

Nothing About Us Without Us: designing services for and with people with disabilities

KEY LEARNINGS

Prototype interventions to increase disabled people's access to sexual and reproductive healthcare were designed using Human Centred Design principles. Survey data indicates an increase in reaching clients living with a disability from 1.2% to 6.1% in 2021 in our outreach operations.

The expertise and experience of people with disabilities is a crucial part of the overall design process.

6.1%

Of outreach clients
are living with a
disability

THE CHALLENGE

People with disabilities face unique barriers to accessing services

People with disabilities can be among the most marginalised groups in any society, with often insurmountable barriers to accessing sexual and reproductive healthcare information and services¹, such as physical accessibility, communication barriers or lack of access to cash or transport solutions. In Sierra Leone, where estimates suggest more than 93,000 people² have a disability, negative stereotypes of disability and sex are pervasive across communities (e.g. that disabled women cannot or should not have children), and are often used by healthcare staff as well. Healthcare workers also often lack the confidence to appropriately serve clients with disabilities.

At MSI we are committed to creating an environment where all people can easily access high quality services free of stigma; everyone has equal right to reproductive choice and a healthy, pleasurable and safe sex life. MSI worked with Leonard Cheshire the Sierra Leone Union on Disability Issues (SLUDI) and design agency ThinkPlace as part of the Women's Integrated Sexual Health (WISH)³ programme to design interventions to make our service delivery more inclusive.

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WHAT WE DID

1. Using human-centred design to develop interventions

Partners embarked on an inclusive human-centred design (HCD) project to develop some responsive interventions to improve access to our services, ensuring people with disabilities were involved in all stages of design.

An 'observation' and consultation phase closely informed by SLUDI found that three key challenge areas for people with disabilities in accessing services were:

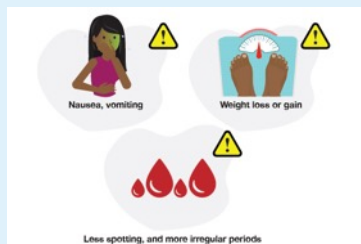
- The experience of being judged
- Lack of empowerment
- Limited disability-specific information.



WHAT WE DID

1. Using human-centred design to develop interventions

Ideas were generated to counter each challenge area and specific opportunities to make an impact were prioritised. ThinkPlace rapidly generated concepts for immediate testing and the three prototypes most successful at this stage were:



Choice Pic: series of visuals for providers to use in counselling to help clients with communication/hearing impairments understand their choices (targeting focus area 3)



Inclusive Services Guide: handy booklet for providers with easy-to-implement guidance on how to better prepare for and tailor services for clients with different disabilities (also targeting focus area 3).

Rumour Cards: set of cards comprising misinformation about people with disabilities and sex for stimulating discussion with the community and dispelling myths. It aims to counter negative stereotypes and foster a more accepting environment for people with disabilities accessing SRH services (targeting focus area 1). The sessions also planned to challenge stereotypes by how they were facilitated (e.g. SLUDI members as active facilitators where possible) (targeting focus area 2).



Rumour:

People with disabilities should not be sexually active.

In October 2020 a team of MSI Sierra Leone and SLUDI members shared the prototypes with people with disabilities and used their feedback to refine them, ensuring they met the needs of potential clients with disabilities.

2. Piloting and refining the prototype interventions

These refined prototypes were piloted with MSI outreach teams in Freetown, Moyamba and Kenema districts over February–March 2021, including visiting 10 communities of people with disabilities twice during the period.

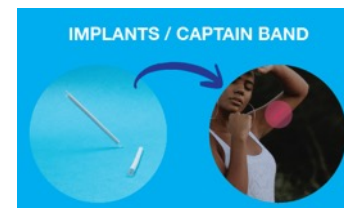
A mix of mechanisms including feedback forms, WhatsApp groups and supervision calls was used to garner ongoing feedback from outreach teams on their experience of using the prototypes. This was key: early on we identified that teams needed more support with the Rumour Cards prototype. We refined our approach and staggered the roll-out of the three prototypes to allow time for extra training on using the Rumour Cards.

We gathered end-line feedback from our teams in an end-of-pilot session in the head office in Freetown, and from clients with and without disabilities in a separate qualitative study conducted immediately afterwards⁴.

WHAT WE FOUND

What was the experience of our outreach teams?

- Choice Pic resulted in high engagement:** the Choice Pic really engaged clients with disabilities and resulted in a lot of questions and clearly filled a gap in accessible information. However, this sometimes meant a counselling session could take approx. 90 minutes instead of 45 minutes
- Community-based mobilisers (CBM) most benefitted from Inclusive Services Guide:** despite it being designed with providers in mind, CBMs may not have necessarily received prior training on disability inclusion; they found it particularly useful in informing them how to select appropriate locations for the outreach team to serve people with disabilities
- Rumour Cards required further training to increase knowledge and confidence:** as the most complex prototype demanding the ability to talk about disability inclusion from a rights-based perspective, further training was required. Specific Rumour Cards generated a lot of engagement – promising for the ongoing conversation with communities that will hopefully shift attitudes in the long term.



“People with disabilities were meaningfully consulted on the design and nature of these interventions.”



WHAT WE FOUND

What impact did these interventions have?

Qualitative feedback from clients with disabilities suggested that the interventions had the intended effect of enabling clients with disabilities to access our services, feel informed about their choices and receive respectful care:

“I think this service has improved a lot. I was counselled and given good information on the side effects of all the commodities”

“I feel the treatment is just the same for both persons with disability and able – bodied... I think it is easy speaking to the staff. I was able to tell the staff all my problems and they also gave me good advice and encouragement”.

Given that disability assessment tools are more suited to surveys than routine data collection⁵, we could not quantitatively measure the change in attendance of clients with disabilities over the pilot period. However, we estimate the percentage of clients with a disability in our annual client exit interview survey at the end of the year.

Given the focus on accommodating clients with disabilities in our Sierra Leone programme and the wealth of technical support given by Leonard Cheshire, it is promising to see that within our outreach teams,

the estimated percentage of clients with a disability rose from 1.2% in 2019 to 6.1% in 2020.



WHAT THIS MEANS

Adapting and refining continues

The nature of human-centred design means that we will continue to refine and adapt the interventions in response to client / team member feedback, as this is what makes the interventions even more effective and future-proof. Following the pilot, all outreach teams now identify potential sites which are accessible for clients with disabilities as part of their monthly scheduling.

Learnings to take away

- Specific and deliberate efforts to accommodate potential service users with disabilities can really support them to access services, and dramatically improve the experience for returning users
- It is crucial to have ongoing communication and coordination with Organisations of Persons with Disabilities (OPD) during piloting to ensure trust by members
- The design team included people with disabilities, and their expertise and experience was a crucial part of the design process
- More complex community sensitisation interventions may require lengthier training, starting with disability inclusion and human rights principles, for the team members who will be facilitating sessions (including the opportunity to practise/role play)
- In services where the user is required to make choices, the team may need the flexibility to allow for longer sessions with clients with disabilities or communication barriers, as it may take them longer to feel informed on all their choices.

Practical guidance on developing meaningful partnerships with OPDs and conducting community engagement workshops with people with disabilities is available on Leonard Cheshire's website.

FOOTNOTES

1. Ganle, J. K., Baatiema, L., Quansah, R., & Danso-Appiah, A. (2020). Barriers facing persons with disability in accessing sexual and reproductive health services in sub-Saharan Africa: A systematic review. *PLoS one*, 15(10)
2. Sierra Leone 2015 Population and Housing Census Thematic Report on Disability: <https://sierraleone.unfpa.org/sites/default/files/pub-pdf/Disability%20Report.pdf>
3. WISH is the UK Foreign Commonwealth and Development Office's flagship programme to scale up support to integrated SRH services to expand access for marginalised people across 12 countries in West and Central Africa. Through WISH, MSI works in partnership with IPPF, Ipas, ThinkPlace, DKT, Leonard Cheshire Disability and Options Consultancy
4. Further insights on clients with disabilities' experience in accessing services and their recommendations for more inclusive services will be included in a forthcoming peer-reviewed paper authored by Leonard Cheshire as part of WISH
5. Implementation Guidelines: How to use the WG questions <https://www.washingtongroup-disability.com/implementation/implementation-guidelines/>



MORE INFORMATION

For more information on MSI Reproductive Choices and the work that we do, please contact:
T +44 (0)20 7636 6200 • evidence@mschoices.org.
Alternatively, visit our website: www.mschoices.org.

Leonard Cheshire Links:

- [Community engagement for inclusive sexual and reproductive health](#)
- [Working together for inclusive sexual and reproductive health](#)