

Her body, her rights

Making sex education work for young women with intellectual disabilities

A case study from Ethiopia

Translation picture front page: 'Remember! It doesn't matter: any kind of attack is bad.'

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1. Introduction

Worke¹ is an 18 year old girl with an intellectual disability. Despite her adult age, her mother, Beletu, has never discussed reproductive health issues with her daughter. “It has never crossed my mind,” she says. “Since Worke has started getting her period, I am only worried that someone will trick her into having sex, and she will bring another burden to the family.” Worke is not shy in letting her family know she wants to have a boyfriend and a child. “I scold her whenever she raises this issue,” Beletu confesses. “I keep telling her that she will never get married.”

Just as in the case of Worke, for many women and girls with disabilities their sexual and reproductive health needs are unheard and unmet. Particularly persons with intellectual disabilities are disadvantaged and excluded from information and services. Persons with intellectual disabilities are often considered to be non-sexual, as well as not interested in having fulfilling sex lives. Sexuality education is withheld from them as it is thought that ‘they won’t need it’ or it ‘just gives them ideas’². Other times parents do want to provide information, but struggle to present it in such a way that their child can understand.

Yet girls with intellectual disabilities, just like Worke, go through puberty at the same time as girls without disabilities. They explore and express their sexuality and desires, and are extremely vulnerable to sexual violence, sexually transmitted infections, and unplanned

pregnancies³. Unlike other youth, however, they don’t have a peer group to discuss the awkward issues of sex and reproduction with. As such, they are kept from gaining vital information regarding their bodies and their sexuality.

In Ethiopia, and particularly in the rural areas, it is the CBR (Community Based Rehabilitation) organisations⁴ that have the most contact with persons with intellectual disabilities. CBR programmes support persons with intellectual disabilities throughout many daily living activities: washing, dressing, eating and household tasks. Yet topics such as understanding their sexuality, menstrual hygiene, and preventing unwanted sex are not being addressed in training and work packages of CBR workers. The issue of sexuality for girls with intellectual disabilities is also not being sufficiently addressed by other services, such as education or health care services. This leaves the girls, as they hit puberty, out of any reproductive health information and services that is delivered in their household and community. In their daily work, CBR fieldworkers came across young women with intellectual disabilities who had started menstruating but didn’t know how to take care of themselves. Other times, they came across cases of sexual violence. Neither the field workers, nor the organisations they worked for, knew how to best provide the women with the support they needed, nor could they find any organisations working on family planning who were able to provide this knowledge.

¹ Although the stories are real, all names used have been changed for privacy reasons

² Kassa, Tigist Alemu et al. (2016). Sexual and Reproductive Health of Young People with Disability in Ethiopia: A Study on Knowledge, Attitude and Practice: A Cross-Sectional Study. *Globalization and Health* 12(5)

³ World Health Organisation. (2009). Promoting Sexual and Reproductive Health for Persons with Disabilities: WHO/UNFPA Guidance Note.

⁴ CBR organisations follow the CBR approach: a multi-sectoral approach to the inclusion of persons with disabilities in their local communities. The CBR approach can, in addition, support the implementation of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) at the community level.

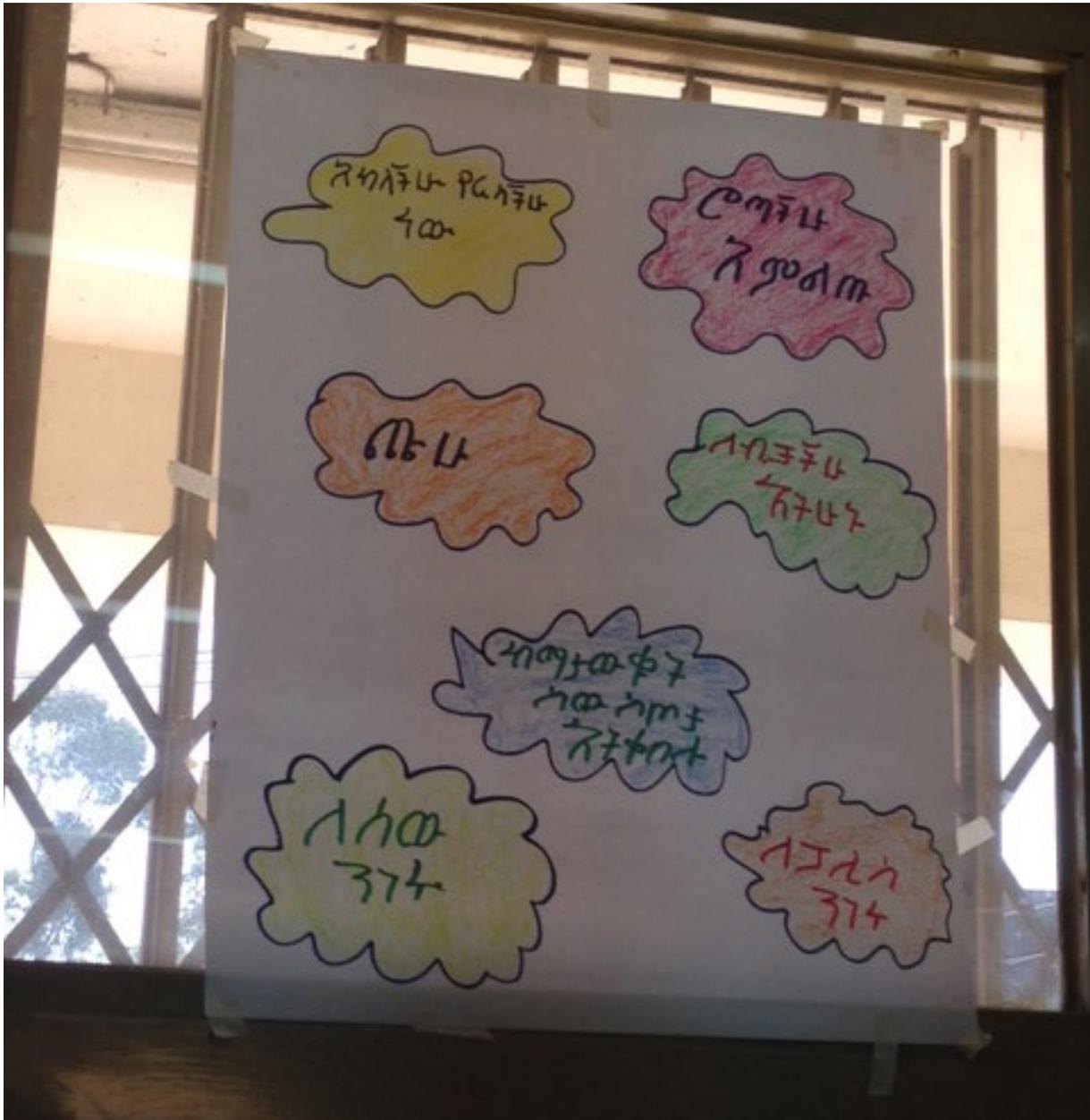
⁵ Addis Development Vision (ADV) in Hawassa and Berehan Le-Hetsanet (BL) in Addis Abeba

Therefore, in 2015, Community Based Rehabilitation Network Ethiopia (CBRNE) and SeeYou Foundation, previously Light for the World Netherlands partnered together to learn how best to provide CBR professionals, service providers and parents the skills they need to reach, teach, inform and discuss with girls with intellectual disabilities about sexuality. As part of the project, CBR organisations attended a three day sensitization workshop, where they discussed the need and possible methodologies to address the sexual and reproductive health needs of women with intellectual disabilities. After a call for proposals, two of the CBR⁵ organisations were invited to implement a pilot project, through which they were able to try out various activities to reach and teach the young women and their families. This publication presents the key lessons learned on how CBR workers and family members can best support and empower young women with intellectual disabilities when it comes to their sexuality and reproductive health.

"All of a sudden, my son's behavior changed, telling me that he wants to get married and have a baby, too. This was astonishing as we didn't expect that he would have such a sexual desire and be eager to get married."

Mother of son with intellectual disability

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'Your body is yours.
You must run away.
You must scream.
You must not be alone.
Don't take presents from strangers.
Tell others.
Tell the police.'

2. Breaking the taboo regarding sexuality of persons with disabilities

One of the main challenges is the widespread assumption that persons with disabilities, and particularly persons with intellectual disabilities, are not sexually active and do not have sexual desires. When the programme managers started approaching concerned stakeholders, it was difficult to convince them on the importance of the issue. Most were concerned that discussing sexuality would “awaken the dormant within the girls.” Even the parents of the girls themselves believed as such. “It required hard work and some long discussions to have everybody on board,” says the head of the ADV field office in Hawassa.

Even if convinced that their daughters required reproductive health services, the girls’ opinion on what they themselves wanted was not asked due to the belief that they would not be able to make such a decision. This left programme managers with a dilemma, as they wanted to applaud the parents’ good intentions to gain services for their daughters, yet also wanted to discuss the girls’ right to self-determination.

"We went house to house to meet the parents and girls. In one of the houses, I discussed with the mother. She decided to go for reproductive health services for her daughter. She thought that her daughter was not mature enough to decide which kind of contraceptive to take, or even if she wanted to take a contraceptive. The mother decided for her, but they were not informing the girl herself."

Programme manager

3. Resolve the service gap

CBR field workers who travel from house to house to work with persons with intellectual disabilities, are often not well trained on disseminating reproductive health information. On the other hand, health extension workers, who are trained to provide reproductive health services, often do not know how to tailor their services to persons with intellectual disabilities. With no one understanding both disability and reproductive health, no one feels responsible or knows how to reach the young women. Bringing together health extension workers and CBR field workers in one training, meant that the two were aware of the issue, and of each others' roles.

"For a long time [...] disability wasn't part of family planning services because of discrimination. When we planned to work with reproductive health in this pilot project, we felt a big responsibility to share our experiences with other CBR organisations. Because one of the things we learned is that if there is a commitment [to the issue] then a lot can be done despite having little money."

Programme manager at a CBR organisation



Easy Read Information Poster: 'Private Body Parts'

1. Breasts
2. Armpit
3. The body part with which we urinate
4. Butt
5. Lips
6. Thighs
7. Stomach and Back

4. Provide practical how-to's in a variety of ways

Another challenge was how to cater the sexual and reproductive health messages in such a way, that the girls with intellectual disabilities would get the information they need. Considering the variety 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. In addition, persons with intellectual disabilities require repetition to ensure that their new insights stick, so the girls need follow up visits and conversations with CBR workers and their family to reinforce the message.

The CBR organisations used a variety of methodologies to reach the girls in order to help them internalize the message. These included:

- Making posters together with drawings and text, colouring these posters, displaying them in the room and discussing their content.

- Develop simple drama plays and perform these for their family members.
- Buy models and posters (educational materials) from the market for use during demonstrations and discussions.
- Practice using menstruation pads on dolls.
- Hold discussion sessions with the girls where they were able to raise issues and questions.

As there currently weren't any materials available on the topic, the CBR organisations worked with existing materials from the health care system and adapted them into easy read materials.

"First, they showed us how to put the clean pad on a doll. We learned how we should open the pad, how we should leave the plastic, and how we should line the pad on the pants. If the pants are not clean, we should put them in the bathroom or in a bedroom so no one can see it. Then, after that, we will wash them. We learned how we should change our pants every day, and how long we should wear one clean pant. We learned how we wear one clean pad and how we dispose of it and change it. We learned all of that with the training."

Girl with intellectual disability

"Before the training, one time, she got her period and she sat on the sofa all day waiting for me. She thought that she was bleeding and needed an ambulance to go to the hospital. Even after I came to the house and told her that this is not being sick, she didn't believe me. After I washed her and everything, I took her to the hospital and the nurse told her that this is not a one-time thing, and that it will come after time and time. Now the teacher at this school always tells them to bring two pads inside their bag. So, they are very self-conscious and even remind their mothers to put the clean pads in the bags when they come to school."

Mother of girl with intellectual disability

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"This training has created more awareness for me. I didn't know that my child could be hurt at home when she sleeps with her brother and relatives or when I leave her in a closed house. I didn't know my child could be hurt within our house."

Mother of girl with intellectual disability



Poster created by the girls during training. The top scene depicts a mother handing her daughter a menstrual pad, which the daughter places. The bottom scene also depicts a mother and daughter; the daughter has blood stains on her skirt.

5. Involve family members

Many women with intellectual disabilities were not informed on reproductive health because their family members were not aware of the need to do so. Many parents refrained from discussing sexuality with any of their children due to cultural barriers, amongst others, and particularly did not expect that discussing the topic with their child with an intellectual disability was even possible. They consider their children with intellectual disability to be small children, despite the fact that as they age in years, their bodies mature too.

Those family members that said they were willing to do discuss sexuality with their children, said they simply did not have an idea what to do! Parents confessed that instead of considering their children's feelings and need for information, they were often focused on protecting their daughters from potential sexual violence. The idea that their daughters could have positive sexual relationships was new, with the predominant consideration regarding the sexuality of their children being the need to protect them from unwanted pregnancy and sexually transmitted diseases. They often discouraged their children from asking questions, telling them "that is not good."

Holding expert sessions with service providers provided parents with the opportunity to ask questions and learn how to discuss and handle reproductive health issues with their children. Some parents stated being relieved to hear that they were allowed to take their children to service providers for contraceptive services.

In addition, involving the parents also meant that the things the girls learned were reinforced outside of the training setting, as parents were now able to communicate the same messages and discuss them with their daughters at home.

"When she gets her period, she gets very angry, and this training has taught me how to handle that anger, how to help her wash her pant, to change the clean pads and stuff like that. I didn't know how to handle all of that".

Mother of fifteen-year-old daughter

6. Provide training to boys as well as girls

The project focused only on girls, however, boys are part of the equation as well. 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 just as vulnerable to abuse, and as much in need of positive information regarding their sexuality and reproductive health, that they deserve more attention in future endeavours.

"One thing they learned when they learned about sexual abuse: even when her father hugs her and he accidentally touches her breasts, she says, 'This is wrong, you shouldn't touch this part.' And when boys stare at her when she is walking, she says, 'I will tell the police!' or 'I will tell someone older that this is wrong!' She has started saying this is wrong and this is not good. I am very happy that my child can protect herself in this way."

Mother of girl with intellectual disability



Poster entitled: 'What is the meaning of "I don't want to"?'
If there are places where you do not want to be touched, you have the right to say 'No.'
Girl says, "No, I don't want to."

7. Conclusion

This project, however small, showed clearly that all parties were relieved to receive more knowledge and skills on how to organize sexual and reproductive health services for women and adolescents with intellectual disabilities.

Health workers learned that it is part of their task, and that they can support women and girls with intellectual disabilities to receive sexual and reproductive health services.

CBR workers learned how to approach the topic of reproductive health during their day-to-day work.

Parents became less scared of the topic, and learned that their girls are able to take care of themselves during their periods, and make informed decisions about their sexual lives.

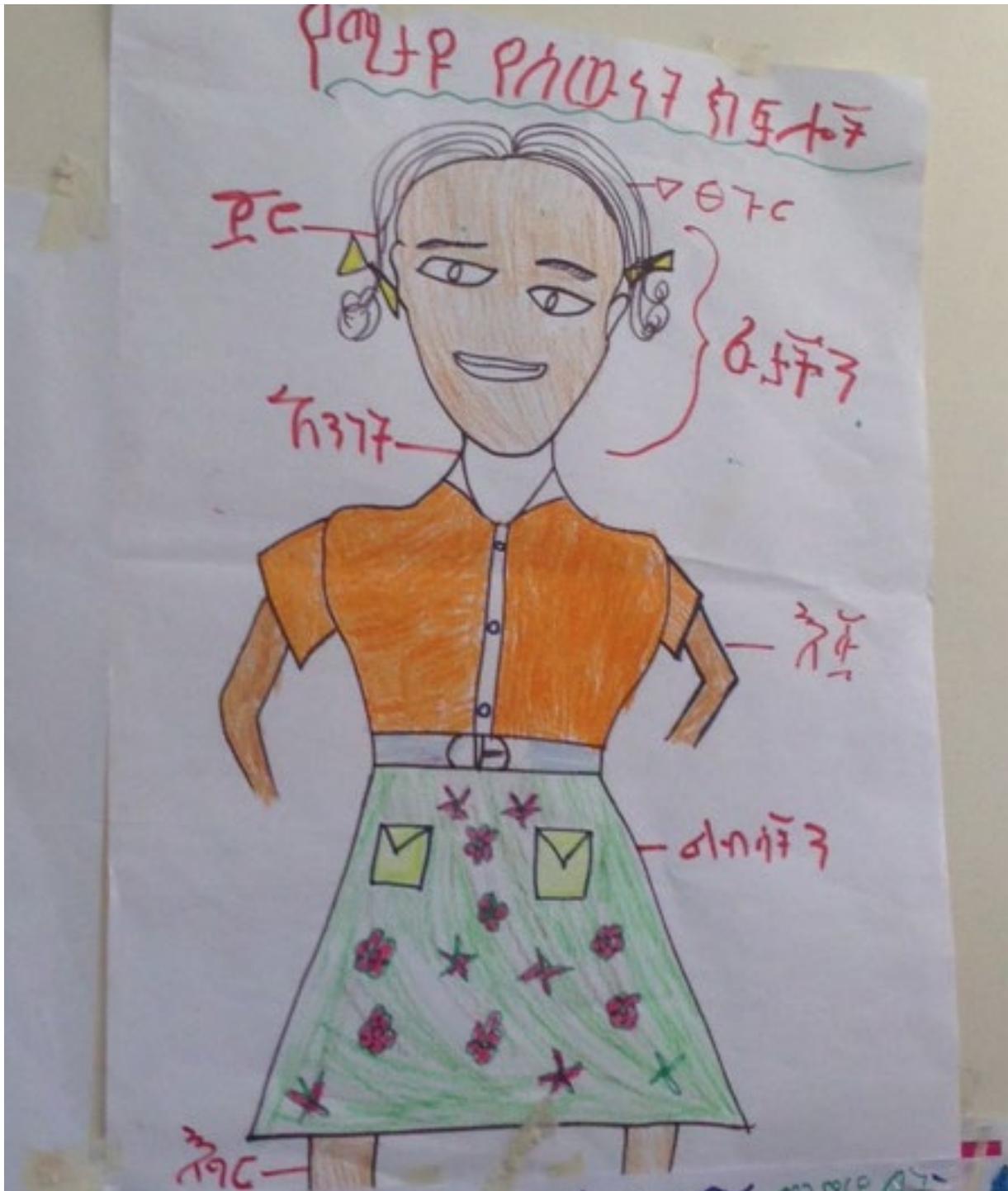
And most importantly, the girls with intellectual disabilities were proud of what they had learned, that they could take care of themselves, and protect themselves when needed.

Worke's mother Beletu, confesses that she now regrets not having started speaking to Worke about her sexuality years earlier. They have now, as a family, decided to support Worke, and allow her to choose for herself if and when she wants to make use of reproductive health services. While Worke understands much better what happens to her body, her mother Beletu also understands better 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.

Girls like Worke have as much right and need as any other to sexual and reproductive health information and services. This pilot demonstrates that more investment is essential, in terms of policy, finance, and attention of professionals and CBR workers so that she, too, knows about her body and her rights.

Making Sex Education Understandable:

- Translate materials into easy language
- Repetition
- Practice on dolls
- Use different methods to pass the message
- Give room for the girls to ask their questions and air their concerns



Poster entitled: 'Visible Body parts'
'Ear, hair, face, neck, arm, leg, dress.'

More information

Would you like more information about the content of the trainings?
Contact Community Based Rehabilitation Network Ethiopia (CBRNE).

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Community Based Rehabilitation Network Ethiopia is a national non-government organisation whose intent is to promote inclusive development. It plays an umbrella role for CBR organisation and coordinates the development efforts of CBR member organisations working in Ethiopia.

SeeYou Foundation is an international development organisation, who works towards the inclusion of people with disabilities in development.

Berhan Lehetsanat is a not-for-profit civil society organisation in Ethiopia which addressed the problems faced by marginalized children in general, and children with disabilities in particular, through a holistic program approach.

Addis Development Vision is a grassroots civil society organisation, working with children, youth and women.

