Women's Integrated Sexual Health (WISH)

Disability Inclusion, Seeking Informed Consent and Safeguarding Clients with Disabilities: Pilot Training Report

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Sightsavers

Contents

Introduction

The World Health Organization[1] estimates that 16 percent of the global population lives with a disability, and that 80% of them reside in low and middle-income countries. Although people with disabilities have the same rights as anyone else, they often face a myriad of barriers that prevent them from exercising their rights, especially when it comes to accessing sexual reproductive healthcare services.

Aside from the environment being inaccessible, people with disabilities also face stigma, negative attitudes and discrimination, as well as disrespectful and inequitable treatment from health workers, the community and family. They oftentimes don't have access to accessible and inclusive sexual reproductive health (SRH) information and can be exposed to coercive practices such as forced sterilisation, forced abortions, forced hysterectomies and forced medications. Moreover, people with disabilities, particularly women and girls, may be subjected to gender-based violence, and in particular intimate partner violence, which can limit access to and use of family planning methods. They are often wrongly assumed to be unable to make decisions on their own and therefore others tend to make decisions on their behalf for their "best interests" (this is particularly relevant for people with psychosocial and intellectual disabilities). This, however, goes against article 12 of the United Nations' Convention on the Rights of Persons with Disabilities[2], which states that everyone has legal capacity and the right to full autonomy over reproductive health decisions.

People with disabilities face additional challenges within SRH services when it comes to informed consent and safeguarding. There is also very limited guidance on what SRH healthcare providers can do to ensure informed consent and safeguarding from clients with disabilities. This only exacerbates the situation and further prevents people with disabilities from exercising their rights. As implementers of health programmes, we have an obligation to understand the rights of people with disabilities and the commitments made to "leave no one behind". We have a crucial role to play in moving away from practices that have not recognised the rights of people with disabilities.

[1] World Health Organization (2022). Global report on health equity for persons with disabilities. Available at: **https://www.who.int/publications/i/item/9789240063600**

[2] UN General Assembly (2007). Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly. Available at: **https://www.ohchr.org/sites/default/files/Ch_IV_15.pdf**

The Challenge: applying disability-inclusive approaches within informed consent and safeguarding processes

Throughout the course of the Women's Integrated Sexual Health (WISH) programme, several partners and country programmes raised challenges that they faced when seeking informed consent from clients that had different types of disabilities. These challenges were made even more apparent when Sightsavers' Inclusive SRHR Technical Advisor (formerly employed with Leonard Cheshire), delivered trainings to doctors and midwives in the Democratic Republic of Congo in November 2022. Although Leonard Cheshire had produced a comprehensive report on how to seek informed consent and safeguard clients with intellectual and sensory disabilities[3], it became evident that WISH partners needed more support to tackle this complex challenge: they needed training. A learning framework for inclusive SRH services (produced by Thinkplace with support from Leonard Cheshire) also highlighted this as a key gap that needed to be addressed. Once Leonard Cheshire exited the programme and Sightsavers became the new disability partner for WISH, one of Sightsavers' key priorities was to produce an engaging and practical in-person training toolkit on disability inclusion, seeking informed consent and safeguarding people with disabilities, particularly the most marginalised. As part of this, Sightsavers was going to incorporate within this toolkit content from existing resources previously developed by Leonard Cheshire as well as build on them.

The key areas of focus and learning objectives of the training package were established as follows:

- Be familiarised with the United Nations Convention on the Rights of Persons with Disabilities (CRPD).
- Gain more knowledge on the barriers to SRH service provision for people with disabilities, and on what can be done to address some of those barriers.
- Be familiarised with the concept of health equity, as described in the World Health Organization's (WHO) global report on Health Equity for Persons with Disabilities.
- Understand SRHR requirements and outcomes of people with disabilities.
- Understand the barriers experienced by people with disabilities in exercising their informed consent and bodily autonomy when accessing SRHR services.
- Identify practical ways to remove or mitigate barriers to informed consent and safeguarding for clients with disabilities in SRH service provision, and learn how to support clients within the informed consent process.

In addition to producing this toolkit, part of Sightsavers' deliverable was to conduct a training of trainers for members of organisations of persons with disabilities (OPDs) in a WISH country, specifically focused on the components of the package. Moreover, Sightsavers was

[3] Leonard Cheshire (2023). Safeguarding and consent in sexual reproductive health services when supporting persons with intellectual and sensory disabilities. Available at: **https://www.msichoices.org/wp-content/uploads/2022/10/Safeguarding-and-Informed-Consent-Report.pdf**

going to organise a pilot training in the same country to a select number of public sector healthcare providers, that was going to be facilitated by OPDs.

The development process for the training pack and the pilot

Setting up a technical support working group

To support with the development of this training package, Sightsavers set up a Technical Support Working Group (TSWG), which included staff from Sightsavers, MSI Reproductive Choices and Thinkplace. Sightsavers held an inception call with WISH partners who formed part of the TSWG to establish the objectives of the training, timeframes for developing and reviewing the training pack, determining the target audience for the training and deciding what WISH country the training pack could be piloted in. The inception call helped determine that the training pack would be piloted in Nigeria, and that the training of trainers (ToT) would be held over five days on the week of the 6th of November 2023. Along with this, the pilot training would be held over the course of four days on the following week of the 13th November.

Aside from setting up this TSWG, Sightsavers met with Thinkplace to have an ideation session for the training pack. The purpose of this session was to brainstorm innovative activities and ideas that would strengthen the training pack aimed at healthcare providers, and that would break down complex disability inclusion concepts into manageable actions that healthcare providers could adopt during consultations with clients with disabilities.

Co-designing with global organisations of persons with disabilities

Seeking informed consent from the most marginalised disability constituencies (for example people with intellectual impairments or with deafblindness) is a complex and very sensitive topic, and is a particularly neglected area in global development. Sightsavers saw this training toolkit as a great opportunity to address this gap and to partner with global organisations of persons with disabilities (OPDs) to ensure that the training pack was as inclusive and representative of people with disabilities who are the most marginalised. Sightsavers partnered with three OPDs so they could provide key technical expertise to the drafting of this training toolkit. These OPDs comprised: Inclusion International (whose expertise is on intellectual disabilities), Sense International (whose expertise is on deafblindness), and Transforming Communities for Inclusion (TCI Secretariat, whose expertise is on psychosocial disabilities).

Sightsavers held meetings with the OPDs to discuss how they could support with the review process for this training pack, and to discuss how they would be remunerated for their time and support. In addition to providing technical assistance to review the training pack (and as part of their agreement with Sightsavers), Inclusion International agreed that they would produce three videos of self-advocates with intellectual disabilities from their member associations sharing testimonies of their experiences as regards informed consent as well as privacy and confidentiality when accessing SRH services. These videos would then form part of the training toolkit.

The review process for the training pack

Once the training toolkit was drafted, it was disseminated to the TSWG and to the OPDs for their technical inputs. The TSWG provided comprehensive feedback on the training manual, the tools and handouts, which were then incorporated into the training pack. Additionally, the global OPD representatives provided extensive feedback on the training manual as well as the handouts, such as the one on different communication approaches to use to communicate with people with different types of disabilities.

Organising the training of trainers and the pilot training

Sightsavers' country office in Nigeria and MSI Nigeria Reproductive Choices were instrumental in planning for and organising the pilot training. Thanks to their unwavering support, the ToT was organised for twenty-nine participants and comprised nine MSI Nigeria colleagues (including safeguarding leads), one staff member from the United Nations Population Fund (UNFPA), two government officials (one from Bauchi State and one from Sokoto State) and seventeen representatives from the following OPDs: Deaf Women Aloud Initiative; Advocacy for Women with Disabilities Initiative; Disability Resource Foundation of Nigeria; Women with Disability Self-Reliance Foundation; Nigeria Association of the Blind; Deaf Resource Centre; Joint National Association of Persons with Disabilities (JONAPWD); and Down Syndrome Foundation Nigeria.

MSI Nigeria Reproductive Choices was also able to contribute financially to the pilot training that Sightsavers was going to hold thanks to underspend that they had identified. For logistical and security reasons (given that Nigeria is a high-risk country and that Sightsavers staff are not encouraged to travel to certain States such as Bauchi), it was established that the preferred location to deliver these activities needed to be Abuja (albeit the healthcare providers working on the WISH project being based in Sokoto and Bauchi States). We were able to use MSI's underspend to fly thirty-six public sector healthcare providers (eighteen from Bauchi State and eighteen from Sokoto State) and to accommodate them in the hotel where the pilot training was going to be held. Accommodating them in the hotel where the pilot training was going to be conducted helped ensure that participants arrived on time (if not earlier) each day of the pilot training.

Sightsavers took the opportunity during the ToT to decide which participants were best placed to be facilitators for the pilot training. Nine facilitators in total were chosen: six OPD representatives and three MSI colleagues who were safeguarding leads. Given the focus of this specific training, it was highly important to select trainers with disabilities that had experience of working in the health sector. The six OPD representatives who were selected as facilitators for the pilot training represented the following Nigerian OPDs:

Number	Name of OPD
1.	Deaf Women Aloud Initiative
2.	Disability Resource Foundation Nigeria
3.	Deaf Resource Centre
4.	Women with Disability Self-Reliance Foundation
5.	National Association for the Blind

6.	Advocacy for Women with Disabilities Initiative

With Sightsavers' support, the facilitators then spent four days on the week of the 13th November cascading the training to thirty-six MSI healthcare providers from public sector sites.

The successes

Attending a five-day ToT and attending a four-day pilot training can be demanding and tiring, especially if a lot of information is being given to you. While one may think that could be overwhelming, the training pack contained various activities as well as useful and practical information that helped keep participants engaged throughout the ToT and pilot training. Throughout both activities, it was very evident that participants' understanding as regards disability inclusion and informed consent was strengthening, and it was fantastic to see them systematically apply learnings they had gained in previous sessions into activities during the training. Moreover, the level of participation from participants continued to increase as each day went by.

The training pack contains a variety of activities that include videos, quizzes, role plays and case studies. The role play activities were carefully crafted to enable participants to (for example) put into practice the steps that a healthcare provider needs to apply to seek consent from a client with an intellectual disability. Participants found all the role play exercises on communication approaches, informed consent and on the will and preference and providing trauma-informed care really interesting, relevant and helpful in terms of putting into practice what they were learning. These activities are accompanied by tools and handouts, which proved to be very useful and educative for the attendees and supported them with the activities.

Some of the tools that were used during these role plays included the Accessible Leaflet of Contraceptive Methods and MSI Reproductive Choices' Choice Kit[4]. Participants found the Accessible Leaflet of Contraceptive Methods particularly helpful to communicate with clients who had (for example) intellectual impairments and hearing impairments, or who had a low level of education. During the pilot training, healthcare providers demonstrated a very keen interest in delving into practical aspects of the training, especially around communication methods. They found the handout and role play exercise on communication approaches to be extremely relevant as well as an "eye opener" for them. The handout, coupled with the other tools helped showcase the many ways one can communicate with (for example) someone with hearing impairments, even when a sign language interpreter is not available or if one doesn't know sign language themself. These communication tactics are relatively simple to implement, don't require any budget, and most importantly, can help a client with a disability make an informed choice.

After partaking in the ToT, the OPD facilitators and MSI Nigeria Reproductive Choices facilitators only had two days to carefully study the training toolkit, prepare themselves and be confident enough to deliver their respective sessions to healthcare providers. Whilst this was no easy feat, the facilitators ended up doing a fantastic job cascading the training to the healthcare providers. The facilitators were well-prepared, knew how to handle controversial points or discussions that arose during the training, and were very organised with preparing

[4] The Accessible Leaflet of Contraceptive Methods is a visual guide which lists the different contraceptive methods that are available and highlights their advantages as well as side effects. The Choice Kit is a kit that belongs to MSI Reproductive Choices and contains contraceptive methods for clients to see and touch these methods.

materials for activities ahead of time and giving clear instructions to participants. Time management is oftentimes challenging to handle, but most of the facilitators were disciplined and did really well in ensuring that they didn't go beyond the time that was allocated for different sessions.

Unsurprisingly, English wasn't the participants' first language, and in several instances during the pilot training there were issues with understanding certain English words. In these situations, the facilitators were proactive in addressing this challenge and translated words and complicated concepts into Hausa (a Nigerian dialect) for participants so they could understand the points that were being made.

One of the many successes of the pilot training was having OPD representatives as facilitators. The significant role they played in this activity served to showcase that partnering with OPDs is invaluable, and that they have significant amounts of expertise in the field of disability inclusion that can help strengthen disability-inclusive practices within the SRH sector. It also gave them the space to share their own experiences (whether positive or negative) of accessing SRH service provision, and the importance of seeking informed consent and properly safeguarding clients with disabilities who may be subjected to abuse. Being inclusive of all types of disabilities was a priority for all facilitators and participants during the pilot training and was demonstrated in various ways. For example, every time that a participant shared reflections or asked questions throughout the training, they systematically ensured they introduced themselves first (by saying "(name of person) speaking" so that facilitators with visual impairments knew who was contributing to the discussion).

Both the ToT and the pilot training benefitted from having two government officials and having a staff member from UNFPA. These stakeholders were consistently engaged and even supported with delivering a few sessions from the training pack too. Involving these stakeholders in the ToT and the pilot training helped give more credibility as well as visibility to the training and helped strengthen the partnership between them and MSI Reproductive Choices as well as Sighsavers.

Lastly, the pilot training for healthcare providers helped shed more light on the safeguarding mechanisms that are available in some public sector strengthening (PSS) facilities in Nigeria. Across Bauchi State, some PSS facilities have a social welfare service/department that can provide trauma-informed care to clients who have been subjected to sexual gender-based violence (SGBV). PSS facilities in Bauchi have at least 2 staff that have been trained on SGBV and the provision of trauma-informed care and can provide specific medical treatment to clients who've experienced SGBV (although they have not received any training on disability inclusion). These staff are also trained on the referral pathways for clients who need additional support, but these referral pathways don't necessarily include or factor in OPDs. Unlike Bauchi State, there are few doctors in Sokoto State who have been trained in SGBV and trauma-informed care. There are however NGOs that can provide support (such as psychosocial support) to GBV survivors. The government officials were particularly keen to apply their learnings within their ministries and strengthen the referral pathways for people with disabilities who've been subjected to abuse.

Areas for further improvement

Although the training was a great way to instil new habits within service providers, it is only a starting point. Changing old habits is challenging and requires self-awareness and time. Healthcare providers and other stakeholders being trained on seeking informed consent and safeguarding will need additional trainings and/or support when it comes to this.

Conducting the ToT and pilot training also shed light on aspects of the training materials that needed further improvement:

- As raised by a few participants, the training toolkit needed to include more representation of people with albinism.
- Although the instructions for most activities were clear, the instructions for some of the role play activities needed simplification in order to make it less confusing. Additionally, more time needed to be attributed to all role play activities, in order to give sufficient time for participants to get into their respective groups, prepare for the role plays, act out the role plays and then have sufficient time to properly debrief.
- The session in the training pack on the different models of disability is very theory-based. It became apparent during both the ToT and the pilot training that it was difficult for several to understand these different models and the differences between them. The activity in this session was too complicated and needed further simplification.
- The flowchart regarding the decision-making process needed to be further simplified in order for people to practically follow the steps needed to check the understanding of a client and determine their decision-making needs.

Understandably, one of the main feedbacks that Sightsavers received from participants as regards the training toolkit was that it needed to be provided in accessible formats (i.e. in braille and large font) for people with visual impairments. Because these tools were being piloted and additional changes were going to be made to the materials after the pilot, Sightsavers was not in a position where they could provide hard copies of all these materials in braille or large font. Sightsavers did however share soft copies of all training materials to participants with visual impairments (as well as anyone else who requested it) so they could access them using their assistive devices.

Final Review of training toolkit

Throughout this pilot, Sightsavers sought to get detailed feedback from participants on further amendments or additions that needed to be made to the pack. Once the pilot concluded, Sightsavers made amendments to the training toolkit based on the feedback from participants as well as from key observations that Sightsavers had made during the pilot. The updated manual, tools and handouts were shared with a select number of staff who formed part of the TSWG for their final inputs. These additional inputs helped strengthen the content of the training materials and overall approach in cascading this training in the future.

Additionally, once all materials (which formed part of this training toolkit) were designed and finalised, Sightsavers' dedicated Accessibility Department conducted a thorough accessibility testing to determine what accessibility features needed to be incorporated to ensure the training toolkit was fully accessible and inclusive for people with all types of disabilities. Amendments to the toolkit were then further made to ensure it was fully accessible.

Logistical Challenges

The Training of Trainers and the pilot training were unfortunately held in a venue that wasn't fully accessible, and the reasonable adjustments that the venue tried to provide were not fully accessible either. Additionally, although the hotel itself had lifts, the bedrooms were not fully accessible for OPD representatives who were being accommodated.

Furthermore, we experienced a myriad of internet connectivity and sound system issues throughout both weeks. Hotel/venue staff were rarely proactive in rectifying the issue and Sightsavers and MSI colleagues constantly had to follow up with them to get them to fix issues we were experiencing.

Recommendations for future piloting

The following are recommendations to consider implementing for future trainings moving forward:

1. It is crucial to conduct a proper accessibility assessment of potential venues before proceeding with renting the venue out to conduct any training. Any temporary ramps that are installed for participants with disabilities need to be shallow in order to ensure that the participant can safely enter and exit the venue. Accessible bathrooms need to be available; these need to be big enough and wide enough for a wheelchair to go through and for someone to close and open the door independently without any issues.
2. Having staff from UNFPA and government officials attend the ToT and the pilot training helped give more credibility and visibility to the training. If possible (and to ensure sustainability), it would be recommended that these stakeholders are involved in future trainings too to encourage the use/application of learning at provider level and to advocate for the adoption of training content at state/regional level.
3. The prayer time for people who practice Islam in Nigeria was between 1pm to 2pm. Lunchtime in Muslim countries should be organised (when feasible) during prayer time so that people can step away and pray as well as have lunch then.
4. Many of the local participants during the ToT had to leave earlier to commute back home. We often had to finish the day at 4pm instead of 5pm (which is what had originally been planned). It could be helpful to reflect this in the agenda for trainings and/or other events. To avoid sign language interpreters arriving late in the mornings, it may be worth accommodating them too (if there is sufficient budget to do so).
5. For the pilot training, we were able to accommodate the participants in the same hotel where the activities were being delivered. This resulted in us being able to start each day ahead of schedule and be on track. If budget allows, it would highly be recommended that this is considered for future trainings.
6. From an accessibility perspective, it would be best to share resources to people who have visual impairments ahead of any training. Moreover, if someone with a hearing impairment is expected to facilitate a session, it would be best practice to provide additional time to them so that the interpretation can be done without any issues.
7. Healthcare providers demonstrated a keen interest in learning more about how to handle caregivers in situations where the provider has a safeguarding concern that concerns the caregiver. Although the training materials touch upon this, additional resources and support needs to be provided in this regard. This sits outside the scope of this training package (for now) but is an incredibly important piece of work that Sightsavers will consider further exploring. Additional tools should also be developed for healthcare providers so they know how to practically work with caregivers to facilitate decision making support needs for clients with disabilities.

We work with partners in low and middle income countries to eliminate avoidable blindness and promote equal opportunities for people with disabilities.

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