see
you

including
everybody

Taking steps towards disability inclusive (sexual and reproductive) health

Reflections, inclusive practices and tools from the Every Life Matters Programme in Ethiopia, Mozambique & Rwanda

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Authors' note

Why this publication?

The Sustainable Development Goals urge us to Leave No One Behind. SDG 3 specifically aims to ensure healthy lives and promote wellbeing for all at all ages[1]. But the reality is that despite all efforts to promote Universal Health Coverage, persons with disabilities are still left out. They face higher healthcare needs, more barriers to accessing services, and less health coverage, resulting in worse health outcomes[2].

But how to overcome the barriers that block persons with disabilities from accessing health services? What interventions are needed to make health care services and the wider health care system disability inclusive? To find an answer to these questions See You foundation (formerly known as Light for the World Netherlands) started *Every Life Matters (ELM)*, a multi-country initiative to promote inclusion of people with disabilities in sexual & reproductive health and eye care in Ethiopia, Rwanda and Mozambique. In this programme See You foundation together with its implementing partners developed, tested and improved disability inclusive interventions to make health care services accessible.

In this publication we want to share the key learnings from this programme. We will explain what went well, but we will also be honest about our struggles, so that you are not going to make the same mistakes as we did. We will also share the tools that have been developed and hope it will inspire you to make health care services accessible for persons with disabilities as well. Even though, the *Every Life Matters* programme concentrated on a small aspect of health care (mainly Sexual&Reproductive Health and Rights (SRHR), Eye Care and Neglected Tropical Diseases), we believe that the lessons learned can also be used for other sectors of health.

For whom?

With this publication we aim to reach out to all NGOs, Government bodies and donor organisations that promote, support and implement health services and hope it will inspire and support the inclusion of persons with disabilities in these services. This publication is also interesting for organisations of persons with disabilities (OPDs), because it provides practical insights on how OPDs can lobby for and support the process of making health services accessible. At the same time we believe this publication is interesting for disability specific organisations that are involved in capacity strengthening for disability inclusive health.

How to use it?

We know you are busy and you are probably not going to read this publication from A to Z. So here are some tips to navigate this publication:
• If you want to know more about the *Every Life Matters* Programme, its partners, philosophy and set-up, please have a look at Part 1.
• If you are interested in the experience and lessons learned from the *Every Life Matters* Programme, Part 2 will offer what you are looking for.
• If you are looking for practical tools to promote inclusive health, you can jump straight to Part 3. Here you will find, amongst others, a complete training toolbox to train health staff, the inclusion game to raise awareness about inclusive health, but also formats for monitoring visits. There are also practical tools for inclusion in sexual&reproductive health services.

About the authors

This publication has been commissioned by SeeYou Foundation. Paulien Bruijn and Klaas Aikes have developed this publication in consultation with Hamsale Fufa of ECDD, Claudine Mukeshimana from UPHLS and Virgilio Mubai from ComuSanas Mozambique.

We hope the offered tools and materials will help you to promote inclusion of persons with disabilities in health programmes. This publication and the related tools are the intellectual property of SeeYou Foundation. You can use the tools in non-profit settings if you make reference to SeeYou Foundation. In all other instances, please get in touch with SeeYou Foundation.

If you have any questions about the publication and the related tools, you can get in touch with **info@seeyoufoundation.nl**.

[1]United Nations, Sustainable Development Goals Platform. SDG 3, 2015.
[2]Kuper, H. and Heydt, P. The missing Billion. Access to health services for 1 billion people with disabilities. 2019

Importance of Disability Inclusive Health

Why is it so important to promote inclusion of persons with disabilities in Health Service provision? It's first of all good to know we are talking about a huge group of people. The 2010 World Disability Report of the WHO estimated that there are a billion people with severe or moderate disabilities worldwide[3]. The majority of this group is living in low- and middle-income countries and they often belong to the poorest sections of society[4].

When we talk about disability in this publication we have the definition of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in mind. The UNCRPD says: Persons 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[5].

Persons with disabilities often experience higher health care needs, since they may need specialised medical care related to the underlying health conditions or impairment, like physiotherapy, hearing aids[6]. They are also more vulnerable to poor health, because of their higher levels of poverty and exclusion. At the same time they also need access to general healthcare services like anyone else, like vaccinations or sexual&reproductive health services.

Despite their greater need for health care services, persons with disabilities face different barriers when they try to access health services. Think of lack of money to pay for services and medicine, inaccessible transport and buildings, negative attitudes and poor training of health staff.

Research shows that Persons with disabilities:
• are 2x more likely to find healthcare provider's skills and facilities inadequate
• 50% cannot afford healthcare
• are 50% more likely to suffer catastrophic health expenditures[7].

The conclusion is simple, without better health services for the 1 billion people with disabilities Sustainable Development Goal 3, health for all, cannot be achieved! It's also good to realise that the SDGs are inter-linked. Enhancing inclusion of persons with disabilities in health will contribute to achieving all SDGs[8].

Apart from that, access to healthcare for people with disabilities is a human rights issue. The UN Convention on the Rights of Persons with Disabilities states that persons with disabilities have the right to free or affordable health care, including sexual and reproductive health and population-based public health programmes. They also have the right to access disability specific health services[9]. Health is important in itself and will contribute to the quality of life and life expectancy of the individual person.

Inclusive Health Services not only benefit persons with disabilities. When the health systems are designed according to the principles of Universal Design everyone will benefit. And if people with disabilities have access to services, it will also prevent unnecessary cost for the health system. People with disabilities often have delayed or reduced access to health services, as a result they may suffer from diseases that could have been prevented or could be easily treated at an early stage. They may present later-stage disease when treatment is more difficult and expensive[10].

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[3] World Health Organization. "Word Report on Disability", 2011.
[4] L.M. Banks, H. Kuper, S. Polack, "Poverty and disability in low- and middle-income countries: A systematic review," PLoS ONE 12(12)(Dec. 21, 2017)
[5] United Nations Convention on the Rights of Persons with Disabilities. Article 1, 2006.
[6] Kuper, H. and Heydt, P. The missing Billion. Access to health services for 1 billion people with disabilities. 2019
[7] Same as above.
[8] Same as above.
[9] UN. United Nations Convention on the Rights of Persons with Disabilities. Art. 26 & 27. 2006
[10] Kuper, H. and Heydt, P. The missing Billion. Access to health services for 1 billion people with disabilities. 2019

Part 1. About the *Every Life Matters* Programme

1.1 Programme set-up

To learn how to overcome the barriers that persons with disabilities face in accessing health services, SeeYou Foundation, formerly known as Light for the World Netherlands, developed the *Every Life Matters* (ELM) programme. The 3,5 year programme started in 2017 and the first phase came to an end in December 2020. The implementation took place in Ethiopia, Mozambique and Rwanda. The programme was supported by several donor organisations and private donors.

The programme has been developed and implemented together with the following expert organisations:
• Ethiopia Centre for Disability and Development (ECDD) in Ethiopia
• Umbrella of Organisations of Persons with Disabilities Fighting against HIV and AIDS and for Health Promotion (UPHLS) in Rwanda.
• ComuSanas and Light for the World in Mozambique,

These expert partners worked with both government and NGO's. In total 14 health centres have been part of the programme:
• Eight Health Centres and two Youth Centres focussing on Sexual and Reproductive Health.
• Three Health Centres and one regional programme focussing on eye care.

The overall objective of the programme is to promote fully disability inclusive health care services in Ethiopia, Mozambique and Rwanda. The specific objectives are:
• Document good practices on inclusive eye health and sexual&reproductive health care and transform these into training packages and guidelines.
• Increase awareness of people with disabilities on their health rights and strengthen their lobby capacities.
• Produce tools and materials for inclusive (eye and sexual & reproductive) health care and use those to improve the services and to advocate for inclusive health.
• Make eye-, and sexual&reproductive health care

interventions of selected mainstream health service providers in Rwanda, Ethiopia and Mozambique fully accessible to and inclusive of persons with disabilities.
• Disability inclusion is promoted among governments, donors and other health partners.

1.2 Learning approach

The ELM programme was set up as a participatory learning programme, with a lot of opportunities to explore effective ways to mainstream disability and to document lessons learned. The following approach was used to enhance learning:
• First of all, the programme was set up with a lot of flexibility. Not everything was cut in stone for the whole three-year period. The donors of the programme gave us the space to let the programme grow organically.
• All key stakeholders: representatives of organisations of persons with disabilities, health clinics, youth centres and health authorities were involved in defining priorities, identifying challenges and testing out solutions.
• The project started with a thorough assessment of current learning and practice. Based on these findings we identified topics and issues that needed more attention. We focussed on solving particular problems in specific local contexts. For example, how to make communication during antenatal care accessible for deaf women in rural Ethiopia.
• To solve these particular problems, we have developed and tested solutions together with a lot of different stakeholders: Persons with disabilities and their representative organisations, health staff, government staff, ministry of health etc. For some products we needed 5 or 6 development loops before everyone was happy with the result.
• We also held regular in-country and regional reflection meetings. In these meetings all project partners came together for learning and sharing. During these meetings they shared challenges and successes and together new priorities were set.

"I go to the health center which is close to my home, even though the service is not as good as compared to the other health centers which are further away."

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Participant with a physical disability
– Focus Group Muhanga

1.3 Key elements of the *Every Life Matters* programme

The overview below shows the key elements of the programme. It is not a complete overview of all activities, but it gives a quick insight of the most important steps. Every step was done in close partnership with the key stakeholders.

Data collection
• Literature study on barriers to health for persons with disabilities
• Focus Group discussions to find out barriers persons with disabilities face in accessing local health services.
• Local baseline surveys in areas covered by the participating health centers.
• Assessment of the Health and Youth Centers with the Disability Inclusion Score Card to collect data on the needs for inclusive health services.

Capacity strengthening
• Appointment and training of focal persons in health clinics
• Training of all health staff: from management to community health workers
• Training of OPD members to become peer educators in the field of Sexual&reproductive health
• Build up partnerships and raise awareness of local and national health authorities

Accessibility
• Making adjustments to the Health and Youth Centers to improve access
• Making Health Information Messages Disability Inclusive
• Development of communication tools to reach out to specific groups

Outreach
• Awareness raising amongst persons with disabilities by peer educators
• Identification and referral of persons with disabilities by Community Health Workers
• Targeted actions to reach out to specific groups of persons with disabilities

Monitoring & Evaluation
• Collection and analysis of disability disaggregated data
• Joint monitoring visits to the Health and Youth Centres by OPDs and local authorities
• Learning and sharing meetings
• Final evaluation

1.4 Understanding barriers to access health

If you want to make health services disability inclusive it is important to have a good understanding of the barriers that persons with disabilities face in accessing health services. At the beginning of the program a literature review was done to identify the main barriers in access to mainstream healthcare services for people with disabilities. This review was carried out by Judith Baart and Florence Taaka and was published in the Disability CBR & Inclusive Development Journal[11]. The literature review concludes that there are 7 main barriers: 4 related to the demand side (related to the individual seeking healthcare services) and 3 barriers on the supply side (related to healthcare provision).

> **"I choose to go to private hospital because there are many chances to be well received. I fear the long queue at public health centers"**
>
> Participant of
> Focus Group Kigali

On the demand side the following barriers appeared in the literature review:
• **Lack of information on the availability of services:** people with disabilities and their family members are often unaware that they can access healthcare services in the mainstream health centers. They have less access to information about the availability of health services. There are different reasons: for example low literacy rates among people with disabilities and people with visual impairments cannot access printed information.
• **Additional expenses to access health care:** persons with disabilities and their caretakers often struggle with poverty and are less likely to access subsidies and insurance programmes. People with disabilities also have higher healthcare needs due to their impairments and have more costs than others. They also have higher transport costs, because of specialised means of transport or they need to give financial incentives to their escort as well.
• **Limited Mobility:** Public transport is often not accessible for persons with disabilities. Inaccessible roads and sidewalks also form a barrier to get to the health clinics.
• **Stigmatisation and marginalisation:** because of negative family and community attitudes towards persons with disabilities they are often not taken to hospital by their family members. And as a result of marginalisation they are not confident to attend health services by themselves.

[11] Baart, J. and Taaka, F., 2018. Barriers to Healthcare Services for People with Disabilities in Developing Countries: A Literature Review. Disability, CBR & Inclusive Development, 28(4), pp.26–40. DOI: http://doi.org/10.5463/dcid.v28i4.656

On the supply side the following barriers appeared:
- **Staff attitude:** in many studies negative attitudes of health care staff are reported. This may be on purpose, but also because of a lack of knowledge about the needs of persons with disabilities. Verbal, physical and mental abuse characterize the negative attitudes that are reported. Think of the use of derogatory language, forced sterilisation or physical restraint during labour. Negative attitudes also derive from frustration on the side of the health staff when they are not able to communicate with deaf patients. The negative attitude is also related to the mind-set that service providers have towards persons with disabilities. For example the assumption that persons with disabilities are a-sexual human beings and are not able to give birth.
- **Communication Barriers:** Barriers between health centre staff and clients with disabilities are a big challenge. This is especially the case for people who have speech and hearing impairments. And is expected to be the same for persons with intellectual and psychosocial impairments. Barriers are not only found in the direct communication between healthcare staff and clients, but also in the indirect communication such as brochures and prevention or awareness campaigns. People with visual impairments are for example unable to access information embedded in pictures and on flip charts.
- **Inaccessible Buildings and Equipment:** this specifically affects persons with physical and visual impairments. Think of barriers such as health centre building without ramps, inaccessible toilets or latrines, but also the absence of adjustable delivery beds for women in labour.

The overall conclusion is that to ensure that people with disabilities can successfully access the necessary health services, the barriers on the demand side as well as the barriers that are part of the healthcare system, should be attended to. You can download the whole review at the website of DCIDJ: "Barriers to Healthcare Services for People with Disabilities in Developing Countries: a Literature Review"

In addition to the literature review, a baseline research was carried out, in order to understand current good practices, gaps and barriers in inclusive health care. We carried out a research amongst persons with disabilities that live in the vicinity of the participating health centres, in order to understand what persons with disabilities' experiences are with regards to access to health care in Ethiopia, Mozambique and Rwanda. In total we organized 14 Focus Groups Discussions with representatives from Organisations of Persons with Disabilities that live in the catchment area of the health centres that are part of the Every Life Matters programme. The outcomes of the Focus Group Discussion confirm the barriers mentioned in the literature review.

> "It is terrible because whenever the healthcare providers meet people with hearing impairment (...) they fear and wonder how to serve them. Some prefer to write negative or positive results to the booklet of a deaf patient without any test in order to have the deaf go away and others prefer to directly transfer them without trying to treat them"
>
> Deaf Participant of Focus Group Kigali

Part 2. Reflections on the experiences within the *Every Life Matters Programme*

2.1 Outcomes

Within the programme the following general achievements have been made:

• Improved physical accessibility in the participating health and youth centers;
• Tools developed to make information and communication more inclusive for patients with disabilities: inclusive posters, leaflets, developed image toolboxes and sign language manuals;
• Health care providers have been trained and made aware of the rights to equal quality health care services for people with disabilities. They became skilled and motivated to communicate with persons with disabilities and be alert about their inclusion needs.
• The user satisfaction of persons with disabilities has increased a lot. They report improved health service provision.
• The number of patients with disabilities visiting the health centers has grown steadily throughout the programme. In total 9931 persons with different kind of disabilities visited the participating Health Units between 2018-2020. In the year 2020 a significant rise in the number of visits of persons with disabilities was noticed. Over the years we have seen a slow increase of the proportion of persons with disabilities, as part of the total user population. But the number of persons with disabilities one would expect, 10 to 15 % of health users, had not been reached yet, by far.

There are several reasons for this: first of all there were some challenges related to data collection at clinic level, but there are also persistent barriers to health care that have not yet been tackled. Our overall conclusion is that the inclusion measures are having the intended effect: the health services are more accessible to persons with disabilities, but persons with disabilities are still underrepresented in the total population seeking health care. In the following paragraphs we will dig a bit deeper into the success factors and challenges within the programme and the remaining barriers to access health.

2.2 Unexpected developments

As with any kind of programme there have been some unexpected developments that have affected the implementation. The first set back was the Cyclone Idai that hit Mozambique in March 2019. Many premises of the participating health centers got severely damaged.

As a result of the huge destructions the programme was put on hold for half a year. Support has been provided to repair the buildings of Buzi Central Hospital and to construct accessible toilets at the same time. Also the baseline data collected in the Mozambique program in 2018 was not actual anymore as people got relocated and left their homes.

The worldwide COVID-pandemic also deeply influenced the programme. Not all activities that were planned could take place, others were delayed. Partner organisations were however able to continue part of their work and ensure inclusion of persons with disabilities in the COVID-19 response programmes.

2.3 Critical success factors

When you implement a programme not all activities are as effective as you thought they would be. Let's start with sharing what strategies proved to be effective to promote inclusion of persons with disabilities in health care. Below we have listed the critical success factors of the ELM programme. These factors are based on the final evaluation report of the *Every Life Matters* programme that was done by Maria and Irko Zuurmond in November 2020.

Understanding barriers

We took time to get a better understanding of the barriers faced by persons with disabilities when accessing health care and what efforts are needed to address these barriers. This was done by involving Organisations of Persons with Disability, by organising focus group discussions with health users with a disability and by a literature study. Also a thorough organisational and accessibility assessment was done at clinic level to identify strengths and areas for improvement. This information formed the basis for the activities in the project.

Staff training

The training provided to the service providers, Community Health Workers and other staff really helped to increase awareness and change attitudes towards persons with disabilities. It was described by one of the participants as a "crash course in disability awareness". The staff got a better understanding of the barriers faced by persons with disabilities when

accessing health care and how to address these barriers. Apart from awareness training the health staff received very practical training, for example on inclusive communication and sign language and received practical tools to support the communication. Of course, training takes time, especially sign language training. But we noticed that the health staff were motivated to receive training, as they know from their own practice it is important to learn to reach out to patients with disabilities as well.

> **"Once we received a deaf woman who came to the center for help. We understood that she was raped and was pregnant, and as showed the test she was HIV positive. Yet, none of us could explain it to her and inform her on necessary treatment. So she left and never came again. We all remember this lady, so we are committed to learn sign language to be able to address such cases next time."**
>
> ———
> Disability Focal Person from Health Centre in Ethiopia

This resulted in a more welcoming environment at the participating Health Centres. In the training also staff with different backgrounds were involved, rather than just service providers. Staff with an administrative background and managers tend to be more permanent and may be close to some of the decision-making (planning and budget) which is important for the sustainability of the changes at the health centre level.

Focal persons
The appointment of focal persons in the clinics proved to be effective. They have played an important role in staying focussed on disability inclusiveness and to support staff to become more inclusive in the way they treat persons with disabilities. At the same time, they play a key role in providing direct support to patients.

> **"The project focal person usually comes to us whenever we are in the compound, and asks if we need any help."**
>
> ———
> Patient with a disability

The most appropriate profile of disability focal persons seems to be a staff member that is involved in the administration and management of the health centre. They are often in a position to influence decisions. They are present at the centre at a daily basis and staff turnover at this level tends to be lower.

Involving Community Health workers
Persons with disabilities do not automatically find their way to the health clinics. Therefor it is important to organise outreach in the community. This was done by involving Community Health Workers. Under the ELM programme the Community Health Workers were trained on a range of topics: disability awareness, rights of persons with disabilities, special needs and care, disability mainstreaming, SRHR for persons with disabilities, identification of persons with disabilities, data collection, sign language and accessibility. They identified persons with disabilities in the communities, informed them about the available disability inclusive services. The Community Health workers also referred persons with disabilities to the clinics if they needed medical care or advice.

"I am a nurse at Biryogo Health Center and I am also a focal person for UPHLS. I was informed by our health center director that I had been selected to represent people who live with disabilities at our health center and I was going to attend training that was being provided by UPHLS through the project called EveryLife Matters. I felt happy and also a little curious about what the training was going to be like! It was going to be my first time attending such trainings. During the training I felt like I was in class back in high school. Imagine a 36-year-old mother standing in front of people, repeating millions of times how to write her name in sign language. It was really fun! We laughed and cracked jokes just like a primary school child would do during break time. (…) We learned a lot including sign language and how to treat and encourage people who live with disabilities. It was really a good experience and was very different from what I was expecting to see the first time I was informed about the training. Having attended three times, now I am practicing what I have been taught! I have shared my skills with my colleagues at our health center, the skills on how we should treat people who live with disability. My colleagues seem to like it! Now we have changed the customer care rule! Form first come first serve to serve a person with disability first! As a result, more people with disabilities come to us because we treat them differently from other health centers that have not been lucky enough to receive the training. It is a pleasure to change how we treat people with disabilities.

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Disability focal person from a health centre in Rwanda

Physical accessibility

Another critical success factor was the improvement of the physical accessibility in the centres. The participating centres were assessed with the Disability inclusion Score Card for Health Centres. The health centre management made plans to improve accessibility in their centres. Recognising that the main focus of the ELM programme was on capacity strengthening and development, nevertheless, some budget was made available for the improvement of the physical infrastructure of the health and youth centres involved in the programme. However, all improvements were realised through joint funding between the programmes and the health or youth centres. The following improvements were made: ramps, walkways, handrails, accessible toilets, signage and priority seats. The improvements were not only beneficial for patients with disabilities. Having clear

signposting is for example also useful for patients who do not want to ask where they can find the HIV counselling department.

Inclusive and accessible health materials

In the programme we have also paid attention to making health communication materials inclusive and accessible. To support communication, posters and image book manuals were developed. The health care workers indicated to appreciate the materials, especially the Community Health Workers. In Ethiopia partner organisation ECDD worked with the Ethiopian Ministry of Health on representation of persons with disabilities in health education materials. The poster below shows that one of the patients is a boy who uses crutches. This is a promising initiative as it can potentially benefit many health centres across the country and give a strong message to persons with disabilities that they are welcome in the clinics.

Joint monitoring visits

Making health services accessible for persons with disabilities is not a one-off activity, but requires continuous attention. In the ELM programme joint monitoring visits were organised. In these quarterly visits, representatives of local organisations of persons with disabilities and the local authorities were involved. These visits helped to create local ownership of the improvements and helped to keep disability inclusiveness on the radar. During these visits persons with disabilities can bring in their own experiences and together with health staff solutions can be found to overcome challenges.

Record Keeping

The success of a disability inclusive programme can only be measured if disability disaggregated data are collected and analysed. Although it was difficult to collect data about the number of patients with disabilities at clinic level, it definitely was one of the critical success factors of the programme. Although not perfect, we have been able to collect the necessary data and could notice a rise of visits by persons with disabilities.

Awareness raising amongst persons with disabilities

To create more awareness amongst persons with disabilities about the available services in the Health and Youth Centres, Organisations of Persons with Disabilities were involved in the programme. They have played an active role in reaching out to persons with disabilities in the communities.

In Ethiopia ECDD supported organisations of persons with disabilities in the vicinity of the clinics to organise a coffee ceremony every 15 days. In these regular meetings different topics were discussed, including topics around empowerment and sexual and reproductive health. These sessions worked out very well, during a cup of coffee or tea serious topics have been discussed and information could be shared.

I am blind in one eye and HIV positive. I got tested positive here at Nyundo Health Center in 2012. I remember a number of years ago I used to get sick quite often. I would come here seeking treatment but they would give me nothing but a couple of pills! They did not seem to care about us. (..) Although I live in this area near the health center sometimes, I would go to a faraway health center hoping to get better service. After hearing from my friends that the service at Nyundo health center has improved, I wanted to see for myself if what they have being saying is true. I cannot believe what I see! (..) When I arrive here, they run to me to ask me, "Console how are you feeling today"? Their support and caring will help me to live longer I am sure! I have started to encourage other people in my area to come here and take the tests so they too will learn about their health status. I am so glad that Nyundo Health Center is now helping us to be in good health".

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Female patient with a visual impairment in Rwanda

However, knowing that Organisations of Persons with Disabilities vary in size and capacity, we learned that awareness creation amongst persons with disabilities should not only be seen as the role of OPDs. There is an important role for the Community Health Workers and other stakeholders as well. For example Faith Based Organisations, CBR programmes and other NGOs.

2.4 Overcoming challenges
Every programme comes across challenges. We want to share these challenges with you, because there are a lot of things to learn from the things that aren't easy!

Disability disaggregated data collection
In the *Every Life Matters* Programme the collection of disability disaggregated data in the participating health clinics was a big challenge. To monitor progress and equal access it is essential to collect data about the disability status of all patients that visit the clinics. The International Standard for collecting Disability Disaggregated Data are the so-called Washington Group Questions. The Washington Group Questions are targeted questions on individual functioning intended to provide a quick and low-cost way to collect data, which allows disaggregation by disability status. The Short Set of WG questions (WG SS) has 6 questions and can be answered in about 1.5 minutes.

Short Set of Washington Group Questions
However, at the beginning of the programme it was decided not to use the Washington Group Questions during the registration in the clinics, but to base the disability status on self-declaration by the patients or on observation from staff. This decision was made

Do you have difficulty seeing, even if wearing glasses?

Do you have difficulty hearing, even if using a hearing aid?

Do you have difficulty walking or climbing steps?

Do you have difficulty remembering or concentrating?

Do you have difficulty (with self-care such as) washing all over or dressing?

Using your usual language, do you have difficulty communicating, for example understanding or being understood?

because the Washington Group Questions were not yet embedded in the standard data collection mechanisms defined by the governments in the respective countries. The fear was that the use of the Washington Group Questions in a parallel data collection system would create too much administrative pressure on the clinics. It needs to be noted that Community Health Workers in Ethiopia & Mozambique have used the Washington Group Questions to identify persons with disabilities in the community and collect information for the baseline survey.

The disadvantage of using self-declaration and the observations from staff as the basis for data collection in the clinics was that the collected data were less reliable. Literature describes that there is a high chance of underreporting when using self-declaration or observation. Without the consistent use of the Washington Group Questions, many patients with disabilities will not be noticed in the service statistics, because not all disabilities are visible and some patients may not want or do not identify themselves as a person with a disability. In the programme the number of patients with disabilities that visited the clinics didn't develop as expected, but because of the chosen data collection method we could not draw clear conclusions about this.

The preferred situation would be that the Washington Group Questions get incorporated in the Government Health Management Information Systems, but this requires a long-term effort at national level, involving many different stakeholders. In the second phase of the *Every Life Matters* programme we will support the health authorities to introduce the instrument in all health centres in a region or at national level. The *Every Life Matters* Programme can serve as a pilot in the use of the Washington Group questions. These experiences will be used to lobby for incorporation of the Washington Group Questions in the Government Health Management Information Systems.

In Ethiopia the staff in the clinics is now being trained on the use of the Washington group questions in patient registration. So that's a first good step towards reliable disaggregated data collection.

It is good to note that the Washington Group Questions cannot be used to categorize persons by type of impairment, nor is it suitable to make a medical diagnose, because it's not a diagnostic tool. So if this kind of information is required, still additional tools will be needed. The choice for a tool depends on the purpose of why you are collecting the information. Is it to inform clinical treatment or do you want to report to your donors what type of impairments the programme beneficiaries have? If used as standard tool in all health facilities, it would not only be a tool for reporting, but

more important: a basis for policy development in health service at national and regional level.

If you want to know more about the use of Washington group questions or disability inclusive data collection we can recommend the following resources:
• Practice note: Collecting and using data on disability to inform inclusive development developed by Plan, CBM & Nossal Institute
• WG Short Set on Functioning (WG-SS)
• Interviewer Guidelines developed by the Washington Group on Disability Statistics:
• Data Collection Training Videos developed by UNICEF

Communication with deaf patients
During the focus group discussions at the start of the programme it became clear that deaf patients face a lot of communication barriers when they visit the clinics. Health staff do not understand sign language and often there is no sign language interpreter available in the clinic. Often deaf patients bring a family member with them to do the sign language interpretation. In the case of sexual and reproductive health, you can image that this is not a desirable situation as it is a sensitive topic. We found out that in some locations, especially outside of the cities, deaf persons have not learned to speak sign language at all. There are also other groups of patients that come across similar communication barriers: for example persons with intellectual impairments and speech impairments.

A lot of efforts have been done to overcome this communication barrier within the ELM Programme. First of all the health staff received basic training on sign language. The use of basic sign language was perceived to be helpful as it shows goodwill and a more inclusive attitude. Despite intensive trainings, it proved to be difficult to reach a high enough level of sign language

skills amongst the health staff to communicate about more complicated topics. One of the reasons was that in some clinics staff did not have enough practice. They only had few deaf patients, so they could not practice their newly learned skills. Also high staff turnover played a role here. New staff did not (yet) receive Sign Language Training. And quite some deaf patients did not speak sign language. So, for more detailed communication, for example on Sexual&reproductive health, we have developed additional tools to support the communication between health staff and deaf patients. In addition to this, partner Organisation UPHLS in Rwanda decided to work with the national deaf association to give sign language classes to deaf people in the environment of the participating health centres. In close consultation with medical experts as well as the national deaf associations we have developed different tools to support the communication between health staff and deaf patients. You can find these materials in part three of this publication: In the Image books on Family Planning, Prenatal Care, Birth and Postnatal care pictures are used to support communication. These image books can also be used to support communication with patients with intellectual impairments and speech difficulties. We have also developed a Sexual&reproductive health Sign Language Manual. The sign language manual contains the same information as the image books, but sign language pictures are used for each word instead of the images.

Some general tips on how to improve two-way communication with deaf patients:
• Provide continuous training on sign language to health staff, also to new staff members. Involve the national deaf associations in providing these trainings.
• Create opportunities for health staff to practice their skills.
• Be aware that not all deaf patients know sign language, actually many do not. In those cases sign language use

is only additional to other means of communication.
- Involve interpreters if available in your local context. But be aware of confidentiality. In some countries distant Sign Language Interpretation Services may be available.
- Hire deaf health staff and deaf Community Health Workers.
- Develop and use additional materials for communication and train staff how to use these.
- Use writing as a supporting form of communication, but this is only useful if the patient can read and write.

Removing barriers on the demand side

A lot of the activities of the *Every Life Matters* programme focussed on improving the health services on the supply side. But to make sure more persons with disabilities are indeed accessing and benefitting from health services, it is also important to focus on the demand side. As mentioned in the previous paragraphs, Organisations of Persons with Disabilities and Community Health Workers were involved to reach out to persons with disabilities in the communities. But more is needed to make sure that persons with disabilities really make use of health services.

Families and communities are often not aware of the basic rights of their members with a disability: the right to equal health care. Stigma, prejudices and lack of knowledge influence the decisions that are made at household and community level. Also the costs of treatment (topped up with transport and accompaniment cost) are important when decisions for medical treatment are taken. With a limited budget, the decision falls easily in favour of treatment of family members without disabilities, as opposed to treatment for those with disabilities. In the *Every Life Matters* program we noticed that in the case of Rwanda, where health insurance is available at a reasonable price, the

number of visitors with disabilities were higher than in Ethiopia and Mozambique. Finances concern not only treatment itself, but also cost of transport, cost of medicine to be bought to continue treatment, assistive devices etc.

Our interventions until now have been mainly on the 'supply-side' of health care. But we will also give more attention to factors that influence the demand-side of health care. In the second phase of the *Every Life Matters* programme we will do the following:
- Experiment with advocacy tools and training for Organisations of Persons with Disabilities and local communities, to increase awareness and support for equal health care services for persons with disabilities.
- Also funds will be available to support treatment decisions, for transport, accompaniment, cost of treatment and need for assistive devices. These will only be additional to provisions already available, such as low-cost health insurance and free or low-cost treatments.

System approach

The focus of the *Every Life Matters* programme was on learning and sharing and creating tools for inclusive health. From the start we knew that more efforts would be needed to make the national health systems disability inclusive. It takes a long-term process with a wide range of actors to make a whole health system inclusive. There are so many aspects to think off: setting up health insurance systems, anchoring disability inclusion in the training curriculum of health training institutes, making national health policies disability inclusive etc. We knew we could not address everything in a three-year programme and just decided to make a start.
In the first phase we have been able to reach some first nice results:
- In Ethiopia partner organisation ECDD has supported

the Ministry of Health to develop a Disability Inclusive Health Manual. The Ministry of Health also appointed a focal person for disability inclusion.

• In Rwanda the Ministry of Health participates in the steering committee of the project and has given approval for other health clinics to use the disability inclusive health materials that have been developed as part of the *Every Life Matters* programme.

• In Rwanda partner organisation UPHLS also trained other NGOs to include persons with disabilities in their health services. So little by little the health services become a bit more accessible and inclusive.

It's very encouraging to see that the programme has a positive impact on the inclusiveness of the national health systems. In the second phase of the *Every Life Matters* Programme we will continue to look for ways to promote change at a system level. There will be specific attention for the improvement of registration tools and

advocacy towards health authorities to make registration of disability mandatory in health care. Advocacy and good registration tools will make visible where the gaps are in uptake of health care by patients with disabilities. With this knowledge, policies can be designed to improve inclusiveness of health care services.

If you are interested to learn more about health care system change and making health services accessible we highly recommend the following two publications:

• The Missing Billion – Access to health services for 1 billion people with disabilities

• The disability-inclusive health services toolkit. A Resource for Health Facilities in the Western Pacific Region developed by WHO.

Part 3. Toolbox

Within the *Every Life Matters* Programme we have developed several assessment tools, checklists and training packages. We will introduce these tools on the following pages and will explain how and when to use these tools. You can access the tools in our online database. We hope you will be able to use these tools in your own practice. If you use these materials please acknowledge the source of the materials. For questions about these materials please contact Klaas Aikes **k.aikes@seeyoufoundation.nl** or **info@seeyoufoundation.nl**

The following tools are available in the toolbox
1.	Disability Inclusion Score Card for Health Centers
2.	Accessibility Audit for Health Centers
3.	Inclusive Health Game
4.	How to Communicate Poster
5.	Image books on Family Planning, Prenatal Care, Birth and Postnatal care
6.	Sexual and Reproductive Health Sign Language Manuals
7.	Disability Inclusive Sexual and Reproductive Health Education Materials
8.	Training Toolkit Inclusive Health For Disability Inclusion Advisors
9.	Monitoring tool for joint monitoring visits

3.1 Disability Inclusion Score Card for Health Centres
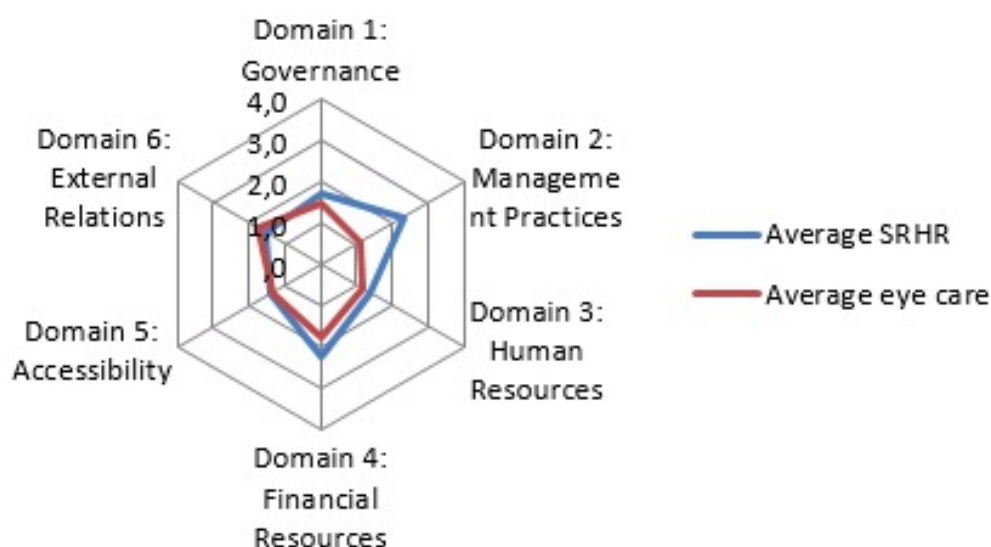
Description of the tool
The Inclusion Score Card is a monitoring tool to measure inclusion at organisational level. It measures how inclusive your organisation is against a set of detailed inclusion criteria. The tool helps you to identify the strengths and opportunities for change in terms of making your organization more inclusive. This assessment tool is developed specifically for use by health facilities.

How to use it
This tool is intended to be used as a guided organisational assessment. The assessment can be carried out multiple times (e.g. at start, 6 months, 1 year and 2 years) to measure change over time. Please note that the inclusion score card is not an awareness raising tool. The organisational assessment should be part of a wider process of capacity building on disability inclusion. Doing an organisational assessment without basic understanding of disability will be less effective. More detailed instructions can be found in the excel format itself, but also in module 9 of the training toolkit.

How it was developed
SeeYou Foundation has developed inclusion score cards for different users: e.g. for NGO's, vocational training centres and employers. The assessment tools are developed together with organisations from the South and have been tested in different countries.

Available versions
English excel file.

Download here

3.2 Accessibility Audit for Health Centres

Accessibility Audit for Health Centres

General information

Name of access auditor:	
Date of accessibility audit:	
Type of premise:	
Name of the institute or company:	
Address:	
Contact person, title:	
Contact telephone number:	
E-mail:	

Checklist

No	Concern item	Yes/No	Recommendations	Status Update
A.	**Getting to the health centre**			
i).	*Approach and route to health centre*			
1.	Is the distance to the health centre from the main road/bus station/park ≤ 500 m?			
2.	Is the route leading to the main gate /entrance clearly labelled?			
3.	Is the route wide enough for wheelchair use (≥ 900mm)?			
4.	Is the route free of such hazardous barriers as; tree roots, open drains, ditches, litter bins, garbage, unused equipment, outward opening windows and doors or overhanging projections?			

Description of the tool
The accessibility assessment format for Health Centres is a checklist that can be used to assess the accessibility in health facilities. The checklist covers the following domains:
• Getting to the health centre
• Getting into the premises/buildings
• Getting around the premises
• Using the services and facilities
• Getting out of the premises
• Management of the premises

How to use it
Ideally the accessibility audit is done with a mixed team consisting of an experienced accessibility auditor, health care staff/management and persons with disabilities who bring in their personal experiences. Doing the audit together will create ownership and commitment for improving accessibility at the premises.

How it was developed
Adapted from existing accessibility checklists

Available versions
English PDF file

Download here

Extra suggestion
Sight Savers International has developed a complete package to audit the accessibility of health services. The Sightsavers' accessibility standards and audit pack offers guidance to governments, healthcare providers and other organisations on how to improve healthcare facilities in low-and-middle income settings. It can be downloaded at the website of Sightsavers

3.3 Inclusive Health Game

Description of the tool
Game to make health care staff and management aware of the barriers that persons with disabilities face in accessing health care services. The players of the game need to think of solutions to overcome these barriers.

How to use it
The Game can be used as a stand-alone awareness raising activity, or as part of a training. It can be played in one to two hours. The game consists of 11 challenges. If you have less time, you can select just a few challenges instead of all of them. The game can also be used in online trainings. The game comes with clear instructions for facilitators

How it was developed
The Game has been developed by SeeYou Foundation. It has been developed in close cooperation with persons with disabilities from the south. The tool has been adjusted based on field tests in Ethiopia, Mozambique, Rwanda and Vietnam.

Available versions
English PDF, Hindi PDF, English Plain text in Word, English Hardcopy, English Online Training Version

Download here

3.4 How to communicate poster
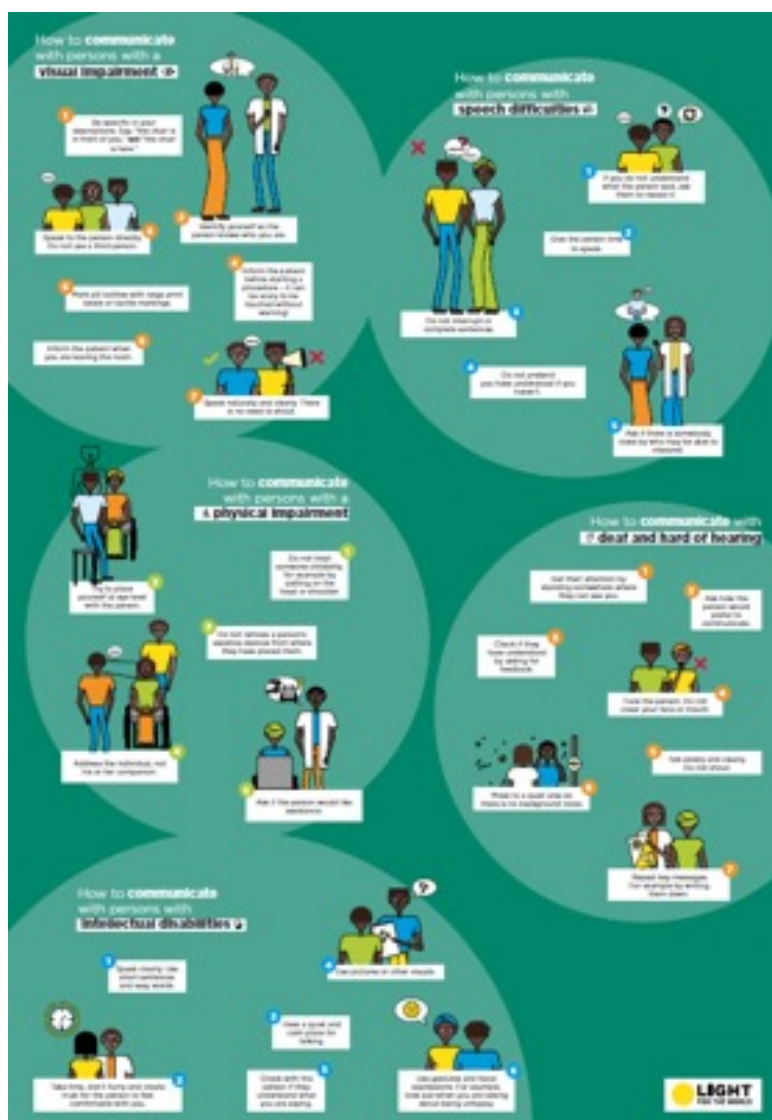
Description of the tool
The "How to Communicate" poster offers inclusive communication tips for health personnel. Health staff sometimes doesn't know how to communicate with persons with disabilities. This poster helps them to communicate in an inclusive and effective way.

How to use it
The poster can be put on the walls of health centres to remind staff how to communicate in an inclusive way. The poster can also be used in training settings.

How it was developed
it was developed based on the programme experiences and adapted to different country contexts

Available versions
Amharic, Dutch, English, French, Khmer, Kinyarwanda, Lao PDR, Myanmar, Portuguese
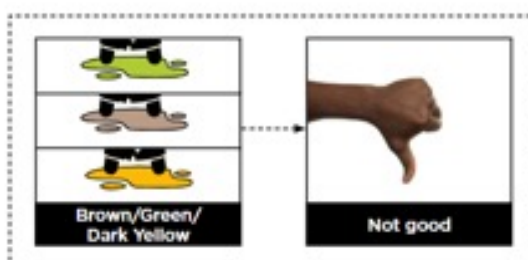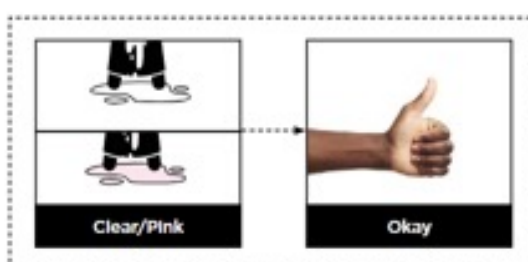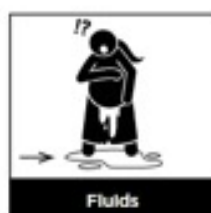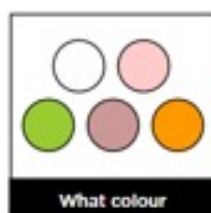
Download here

3.5 Image books on Family Planning, Prenatal Care, Birth and Postnatal care

Have you lost amniotic fluids?

You | Lose amniotic fluids | yes | no

What is the color of the fluids?

What colour | Fluids | Clear/Pink → Okay | Brown/Green/Dark Yellow → Not good

Description of the tool

The image books are designed to support the communication between health care staff and deaf women about Sexual and Reproductive health. The image books cover the most important topics in the area of Family Planning, Prenatal Care, Birth and Postnatal care. The image books contain the most important anamnesis questions. The questions and possible answers are explained with pictures and icons.

How to use it

The image books can be used to support communication during health education, consultations, health check-ups, delivery and during provision of postnatal care. The image books are especially useful for communication with deaf women who do not use sign language.

How it was developed

The image books have been developed in cooperation with health professionals, deaf women, National Associations of the deaf, sign language interpreters & designers. The manuals have not yet undergone intensive field testing. Are you using the manuals and do you have feedback? Please share your experiences via info@seeyoufoundation.nl.
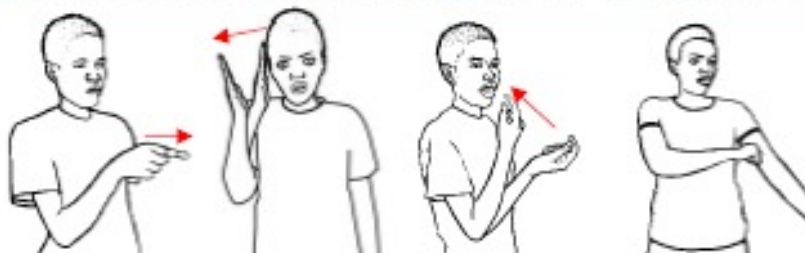
Available versions

The Image books on Family Planning, Prenatal Care, Birth and Postnatal care are available in Amharic, English, Kinyarwanda, Portuguese. Some manuals are still under construction. So check for updates.
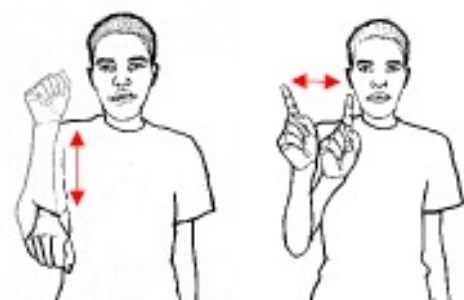
Download here

3.6 Sexual&reproductive health Sign Language Manual

Previous contraceptive use/Igikoresho cyangwa uburyo wakoresheje mbere

Do you know what contraceptives are? /You Know Contraceptives/ *uzi ibikoresho twifashisha mukuboneza urubyaro ari ibihe?*

[Yes/*Yego*]   [No/*Oya*]

Description of the tool
The Sign Language Manual is developed to support the communication between health staff and sign language users.

How to use it
The manual can be used during training of health staff and during consultations.

How it was developed
The manuals are developed by the national deaf associations in close cooperation with health care providers.

Available versions
The sign language manuals are available in Kinyarwanda National Sign Language, Amharic National Sign Language, Mozambique National Sign Language version

Download here

3.7 Disability Inclusive Sexual and Reproductive Health Education Materials

Description of the tool
Presentation on sexual and reproductive health for youth with and without disabilities. The pictures include persons with disabilities.

How to use it
Health care providers can use these materials to teach youth (with and without disabilities) on sexual and reproductive health.

How it was developed
Developed by UPHLS

Available versions
One version for youth between 10 to 14 years old and one version for youth between 15 to 24 years old. Only available in Kinyarwanda.

Download here

3.8 Training Toolkit Inclusive Health For Disability Inclusion Advisors

Description of the tool

This training toolkit is created for disability inclusion advisors & facilitators that want to build capacity of stakeholders that are involved in promoting inclusive health care. The toolkit includes training modules for:
- Health centre management
- Focal persons for disability inclusion
- Health centre Staff/ medical staff
- Community health workers

The training toolbox contains different elements:
1. Introduction & how to use the toolkit.
2. Training needs & programme outlines for different stakeholders
3. Training module library with a detailed description of the training sessions
4. Resources

How to use it

You can pick and choose the modules & tools that are relevant for your target audience and design your own training programme that meets the needs in the context that you are working on.

How it was developed

The training is based on existing disability inclusive development training materials of SeeYou Foundation. These training modules have been made specific for health care settings. This manual has not yet been field tested. Please share your experiences and suggestions with info@seeyoufoundation.nl

Available versions

The trainer's Toolkit is available in an English PDF-version. There is also an accompanying manual for training participants.

Download here

3.9 Monitoring tool for joint monitoring visits

Monitoring tool for joint monitoring visits

1. **Daily procedures:** please, reflect on daily activities that the health center (including outreach services) undertakes on disability inclusion (specifically, what is the health doing for prioritization of patients with disabilities, how are patients with disabilities registered, which visual tools for directions are used, how does medical team update staff on inclusion and other activities).

Steps that health center took for mainstreaming disability inclusion in daily activities:

Challenges that the health center have in mainstreaming disability inclusion in daily activities:

Improvements that health centers shows in mainstreaming disability inclusion in daily activities:

2. **Inclusive communication:** please, reflect on the capacity that the medical staff (including outreach staff) is developing/has developed in regard to inclusive communication

Which trainings/tools did the medical staff use so far for improving its capacity in inclusive communication?

Which gaps does the medical staff still show in their communication with patients with disabilities?

What has been improved in the capacity of medical staff to communicate inclusively since your last monitoring visit?

3. **Attitude:** please reflect on the attitude change among the medical staff (including outreach staff) to patients with disability.

How aware is the medical staff about disability inclusion and social approach to it? Note what you have observed.

Which exclusive attitudes does the medical staff (incl. outreach staff) still show to patients with disabilities?

What has been improved in staff's attitude to patients with disabilities since your last monitoring visit?

4. **Accessibility:** please, reflect on the initiatives that health center takes in improving its physical infrastructure.

Which actions did the health center take in building up/adopting its infrastructure, or providing patients with disabilities with assistive devices during their visit of health center (like wheel chairs, adjustable beds etc.)?

Description of the tool
This tool contains a list of questions that helps the monitoring committee to assess the progress with regards to disability inclusion in the health centres. 6 domains are covered: daily procedures, Inclusive communication, Attitude, Accessibility, Inclusive Management, and Partnerships.

How to use it
The monitoring committee, consisting of representatives of local Organisations of Persons with Disabilities and local health authorities, can use the checklist to prepare their joint monitoring visit and use it as a reporting template. We advise to have two monitoring visits per year.

How it was developed
It was made by the coordinator in consultation with programme staff.

Available versions
English PDF version & Amharic version

Download here