

Community engagement for inclusive sexual and reproductive health

A guide for conducting workshops
with persons with disabilities

December 2020

In partnership with



List of acronyms

Acronym	Word
CEI	Client Exit Interview
FP	Family Planning
MSI	MSI Reproductive Choices
MSSL	MSI Sierra Leone
MSZ	MSI Zambia
OPD	Organisation of Persons with Disabilities
SLUDI	Sierra Leone Union on Disability Issues
SRH	Sexual Reproductive Health
SRHR	Sexual Reproductive Health Rights
UNFPA	United Nations Population Fund
WHO	World Health Organization
WISH	Women's Integrated Sexual Health

About WISH

The Women's Integrated Sexual Health (WISH) programme is the UK government's flagship programme aiming to strengthen support for sexual and reproductive health and rights in African and Asian countries by 2021.

The goal of the programme is: a world in which every mother can enjoy a wanted and healthy pregnancy and childbirth, every child can survive beyond their fifth birthday, and every woman, child and adolescent can thrive to realize their full potential, resulting in enormous social, demographic and economic benefits.

The programme aims to contribute towards the "Leave no one behind" agenda, by reaching women with disabilities whose needs have previously largely been unmet through family planning and sexual reproductive health (SRH) service provision.

How to use this guide

One of the main components of WISH is to ensure that project interventions are disability inclusive, so that clients with disabilities can have access to Sexual Reproductive Health Rights (SRHR) service delivery and are included in mobilisation strategies. This report is to be used by WISH partners as a guide on how to hold community engagement workshops with clients with disabilities and Organisations of Persons with Disabilities (OPDs), in order to strengthen project adaptations.

This guide will help WISH partners know how to:

- Implement a community engagement workshop, and know what to consider before and on the day of the workshop.
- Understand the different elements to include when holding a community engagement workshop.
- Explore case studies from previous community engagement workshops, and lessons learned.
- Develop action plans and put them into practice.

Contents

Introduction	5
Implementing a community engagement workshop	9
What is involved in the community engagement workshops	11
Lessons learnt	15
Developing action plans based on insights	17
Putting action plans into practice	17
Annex: Examples and evidence – Actions required	18

Introduction

The World Health Organization (WHO) (2011) estimates that 1 billion (15%) of the global population living in the world today have a disability (2011).¹ This increases to 19.2% for women and girls, and up to 220 million young people are living with a disability. Persons with disabilities have the same sexual and reproductive health (SRH) needs as other people. However, they often face barriers to information and services. These barriers are commonly associated with ignorance and negative societal and individual attitudes (including from healthcare providers), and can also be associated with high levels of poverty. Globally, persons with disabilities are likely to be the poorest of the poor, with disability being both a cause and a consequence of poverty.

“Nothing about us without us” is a key principle among persons with disabilities, and is clearly reflected in language of the UN Convention on the Rights of Persons with Disabilities. It underscores the importance of including persons with disabilities at all stages of policy development, programme planning, and implementation.

Persons with disabilities are an important segment to our donors and the global agenda of leaving no one behind, and disability inclusive programming is a relatively new concept within the sexual and reproductive health sector. As the WISH consortium, we are at the start of a journey to understand what interventions are most effective to serve clients with disabilities. The WHO and United Nations Population Fund (UNFPA)² suggest that existing interventions can be adapted easily to accommodate persons with disabilities. However, this requires involving persons with disabilities in programme design, implementation and evaluation to ensure that messages, services and models resonate with their needs and barriers.

WHO estimates that

1 billion

(15%) of the global population have a disability

Persons with disabilities are often overlooked or excluded from development processes, which results in their needs not being considered. For this reason, the WHO and UNFPA recommend five actions towards full inclusion of the sexual and reproductive health of persons with disabilities, as seen below:



Components of the full inclusion framework:

- 1. Establish partnerships:** Policies and programmes are consistently better when Organisations of Persons with Disabilities (OPDs) take part in their development.
- 2. Raise awareness:** The needs of persons with disabilities should be an integral part of current work. Separate or parallel programmes are usually not needed.
- 3. Reach and serve:** Adapt Sexual Reproductive Health Rights (SRHR) programmes to reach and serve persons with disabilities. Most persons with disabilities can benefit from inclusion by SRHR programmes designed to reach the general community.
- 4. Policy, laws, and budgets:** Work with OPDs to make sure that all legislation and regulations affecting SRH reflect the needs of persons with disabilities.
- 5. Promote research:** Promote research on the SRHR of persons with disabilities. A stronger evidence base will help improve SRHR programmes for persons with disabilities.

Engaging with Organisations of Persons with Disabilities

“The best way to begin thinking about SRH issues for persons with disabilities is to establish a dialogue with local organisations of and for persons with disabilities and other advocacy organisations working on behalf of persons with disabilities.”

WHO and UNFPA guidance note, 2009³

What are Organisations of Persons with Disabilities?

- Organisations of Persons with Disabilities (OPDs) are led and run by people living with disabilities and advocate for equal rights and systemic change.
- They exist at local, national, and international level.
- They can represent specific groups (e.g. for people living with physical disabilities, for women with disabilities) and act as umbrella organisations representing numerous groups.

Why work with Organisations of Persons with Disabilities?

- They understand the needs and priorities of the groups they represent.
- They know the social and legal context for persons living with disabilities.
- They know what has been tried before, what works and what does not.

What are possible roles of Organisations of Persons with Disabilities?

- **Design** - informing proposals, materials, and message development.
- **Planning** - site mapping/selection, coordinating training/workshops, informing budgets.
- **Intervention** - community sensitisation/mobilisation, training, pre-testing materials.
- **Evaluation** - research assistants, key informants, mystery clients.
- **Advocacy** - active members of the advocacy advisory committee, supported to participate in SRHR Technical Working Groups.

Why community engagement works

Clients with disabilities are diverse and experience intersecting barriers due to their impairments, and the social context in which they live. That is why conducting community engagement workshops is a critical initial step in generating contextual insights to inform potential adaptations of our programming to be more inclusive of clients with disabilities.

Community engagement workshops:

- Provide a platform to ensure that persons with disabilities have a say in interventions which will affect them.
- Create an opportunity to gain in-depth insights into the lived realities of people living with disabilities.
- Build the awareness of participants with disabilities about our work, and at the same time build awareness amongst our staff about the challenges that persons with disabilities experience.
- Support the development of interventions which are based on evidence and not assumptions about the lives of persons with disabilities.
- Allow us to identify the value of the skills and expertise that persons with disabilities hold that can improve the quality of the interventions developed.

The WHO and UNFPA's guidance note⁴ underscores that policies and programmes at all levels are consistently better when OPDs take part in planning from the outset. In fact, lessons learned from participatory assessments like **Human Centred Design** show that insights from consultations with the target audience facilitate the design of messages, services and models that resonate with their real needs and barriers.

Human Centred Design is: “the idea that solutions should be crafted with input from and empathy for the end users who will experience them.”⁵

In Uganda, to support the increase of contraceptives and “reduce the negative health, social and economic consequences of high fertility”,⁶ MSI made deliberate efforts to engage the leadership of persons with disabilities during the project design and implementation. This has resulted in an increase of persons with disabilities being reached through mobile service providers. These service providers (people such as trained nurses who are medically qualified to deliver SRH services) drive out to communities to deliver services to marginalised communities in hard-to-reach areas, or areas where SRH services are not available.

Implementing a community engagement workshop

Prior to adapting mobilisation strategies or service delivery to be more inclusive of clients with disabilities, we recommend that you conduct engagement workshops with persons with disabilities and OPDs to help shape your interventions.

What to consider before the workshop

Who should be involved: Invite participants from a diverse range of disability organisations, locations (rural and urban), and who have different impairments – including physical, sensory (visual and hearing), and intellectual impairments. Liaise with local OPDs to identify and agree representation.

How long should a community engagement workshop run for: It is recommended that community engagement workshops are divided into sessions based on the different impairments, in order to allow meaningful discussions and discussions tailored to the needs of participants. One day per group is recommended.

Who can conduct community engagement activities: A pool of facilitators including a Disability lead, Marketing lead, Programme lead, and OPD representative(s). It is recommended that you include a translator if participants will be using a language the facilitators are not fluent in, and a sign language interpreter for groups that include participants with a hearing impairment.

What to budget for a community engagement workshop: Planning with an OPD will help you think through what budget is required. You should consider:

- Including travel budget for assistants, interpreters and appropriate modes of transport to the venue (e.g. some participants may need a taxi rather than local bus).
- Sign language interpreters and other communication support – best practice is for a minimum of two interpreters (to allow for taking a break). Ask participants to recommend interpreters they use and trust.
- Budget for a large room. If you have 15 participants – book a space for 25 (this will allow space for assistive devices e.g. crutches and wheelchairs).



Before the workshop, plan for:

Accessibility

- Ensure that accessibility requirements are factored into your budget for the activity. Participants may require an assistant or an interpreter.
- Liaise with OPDs to recommend accessible venues – book a large room to allow for ease of movement.

Maximising participation

- Seek guidance from participants and OPDs on what is required to ensure active participation.
- Develop activities which do not rely on reading or writing for participation.
- Provide opportunities for feedback to be shared in the way that participants feel most comfortable – this may be spoken, role-play, drawing, sign language etc.

What to consider on the day of the workshop

Accessibility

- Minimise obstructions, remove unnecessary tables, chairs, power cables etc.
- Respect people's personal space, which includes assistive devices (do not move or touch wheelchairs, crutches etc. without asking first).
- Build in a break every hour to allow participants to rest and move as necessary.

Maximising participation

- Clarify communications and accessibility requirements at the beginning e.g. group agreement – this will help both participants and facilitators.
- Always speak to the participants directly (not their assistant or interpreter).

What is involved in the community engagement workshops

A facilitation tool and activities were developed to guide the discussion with participants. Activities were designed to allow active participation of all participants using group work, scenarios, and visual images to maximise information sharing.

Components to implement for the workshop:

- **Introductory activities:** These enable participants to understand the purpose of the workshops and structure, provide consent and expectations, and agree participation rules and welfare.
- **Persona activity:** People in workshops are put into groups and asked to create a fictional but realistic persona of women with disabilities who could be or not be accessing health services. The rationale for this activity is to know details about the person's life, not just about her disability – so that the facilitators and members of the workshop can understand her experience. The activity serves as a gateway for exploring detailed social and cultural motivators and barriers to accessing services.
- **Client journey activity:** To explore the positive and negative experiences the personas developed may experience in relation to the client care journey and start to explore solutions.
- **Prioritising barriers:** Uses visual images and a ranking system to allow participants to interact and prioritise their barriers to healthcare access.

Adapting activities for different groups

Participants with visual impairments will benefit from sessions where activities are adapted to ensure visual cues are not required for activities and additional materials are available to touch e.g. examples of contraceptives. A quiet space will aid hearing and concentration. Participants with hearing impairments will benefit from visually stimulating activities e.g. drawing and role plays.



Examples and evidence

Case study 1: Sierra Leone

In Marie Stopes Sierra Leone (MSSL), a concerted effort has been made to improve disability inclusive care through collaboration with Sierra Leone Union on Disability Issues (SLUDI). In February 2020, MSSL, supported by Leonard Cheshire, conducted community engagement workshops with OPD leaders and disability community leaders (including 25 participants with physical impairments and 10 participants with hearing impairments).

- Separate workshops were held with a group with physical impairments and a group with hearing impairments, due to the anticipation that the barriers they experience would be different and require separate exploration.
- Using participatory and expressive approaches, participants were taken through the workshop activities to gain an in-depth picture of the lives and relationships of women with disabilities and explore barriers that they face when accessing sexual reproductive health services.

Insights: Sierra Leone case study



Participants with physical impairments

Persona exercise (details on fictional woman with a disability's life): Early first birth – age 13/14/15, has large family, shame of large families, has secret relationships, high dependency, power dynamics, low awareness and utilisation of SRH services especially family planning.

Client journey: The challenges were on the early stages of the client journey, associated with mobilisation, location of service provision, and awareness of service delivery sites.

Prioritising barriers: Service delivery barriers, cost of transport, accessibility of the site, negative attitudes of service providers.



Participants with hearing impairments

Persona exercise (details on fictional woman with a disability's life): Later childbirth (commonly in 20s), large families, relationship with men with similar impairments, completed primary education (deaf school), life aspiration more business/skills-oriented, preferred materials in English than local language, higher awareness/utilisation of SRH services but with negative family planning (FP) experiences and perceptions.

Client journey: The greatest challenge was overcoming the communication barriers and provider attitudes when they arrive at the service.

Prioritising barriers: Lack of sign language interpreters and attitudes of service providers.

Note: Generally, participants from urban communities had higher knowledge and utilisation of FP/SRH services than rural participants.

Case study 2: Zambia

In July 2020, Marie Stopes Zambia (MSZ) conducted community engagement workshops, building on the experience and learning from MSSL. In Sierra Leone, participants' knowledge of family planning and the services offered by Marie Stopes were lower than had been anticipated by the facilitators.

To address this, the following adaptations were made by MSZ:

- Included a group counselling session to sensitise participants on family planning methods.
- Separate workshops were held with leaders from OPD Zambia Agency for Persons with Disabilities (ZARP) and potential clients with disabilities, providing the opportunity to gather insights from different perspectives within the disability community.

Insights: Zambia case study



Participants with visual impairments

Persona exercise (details on fictional woman with a disability's life): Life aspirations more family and education oriented, fear of judgmental service providers, lack of confidentiality, fear of sexual violence due to lack of protection skills, lack of access to correct SRH information due to myths and misconceptions in the community, lack of knowledge about where to access safe SRH services.

Client journey: The needs are more inclined to overcoming communication barriers during the client care process, participation and confidentiality.

Prioritising barriers: Privacy and confidentiality, where to access services, long queues at facilities.



Participants with physical impairments

Persona exercise (details on fictional woman with a disability's life): Life aspirations inclined to family and business skills, provider judgment and stigma, fear of community shaming and labelling, family expectations, inaccessible health facilities, lack of knowledge on where to access safe SRH services.

Client journey: The needs under this segment are cross-cutting and inclined to overcoming physical and information accessibility, provider judgment/stigma, negative community perceptions.

Prioritising barriers: Inaccessible buildings, provider attitudes.



Participants with hearing impairments

Persona exercise (details on fictional woman with a disability's life): Life aspirations more inclined to family, education, and economic stability, fear of communication barriers with service providers, no sign language interpreters, lack of confidentiality, long waiting hours, lack of involvement in the care process.

Client journey: Like Sierra Leone, the needs are more inclined to overcoming communication barriers during the care process.

Prioritising barriers: Difficulty communicating with providers, privacy and confidentiality, site location.

Insights: Zambia case study – separate workshop with OPD leaders

Consultation with OPD leaders was focused on mapping, prioritising, and identifying possible solutions. Generally, the selected priority barriers were similar to those identified during the consultations with beneficiaries from the respective segments and prioritising barriers including possible solutions.

Recommendations by OPD leaders:

- Address attitudinal barriers with health workers and communities.
- Inclusion of persons with disabilities in the development of SRHR policies and programmes.
- Partner with local disability organisations to improve accessibility.
- Adapt peer education approach to increase FP/SRHR awareness among persons with disabilities.
- Develop messages and materials that speak to the diverse needs of persons with disabilities (whether they are voice recorded, in large print, braille, easy read format etc.).
- Equip health workers with basic sign language skills (to make clients feel welcome, not for the purpose of counselling which will require advanced skills).

Lessons learnt

Whilst the experiences of women living with disabilities are unique to the contexts in which they live, the insights from the community engagement workshops can be synthesised into some common themes.

1. Experience of stigma and negative societal attitudes influencing access to services.

For women living with disabilities, stigma exists at:

- a. **Individual level** (self-stigma).
- b. **Interpersonal level** (interactions between themselves and the healthcare provider).
- c. **Structural levels** (societal level conditions, cultural norms).

Fear of judgement as a result of societal attitudes was a recurrent theme in the consultations as a barrier for accessing services.

Negative societal attitudes influencing access to services

Women with disabilities can't/should not have sexual relationships

Sexual relationships which are not supported by an open social relationship are often kept secret. This contributes to low self-esteem/low power relationships.

Disapproval of children outside of marriage

Women with disabilities may use pregnancy as a strategy to maintain a relationship (largely unsuccessful) – resulting in children from different relationships.

Women with disabilities are not physically capable of raising children

Rather than impairment, it is more likely that their social/economic status will be the greatest challenge when raising children. It is common for children to be living with extended family.



2. Access to information

Lack of information impacts women with disabilities' levels of awareness and knowledge of their SRH options. Women with disabilities have limited access to trusted networks, linked to different dimensions of stigma.

SRH information is offered in limited formats

SRH information is not available in multiple formats to meet different needs of clients living with disabilities.

Communication barriers between service provider and client

Ensuring full understanding of choice available and consent is a barrier to quality service provision.

Low exposure

Lack of shared information in accessible formats and lower likelihood of basic education reduces the chance of persons with disabilities knowing some of the basics – about their bodies, health etc. (particularly likely amongst clients with hearing impairments).

Disability community networks

They are a trusted and a desired source of information.

3. Physical access

Clients with physical disabilities face environmental and physical barriers to independently accessing service delivery sites themselves.

Waiting lines

Clients with disabilities are concerned with queues at health facilities. There are fears of being served last and concerns about being seen or judged while waiting.

Transport costs

These are often not affordable for persons with disabilities, limiting their ability to reach health centres for SRH services. Cost rather than distance or accessible transport is the greatest barrier.

Developing action plans based on insights

Key questions to ask during your analysis and action planning include:

1. What solutions did the participants from the workshops prioritise?
2. What are we already doing that could be adapted to address the issues raised? Consider – experience with other vulnerable groups e.g. adaptations made for adolescents.
3. What opportunities are there for trying something new and innovating?
4. Who do we need to take this forward? Consider at what points to continue engagement with OPDs at both a local and national level.
5. What can be done within existing budgets and capacity? What needs to be planned into next year's business plan?



Putting action plans into practice

Here are a few examples of how the insights gathered during community engagement workshops have been put into practice:

Adapting existing resources

Marketing animations previously existed and were used during group consultations with people with hearing impairments. These were deemed very useful but needed to be made more accessible by including captioning. Animations to inform clients on FP methods now include captions, which make these animations inclusive for people with hearing impairments.

Design and testing adaptations

Insights from these community engagement consultations have been used as evidence to identify challenges, problem-solve and design new outreach activities that are more inclusive.

Power of partnership

In Sierra Leone we continued engagement with OPDs at a local level to further support the mobilisation of clients.

Annex: Examples and evidence – Actions required

Guided by the MSI Behavioural Change Framework, the team in Sierra Leone and Zambia mapped the following actions to improve disability inclusive care.

Behaviour change domains	Priority barriers/needs	Actions required
Individual	Lack of information on FP/SRH and service points	<ul style="list-style-type: none"> ■ Partner with OPDs for community awareness (training and guidance required). ■ Leverage existing local structures e.g. group WhatsApp for deaf clients, OPD meetings.
Interpersonal	Lack of sign language interpreters	<ul style="list-style-type: none"> ■ Explore approaches to facilitate provider-client communication during the care process (e.g. use interpreters, animations, pictorials).
	Provider stigma, attitude and bias	<ul style="list-style-type: none"> ■ Train service providers in disability inclusion. ■ Involve persons with disabilities in service provider trainings.
	Privacy and confidentiality (presence of third party)	<ul style="list-style-type: none"> ■ Seek client's approval prior to engaging third parties in the care process.

Behaviour change domains	Priority barriers/needs	Actions required
Community	Negative community perception of disability SRH	<ul style="list-style-type: none"> ■ Partner with OPDs in community sensitisation and awareness on disability SRH needs and rights. ■ Provide discreet referrals and services. ■ Train persons with disabilities as change agents.
Institutional	Cost of transport to service sites	<ul style="list-style-type: none"> ■ Capitalise on mobile service models e.g. one-to-one service providers, Mobile Outreach teams.
	Inaccessible service locations	<ul style="list-style-type: none"> ■ Co-schedule service delivery with OPD meetings. ■ Work with OPDs to map, select and share service sites.
	Long queues at service sites	<ul style="list-style-type: none"> ■ Identify clients with disabilities and provide option for prioritisation if they wish.

Endnotes

1. World report on disability, WHO and World Bank, 2011.
Available at: www.who.int/disabilities/world_report/2011/report.pdf
2. Promoting sexual and reproductive health for persons with disabilities, WHO and UNFPA guidance note, 2009.
Available at: www.unfpa.org/sites/default/files/pub-pdf/srh_for_disabilities.pdf
3. Promoting sexual and reproductive health for persons with disabilities, WHO and UNFPA guidance note, 2009, p 15.
Available at: www.unfpa.org/sites/default/files/pub-pdf/srh_for_disabilities.pdf
4. Promoting sexual and reproductive health for persons with disabilities, WHO and UNFPA guidance note, 2009.
Available at: www.unfpa.org/sites/default/files/pub-pdf/srh_for_disabilities.pdf
5. Human-centred design builds disaster resilience in Myanmar, ThinkPlace.
Available at: www.thinkplaceglobal.com/work/human-centred-design-builds-disaster-resilience-myanmar
6. FCDO-funded project: Reducing high fertility rates and improving sexual reproductive health outcomes in Uganda.
Available at: devtracker.fcdo.gov.uk/projects/GB-1-204633

This material has been funded with UK aid from the UK Government.

Leonard Cheshire Disability is a registered charity no: 218186 (England & Wales) and no: SC005117 (Scotland), and a company limited by guarantee registered in England no: 552847.
Registered office: 66 South Lambeth Road, London SW8 1RL

For further information, please contact:

Leonard Cheshire

66 South Lambeth Road, London, SW8 1RL

+44 (0)20 3242 0200

info@leonardcheshire.org

Visit: leonardcheshire.org

