

Sexual and Reproductive Health and Rights (SRHR) education for young people with complex disabilities in Bangladesh.

Lessons learned and factors for success:

- The trainers come from within the organization, they have been working with the target group for a long time and therefore there is already a degree of trust, which is very important when teaching about SRHR to a vulnerable group of young people. As a result, parents are comfortable and convinced to bring their children to the training.
- Consultation with parents and adolescents beforehand is a critical component of the training: students and parents must understand the importance of learning about SRHR. Parents continue to be meaningfully engaged.
- It can be challenging to teach adolescents with intellectual disabilities on SRHR. Therefore, also training their parents/caregivers is important.
- Trainers need to repeat the key messages multiple times to explain and reinforce the critical lessons. Therefore, the training has no time limit. The trainers may take as much time as the group needs. The module is adapted to the needs of a group regarding the levels of understanding and experiences of trainees. This means that some groups take longer to complete module.

- Training young people with different levels of understanding in the same group can be difficult. Trainers form homogenic groups of trainees with similar intellectual levels to make the training more effective.
- Finding peers without disabilities for the girls' group and retaining them for the training can sometimes be difficult. However, the peers without disabilities find the training very valuable too. In addition to the lessons on reproductive health, they say they learned a lot about disabilities. It changed their perception about disability and they built friendships with the girls with disabilities.
- The trainers maintain friendly communication with the young people, teach through jokes and enjoyment but at the same time try to deal with SRHR issues of their students with respect and confidentiality. The majority of the adolescents with disabilities benefit from the SRHR training, as revealed through the interviews. Not only do they learn but also are able to apply their knowledge and rights in daily life.

1.The importance of educating young people with complex disabilities about SRHR.

Sexual and reproductive health is complex and controversial in Bangladesh, and in particular for young people with disabilities [1]. Due to the historic denial of rights and needs related to sexuality, people who have disabilities may demonstrate inappropriate sexual behaviour [2]. They have been victimized by others due to lack of information how to protect themselves or what is perceived as appropriate. In traditional societies such as in Bangladesh, people with intellectual disabilities in particular tend to be seen as "children" due to their lower-than-average level of intelligence and they are thus prohibited from having sex and related education [3]. Such imposed rules may lead to frustration, oppositional behaviour and deviant behaviours as they attempt to have their physical and emotional needs met [4].

Niketan is a Dutch disability-organisation focusing on participation of young people with (complex) disabilities in Bangladesh. They work together with Disabled Rehabilitation and Research Association (DRRA), their partner organisation in Bangladesh. The aim of the current project is to provide SRHR education for young people with a disability. This addresses youth who live with physical and/or mental disabilities— including, but not limited to hearing, sight, and motor function impairments; Down syndrome; cerebral palsy; autism spectrum disorder and developmental disorders.

2.Objectives of this Learning Brief

With this Learning Brief we wish to demonstrate initial results and potential impact of this Niketan/DRRA project. Based on project visit observations and interviews with stakeholders and beneficiaries, a positive story is emerging. The project team in Bangladesh wanted to find out whether SRHR trainings help young people to gain knowledge, to change perceptions, attitudes, and behaviour. The Learning Brief is rooted in qualitative evidence, however, it is not a research paper or evidence report.

3.What and How – Our approach

To empower young people with a disability, aged 13 to 25, and teach them about sexual and reproductive health, Niketan/DRRA started in 2017 a course "It's my body!". This course includes subjects such as knowing your own body, personal hygiene, social relations, friendship and abuse.

Step one: training teachers of special schools on SRHR

Niketan/DRRA partnered with the SRHR-organisation Rutgers Foundation in the Netherlands to develop a training toolkit. Before, Rutgers had already trained local SRHR-consultants. These consultants in turn 'trained the trainers': teachers and confidants of the target group who were disability-experts at the grassroots level and having a close (working) relationship with these young people.

The Training of Trainers (ToT) focused on the existing psychological, social and cultural barriers leading to the negation of rights surrounding the sexual life of young people with (intellectual and/or physical) disabilities. To break the taboo about sexuality – both for people with and without disabilities – Niketan/DRRA brought teachers, management and caregivers working at special schools together to talk about sexuality and disability in 2013. During the first meetings, participants were too shy or just reluctant to talk. Slowly they got used to the idea and meetings with parents of young people with a disability convinced them that the eyes could not remain closed for this subject.

The TOT in 2016 was an eye-opener for the trainers. For them to be able to teach young people with a disability about sexuality, they first needed to learn how to openly share their own thoughts, experiences and beliefs on sexuality. Their thinking was based on myths and beliefs, which were reflected in their attitude and behaviours. Breaking this and teaching them SRHR or rights-based values was the biggest challenge. Eventually though, all trainees were able to talk openly about SRHR, a topic they had never spoken about before. They were now equipped to start teaching their students with disabilities. A textbook with supportive material was developed together with Rutgers and Ipse de Bruggen, a Dutch organization working with people with complex disabilities. Separate books for males and females were developed. Using the books and other visual aids, a SRHR training module was developed. Through the textbook and the training module, adolescents with disabilities learned about their body, private body parts, gender, puberty, friendship and relations, marriage and reproductive health. Additional materials like posters of human growth, pictograms, a doll family and storybooks were developed to complement the training materials.

Step two: sexual education at special schools for young people with disabilities.

Before starting the training, parents were informed about the importance and content of the training. Interviews were conducted with a parent, mostly the mother, about what the child already knows about e.g. his/her own body, relationships and similar topics. This provided a picture of what a parent thinks of his/her child and also the parent's own level of knowledge of SRHR. The adolescent with disability was then asked the same questions but in a simple way and using dolls and pictograms where needed. On average, each interview took about two hours.

Parents:

The interviews revealed that mothers were more likely to talk with their daughters about sexuality and reproductive health than with their sons. Most fathers were not involved in parenting and did not have an open relationship with their sons. Mothers stated that porn videos were sometimes used by other family members to teach boys about sexuality. Parents/mothers said their children were in need of SRHR training as they encountered different problems raising their adolescent children, such as:

- Girls do not understand the importance of cleanliness during their menstruation periods and there is no place to dry washable sanitary pads,
- Girls are not safe with neighbours and even with family, as they don't understand their private body parts,
- Boys expose their genitals, undress and masturbate in public places,
- Boys often keep their hands in their pants,
- Both boys and girls want hugs and be touched inappropriately.

Parents allowed their children to receive this training. They expected their child would show appropriate behaviour after such training, and would better understand what should be done in private and public, and so decrease risks of sexual abuse.



Trainees:

Boys: Young boys with disabilities in resource-poor rural settings do not have access to SRHR information on the internet or other ways like the rest of the world. They also do not talk about these issues with their parents, brothers or classmates as they feel shy. The taboo is too big and there is great embarrassment in letting others know that you do not know how it works. At present, there are two groups with 10 boys, their ages ranging from 12 to 20. Since 2017, we have trained a total of 4 boys' groups. The level of knowledge on sex education among the boys is very low. Most of the questions they could not or did not answer. Knowledge about their own body was practically "zero" among nine boys with intellectual disabilities. A recurring answer was that their bodies belong to Allah and only He decides what to do with them.

One of the questions at the intake focused on whether or not to engage in paid or forced sex. Most young people gave the desired answer to this: they do not have sex against their will. However, their stories reveal that they are both victims and perpetrators, without even realizing what is being done to them or what they are doing.

The girls: The girls' groups take on a peer-support approach that is different from the boys' group. There are two groups of girls between 11 - 15 years of age, that include both girls with disabilities and their friends/peers without disabilities. Since 2017, training has been provided to a total of nine girls' groups. Some girls already had their periods but others not. The girls all indicated that they were not taught anything at school or at home about puberty or menstruation. Those who have their periods said they were very shocked the first time they had it. They did not dare to talk to their mothers about it, hid it from parents or thought they were seriously ill or had cut themselves. This was said by both girls with and without disabilities. Noteworthy is that girls talk much more freely than the boys. At home, girls share more among themselves, and mothers and elder sisters share their personal problems with their daughters/sisters.

The mothers of girls with disabilities experience menstruation-related issues with their daughters: the girls do not want to keep the sanitary pads on and they publicly throw them away. We started to train girls earlier, starting with those 11 years of age, in the hope they will not become a victim of sexual abuse as they grow older. Among the first 20 girls we trained, 18 were abused:

"Teachers give us a higher grade on tests when we allow them to touch our breasts." – Shilpi (fictious name)

Amina (not her real name) has spastic paralysis and is 15 years old. She lives with her parents in a typical slum house and other family members live next door. She helps her mother as much as she can. She is their only child and her parents have financial problems. Information dolls were used when Amina was interviewed. With facial expressions, body language and the dolls, Amina showed us that she has been a victim of sexual abuse, oral sex and sexual intercourse. Amina showed us that she likes it, but that she has no idea of right and wrong. She could not say whom she has sex with; it could be one person or more.



4.Our impact

The impact of Niketan/DRRA's SRHR training was assessed qualitatively. We conducted a pre-and postevaluation of the "It's my body" training. The tool consists of three parts. The first part has to be filled in by the caregiver or parent. It shows his/her perception, knowledge and behavior on SRHR. Young people with disabilities participate in the second part. It indicates their reproductive health and rights knowledge reasonably well. The third part is for the teacher and shows his/her perception of change in the student. This assessments tool cannot be used with all adolescents. In some cases, the tests were complemented with a semi-structured interview or professional discussion about sexual concerns.

Qualitative data collection consisted of in-depth interviews (IDIs) with mothers of adolescents with disabilities who received SRHR training, IDIs with trainers who conducted SRHR training sessions and focus group discussions (FGDs) with adolescent girls and boys with disabilities (trainees). The objective of the interviews was to understand the experiences, including trainer effectiveness and the barriers of the SRHR training among trainees, parents and trainers.

Trainees: We separately interviewed a small group of girls and a larger group of boys about their experiences with SRHR training at Niketan. The girls were able to tell that they gained knowledge on topics such as puberty, menstrual health/hygiene, how to wear and dispose different types of sanitary pads (panty and belt system), how to communicate with the opposite gender and act in a culturally appropriate way as a female. All of them claimed that they are happy with the way the training was conducted and that the female trainers were very friendly. They claimed that they feel comfortable talking to their "madams" about their personal problems and feel safe disclosing their SRHR issues. In some cases, they feel they are more comfortable talking about these issues with their trainers than their mothers/family members.

When prompted, one girl said that they know about sexual abuse:

"I know that there are some parts of my body I cannot let a male touch. If someone does that, I will tell my mother and my teacher here."

The boys' group said that they learned about puberty, how to maintain hygiene, about wet dreams, how to communicate with the opposite gender and act in a culturally appropriate way as a male. One boy (age 15) said that before this training, he did not understand that he needed to maintain boundaries with a female peer:

"I used to put my arms around or hug my female friends/peers in the same way I act with my male friends. But now I know that I am not a child anymore and should keep physical distance with a female."

Most of them expressed that they were happy with the way the training was conducted and that the male trainers are very friendly. They expressed that they feel comfortable talking to their "sirs" about any issues they face and ask questions when getting confused about how to deal with a situation. However, the boys seemed more shy in comparison to the girls.



Parents/Mothers: All parents interviewed were mothers. Fathers are rarely involved as they are engaged with work/ wage earning. We interviewed a total of nine mothers, with their ages ranging from 30-45 years and their children's age ranging from 13-23 years. We asked the mothers how the SRHR training/education at Niketan/DRRA helped them in addressing SRHR needs of their children. The mothers revealed that the SRHR training had tremendously helped them and their children. The mothers of the girls think that peer-support sessions for their daughters helped them clearly understand and practice menstrual hygiene at home. Their understanding of their bodies and pubertal changes improved after the training and, in some cases, the girls even educated their friends in the community regarding such issues. Most mothers said that their daughters understand the concept of courtship/marriage and sometimes express such an interest when seeing an attractive male. The girls are now aware about good touch/bad touch and know how to protest when someone approaches them inappropriately. And sometimes it works better if mothers seek help from their daughters' friends/peers in the village:

"I was worried that my daughter was still not having her menses and concerned that she would not tell me even if she did have her period. So, I approached her peers in our village and told them to keep an eye on my daughter and let me know when they came to know that she (daughter) started having her period."-Mother of Jerin (Fictitious name)



In case of boys, the benefits of the SRHR training are slower to manifest compared to the girls. Mothers said that most boys now understand that they have to wash their pants/clothes after a wet dream. Mothers said that they have provided their sons with razors, hair removal creams for cleaning pubic hair. However, some boys are not able to shave on their own. Even though some boys cannot maintain hygiene on their own, they have learned to seek help from their parents. The mothers expressed their satisfaction about the male trainers, who are very friendly and openly communicate with the boys about everything including female bodies, wet dreams, hygiene and cleanliness, communication with females and even marriage. One of the boys reacted to the content of the SRHR training. He was very shy and unwilling to come to the session about the female body. The mother said:

"My son has been reacting in an extremely shy and defensive way to the SRHR sessions. He did not want to come to the session. So, I called 'sir' (the trainer) to inform him. Sir told me to convince my son to come at least to the office gate and he would take care of the rest. Once I got there, my son sat down stubbornly and was still not willing to attend the session. Sir came down and talked to my son. After quietly counselling my son, after 10 minutes, my son was willing to be present at the session."

Trainers: We interviewed four trainers: two males and two females. All of them have been working with DRRA and Niketan for a while and are now very experienced in providing the SRHR training. They believe that their careers and perspectives took a new turn when they started conducting the SRHR trainings.

One female trainer said that some of her own misconceptions around sexual and reproductive health were eliminated by this training.

They now know how to openly communicate with young people without shame. The trainers expressed that initially parents were not comfortable about their children receiving SRHR training and some were outraged at the content. To handle this issue, the trainers met the parents and counselled them about the importance of the training and what grave consequences could occur if their children did not have SRH knowledge and skills. In the girls' group, it is sometimes difficult to identify and retain peers without disabilities. They are usually identified from the school or community of the girl with a disability. However, the parents of peers without disability may not want to send their daughters to sessions with children with a disability. Trainers patiently counsel these parents of "peers" and in case of a peer dropout, they try to find a replacement as quickly as possible. Often the young people are shy and find it difficult to openly communicate with the trainers or reveal an issue in group sessions, especially at the beginning. To mitigate this challenge, the trainers try to be very friendly with their students. The male trainers crack jokes to make the lessons light and engaging. Sharing the trainers' own experiences/personal stories during their adolescence often help students open up.

One female trainer was trying to assess whether a particularly shy girl had her period. To make the girl comfortable in talking about this, she made up a story:

"I wanted to know whether Hafsa's (fictitious name) period had started to help and support her needs. She was 15 and most girls her age were already menstruating. I was worried that she should have her menses by now. However, Hafsa did not share anything. So, I made up my own story about when I first started menstruating. Last month, Hafsa revealed to me that her period had started."

The impact of the programme is clear: the teachers have dramatically changed their attitude: one year before the programme, the subject was still strictly taboo and today they teach the class without embarrassment and speak with confidence about reproductive and sexual health and rights. The young people now know about their private body parts, learnt about relationships and sex, and know how to set boundaries (it's my body!). The benefits of the course were not limited to these young people themselves, but transcended to their family members as well. Both teachers and young people with disabilities showed an eagerness to learn more and to share the lessons with their families.



5.Statements and case studies from young people, their parents and trainers.

Most adolescents became more open and comfortable in their communication after the training. For instance, one girl was seen to experience high levels of stress when asked about male body parts during post-test. Hence, the questions about male body parts were skipped for her. She revealed traumatic experiences to her trainer:

"I was raped by my paternal uncle and I keep thinking about it; I feel guilt and shame. I am also abused by my father every week, but my mother is not aware of it. I don't want my mother to know, as she is regularly beaten up by my father. If my mother knows and confronts my father about this, the situation at home will only get worse." Another adolescent girl expressed to her trainer:

"Now I dare to talk openly about rape and I understand what it is. A 12-year-old girl from class 6 at my school was raped by a teacher. Some teachers try to fondle the breasts of female students. I'm less shy around boys now. My whole family now understands sexuality better."

One female trainer described how an adolescent girl with hearing and speech impairment was once raped by a neighbour:

"The girl was in her home in the same room with her paternal grandmother. A male neighbor came into her home and raped her. She wanted to protest but her grandmother and parents suppressed her. She was prevented from speaking up. As she had a speech disability, she came to me at Niketan and expressed through sign language how she was raped and that she wanted legal action against the offender. We supported her and she fought her way and complained to the local legal authorities. She was compensated financially and the male neighbor received some form of punishment...."

The trainer believes this legal action and compensation was a noteworthy success for her and the Niketan/DRRA's SRHR program.

A mother expressed:



"The SRHR training has changed my son. He is much more aware of himself and has gained much more selfesteem. He now understands the difference between man and a а woman and how to communicate and interact with the opposite sex".

6. Recommendations

When we asked trainers, parents and trainees about what they would like to learn more from the SRHR training, they said it would be good to learn about:

- Marriage, how to start and maintain a family (childbirth, family planning, birth spacing, financial management) and related topics
- How to protect themselves from gender-based violence, provide resources to adolescents and their parents so that they can report/seek help from legal authorities and healthcare facilities. Niketan/DRRA can support the creation of a "safe space" in the local community to report and handle such issues at the initial stage so that adolescents can complain about violence without fear.



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