MSI REPRODUCTIVE CHOICES

UKaid from the British people

Committed to Leaving No One Behind

Contributions of the WISH programme to increasing disability inclusive sexual and reproductive health and rights in West and Central Africa

Natacha Bobin
December 2023

Mbalu Kalie (left) speaks to Hannah Yenoh Sandy, a disability advocate working with the Sierra Leone Union of Disability (SLUDI), Moyamba, Sierra Leone.

Ipas dkt INTERNATIONAL IPPF International Planned Parenthood Federation Leonard Cheshire Options ThinkPlace Sightsavers

Leonard Cheshire and Ipas team members pose for a photograph during their visit to Kintambo hospital with the objective of understanding how the inclusion of people with disabilities can be facilitated, Kinshasa, DRC, November 2022.

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Introduction

The World Health Organisation (WHO) estimates that 1.3 billion of the global population have a disability (2022). While this represents approximately 16% of the general population, the estimate is higher for women and girls (18.4%)[1].

According to United Nations estimates, there are between 180 and 220 million youth with disabilities worldwide, and nearly 80 percent of them live in developing countries[2]. Persons with disabilities have the same sexual and reproductive health rights (SRHR) and needs as other people, yet often face far greater barriers to accessing information and services.

These barriers are commonly associated with stigma and negative societal and individual attitudes, including from healthcare providers, and often result from a skills gap, inadequate infrastructure, materials, equipment, policies and programming which are unable to effectively address the needs of persons with disabilities.

MSI Reproductive Choices have made persons with disabilities an important segment of their global agenda:

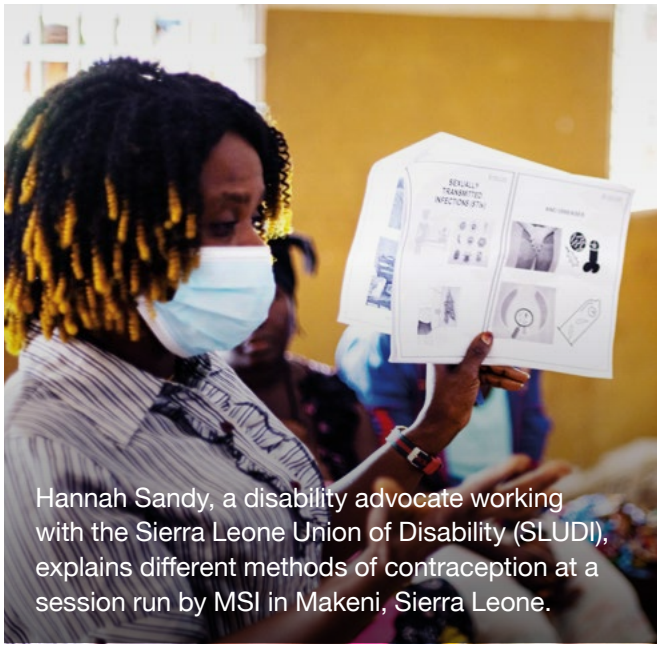
Leave No One Behind

The MSI 2030 Strategy[3] commits to placing a strong focus on reaching adolescents, those living in extreme poverty and marginalised communities who have little or no access to public sexual reproductive health (SRH) services.

A key objective of the strategy is closing the SRHR gap for all, ensuring that everyone is only one contact away from a safe high-quality service.

The Women's Integrated Sexual Health (WISH) programme, the UK Foreign Commonwealth and Development Office (FCDO)'s flagship programme which aims to strengthen SRHR across 27 countries in Asia and Africa, sets Leaving No One Behind as a strategic priority, which MSI´s 2030 Strategy is fully aligned with.

Capacity building for a women's network of organisation of persons with disabilities, N'Djamena, Chad, December 2022.



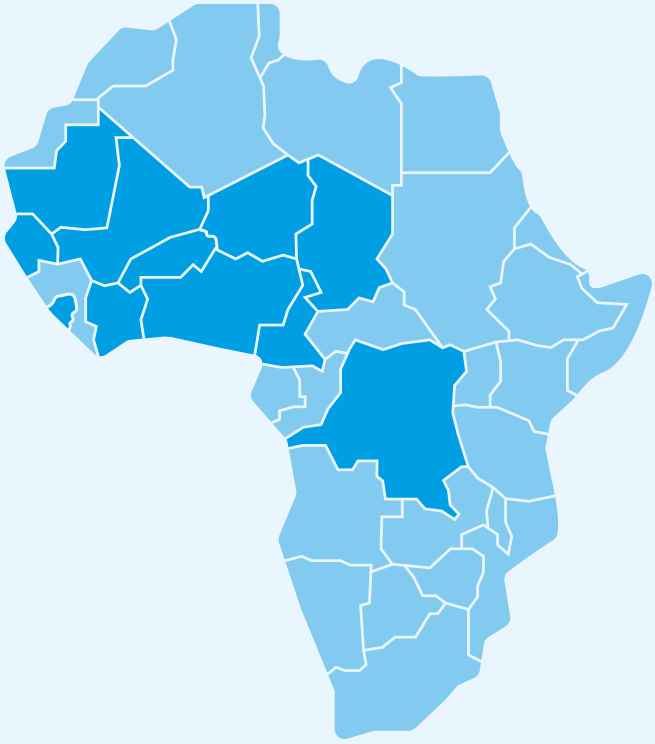
Hannah Sandy, a disability advocate working with the Sierra Leone Union of Disability (SLUDI), explains different methods of contraception at a session run by MSI in Makeni, Sierra Leone.

The WISH programme contributes towards this agenda by reaching women with disabilities whose needs have previously largely been unmet through family planning and SRH service provision.

> **One of the main components of WISH is to ensure that project interventions are disability-inclusive.**

This is so that clients with disabilities can access high-quality adequate SRHR services, and are included in mobilisation strategies, in a context of informed consent and safeguarding.

The WISH programme is implemented through two consortium structures (called Lots). This report focuses on WISH Lot 1, implemented from 2018 to 2023, in West and Central Africa, and led by MSI Reproductive Choices with eight of its country programmes, six IPPF member associations, Leonard Cheshire Disability (LCD), who was replaced by Sightsavers in April 2023 as the technical disability lead, DKT, Ipas, Options, and ThinkPlace.



WISH Lot 1 countries that implemented disability inclusion programming included include Burkina Faso, Chad, Senegal, Mauritania, Mali, Sierra Leone, DRC, Niger, Nigeria, Cameroon, Côte d´Ivoire and Ghana[4].

At the five-year mark, the WISH Lot 1 programme successfully laid the foundation for disability-inclusive SRHR programming, increasing the proportion of people with disabilities reached from an estimated 2.5% in 2019 to 5.1% in 2022[5].

Through solid collaboration between consortium partners, sustained technical support and expert capacity strengthening from Leonard Cheshire Disability (LCD) and Sightsavers, and a highly adaptive approach, the WISH Lot 1 consortium has made great strides in understanding the barriers that clients with disabilities face when accessing SRH service provision. As a result, **the WISH programme was successful in designing innovative interventions to address and better serve clients with disabilities.**

Disability Inclusion Model

To achieve disability inclusion, the WISH Lot 1 programme implemented a twin-track approach, combining disability mainstreaming and targeted strategies to increase SRHR access for persons with disabilities. Making disability inclusion a cross-cutting issue throughout SRHR programming aimed to ensure that interventions were accessible and beneficial to persons with disabilities.

Twin Track Approach

Full Inclusion Framework

To plan for SRHR disability inclusion at the intervention level, the WISH Lot 1 programme applied a full inclusion framework, based on WHO and the United Nations Population Fund (UNFPA) recommendations, allowing barriers and needs faced by people with disabilities to be met on multiple fronts. WISH Lot 1 integrated each of the five key elements of the full inclusion framework by:

Mainstreaming

Ensuring that persons with disabilities have access to their basic needs in all interventions and projects and on an equal basis with others in the community.

Targeting

Addressing the specific needs of the individuals with disabilities in order to empower them and improve their situation.

Equality Of Rights And Opportunities For Persons With Disabilities

Under the technical leadership of LCD and at a later stage of Sightsavers, the WISH consortium partners focused on strengthening and mainstreaming disability inclusion at programmatic and organisational levels.

To achieve this, the WISH Lot 1 programme scoped, piloted and evaluated approaches in one country programme, Sierra Leone, (See Power shifting in Sierra Leone box, page 9), later adapting and replicating them in other countries for wider programming.

Simultaneously with mainstreaming efforts, the WISH consortium partners ensured barriers faced by persons with disabilities were effectively addressed and activities were tailored to their needs.

1 Establishing partnerships

The close collaboration with disability-focused consortium partners and the meaningful engagement of Organisations of Persons with Disabilities (OPDs) have been critical to WISH Lot 1 disability inclusion programming.

2 Raising awareness

The needs of persons with disabilities, and particularly young women and adolescent girls with disabilities, were integrated into SRHR interventions, raising awareness among clients and healthcare providers.

3 Reaching and serving

Through adapted interventions, persons with disabilities were able to access SRH information and services in their community.

4 Policy, laws and budgets

In multiple countries, WISH Lot 1 worked with OPDs and other relevant stakeholders to ensure that SRHR legislation and regulations take into account the needs of persons with disabilities.

5 Promoting research

The implementation of the WISH Lot 1 programme generated strong evidence which contributed and will continue to contribute to strengthening SRHR disability inclusion programming.

Our Journey to Success

In 2019, an estimated 2.5% of MSI clients in West and Central Africa were persons with disabilities.

In 2022, this number increased to 5.1% making the WISH programme, and support from FCDO, the catalyst for the consortium partners´ commitment to SRHR disability inclusion.

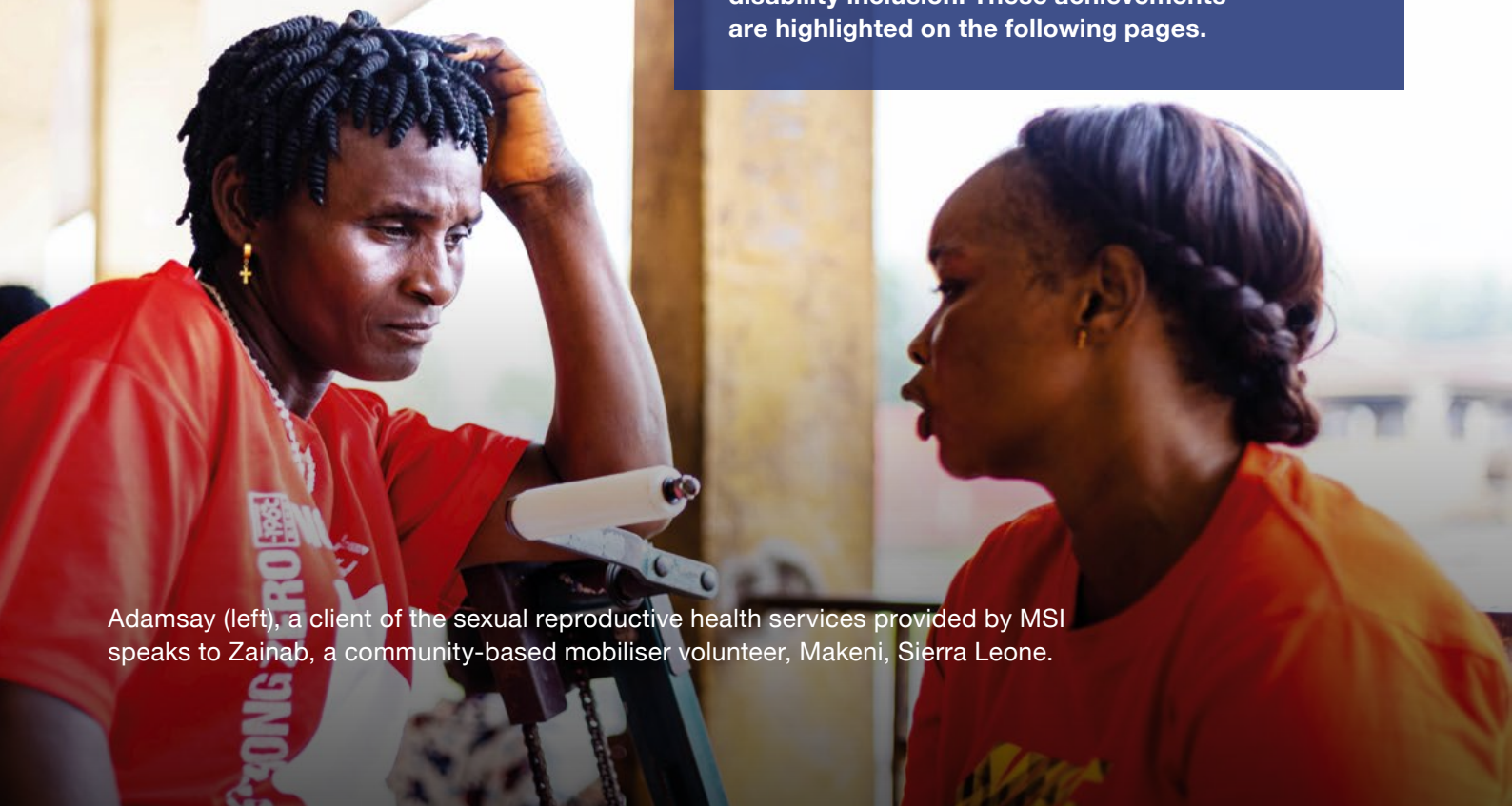
Key successes from the programme include:

1. Strengthening the community engagement
2. Increasing equitable access to services
3. Producing an extensive collection of disability inclusion resources
4. Increasing public sector engagement
5. Introducing innovative and adaptive approaches to SRHR disability inclusion

During the five-year WISH Lot 1 programme period, despite the COVID-19 pandemic and ongoing political instability in the region, the WISH Lot 1 consortium partners successfully embedded a disability inclusion approach into the programme´s overall SRHR strategy, and significantly increased access to SRHR information and service provision among people with disabilities.

This has been a productive and fruitful journey for WISH consortium partners to embark on. At the start of the WISH programme, only an estimated 2.5% of MSI clients in West and Central Africa were persons with disabilities. Since then, this number has increased to over 5.1%, making the WISH programme, and support from FCDO, the catalyst for the consortium partners´ commitment to SRHR disability inclusion.

Key successes from the programme include strengthening community engagement, increasing equitable access to services, producing an extensive collection of disability inclusion resources, increasing public sector engagement and introducing innovative and adaptive approaches to SRHR disability inclusion. These achievements are highlighted on the following pages.



Adamsay (left), a client of the sexual reproductive health services provided by MSI speaks to Zainab, a community-based mobiliser volunteer, Makeni, Sierra Leone.

Community Engagement

Partnering with **Organisations of People with Disabilities (OPD)** to ensure effective community engagement is a cornerstone of the WISH Lot 1 disability inclusion approach. The WISH Lot 1 consortium partners extensively involved OPDs in the implementation of SRH interventions, ensuring their participation through workshops and other methodologies, including Human Centred Design (HCD)[6], a critical first step to capture insights from people with disabilities to inform the design of messages and adaptation of Social and Behaviour Change Communication (SBCC) tools and campaigns.

Building a cadre of community-based mobilisers (CBM) among OPDs and people with disabilities has proven to be a successful strategy of the WISH programme to effectively reach persons with disabilities and increase access to information and services at the community level.

In DRC, Chad and Sierra Leone, OPD community agents have been instrumental in mobilising people with disabilities,

disseminating information and enabling access to products and services, through direct product provision, e.g. condom distribution, and health centre referrals. In **DRC**, Ipas partnered with the Association Congolaise pour la Libération et le Développement de la Maman Handicapée (ACOLDHEMA) to integrate SRHR messaging into their programming, while DKT worked with Debout et Fier and CENAPROPHY to conduct awareness sessions followed by service provision days at a DKT partner clinic.

In **Niger**, MSI partnered with the National Disabled People Organisation to identify and train SRH champions. In **Senegal**, following a mapping of OPDs, partnerships were established with the Association des Femmes Handicapées de Saint Louis et de Thiès and the Association Départementale de Dakar des Femmes Vivant avec un Handicap, to conduct group discussions around SRH/FP and service provision for clients.

In **Mali**, MSI partnered with the umbrella organisation Fédération Malienne des Personnes Handicapées (FEMAPH), which regroups 15 national associations of persons with disabilities and acts as the main liaison with the State for the promotion of persons with disabilities.

In Mali, Burkina Faso, Cameroon, Sierra Leone, DRC and Nigeria, WISH consortium partners provided ongoing support to strengthen the involvement of OPDs in SRHR legislative discussions, to advocate for disability inclusive policies and their effective implementation. This resulted in positive change in a number of countries, leading OPDs to be recognised as key stakeholders who should systematically be included in the national SRHR (see more details in section '***Public sector engagement***' page 16).

Power shifting in Sierra Leone

In **Sierra Leone**, with technical support from LCD, Marie Stopes Sierra Leone (MSSL) tested an inclusive SRH service for persons with disabilities. LCD advocated for the inclusion of the umbrella organisation Sierra Leone Union on Disability Issues (SLUDI), whose membership includes OPDs from across the country, with about 120 registered members across the Northern, Southern and Eastern provinces. The three-way partnership between MSSL, LCD and SLUDI resulted in a high level of **power-shifting**. SLUDI was integrally included in all design and implementation activities and given the opportunity to lead certain components of the intervention. For MSSL, designing and implementing disability-sensitive SRH services meant allowing SLUDI to lead when engaging with persons with disabilities. **SLUDI was able to engage its community of persons with disabilities in a way that neither LCD nor MSSL could on their own**. After the involvement of SLUDI, the percentage of people with disabilities reached with SRH information, counseling and services through the WISH Lot 1 programme increased from 1% to 4% (data based on annual Client Exit Interviews in Sierra Leone, 2019).

Partnership for policy implementation in Jigawa State, Nigeria

In **Nigeria**, violence against women is considered by some as a national crisis. Following 13 years of successful advocacy by women's rights organisations, the Violence Against Persons (Prohibition) Act or the VAPP Act was passed in 2015. The VAPP Act prohibits all forms of violence against persons in private and public life and provides maximum protection and effective remedies for victims and punishment of offenders. While the VAPP Act represented a significant step forward towards protecting victims of violence, the level of enforcement has been limited due to low levels of awareness about the Act and structural limitations in the jurisdiction of the Act. As such, only 16 of 36 states had adopted legislation needed to implement the VAPP Act at the State level by August 2020. To ensure greater State support for the VAPP Act, the WISH programme, through its implementation partner Ipas, supported a coalition of like-minded organisations.

The coalition was led by the Village Community Development Initiative (VILDEV) and consisted of 10 civil society organisations (CSOs), including women's rights organisations, two government agencies and the Joint Association of Persons Living with Disabilities (JONAPWD). JONAPWD had previously advocated for the Domestic Violence Bill and so had strong influence in the State Assembly to ensure that the voices of persons with disabilities who were victims of violence were heard. In partnership, Ipas, VILDEV and JONAPWD ensured that OPDs played an active role in the coalition, recognising that they had previously been excluded. OPDs joined the coalition and contributed to evidence-based advocacy activities supported by data from the Sexual Assault Referral Centre (SARC). The coalition ensured that OPDs were active in all legislative advocacy activities and worked to support their self-representation (e.g. OPDs visited legislative members personally and spoke to them directly instead of having others speak on their behalf.)

OPDs involved in the coalition underscored the unique challenges faced by persons with disabilities who were victims of violence. Their deep understanding of the difficulties and challenges experienced by persons with disabilities in accessing appropriate health services brought credibility to their case for greater State support of the VAPP Act. This ultimately contributed to the VAPP Bill being signed into law in Jigawa State.

An MSI staff member explains the different types of available contraceptives to women with disabilities, Sierra Leone.

Equitable access to healthcare

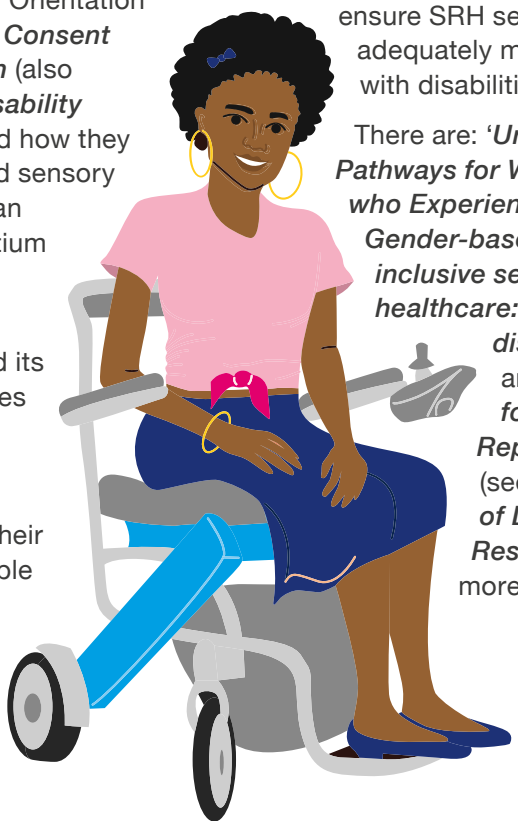
"We cannot thank MSI enough for thinking of women living with disabilities and providing them with access to family planning services. Difficulties of access to the health centres in our neighbourhoods constitutes a barrier for us. Whenever I go there, the midwife uses the manoeuvres to help me get up there and it bothers me. By offering us your services, you show us how much our wellbeing is important to you and we are honoured". Fati, Head of the Group for Women Living with Disabilities, family planning client, **MSI mobile clinic, Niamey, District 3, Niger.**

Ensuring equitable access to SRHR information and quality services among people with disabilities – especially young women and adolescent girls with disabilities – was a key objective of the WISH Lot 1 programme. At the country level, consortium partners implemented a range of adapted demand creation activities, supported by tools developed by LCD and ThinkPlace using HCD approaches, including the ***Choice Pic*** and ***Rumour Cards*** (see more details in section '***Production of Disability Inclusion Resources***', page 14). Disability-inclusive Social and Behaviour Change Communication (SBCC) campaigns were conducted via trained community mobilisers reaching people with disabilities with information, products and referrals for counselling and services. SRH service providers were oriented on how to assist people with disabilities during counselling using ***the Inclusive Services Guide*** developed by LCD. Orientation about ***Safeguarding and Informed Consent in Sexual and Reproductive Health*** (also described under '***Production of Disability Inclusion Resources***', page 14), and how they apply to people with intellectual and sensory disabilities, was delivered through an online webinar attended by consortium in-country partners, OPDs and service providers.

Each country programme leveraged its most relevant and effective strategies to increase equitable access to SRH services among people with disabilities. In **Niger**, MSI mobile midwives engaged OPDs to make their service delivery sites more accessible and disability friendly.

In **Chad**, Association Tchadienne pour le Bien-Etre Familial (ASTBEF), an IPPF Member Association, ensured its team of community health workers included people who identify as living with a disability in order for messaging and inclusivity to be streamlined into service delivery. In **Nigeria**, following feedback from OPDs, the Planned Parenthood Federation of Nigeria (PPFN) built wheelchair accessible ramps in a number of WISH-supported facilities. In **DRC**, Ipas partnered with ACOLDEMHA to improve access to SRH services through telemedicine and the network of WISH-supported sites.

In collaboration with ThinkPlace, LCD conducted three pieces of research which informed the design of a comprehensive framework to outline the skills gap and training needs required for relevant stakeholders to ensure SRH services are accessible and adequately meet the needs of clients with disabilities.



There are: '***Understanding Support Pathways for Women with Disabilities who Experience or Are at Risk of Gender-based Violence***'; '***Towards inclusive sexual and reproductive healthcare: Insights from women with disabilities in Sierra Leone***'; and '***Learning Framework for Inclusive Sexual and Reproductive Health Services***' (see section '***Production of Disability Inclusion Resources***', page 14, for more details).

Disability often intersects with other factors, such as age, gender and socioeconomic conditions – and persons with disabilities experience higher risks of poverty,stigma and SGBV.

The WISH Lot 1 consortium has endeavoured to factor in intersectionality in its approach to marginalised and vulnerable groups, including persons with disabilities. In **Sierra Leone**, MSI is in the process of adapting its service delivery model to a more inclusive approach for persons with disabilities, particularly women and girls, based on the learnings from the LCD research '***Understanding support pathways for women with disabilities who experience or are at risk of gender-based violence***' that explored how Sexual and Gender-Based Violence (SGBV) interacts with disability-inclusive service provision.

As a result of these strategies, the percentage of clients with disabilities served by WISH in the West and Central Africa Region more than doubled (from 2.5% to 5.1%) during the five years of programme implementation, exceeding the programme´s milestone of 3%. In 2021 alone, more than 6,000 people with disabilities received services from WISH partners in **DRC, Sierra Leone and Niger.** Technical leadership from LCD and Sightsavers, piloting and using tools and approaches, extensive engagement from OPDs and the integration of more inclusive practices were key to these results.

Lauraine Ntomboka, WISH Programme Community-based Mobiliser, leading a family planning community awareness raising activity among persons with disabilities in Bandundu, Kwilu province, DRC.

Lauraine´s journey to self-empowerment and becoming a community-based mobiliser in Bandundu, DRC

Lauraine Ntomboka, a person with albinism, is married to an officer of the national police force. Their union began in February 2020 when Lauraine realised that she had missed her period after a series of unprotected sexual encounters with the officer. They decided to keep the pregnancy. On delivery, Lauraine gave birth to male twins at the police medical centre in the town of Bandundu. Eight months later, Lauraine became pregnant again, and since she had twin babies to care for, she and her partner decided to seek an abortion. The post-abortion care provided was not of a high standard, resulting in generalised septicemia with Lauraine hospitalised for 21 days. Thankfully, she recovered. When the WISH programme launched a family planning awareness-raising campaign and offered the free provision of modern contraceptive methods in the town of Bandundu, intrigued, Lauraine joined the activities. After learning about the benefits of the family planning programme, she decided to enroll in it, and chose IMPLANON NXT to avoid repeating the suffering she had endured. She was relieved to learn about the life-saving benefits of modern contraceptive methods. She decided to join the WISH programme as a community-based mobiliser to bring messages about family planning to the community of people living with disabilities in the most remote rural areas of the Kwilu province.

Kapinga Ngalula Annie, a 50-year-old member of the Association of People with Disabilities, participates in a workshop for service providers to explore different models of supporting clients with disabilities in accessing sexual and reproductive healthcare in Kinshasa, DRC, November 2022.

Production Of Disability Inclusion Resources

The programme´s impressive results in increasing equitable access to SRH services among people with disabilities can be credited in no small part to the availability and dissemination of a collection of resources and materials created by LCD, Sightsavers, ThinkPlace, MSI and Ipas.

These tools provided significant support as well as practical tips and guidance for WISH consortium partners to build more inclusive, gender-responsive, and equitable health services for clients with disabilities.

The materials developed are primarily aimed at implementing partners, OPDs, country-level SRH service providers and community health workers, as well as government and policymakers.

All technical assistance guidance produced by LCD was translated into French. Eight e-learning modules have been developed, available in both French and English, based on the tools developed under the WISH programme.

LCD and Sightsavers conducted extensive technical assistance and training activities using these resources. The disability inclusion tools, research studies and e-learning modules developed under the WISH Lot 1 programme include the following:

Disability Audit Tool

Helps assess the extent to which organisations are disability-inclusive, and how to develop an action plan for inclusive practices.

Guidelines on Conducting Community Engagement Workshops with Clients with Disabilities and OPDs

Provides tips on how to conduct community engagement workshops with clients with disabilities and OPDs, in order to adapt programmes and interventions. Electronic version: www.leonardcheshire.org/sites/default/files/2021-11/Community-engagement-inclusive-sexual-reproductive-health.pdf

Accessible Communications and Inclusive Information Guidelines

Explains how to format documents, presentations, videos, etc. to make them accessible to people with disabilities.

Design by Distance Prototypes: *The Choice Pic, Rumour Cards,* and *Inclusive Services Guide*

The ***Choice Pic*** is an inclusive visual guide presenting modern contraceptive methods and their side effects/advantages. It is meant to facilitate open dialogue between SRH service providers and people with hearing impairments, intellectual impairments, and communication difficulties, but it is also beneficial for people who may not speak the local dialect or the language in the country (think of refugees for example). The illustrations in it include different representations of disability types (for example there is an illustration with someone with a hearing impairment, another one with a visual impairment, etc.). It uses easier-to-understand language so people can comprehend the information that is being provided (i.e. advantages and side effects). The ***Rumour Cards*** is a set of cards addressing stereotypes about people living with disabilities. It is used during counselling sessions to break down misconceptions that communities have about people with disabilities and aims to reduce the attitudinal barriers that people with disabilities are faced with when it comes to accessing SRH service provision. ***The Inclusive Services Guide*** is meant to orient service providers on how to assist people with disabilities during SRH counselling sessions. It provides key tips for service providers to apply to ensure they are being inclusive and accessible for clients that have different types of disabilities. Guidance was also produced on how healthcare providers should implement the ***Choice Pic***, ***Rumour Cards*** and Inclusive Services Guide within their interventions.

Disability Inclusion Values Clarification and Attitude Transition Toolkit (VCAT)

Adaptation of Ipas' original ***VCAT toolkit***, with support from LCD and Inclusive Development Centre, to address disability-inclusive safe abortion and contraceptive care programming. This toolkit is a resource for organisations looking to build a disability inclusion mindset among staff and partners who design and implement abortion and SRHR programming. Electronic version: www.ipas.org/resource/disability-inclusion-in-reproductive-health-programs-an-orientation-and-values-clarification-toolkit/

Working Together for Inclusive Sexual and Reproductive Health

Outlines the human rights imperatives underpinning disability-inclusive SRH services and describes the important role of OPDs in designing and supporting the implementation of such services. It provides information on the principles of developing meaningful partnerships with OPDs, with a strong rationale for why such partnerships are pivotal in designing services that meet the needs of persons with disabilities. This learning product harnesses the experiences of WISH country teams by documenting emerging pockets of good practice and highlighting efforts made to strengthen the meaningful participation of OPDs. It also includes a practical toolkit with checklists for healthcare providers to use with OPDs to establish or strengthen meaningful partnerships with OPDs. Electronic version: www.leonardcheshire.org/sites/default/files/2021-11/Working-together-inclusive-sexual-reproductive-health.pdf

Safeguarding and Informed Consent in Sexual and Reproductive Health

Explains the concepts of safeguarding and informed consent, notably as they relate to SGBV, and is particularly aimed at persons with intellectual and sensory disabilities. Two e-learning modules were produced for WISH Lot 1 consortium partners on informed consent and safeguarding (links provided next page). Sightsavers also piloted an in-person training package on disability inclusion, informed consent and safeguarding of clients with disabilities. This training provides very practical tips for healthcare providers on different ways of communicating with clients that have all types of disabilities, and steps that they need to take to seek informed consent from clients and safeguard them.

Understanding Support Pathways for Women with Disabilities who Experience or Are at Risk of Gender-based Violence

This study looks at how women with disabilities at risk of experiencing gender-based violence can be supported by sexual and reproductive health services in Sierra Leone. It examines how responsive policies in Sierra Leone are towards the needs of women with disabilities experiencing GBV, and the existing evidence base on women with disabilities and GBV in Sierra Leone as well as the wider continent. Suggestions of support for women with disabilities are placed in the context of their lived experience as women with disabilities in Sierra Leone, as derived from qualitative research.

Towards inclusive sexual and reproductive healthcare: Insights from women with disabilities in Sierra Leone

This research project consisted of qualitative semi-structured interviews with three participant groups in Sierra Leone: women with disabilities, women without disabilities and healthcare providers. Findings include what women with disabilities value in terms of SRH services. The report presents recommendations for service improvement. Electronic version of research brief: www.msichoices.org/media/4792/evidence-brief_sierra_leone-disability-inclusion.pdf

Learning Framework for Inclusive Sexual and Reproductive Health Services

This comprehensive ***Learning Framework*** is intended to provide an outline of the skills gaps and training needs of relevant stakeholders and provide a comprehensive overview of the core components implementing partners should consider when developing training and materials that promote the accessibility of SRH services for clients with disabilities. It was used by WISH consortium partners to reflect on current gaps in their disability inclusion programming and training and adapt or design training to respond to the needs of OPDs, health workers and government officials to reduce barriers to access to SRH services for people with disabilities.

Disability Inclusion Programme E-Learning Modules:

Course:
MSI Disability Inclusion (kayaconnect.org)

Summary of Module 1:
Introduction to Disability Inclusion (kayaconnect.org)

Summary of Module 2:
Accessible Communications (kayaconnect.org)

Summary of Module 3:
Partnerships with Organisations of Persons with Disabilities (kayaconnect.org)

Summary of Module 4:
Partnership Project Cycle (kayaconnect.org)

Summary of Module 5:
Community Engagement Workshops (kayaconnect.org)

Safeguarding & Informed Consent for Clients with Intellectual & Sensory Disabilities:
Part 1

Safeguarding & Informed Consent for Clients with Intellectual & Sensory Disabilities:
Part 2

Participants of the Ipas' workshop on Standards and Guidelines for Medical Management of Victims of Gender Based Violence in Adamawa State, Nigeria, August 2022.

Public sector engagement

Mobilising governments to recognise the fundamental importance of SRHR disability inclusion within policies and services is critical to achieving systemic and sustainable SRHR disability inclusion. Building the capacity of the public sector to implement SRHR disability inclusion is an essential step in this process. While much remains to be done to achieve full equity and inclusion, the WISH Lot 1 programme celebrated notable successes engaging the public sector and pushing disability inclusion higher on governments´ agenda.

In **Cameroon**, the Cameroon National Planning Association for Family Welfare (CAMNAFAW) prioritised working with the Ministry of Health department dedicated to supporting people with disabilities to co-design SRH services with this Ministry's counterparts to ensure equitable access.

In order to better recognise and address the intersections between poverty, disability and SGBV, CAMNAFAW and the Cameroonian Ministry for the Promotion of Women and the Family facilitated a joint workshop on SGBV vulnerability and disability for regional delegations from the Ministry of Social Affairs.

In **Burkina Faso**, Options partnered with the National Association of People with Disabilities (FEBAH) to ensure that the country's 2021-2025 Family Planning (FP) Costed Implementation Plan and 2030 Family Planning commitments are disability-inclusive.

Advocacy by Options and FEBAH resulted in FEBAH's inclusion on the technical committee for monitoring the national FP plan, a commitment to include indicators for monitoring people with disabilities as users of FP services in the plan's monitoring mechanism, and the selection of FEBAH as one of the community actors which will receive funding for the implementation of activities under the national FP plan.

In **DRC**, following a training on disability inclusion conducted in collaboration with LCD, Ipas strengthened the capacity of public sector service providers and community health workers by providing VCAT training on disability inclusion. The training encouraged service providers to recognise the limitations of the current service provision model to care for people with disabilities, the resources needed to improve the infrastructure, and efforts to improve attitudes of healthcare providers.

Staff from the National Health Programme, health zones and Ipas integrated questions about disability inclusion in their discussions with providers during supportive supervisions. Also in DRC, Options worked with Ipas and LCD to update the national standard guidelines and technical sheets on family planning to ensure disability-inclusive practices were integrated into these key resources. The documents were approved and updated by the Programme National de Santé de la Reproduction (PNSR). LCD also delivered in-person training to the PNSR on disability inclusion.

In **Nigeria**, the inclusion and leadership of OPDs in advocacy and implementation efforts ensured that the Violence Against Persons Prohibition (VAPP) Law and Protocol reflected the SRH rights and needs of persons with disabilities. With Ipas' support, a technical working group (TWG), chaired by the Jigawa State Attorney General's Office and led by three critical State government ministries (Health, Justice, and Women Affairs), was created to lead on developing the Protocol. The TWG's governance structure and diverse membership promote disability inclusion as well as government accountability. A designated office within the TWG membership structure was included for OPDs.

Sightsavers in-person training of trainers on Disability Inclusion fundamentals and Safeguarding and Informed Consent, November 2023, Abuja, Nigeria.

Adaptive approaches and innovations

The WISH Lot 1 programme faced several difficulties during implementation, notably, like the rest of the world, restrictions imposed by the COVID-19 pandemic. Thanks to strong collaboration between consortium partners and adaptive approaches to problem-solving, these challenges were transformed into opportunities and resulted in the introduction of innovative SRH disability-inclusive interventions.

Although restrictions on travel due to the COVID-19 pandemic meant a number of planned activities had to be re-programmed, these delays also created opportunities to adapt and re-think technical support to country programmes. In February 2020, two community engagement workshops were held in **Sierra Leone** with women with disabilities to identify the barriers to accessing services, and inform the development of adaptations to service delivery. However, due to COVID, LCD staff were prevented from further travel to Sierra Leone. As an alternative, a remote model of design was developed in partnership with MSI **Sierra Leone** and **Senega**l, WISH consortium members LCD and ThinkPlace, as well as representatives from OPDs in both countries.

To address overlapping barriers to disability inclusion, shared challenges between the two countries were identified and a workshop was held to explore solutions to these challenges. As a result, three prototypes were developed in Senegal, tested and subsequently refined for the Sierra Leone context. This innovative approach meant critical work on disability inclusivity moved forward, despite the pandemic.

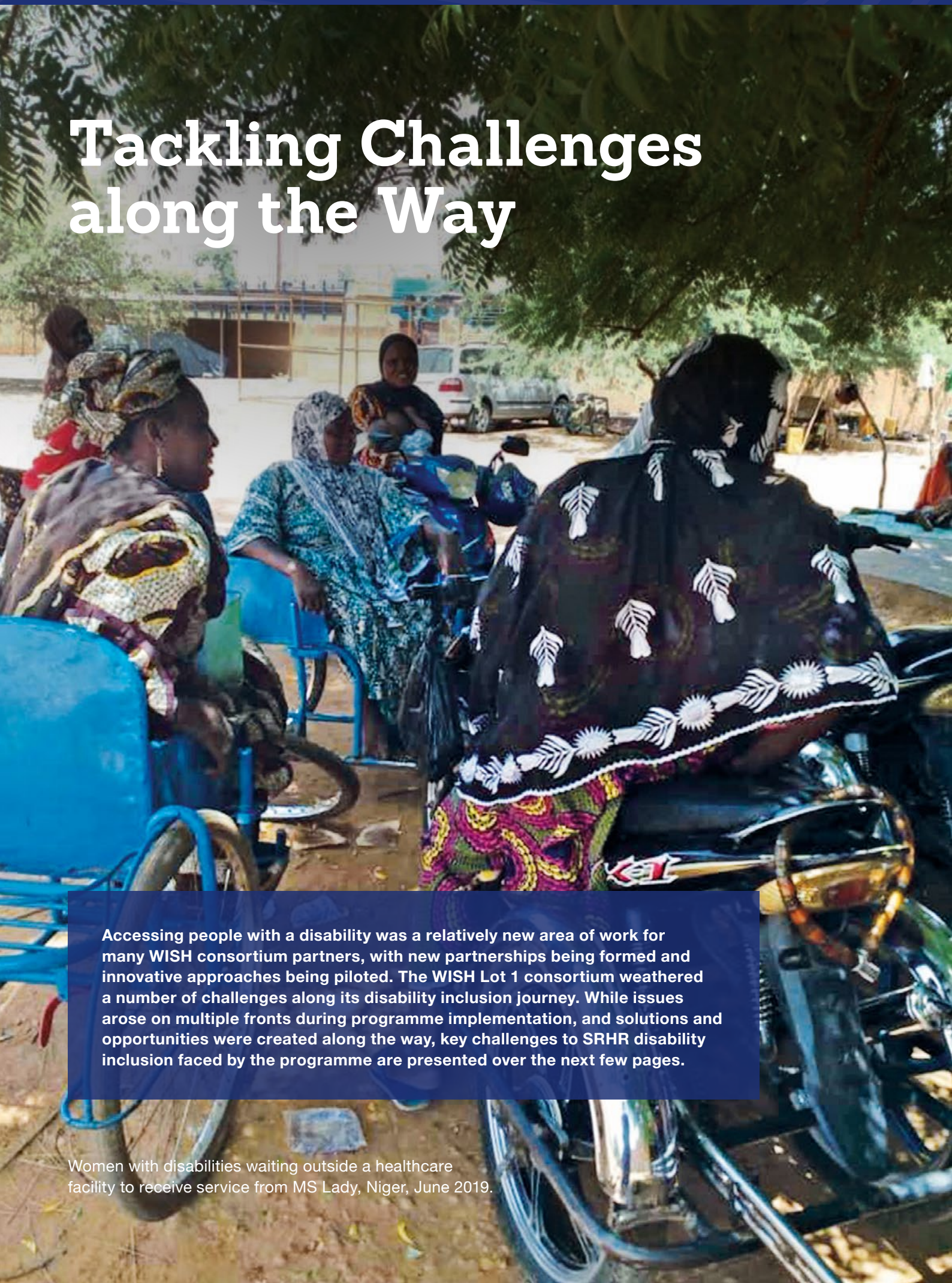
In **DRC** and **Nigeria**, disability VCAT workshops were originally planned to take place in person. Due to the COVID-19 pandemic, the methodology was adapted to be conducted online as a Disability Orientation for VCAT facilitators to Ipas-supported providers and community health workers.

This enabled more inclusive participation from a wider range of countries within the WISH consortium, as well as OPD expert facilitators.

The process of adapting the methodology for online workshops enabled both LCD and Ipas to identify how each session could be strengthened and therefore led to important changes being made to the existing disability inclusion ***VCAT toolkit***. Key changes included adapting activities and tools used by VCAT facilitators so they could conduct the trainings virtually while ensuring accessibility to people with different types of disabilities.

The activities covering the theme of terminology were further adapted to strengthen people's understanding of positive versus stigmatising terminology.

Tackling Challenges along the Way



Accessing people with a disability was a relatively new area of work for many WISH consortium partners, with new partnerships being formed and innovative approaches being piloted. The WISH Lot 1 consortium weathered a number of challenges along its disability inclusion journey. While issues arose on multiple fronts during programme implementation, and solutions and opportunities were created along the way, key challenges to SRHR disability inclusion faced by the programme are presented over the next few pages.

Women with disabilities waiting outside a healthcare facility to receive service from MS Lady, Niger, June 2019.

Measurement

Until recently, systemic collection and analysis of statistics related to people with disabilities was largely overlooked (Altman 2016). While some organisations have collected data on disability, this lack of systematic data collection reflects the low priority that disability has received within the global development community and beyond. The field of sexual reproductive health is no exception. Although now an issue better acknowledged[7], there is still much progress to be made. While there is momentum to push governments and international organisations to improve data collection around disability, lack of adequate contextual and global data makes it a significant challenge. Data collection on disability also presents ethical complexities, namely around the issue of collecting data from persons with disabilities when services are not available to them and also because it can be stigmatising for these persons. Another challenge relates to lack of reliable population data on access to SRHR among people with disabilities – which complicates the analysis of data collected at project level. Furthermore, public data systems at country level often suffer from poor infrastructure and do not collect routine data on disability, which creates issues from a sustainability perspective.

Disability prevalence was measured annually across the WISH programme through a Client Exit Interview (CEI) process using the Washington Group Short Set on Functioning (WGSS) questions. Integrating WGSS within existing CEI data collection is an appropriate starting point to capture a key WISH result – the level of access being provided to persons living with a disability. Including them in the CEIs allowed WISH consortium partners, to some extent, to understand how well healthcare services were meeting the needs of people with a disability, enabling the programme to look at client experience metrics for this group, and comparing them to the whole population. However, the scope of measurement was limited due to the fact WGSS were only used in the CEIs which were only implemented on an annual basis. Additionally, key elements of inclusive care were not reflected, as measurement only focused on one reach measure to understand a complex issue.

The discussions around the challenges of measurement prompted by the WISH programme have been very valuable in evolving the consortium partners´ thinking around measuring and monitoring the inclusivity of programme services. Future programming will need to adopt an inclusive approach to measurement, not only focusing on data for reporting, but involving populations in the design of measurement, and strengthening capacity to analyse and use data and making sure an ethical approach is taken. Ensuring data collection is value-neutral, reliable and representative, and developing a comprehensive strategy to fully integrate disability inclusion within the broader monitoring and evaluation programme strategy will be key.

The challenges faced during programme implementation in the area of measurement present great potential and opportunities for WISH cross-lot learning and beyond.

Safeguarding and informed consent

Ensuring all clients seeking SRH services are able to exercise their bodily autonomy and make free and informed choices, in safe spaces with clear safeguarding mechanisms in place, is an essential and critical aspect of SRH service provision. This naturally applies to clients with disabilities, especially young women and adolescent girls with disabilities. However, people with disabilities, and particularly those from more marginalised communities and disability constituencies, face additional barriers compared to people without disabilities – as they are often deprived of their bodily autonomy and other people end up making reproductive choices on their behalf, without them being even consulted. During the implementation of the WISH programme, consortium partners noted the struggle that service providers often experience in explaining SRH options to clients with intellectual and sensory disabilities. Providers lacked the confidence and skills to ensure the voluntary and informed consent of clients with disabilities. SRH service providers also need to care for clients who face abuse, including SGBV, or coercion from others including caregivers and intimate partners, but they may not always have the safeguarding knowledge, skills or confidence to do so effectively.

Privacy considerations, lack of accessible and relevant training materials, in situ training and appropriate support tools for SRH service providers and health workers on how to work with persons with intellectual and sensory disabilities, and provide trauma-informed care, are genuine challenges for SRH providers seeking a client with disabilities´ informed consent. As these challenges surfaced during the WISH programme implementation, LCD captured lessons learned and identified opportunities to support the creation of an enabling environment for people with intellectual and sensory disabilities to be able to access SRH services in a safe environment. Leonard Cheshire Disability's ***Safeguarding and Informed Consent in Sexual and Reproductive Health report*** was therefore developed to help healthcare workers in SRH services with informed consent and safeguarding concepts and processes, so that clients with intellectual and sensory disabilities can exercise choice and freedom in their SRH lives. Two e-learning modules were also produced for healthcare providers based on this report. Alongside these resources, Sightsavers produced an in-person training package for healthcare providers to understand the barriers faced by people from various disability constituencies in exercising their informed consent and bodily autonomy when accessing SRHR services, and identify practical ways to remove or mitigate these barriers. This training package was recently piloted in Nigeria and feedback from participants highlighted just how practical and paramount this training was for them. This training package will be finalised and made available before the end of the WISH programme for partners to use moving forward.

MSI information session about contraception for women with disabilities, Makeni, Sierra Leone, 2021.

Comprehensive disability inclusion

People with disabilities are not a uniform group, and people living with different impairments and conditions experience different forms of discrimination in society, as well as barriers to accessing essential services. Designing, implementing and evaluating comprehensive SRHR programmes which systematically address the barriers and respond to the requirements of people with disabilities in all their diversity is very complex. During the implementation of the WISH programme, consortium partners noted the limited understanding of the barriers experienced by people from different disability constituencies among SRH providers, policymakers and other stakeholders, and the fact that limited availability of resources dedicated to disability inclusion poses notable challenges to comprehensive disability inclusion. WISH worked to mitigate these issues by developing resources to address the lack of understanding of the barriers faced by persons with disabilities (see section '***Production of Disability Inclusion Resources***', page 14). While work is still required, thanks to the WISH programme, progress has been made in the West and Central Africa region, from increased access to SRH services by persons with disabilities, to the advancement of SRHR disability inclusive policies.

COVID-19 pandemic

While travel restrictions due to COVID-19 created opportunities to adapt and expand WISH´s technical support in disability inclusion, namely by adapting research, piloting, training and VCAT methodologies online, the shift to online activities also resulted in trade-offs with regard to levels of engagement and motivation, and exacerbated the risks of excluding people with no access to electricity or internet, people with visual or hearing impairments (who often experience increased communication barriers) and those with low literacy levels. Once these challenges were identified, WISH partners worked to mitigate these risks, to ensure equity remained at the heart of all activities, including adapting the Disability Orientation VCAT methodology online for Ipas-supported providers and community health workers.

Planning for disability inclusion

While efforts were made to integrate disability inclusion programming at the design stage of the WISH programme, including budget allocations and the engagement of disability-focused partners, it became apparent during implementation that additional resources would have been beneficial. This is particularly relevant given the high requirements at programme design in terms of outputs to be achieved and budget distribution across various countries. The challenge involved addressing a complex issue like disability within an already complex SRHR project. Nevertheless, the high level of motivation, engagement and innovation of consortium partners, including in-country teams and partners, allowed the programme to exceed its SRHR disability inclusion objectives and account for notable achievements, as noted in the above section '***Our Journey to Success***' (see page 8).

Sustainability

As the current phase of the WISH programme comes to a close, ensuring the sustainability of SRHR disability inclusion and positive systemic change at the individual, community, health provider, institutional and policy levels will be challenging.

While the foundation has been laid in many countries thanks to consortium partners´ commitment and efforts to ensure public sector transition, additional investment to support greater national ownership to continue to create a more enabling environment and more sustainable demand for, and supply of, SRHR disability inclusion is still needed.

Lessons Learned and Recommendations

The WISH programme has provided a valuable learning opportunity on how to effectively implement disability inclusion in SRHR. The barriers to SRH services for persons with disabilities are complex and multifaceted. As a result, they must be clearly identified, and multiple systems and actors need to be meaningfully engaged from the design phase, to ensure health equity for all. The recommendations in this section aim to support the creation of an enabling environment for people with all disabilities, particularly women and girls, and people from more marginalised disability constituencies, with a view to realising their SRHR, and ensuring the provision of safe, inclusive and accessible SRH services. The lessons learned summarised provide guidance and recommendations to inform and scale-up future SRHR disability inclusion programming.

The chairlady for United Polio Brothers and Sisters Association, Maiteh, Freetown, Sierra Leone

Planning for disability inclusion

- Including disability inclusion into the programme design process, including a well-defined approach to disability inclusion measurement, as well as ensuring adequate budget allocation is critical.
- Integrating the disability inclusion approach and interventions within existing approaches facilitates disability inclusion mainstreaming and promotes sustainability.

Prioritising partnership and community engagement

- OPDs play a critical role as a link between programming, healthcare providers, policymakers and people with disabilities at the community level. They are the cornerstone of effective disability-inclusive SRHR programming. Establishing meaningful partnerships with OPDs and understanding why these partnerships are crucial in terms of addressing the barriers to SRH services is critical.
- Along with the establishment of these partnerships, it is important to promote the meaningful engagement of persons with disabilities and OPD representatives throughout the project cycle of SRHR initiatives, from the initial design stage, to implementation, monitoring and evaluation.
- Many local implementing partners and OPDs lack the capacity to effectively engage with influencers, government leaders, district health officials and other stakeholders to advocate for inclusive programming and services. Advocacy is a continuous process involving campaign events, media, developing campaign material with clear key messages, meetings to lobby decision-makers and gather allies. Adequate plans and budget allocations are required to promote the meaningful engagement of persons with disabilities and their representative organisations in advocacy initiatives – including investments aimed at increasing the institutional and technical capacity of OPDs at national and sub-national level.

Adopting an intersectional approach

- Persons with disabilities are not a homogeneous group. Disability often intersects with other factors, such as age, gender and socioeconomic conditions – and persons with disabilities experience higher risks of poverty, stigma and SGBV.
- The WISH Lot 1 consortium has endeavoured to factor in intersectionality in its approach to marginalised and vulnerable groups, including persons with disabilities. Yet there is still a long way to go. Future SRHR disability inclusion programming will need to further explore an intersectional approach to fully take into account the complexity of promoting disability inclusion and ensuring no one is left behind.

Supporting and building the capacity of healthcare providers and community health workers

- Healthcare providers need support to understand disability. Capacity building of providers and community actors through regular training on the fundamentals of disability inclusion, different disability constituencies, health equity for persons with disabilities, how to identify women with disabilities in the community, understanding and addressing their own behaviours and attitudes toward disability, and other relevant topics is key to successful disability inclusive service delivery. Future SRHR programmes should roll out existing e-learning modules and the in-person training package developed through the WISH Lot 1 programme.
- Service providers do not necessarily have the time to establish good relationships with clients/caregivers when they first come to seek a contraceptive method or other SRH services. To address this, specific and/or longer appointment slots (e.g. one day per week/month, whichever is feasible for the clinic) could be dedicated to clients with disabilities who may need extra time to understand different options that are available so they can make an informed decision.

Future WISH programming could focus on ensuring a set of standards for disability-inclusive SRH services is put in place and implemented at facility level, using existing national standards as a starting point and working from there to align them with the UN Convention on the Rights of Persons with Disabilities (CRPD). The ***Safeguarding and Informed Consent*** report developed by LCD contains specific recommendations that may be used as reference.

Ensuring appropriate tools and resources available

- Programmes should ensure SRH communications materials are accessible across a range of formats. Communications and marketing staff should be trained on how to develop and adapt communications materials so they are accessible and inclusive. Adapting communications to ensure accessibility, e.g. adapting tools and adding Braille information, more image/less text, larger font, etc. on posters and flipcharts, is essential to overcome communication barriers.
- The training package on how to design accessible disability-inclusive materials developed by WISH consortium partners should be further tested across countries to generate evidence of its effectiveness and subsequently be rolled out at scale. As noted in the ***Safeguarding and Informed Consent*** report produced by LCD, additional gaps noted under WISH which could be addressed in future programming through the development of new training materials include the following:
  - Privacy considerations can be a challenge for SRH providers seeking a client's informed consent. In collaboration with OPDs, future programmes could develop a picture guide to use with clients to facilitate discussions about privacy, who they would like in the consultation room with them, and when they would prefer not to be accompanied.
  - The training package piloted in Nigeria by Sightsavers has started to provide guidance on supporting healthcare workers on how to identify and act on safeguarding concerns, and similarly guidance for those who think their client may be experiencing violence, abuse or coercion, especially from caregivers. Future programmes should do more to focus on this aspect. It is crucial for organisations to review and, if necessary, adapt organisational policies to ensure the right mechanisms are in place to support healthcare providers in instances where a client with a disability is being subjected to violence, abuse or coercion. Training is just not sufficient.
  - Much of the information on informed consent and SRHR developed under WISH applies to adults of all ages. However, the informed consent and safeguarding requirements can be different for people classified as children. Future programmes could develop a guide specific to people under the age of consent that may be used as reference.
  - Strengthen mechanisms to ensure consortium partner staff, service providers and community health workers actually use existing resources, and develop a mechanism to track material content updates.

Strengthening monitoring and evaluation

- Strategies and models to improve systemic data collection on SRHR disability inclusion and to better understand target audiences for the adaptation of communications materials should be prioritised and given adequate resources, including budget allocation.
- Additional technical support should be provided to Health Promotion Departments within Ministries of Health to promote sustainability.
- The use of pop-up questions or pulse surveys in data systems to routinely capture disability data should be explored.
- Lessons learnt from increasing reach to youth and adolescents should be reviewed and adapted to reaching clients with disabilities.

Ensuring safeguarding and informed consent

- Every SRH service delivery site, organisation or administration should have a safeguarding policy, protocols and guidance specifically addressing the needs of persons with disabilities, supported by named staff, to ensure healthcare workers know who to report concerns to and what referral pathways are available for their client.
- Checklists and tools compiled under WISH should be tried and validated with OPDs and WISH partners.
- The WISH consortium should continue to recognise the pressure on healthcare workers striving to provide a good SRH service that supports the informed consent of clients with disabilities, and the trauma they may experience in aiming to provide this. Supportive approaches, including self- and collective care, and trauma-informed care supervision, should continue to be offered to healthcare providers and prioritised.

Promoting sustainability

- Investing in advocacy and identifying champions, including in OPDs, to promote disability-inclusive policies and legislations is key. Programmes should aim to align interventions with government priorities, and provide technical assistance to government partners to integrate disability inclusion into existing service delivery models and services – e.g. incorporating disability inclusion within existing training curricula for healthcare workers.
- People with disabilities and their representative organisations must be meaningfully involved to design and lead the implementation of key advocacy interventions aimed at promoting disability inclusion within SRHR systems and policies.

Conclusion

The WISH Lot 1 Disability Inclusion Journey

Persons living with disabilities are one of the world's largest minority groups, yet they continue to face significant barriers to accessing SRHR information and services. Through WISH, the WISH Lot 1 consortium partners have contributed to addressing key barriers and increasing equitable access to SRH services among people with disabilities in West and Central Africa, leveraging expertise from disability-focused partners and establishing solid partnerships with local OPDs. As a result, the percentage of clients with a disability served by WISH increased from 2.5% to 5.1% over five years, exceeding the programme´s 3% milestone indicator.

The road to achieving equitable access and realising disability inclusion in the SRHR sector is still long, but the foundation has been laid through the WISH programme – learnings, tools and good practices developed by the programme are progressively being embedded into SRHR programming. As WISH partners broadened their engagement with other partners and focused on using more participatory, inclusive approaches, the intersections between different realities, particularly poverty and disability, have become clearer. A cultural shift and focus can be seen at the five-year mark within the WISH consortium – a success of WISH disability inclusion efforts to date. Integrating work to address barriers and meet the needs of people with disabilities can be seen more systematically and organically among consortium members and country programmes, contributing to the Leave No-One Behind agenda.

Percentage of clients with a disability served by WISH in 2022: **5.1%**

References:

1 Global report on health equity for persons with disabilities, WHO (2022). www.who.int/publications/i/item/9789240063600

2 www.un.org/development/desa/youth/youth-with-disabilities.html

3 www.msichoices.org/media/3919/msi-2030-external-strategy-11112020.pdf

4 Activities in Cameroon, Côte d´Ivoire and Ghana closed out in August 2021 and in Burkina Faso in March 2022

5 Data collected from annual Client Exit Interviews, WISH programme

6 Human Centered Design (HCD) is an approach that puts people at the center of the development process, enabling the creation of products and services that resonate with and are tailored to an audience´s needs (Harvard Business School).

7 www.data4sdgs.org/initiatives/inclusive-data-charter

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