only about ramps, but includes physical accessibility, as well as communication skills and information, education and communication materials in braille, sign language, plain language, audio and video formats and pictograms.

Nearly all the good practices in this book integrate accessibility as a core topic. Comprehensive sexuality education

materials and lessons were made accessible by Niketan (Bangladesh), Rutgers (the Netherlands), Light for the World (Ethiopia) and Leonard Cheshire Disability Zimbabwe. SRHR-organisations Israel Family Planning Association, Marie Stopes Nepal and Profamilia (Colombia) with the help of their partners, all made sure their mobile helpline, information materials, and in-house buildings became accessible.

The dance group, Dance Into Space, provided HIV-tests and advocated for accessible health centres. The deaf-empowerment organisation FEDWEN-Kenya provided basic sign language for police officers and helped with sign language when necessary in legal cases.

Comprehensive sexuality education

Comprehensive sexuality education enables young people to protect their health, well-being and dignity¹⁹. Exclusion from comprehensive sexuality education is another topic that is widely recognised as problematic for the SRHR of people with a disability^{15/17}. One consequence may be – as Nidhi Goyal explained – that people with disabilities also do not perceive *themselves* as sexual beings; they internalise the ideas of others regarding their own sexuality, leading

to suppressed feelings and desires. Moreover, this decreases the likelihood that people with a disability who experience sexual violence seek justice. Organisations paying attention to comprehensive sexuality education include first and foremost Niketan (Bangladesh) and Rutgers (The Netherlands). Also Leonard Cheshire (Zimbabwe), Israel Family Planning Association and the Colombian alliance give sexuality education to adolescents with different disabilities.

Apart from comprehensive sexuality education curricula, there is a general lack of guidance for families and teachers on how to talk about sexuality and equality with children and adolescents with disabilities¹⁸. To address this, many organisations in this book recommend to involve parents in developing sexuality education programmes.

Protection against violence

Children and adults, both male and female, with disabilities face higher risks of becoming victims of gender and disability based violence than their peers^{13/14/15/16}. People with intellectual and mental disabilities appear to be the most vulnerable¹⁶. In some cultures there is a belief that sex with a virgin or person with a (specific) disability is a cure for

HIV or other diseases⁴⁸. Often people with a disability are just seen as an ‘easy victim’, e.g. the assumption that a blind person cannot see (and thus identify) a perpetrator or that someone is not able to and will not communicate about it, according to Toyin Aderemi. When seeking justice, communication barriers can turn into larger obstacles, given the often-negative attitudes amongst police officers and family members⁴⁹. This all is compounded by the fact that many people with disabilities are dependent on those who abuse them, as perpetrators are often family members or other caregivers⁵⁸, elaborated clearly by Niketan (Bangladesh) and FEDWEN (Kenya).

Lobbying and advocacy activities need to address the existence, implementation and compliance of legal protection frameworks^{15/17}, as shown in the programmes of almost all good practices.

FEDWEN Kenya organised sign language lessons for police officers and other justice providers, and stressed the importance of professional sign language interpreters. Additionally, both FEDWEN and Leonard Cheshire (Zimbabwe) integrated safe spaces in their approaches, with the purpose of sharing (negative) sexuality experiences with other people with disabilities, helping to empower them.

Women and girls with disabilities are ‘doubly marginalised’¹⁵, and often face gender-specific issues such as forced marriage, and higher risks of violence than men with disabilities. However, boys and men with disabilities are also in danger for gender and disability based violence. This should not be overlooked.

Autonomy and decision-making

Family members and professionals tend to make decisions for children and adults with disabilities, rather than helping them express and pursue their own needs and desires. This can result in harmful practices such as forced sterilisation, forced abortion, forced (child) marriage and the denial of comprehensive sexuality education^{15/17}, that is perceived as ‘only awakening the dormant’ in adolescents with disabilities.

Plan Norway recently conducted a study to uncover child marriage among children with disabilities⁵⁰, stressing that whilst in many countries child marriage is common in the context of poverty, social norms and gender relations, disability adds an additional layer of vulnerability to this practice. Marriage is seen as a way for girls with a disability to get long-term social security and protection from potential sexual violence, ignoring the issue of vulnerability to domestic abuse.

Although United Nations instruments, mechanisms and agencies have criminalised the forced sterilisation of people with a disability, the practice is still legal and applied in many countries: allowing judges, healthcare professionals, family members and other caregivers’ consent on behalf of people with disabilities, as it would be in their ‘best

interest’⁵⁴.

The Colombian alliance of Profamilia, PAIS, LICA and ASDOWN successfully lobbied with the Colombian government to implement a new law against the forced sterilisation of people with a disability. They also raised societal awareness by campaigning against this practice.

The twin track approach

Several of the good practices showed that they act in line with the Twin Track approach, ensuring inclusion on the one hand and use specifically targeted laws, policies, services and programmes on the other²². Valuable examples are Marie Stopes Nepal and the Colombian alliance, making sure that the SRHR services they already had in place were made accessible for people with disabilities, and in the meantime empowering specifically young leaders with disabilities to play an exemplary role for their peers. Also Karuna Foundation Nepal takes the twin track approach, as a disability organisation targeting people with a disability, while at the same time strengthening the existing reproductive healthcare in the community and working towards full inclusion within this system. Light For The World in Ethiopia conforms to the concept of the twin track approach by linking community based rehabilitation workers to SRHR specialists, and Leonard Cheshire Disability Zimbabwe lobbies and raises awareness for access to services and simultaneously targets young leaders with disabilities for empowerment. These stories describe how combining the two elements of the twin track approach is a powerful tool in working towards full inclusion.

Concluding remarks

People with a disability are not a homogeneous group and disability is a cross-cutting issue, interconnected to other identities and issues. This is adopted in the UN Convention for the Rights of People with Disabilities and it must accordingly engender action for full inclusion. To quote the latest report of Catalina Devandas, the UN Special Rapporteur on the rights of persons with disabilities¹⁷: “Only when the sexual and reproductive health and rights of [people] with disabilities are protected will they realise their full potential.”



Conclusion and recommendations

The stories selected for this book highlighted different parts of the world, types of disabilities, age groups, various kinds of organisations, components of SRHR, and different overall approaches, making each case unique. However, when presented side-by-side, similar lessons and recommendations can be drawn. They highlight that there are still barriers that leave many of us behind, but also show what should and can be achieved.

To achieve inclusive SRHR for people with disabilities, working together is the only way to go. This book came about through a partnership between a disability coalition and a SRHR network: the Dutch Coalition for Disability and Development (DCDD) and Share-Net International, the knowledge platform on SRHR. In practice, whilst NGOs working on SRHR need to equip themselves to reach people with disabilities in their programmes, NGOs aiming for disability inclusion should address SRHR in their programmes. Besides, there are roles for all stakeholders with different expertise and power. From grassroots to the international (policy) level: each actor has a role to play. From raising awareness on the intersectionality of the topic and making local health and justice services accessible, to setting inclusion criteria for funding mechanisms and ensuring inclusive policies, laws and budgets. These joint efforts are most effective when they follow the so-called twin track approach: focus on the one hand on full inclusion of people with disabilities in society and programming, and ensure specifically targeted initiatives for people with disabilities on the other.

The good practices presented in this book form the evidence: it is not necessarily difficult to work on inclusive SRHR, as long as commitments are made to give it persistent attention. Step by step we can make a difference. We hope that this book has given you inspiration to take action yourself, together with others, so that people of all ages, abilities and gender can pursue pleasurable, healthy and safe sexual and family lives, which every person is entitled to.

Through the interviews with activists Toyin Aderemi and Nidhi Goyal, the eleven strong stories in this book, and relevant literature, we have put forward several key principles and recommendations that are at the core of a disability-inclusive approach to sexual and reproductive health and rights.

First and foremost, in working towards fully inclusive SRHR services or programmes, the following three principles need to guide any approach:

Nothing about us without us

As all the stories without exception in this book prove: only if people with disabilities are involved in programming, policy making and implementation, real and sustainable inclusion can take place.

Empowerment

Empower people with disabilities of all ages and gender to be self-confident, to have positive ideas about their own sexuality, to raise their voice and make their own informed choices regarding their sexuality and the SRH services they require.

Access for all

All services regarding SRHR and justice for gender and disability based violence must be accessible for everyone. Taking the accessibility needs of people with disabilities into account is a non-discrimination principle. It should not be considered as a special favour or something 'extra'. It is everyone's right to have access to the same services.

Hinging on the former chapter, which highlighted the common challenges and the way the good practices in this book worked on solutions, the figure on the next page summarises concrete recommendations for action. In their report, 'Promoting sexual and reproductive health and rights for people with disabilities', UNFPA and the WHO identified five intervention areas that we consider extremely relevant and useful¹⁵. These five areas are: 1) Establishing partnerships, 2) Raising awareness, 3) Reaching and serving, 4) Policy, laws and budgets and 5) Promoting research. The stories in this book show that these are the areas that remain highly relevant and need to be addressed, keeping people with disabilities at the main focal point: nothing about us without us.

Establish partnerships

Build and invest in partnerships and coalitions. Disability organisations and SRHR organisations should join forces at all levels. Organisations with different expertise sharing knowledge and establishing networks are more likely to be successful.

Reach and serve

Ensure that all SRHR programmes, comprehensive sexuality education and health and justice services reach and serve people with disabilities. Improve the accessibility of all services, communication and information, including in-house. Use the twin track approach: mainstream disability in all programmes, and use disability-specific programmes when needed. Reach persons with disabilities of all ages and gender.

Raise awareness

Knowledge should be provided and awareness should be raised from the grassroots to the international level. Make sure people with a disability are visible in society and represented in public arenas, in the media, and in research. This also means sensitising all stakeholders on both disability and SRHR.

Promote research

To develop stronger evidence, research on SRHR of people with disabilities needs promoting and funding. This in turn will help in lobbying and advocacy and raising awareness. Additionally, people with disabilities must be included in mainstream SRHR research.

Policy, laws, budgets

Anchor disability inclusion in national SRHR policy, laws and budgets. Protection against violence as well as strengthening autonomy and decision-making need to be embedded in laws. Priorities for SRHR and disability inclusion need to be set by governments and reflected in their policies, rather than driven by priorities set by donors. Make sure that implementation and compliance is adequately executed.

“The SRHR of persons with disabilities is not a unique, complex, or highly specialised issue. It is, however, an issue that needs more attention and greater creativity, and it needs more attention now”
WHO (2009)

List of acronyms

AIDS	Acquired Immune Deficiency Syndrome
ASDOWN	Colombian Association of Down Syndrome
(UN)CRPD	(United Nations) Convention on the Rights of People with a Disability
CSE	Comprehensive Sexuality Education
DCDD	Dutch Coalition on Disability and Development
FEDWEN-K	Federation for Deaf Women Empowerment Network - Kenya
FENDIM	The Federation of Entities for Attention to People with Intellectual Disabilities
HIV	Human Immunodeficiency Virus
IFPA	Israel Family Planning Association
IPPF	International Planned Parenthood Federation
LCDZ	Leonard Cheshire Disability Zimbabwe
LICA	Colombian League of Autism
MIW	Making-It-Work initiative (of Handicap International)
NGO	Non-governmental organisation
PAIIS	Action Program for Equality and Social Inclusion
SRHR	Sexual and reproductive health and rights
SRH	Sexual and reproductive health
UN	United Nations
UNFPA	United Nations Population Fund
WHO	World Health Organisation

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