# Working together for inclusive sexual and reproductive health

Leonard Cheshire

# Contents

## List of abbreviations

| | |
|---|---|
| CAMNAFAW | Cameroon National Association for Family Welfare |
| CRPD | United Nations Convention on the Rights of Persons with Disabilities |
| CSO | Civil Society Organisation |
| FEBAH | Fédération Burkinabé des Associations pour la promotion des personnes handicapées |
| FEMAPH | Fédération Malienne des Personnes Handicapées |
| HIV | Human Immunodeficiency Virus |
| IDA | International Disability Alliance |
| JONAPWD | Joint Association of Persons Living with Disability |
| MINAS | Ministry of Social Affairs |
| MOU | Memorandum of Understanding |
| MSSL | MS Sierra Leone |
| OECD | Organisation for Economic Co-operation and Development |
| OPD | Organisations of Persons with Disabilities |
| SARC | Sexual Assault Referral Centre |
| SGBV | Sexual and Gender Based Violence |
| SHGs | Self-Help Groups |
| SLUDI | Sierra Leone Union on Disability Issues |
| SRH | Sexual and Reproductive Health |
| SRHR | Sexual and Reproductive Health Rights |
| STI | Sexually Transmitted Infection |
| VAPP Act | Violence Against Persons Prohibition Act |
| VILDEV | Village Community Development Initiative |
| WHO | World Health Organization |
| WISH | Women's Integrated Sexual Health |

## Acknowledgements

This Learning Product was developed by Leonard Cheshire, a consortium partner of the Women's Integrated Sexual Health (WISH) programme. Sarah Palmer (Disability Advisor, Inclusive Programmes) and Amalie Quevedo (International Project Officer) led the development of the publication with support from Ms Thesandree Padayachee (Consultant). Kate Grant (Consultant) and Lucy Bentley (Writer and Editor) provided support with editing and finalisation.

On behalf of Leonard Cheshire and the Women's Integrated Sexual Health (WISH) Programme, we would like to thank the following individuals who participated in this project:

From CAMNAFAW, Dr Pierre Bayi and Pie Anicet Ndzie. From Ipas, Tracy Di Tucci, Lucky Palmer, Doris Ipkeze. From JONAPWD, Muhammad Usman. MSI Reproductive Choices, Gloria Tucker, N'Toumbi Tiguida Sissoko, Alima Dicko, Abdoulaye H Traore, Susan Camara and Kaitlin Keane. From Options, Lamine Thiam, Ousmane Ouedraogo. From Sierra Leone Union on Disability Issues: Santigie Kargbo and Hannah Sandy.

We would also like to thank the WISH Disability Inclusion Technical Working Group for their expert contributions throughout the development of this Learning Product.

This material has been funded with UK aid from the UK Government; however the views expressed do not necessarily reflect the UK Government's official policies.

# Executive summary

Within the context of sexual and reproductive health rights, persons with disabilities remain disenfranchised. This is despite the fact that they have the same rights as persons without disabilities. Persons with disabilities continue to encounter multiple and significant societal, environmental and individual barriers to sexual health services, leading to increased vulnerabilities and poor health outcomes.

The Women's Integrated Sexual Health (WISH) programme, of which Leonard Cheshire serves as a consortium partner, aims to:

**"Create a world in which every mother can enjoy a wanted and healthy pregnancy and childbirth, every child can survive beyond their fifth birthday, and every woman, child and adolescent can thrive to realize their full potential, resulting in enormous social, demographic and economic benefits".**

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

Organisations of persons with disabilities (OPDs) play a pivotal role in developing and implementing SRH services that are disability inclusive. The World Health Organization (WHO) recommends and advocates for meaningful engagement of OPDs. This creates health services that not only address the needs of persons with disabilities, but also further support active sharing of grassroots initiatives that make a difference in enhancing access to good quality SRH services that are appropriate for and acceptable to persons with disabilities.

Creating disability inclusive SRH services may not always be part of routine practice for health service implementers in many parts of the world. For many, the task of modifying and accommodating the needs of persons with disabilities can seem daunting. Awareness of the rights of persons with disabilities, and the rationale for why special attention must be given to designing inclusive health services, is the cornerstone of bridging the policy implementation gap and creating more accessible and equitable health services. Yet guidance for health service implementers on how to plan for and implement such services is currently lacking.

This Learning Product serves to address this need and presents a comprehensive package of information, guidance and practical tips for health service implementers. It has been designed with SRH service implementers in mind. However, much of the information is easily generalisable to other health programmes. The Learning Product serves three main purposes.

Firstly, it 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 important 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.

Secondly, the Learning Product harnesses the experiences of WISH country teams by documenting emerging pockets of good practice and highlighting efforts made to strengthen active and meaningful participation of OPDs.

Finally, we provide health service implementers with ‘A toolkit to establish meaningful partnerships with OPDs’. This toolkit has been developed by Leonard Cheshire to assist health service implementers to form mutually beneficial and meaningful partnerships in order to improve the quality of and access to healthcare for persons with disabilities. This compendium of tools is based on the insights of implementation teams working on Lot 1 of the WISH Programme who shared valuable lessons learnt after having forged partnerships with OPDs in Sierra Leone, Burkina Faso, Nigeria, DRC and Mali.

It is hoped that collectively, the offering will provide health service implementers with appropriate support and guidance as they build more inclusive and equitable health services.

# 1

# Introduction

The Women's Integrated Sexual Health (WISH) programme is the UK government's flagship programme aiming to strengthen support for sexual and reproductive health and rights (SRHR) in African and Asian countries by 2021. WISH aims to reach the most under-served people, particularly young people under the age of 20, and very poor and marginalised populations, including persons with disabilities. As such, the WISH consortium includes disability-focused partners and works with organisations of persons with disabilities (OPDs) in a variety of ways. This Learning Product is intended to provide important principles and practical guidance for sexual and reproductive health (SRH) programme designers and implementation teams who want to build stronger partnerships with OPDs, in the interest of providing more inclusive and accessible health services.

Important in-roads have been made in extending the coverage of SRH services universally. However, there are significant inequities that exist in the design and implementation of such services, especially as they relate to persons with disabilities, who represent an estimated 15% of the world's population[1]. SRH services cover a broad range of integrated services including family planning, screening and treatment for HIV/STIs and pelvic inflammatory disorders, access to contraception, safe abortion services and maternal, neonatal and child healthcare. While persons with disabilities have the same SRHR as persons without disabilities, their right to exercise them is often not realised. The challenges faced by persons with disabilities in accessing these services are not necessarily part of having a disability, but often reflect lack of social attention, legal protection, understanding and support[1].

Active steps must be taken to ensure that persons with disabilities participate and engage with SRH service designers and implementers so that that these barriers are overcome and their rights to SRH services are realised. In accordance with recommendations from the World Health Organization (WHO), the establishment of partnerships with OPDs represents an important driver towards realising the SRHR of persons with disabilities[1]. Close consultation and involvement of persons with disabilities in any planning process that concerns them is a right recognised in a variety of international conventions, strategies and polices. Of significance is the UN Convention on the Rights of Persons with Disabilities (CRPD) (Articles 9, 12, 16, 22-23, 25 and 32)[2] which outlines the commitments of member states to guarantee access to SRH services and protect the rights of persons with disabilities in this regard.

Developing effective partnerships with OPDs is therefore a cornerstone of any disability inclusive development effort. Harnessing lessons learnt about 'what works' in more contexts around the world will be paramount to realising disability inclusive health programming. Sharing lessons learnt about how to develop and sustain effective partnerships with OPDs is therefore the focus of this Learning Product. In compiling this resource, we drew on the experiences and expertise of the WISH Lot 1 country programme teams,* OPDs and persons with disabilities on 'what works' when developing inclusive, disability sensitive SRH services. While SRH services define the context of this Leaning Product, many of the general principles of working with OPDs are applicable to other health service programmers wishing to design and implement more inclusive health services.

---

* Lot 1 is a consortium managed by MSI Reproductive Choices with 8 of its country programmes and 6 IPPF Member Associations, DKT, Ipas, Leonard Cheshire and ThinkPlace, with a focus on West and Central Africa.

# 2

# Disability and the right to sexual and reproductive health services

## 2.1 What are sexual and reproductive health rights?

Sexual and reproductive health rights (SRHR) refers to the right for all people, regardless of age, gender and other characteristics, to make choices regarding their own sexuality and reproduction, provided that they respect the rights of others[3], [4]. The term includes the right to access information and services to support these choices and promote SRH[5]. The current focus on rights-based approaches to SRH represents a shift from policymaking based on population level rationales such as population growth, economic and environmental issues, to the recognition of the needs and rights of individuals[6]. SRHR apply to all people in the world, regardless of religion, ethnicity, culture, gender, age or impairment and are critical for gender equality[4]. SRHR combine four distinct but connected concepts: sexual health, reproductive health, sexual rights and reproductive rights[6].

The WHO contributes the following definition of sexual rights[1]:

"Sexual rights embrace human rights that are already recognized in national laws, international human rights documents and other consensus statements. They include the right of all persons, free of coercion, discrimination and violence, to:

- Achieve the highest attainable standard of sexual health, including access to sexual and reproductive health care services
- Seek, receive and impart information related to sexuality
- Access sexuality education
- Choose their partner
- Decide to be sexually active or not
- Enjoy consensual sexual relations and consensual marriage
- Decide whether or not, and when, to have children
- Pursue a satisfying, safe and pleasurable sexual life

The CRPD is an international human rights treaty of the United Nations that protects the rights and dignity of persons with disabilities[2]. Article 25 of the CRPD focuses specifically on the rights of persons with disabilities in relation to access to healthcare and recognises that "persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability"[2]. This is a powerful commitment that Member States make to upholding the rights of persons with disabilities. In so doing they must "take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation"[2].

In particular, clause (b) under Article 25 states that signatories to the Convention shall:

"Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons"[2].

Within the context of SRH, the CRPD obligates states to:

- Eliminate discrimination against persons with disabilities relating to marriage, family, parenthood and relationships, including recognition of the rights of persons with disabilities who are of marriageable age to marry and to find a family.
- Provide persons with disabilities with the same range, quality and standard of free or affordable healthcare and programmes as provided to other persons (including SRHR).
- Recognise the diversity of persons with disabilities and different needs of persons with different impairments.
- Ensure that multiple sectors, including health, education and justice sectors and their workforces, are sufficiently trained on the needs of persons with disabilities and their rights under the convention.
- Recognise that equal access to services includes considering accessibility to the physical, social, economic and cultural environment, and to information and communication.
- Emphasise the importance of mainstreaming disability issues as an integral part of relevant strategies to ensure sustainable development.
- Recognise the valued contributions made by persons with disabilities to society and the potential for enhanced participation in a nation's human, social and economic development.

Despite this, many persons with disabilities have unequal access to health services and therefore have unmet healthcare needs compared with persons without disabilities. This makes them more vulnerable to poor health outcomes. In the context of SRH services, persons with disabilities experience significant barriers to accessing such services due to societal attitudes and perceptions about persons with disabilities having active and healthy sex lives, despite their disabilities[6]. Persons with disabilities are often thought of as being asexual or hypersexual, incapable of reproduction and unfit for marriage and parenting or engaging in normal and healthy sexual relationships. It is because of these stereotypes that persons with disabilities are often not prioritised in the design and implementation of SRH services.

## 2.2 Barriers faced by persons with disabilities

The WHO has acknowledged that the ignorance of society and individuals, including healthcare providers, is most to blame in creating barriers to access SRH services[1]. Persons with disabilities encounter significant barriers when accessing SRH services, including individual, environmental, attitudinal and institutional challenges[7].

**Table 1: Factors affecting access to and uptake of family planning for women and girls with disabilities**
(Adapted from: Disability Inclusion Helpdesk Report [7])

| Individual | Environmental | Attitudinal | Institutional |
|---|---|---|---|
| **Intersecting and compounding** forms of discrimination and disadvantage, with barriers differing depending on type and severity of impairment.<br>**Universal factors** (aspects of one's identity regardless of setting), including age, gender, disability and health status.<br>**Contextual factors** (more complex and changeable factors that vary by setting), including language, race/ ethnicity/ caste, migration and refugee status, sexual orientation, family status. | **Physical barriers to access** at health centres and clinics e.g. a lack of ramps, adjustable beds, wheelchairs and disability-friendly sanitation facilities.<br>**Queues at health facilities** can compound physical barriers to accessing services.<br>**Long and difficult journeys to clinics,** particularly in rural and remote areas.<br>**Accessibility of family planning messaging,** e.g. difficulty understanding radio messages for people with hearing impairments, or TV not captioned or sign language. | **Perceptions that persons with disabilities are asexual** can lead to withholding information on the assumption that they will not need to know about sexual and reproductive health.<br>**Stigma, negative attitudes and discrimination** from health workers.<br>**Overprotective attitudes** and lack of communication by parents and caregivers.<br>**Gender-based violence** and particularly intimate partner violence can limit access to and uptake of family planning methods. | **Need for national policies** to tackle the reproductive rights of persons with disabilities.<br>Lack of age, gender and impairment-**disaggregated data** on access to and uptake of family planning.<br>**Lack of technical expertise** around family planning programming from a disability perspective.<br>**High costs** to persons with disabilities of accessing family planning services.<br>**Lack of confidentiality** if help with communication is required, particularly the case for adolescent girls. |

| Individual | Environmental | Attitudinal | Institutional |
|---|---|---|---|
| **Potential solutions** | **Potential solutions** | **Potential solutions** | **Potential solutions** |
| • Adopt person-centred care models that respond to the unique and possibly changing needs of a person with a disability over the life course.<br>• Promote linkages to support groups and psychosocial support services as early as possible to encourage a positive attitude towards disability.<br>• Organise sensitisation workshops with health service providers to raise their awareness on attitudinal barriers such as stereotyping, stigma, prejudice and discrimination and how this impacts persons with disabilities. | • Include accessibility as a criterion for outreach sites, and renovation or relocation of fixed sites.<br>• Bring the service closer to the client.<br>• Identify locations which are commonly used by clients with disabilities.<br>• Ensure queuing systems are accessible – e.g. provide chairs, inform clients about expected wait time and the system (calling numbers, number tokens etc).<br>• Provide client facing communications in multiple formats. | • Normalise serving clients with disabilities.<br>• Feature clients with disabilities within marketing materials.<br>• Include disability inclusion activities within provider training.<br>• Consider whether other experiences with gatekeepers can be learnt from and potentially adapted for clients with disabilities.<br>• When clients are brought by a caregiver, the focus must be on supporting the client to decide about the choices available to them. | • Invite OPDs to be part of national coalitions.<br>• Include disability in advocacy strategies.<br>• Develop partnerships with local OPDs.<br>• Identify a 'Disability Champion' within your organisation.<br>• Build inclusion into organisational and programme budgets. |

## 2.3 Building inclusive sexual and reproductive health services for persons with disabilities

The concept of SRH has evolved over time, from a sole focus on maternal and child health to including a more comprehensive set of services, designed to empower and promote healthy SRH choices over the course of a person's life[8], [3]. While advancements in approaches to SRH services have occurred over the years, the exclusion of persons with disabilities in the design of these services has resulted in this group being denied information about SRH and their right to have healthy sexual relationships. Being on the periphery of decisions about one's sexual health often means that persons with disabilities have to endure forced sterilizations or forms of contraception, forced abortions, or forced marriages[9], often without their consent. Research has shown that persons with disabilities are up to three times more likely than non-disabled persons to be victims of physical/sexual abuse and rape and that persons with intellectual and mental disabilities are the most vulnerable[10].

Responding to these historical injustices and building inclusive SRH services for persons with disabilities must become a priority for all health service designers. This can be achieved by [1]:

- Establishing partnerships with OPDs.
- Raising awareness and increasing accessibility for persons with disabilities.
- Ensuring that all SRH programmes reach and serve persons with disabilities.
- Addressing disability in national SRH policy, laws, and budgets.
- Promoting research on SRH of persons with disabilities at local, national, and international levels.

OPDs play a pivotal role in advocating for inclusive SRH services for persons with disabilities. As such, a fundamental component of any strategy aiming to fulfil the sexual and reproductive health rights of persons with disabilities should include meaningful partnerships with OPDs so that their unique SRH needs are comprehensively understood.

# 3

# Organisations of Persons with Disabilities (OPDs) and their value in society

## 3.1 What are Organisations of Persons with Disabilities?

Organisations of Persons with Disabilities (OPDs) are organisations established by and for people with disabilities. They are composed of and governed by a majority of people with disabilities at membership and leadership level, but may also include family members or caregivers where individuals have less agency to themselves (e.g. children with disabilities or individuals with profound or intellectual disabilities)[11], [12].

There are different types of OPDs: those that represent a particular kind of disability, those that have a specific population focus and those that have a cross disability focus. In many countries, OPDs will undergo a process of formal registration, but this is not the case for all groups. OPDs may go by a number of different names such as disability Self-Help Groups (SHGs) or savings and lending groups which focus on the needs of persons with disabilities. While the structure of each of these types of organisations may differ slightly, the general term ‘OPD’ is used to describe all types of Organisations of Persons with Disabilities.

Previously, the term Disabled People’s Organisations (DPOs) has traditionally been used; however, internationally, there appears to be a shift towards the adoption of the term Organisations of Persons with Disabilities (OPDs) in alignment with the language of the CRPD. The terms ‘Organisations of Persons with Disabilities (OPDs)’ and ‘Disabled People’s Organisations (DPOs)’ may sometimes be used interchangeably. However it is good practice to encourage the use of the former and be directed by the organisations themselves.

## 3.2 Definitions and terminology

**Organisations of persons with disabilities (OPDs)**
The International Disability Alliance (IDA) defines OPDs as “....global or regional organisations whose mission and objectives are about the promotion of the rights of people with disabilities”[13].

The Office of the High Commissioner for Human Rights (OHCHR) defines OPDs as those that are “governed, led and directed by persons with disabilities, are comprised by a majority of persons with disabilities themselves, and representative of persons with disabilities”. The OHCHR defines the following characteristics of OPDs[14]:

1. Persons with disabilities themselves can be representatives and employees of OPDs, entrusted by and specifically appointed by OPDs. The large majority of OPDs are not affiliated to political parties and are independent from non-governmental membership-based organisations. They are established with the aim of collectively acting, expressing, promoting, pursuing and/or defending the rights of persons with disabilities and should be generally recognised.

2. They may represent one or more different constituency (ies) among persons with disabilities, and reflect a broad range of persons with disabilities, which reflects the diversity of people’s backgrounds, including race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status, and should meaningfully participate in an inclusive and accessible manner in direct

decision-making processes that affect the lives of persons with disabilities at all levels and within all sectors of States parties.

3. They can operate as individual organisations, coalitions, cross-disability or umbrella organisations of persons with disabilities, including among other women, children, indigenous and sports organisations of persons with disabilities, seeking to provide a collaborative and coordinated voice of persons with disabilities in their interaction with, among others, public authorities and private companies.

**Umbrella organisations of persons with disabilities**
OPDs that gather, coordinate and represent the activities of a number of member organisations, which promote the accessibility for and inclusion of all persons with disabilities within a country. Preferably the organisations represented work with persons with different impairments. As such, an umbrella DPO/OPD can and should ensure the participation of persons with all types of disabilities in the consultation, decision-making and monitoring processes [14].

**Cross disability organisations**
Organisations that represent persons with different kinds of disabilities. By contrast umbrella OPDs represent a number of organisations which each represent one or more related disabilities. There is usually only one or perhaps two umbrella OPDs in a country[14].

**Organisations of self-advocates**
These are composed of and represent persons with intellectual disabilities, autistic persons or persons with psychosocial disabilities. Their establishment, with appropriate, sometimes extensive, support to express their opinions, is indispensable to guarantee their participation in decision-making, monitoring and implementation processes. Such support includes any necessary form of reasonable accommodation. While organisations of parents and relatives of persons requiring support have often played a role in providing such support, it is important to ensure that persons with disabilities are and remain in full control [14].

**Organisations of parents of children with disabilities**
These organisations are key to facilitating, promoting and securing the interests, autonomy and active participation of their children with disabilities and should be included in consultation, decision-making and monitoring processes [14].

**Organisations of women with disabilities**
These organisations ensure the participation of women with disabilities and must also be considered as a requisite in consultations addressing specific issues impacting exclusively or disproportionately on women with disabilities, as well as issues related to women in general, such as gender equality policies [14].

The United Nations Department of Economic and Social Affairs provides the following key definitions aligned to CRPD[14]:

- **“Communication”** includes languages, display of text, Braille, tactile communication, large print, and accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.
- **“Language”** includes spoken and signed languages and other forms of non-spoken languages.
- **“Discrimination on the basis of disability”** means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.
- **“Reasonable accommodation”** means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.
- **“Universal design”** means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design. “Universal design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.
- **“Leave no-one behind”** refers to the 2030 Agenda which consists of a Declaration, 17 Sustainable Development Goals (SDGs) and 169 associated targets. It is a vision and set of plans that seeks to ensure that all nations and all people everywhere are reached and included in achieving the SDGs. Paragraph 23 states that “Those whose needs are reflected in the Agenda include all children, youth, persons with disabilities (of whom more than 80% live in poverty), people living with HIV/AIDS, older persons, indigenous peoples, refugees and internally displaced persons and migrants.

## 3.3 What functions do OPDs play in society?

OPDs are important structures within societies and play a role in facilitating self-representation and amplifying the voice of persons with disabilities. A review of literature on the functions of OPDs in low and middle-income countries found evidence that OPDs often engage with persons with disabilities to promote their participation in society [11]. The role of OPDs is central to addressing the persistent challenges faced by persons with disabilities in accessing SRH services[15], [16].

However; the OHCHR [14] highlights the importance of distinguishing between organisations ‘of’ persons with disabilities, which are composed of and controlled/led by persons with disabilities, and organisations ‘for’ persons with disabilities, which are any organisations established to provide services to and for persons with disabilities, as there exists the risk that the latter, in advocating on behalf of persons with disabilities, may instead advocate for their own gain.

By virtue of their mandate, OPDs:

- Have greater awareness and knowledge of the rights of persons with disabilities and can build confidence among persons with disabilities to become active members of society.
- Have strengths in driving advocacy activities and engaging in political processes that support greater representation of persons with disabilities.
- Can support the various agendas that seek higher levels of inclusion and self-representation by facilitating greater sense of connection to society among persons with disabilities and ensuring self-representation.
- Have a broad range of functional scope and can be active at grassroots level all the way through to functioning as national umbrella bodies that lobby support for disability rights and democratic representation of persons with disabilities.
- Play an important role in facilitating information-sharing among organisations of persons with disabilities and have access to a wide network of organisations who support people with disabilities and promote the realisation of their rights.

Useful resource: **www.independentliving.org/docs5/RoleofOrgDisPeople.html**

## 3.4 Obligations of States to ensure participation of OPDs in decisions that impact persons with disabilities

The participation of OPDs is a fundamental principle of democratic societies[17]. If persons with disabilities are not involved in decision making processes that involve and impact their lives, their ability to have control over their lives is compromised. This is in stark contrast to Article 4.3 of the CRPD [2] which clearly articulates the obligation for States to closely consult and actively involve persons with disabilities, including children with disabilities, through their representative organisations. This obligation applies at all levels (local, national, regional, international), in all areas that directly or indirectly impact the rights of persons with disabilities and across all decision-making mechanisms. This also applies to international cooperation, which should be inclusive of and accessible to persons with disabilities (as recalled by CRPD Article 32)[2]. OPDs are also given scope to serve as representative organisations and intermediary bodies between policy makers and persons with disabilities, who bring a unique perspective to speak on behalf of persons with disabilities[17].

## 3.5 Understanding the barriers faced by OPDs

To be able to engage meaningfully with OPDs, it is vital to understand the reasons behind their existence, and the international imperatives supporting their participation. It is also important to have an appreciation of the challenges they experience as organisations. The existence of OPDs has been largely driven by barriers which impact on the rights of persons with disabilities to enjoy equal participation in society. Persons with disabilities are often “spoken for” by health professionals, family and others without regard to their needs, priorities or choices. However, persons with disabilities have their own voices and should be given the opportunity to express their own needs and aspirations. OPDs therefore play an important role in promoting self-representation and full participation of persons with disabilities. Despite best efforts, many OPDs experience persistent challenges that often impact on their ability to function optimally.

Some of the reported challenges faced by OPDs include[11]:

- Lack of financial and human resources
- Lack of empowerment experienced by persons with disabilities who are involved in partnerships with external organisations and professionals
- Difficulty in maintaining continuity of group members
- Attitudinal barriers of societies that promote discriminatory practices towards persons with disabilities
- Poor access to OPDs for persons with disabilities living in rural areas
- Difficulty in accessing venues and transport for group meetings
- Exclusion of persons with disabilities from mainstream self-help groups (SHGs)
- Lack of accurate raw data on disability type and prevalence in developing countries

While not all OPDs may encounter challenges, it is important to be aware of them so that partnerships can be designed to strengthen OPDs’ effectiveness and create opportunities for improved sustainability. Barriers faced by persons with disabilities in accessing SRH services can also be categorised into five levels: broader national level barriers; healthcare system/institutional barriers; individual level barriers; community level barriers; and economic barriers. The barriers may also be specific to particular forms of disabilities and varied across different SRH services[18].

## 3.6 Key principles in developing meaningful partnerships and engagements with OPDs

To engage OPDs in a meaningful way for the benefit of persons with disabilities, we must first assess our commitment to living the values of the “leave no one behind” agenda. This is not just about ensuring the minimum standards of societies are met, but is also about enabling people and groups who are left behind to progress at a higher rate than those who are better off[1]. Partnerships with OPDs create new opportunities to strengthen disability inclusion within a variety of development programmes and are particularly important within the health sector. SRHR are fundamental rights which are currently not being met for persons with disabilities. When embarking on a partnership with an OPD, we should have a solid understanding of the following five principles:


Principle 1: The human rights rationale
Principle 2: Meaningful partnerships
Principle 3: Power-shifting
Principle 4: Commitment to build capacity
Principle 5: Creating opportunities for sustainability

## Principle 1

### The human rights rationale

Health programme designers and implementers have an obligation to fully understand the rights of persons with disabilities, the commitments of countries to the international agenda to "leave no-one behind" and the impact that inaccessible health services have on persons with disabilities. Within the context of SRH services, inclusion and participation should include[19]:

- Recognition of persons with disabilities as a vulnerable population in need of special protection, especially in areas of health service delivery where barriers have significant impact on their right to choice and self-representation.
- Protection of the rights of persons with disabilities, in particular the rights to equality and prohibition of unfair discrimination and inequality. This includes the right to privacy, a consensual sexual life, family planning, parenthood, violence protection, and access to health and educational services including all SRH services.
- Application of the CRPD concepts of universal design and reasonable accommodation in the provision of SRH-related intervention, prevention, treatment, care and support services so that they are also accessible and appropriate for persons with disabilities.
- Promotion of inclusion of disabilities in mainstream research, monitoring and surveillance relating to SRH as well as targeted research programmes.
- Provision of awareness, information, education and training on the rights of persons with disabilities in the context of SRH, in order to increase awareness of rights, improve access to justice and enforcement, and to change attitudes of discrimination and stigmatisation associated with disability.

## Experience from WISH

### 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 finally 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[18].

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 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.

## Principle 2
Meaningful partnerships

> **“Give us a voice, give us a chance to contribute to decisions. We are able to decide what we think is important for us.”**
> OPD Leader, WISH annual learning event

Partnerships are sometimes difficult to define because they exist for many different reasons and serve a variety of different functions. When partnerships are created with a clear common purpose and well-defined objectives, all parties involved enter into the partnership carrying expectations and responsibilities to deliver in accordance with the mandate of the partnership.

The International Disability Alliance describes meaningful participation as “participation that respects, values and considers the unique role and perspective of OPDs as organisations representing the diversity of persons with disabilities, and enables their regular and effective engagement, by ensuring equal opportunities to contribute to decision making. Meaningful participation as expected from OPDs is participation that seeks the highest levels of shared decision-making on all issues that concern persons with disabilities, whether for domestic issues, through international cooperation or in situations of risk and humanitarian emergencies.”

There is often a mismatch between OPDs and health service planners and implementers on the definition of a meaningful partnership. It is important that time is invested at the beginning of a partnership to discuss shared values and expectations of each partner in relation to what the partnership means and what it will achieve. A project charter or Memorandum of Understanding (MOU) capturing commitments and shared values may be a valuable guide for those entering into a partnership with an OPD. Persons with disabilities want to have the opportunity to function as equals within a partnership and are strongly in favour of self-representation. For example, A meaningful partnership for an OPD may be a commitment to self-representation and the creation of spaces where persons with disabilities can voice their concerns and suggestions.

## Experience from WISH

### Partnership for policy formulation in Burkina Faso

In Burkina Faso, under the leadership of Options, the WISH programme has supported the Reproductive Health Technical Working Group (Le Groupe Technique de la Sante de la Reproduction (GT/SR) – a group of around 30 international organisations, NGOs and national associations working in the field of SRHR. The group has been working with the government to create a more enabling environment for the respect, protection and fulfilment of SRHR and holds the government to account for those commitments.

Despite Burkina Faso's political will and subscription to conventions and commitments, there remain obstacles for the inclusion of persons with disabilities in the processes of SRHR policy formulation. This impacts on their ability to access quality services. In order to address this, Options has worked in partnership with the Burkinabé umbrella organisation of persons with disabilities (la Fédération Burkinabé des Associations pour la promotion des personnes handicapées or FEBAH), to understand and address the barriers faced by persons with disabilities to equitable access to SRH services in their communities. This partnership has involved a number of different activities, including:

- Strengthening the role of OPDs within civil society.
- Ensuring persons with disabilities are involved in decision making processes within civil society coalitions focused on SRH, including the GT/SR, by updating their governing terms of references to recognise the contribution of OPDs.
- Involving persons with disabilities in the planning and implementation of the organisational self-capacity assessment of the GT/SR.
- Initiating an implementation plan with national SRHR stakeholders to accompany actions to improve the SRH environment for people with disabilities.
- Building the capacity of OPDs to influence SRHR advocacy efforts.
- Developing FEBAH's capacity on accountability and evidence-based advocacy for its inclusion at the design phase as well as in implementation mechanisms of SRHR plans and programmes.
- Orienting persons with disabilities on Burkina Faso's policies and programmes and commitments on SRHR and the advancement of marginalised groups.
- Options supported FEBAH to hold a 2-day national consultative stakeholders meeting to discuss policy and services delivery barriers which are limiting persons living with disabilities to have access to quality SRH / Family Planning (FP) services. Based on the findings of this consultative meeting, FEBAH developed a roadmap to advocate for an acceleration of access to SRH services for people living with disabilities in Burkina Faso.
- FEBAH, as a member of the national Civil Society Coalition, participated actively in the Ministry of Health national consultative meeting aimed to collect civil society perceptions and feedback on the degree of effectiveness of the Burkina FP 2017-2020 Costed Implementation Plan.

## Principle 3
### Power-shifting

Power-shifting refers to the shift in the balance of power regarding how, and by whom, disability issues are raised. It is about giving persons with disabilities a seat at the decision-making table and is central to creating meaningful partnerships with OPDs. It is a commitment that should not be entered into without a comprehensive understanding of the implications on resources and time. To shift the locus of power to an OPD means having trust that certain decisions and/or tasks are better driven by OPDS, who have greater experience and expertise in understanding the needs of persons with disabilities. Power-shifting requires careful consideration of the strengths and weaknesses of both partners and the ability to have an open discussion about who is best placed to lead certain activities, and under which conditions this leadership would be most effective. Implementing organisations who typically adopt the leadership role and are the locus of power in such partnerships must be willing to critically reflect on the ways in which they may be limiting or promoting power-shifting when working with OPDs.

## Experience from WISH

Shifting power in Sierra Leone

MS Sierra Leone (MSSL) provides post-abortion care, family planning, HIV/STI testing and maternal services across all regions of Sierra Leone, and has been doing so since the late 1980s. Despite the organisation's excellent track record in providing SRH services in Sierra Leone, their exposure to designing health services for persons with disabilities was somewhat limited.

Through the consortium, MSSL, with technical support from Leonard Cheshire, piloted an inclusive SRH service for persons with disabilities. Leonard Cheshire advocated for the inclusion of the Sierra Leone Union on Disability Issues (SLUDI). SLUDI is a disability umbrella organisation in Sierra Leone consisting of national civil society organisations working on disability issues. Membership includes OPDs from across the country, with about 120 registered member organisations across the Northern, Southern and Eastern provinces. In this case, there was little doubt that SLUDI had a powerful national footprint as a formidable disability advocacy organisation and would make an ideal partner to drive disability inclusive SRH services within MSSL.

Together, this three-way partnership between MSSL, Leonard Cheshire 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. As a disability umbrella organisation in Sierra Leone, SLUDI was able to engage its community of persons with disabilities in a way that neither Leonard Cheshire nor MSSL could on their own.

Partnerships expand access to persons with disabilities. The partnership between SLUDI, Leonard Cheshire and MSSL facilitated improved access to services for persons with disabilities, OPDs and service clusters. The partnership also raised MSSL's awareness of the missing scope of some of its services, such as reaching women with disabilities in the rural interior.

## Principle 4
### Commitment to build capacity

OPDs are often financially constrained, as they often function as volunteers and do not get paid for the work they do. While there has been some improvement in financial support for OPDs in recent years, many OPDs still experience funding constraints that impact on their ability to function independently and autonomously [17]. They can also experience a lack of technical and operational capacity to engage as may be required in a partnership. When setting up a partnership, financial support for OPDs is an important issue to be considered upfront. Guidance on budgeting and understanding additional costs for accessibility are critical conversations to be had at the beginning of the partnership. This should be combined with open discussion with the OPD about what they feel their capacity weaknesses are and what kinds of support they would need for optimum functioning within the partnership. Supporting OPDs with costs to travel may have a direct impact on their ability to participate meaningfully in project activities and should be considered as a high value item on a project's budget.

Supporting evidence-based decision making is an important skill for all partners working in the development sector. At an operational level, reliable collection of data for project management and evaluation purposes may be negatively impacted by the poor data collection infrastructure or limited capacity of OPDs. Supporting OPDs to improve their ability to collect and/or use data for planning and decision making and investing in more accessible data collection systems may be a valuable investment for the partnership. At a strategic level, supporting OPDs in the use of high-quality evidence for advancing their advocacy programmes is an investment in their sustainability and support for disability inclusive health services.

## Experience from WISH

### Establishing partnership frameworks in Mali

In 2008, MSI Reproductive Choices began working in Mali and has since achieved significant increases in contraceptive services through its dedicated work to reach youth, and other critically under-served groups, in accessing accurate information about contraception and family planning services. MS Mali partnered with the Fédération Malienne des Personnes Handicapées (FEMAPH) to implement the WISH programme, through promoting access to reproductive health and family planning services for persons with disabilities. FEMAPH is the Malian umbrella federation of 15 national associations of persons with disabilities with regional and local federations. It is the main liaison with the State in the implementation of its policy for the promotion of persons with disabilities.

Discussions between the partners led to the agreement of a Framework designed to:

- Strengthen the partnership and ways of working by sharing information and contact details of FEMAPH member associations throughout the country and designating focal points within MS Mali at national, regional and district level for effective programming and coordination of activities.
- Increase access to inclusive, accessible SRH information through the development of a plan and a common agreement to deliver awareness sessions, and through sharing information about the services provided by MS Mali's mobile teams. The awareness sessions consisted of five educational talks/lessons/focal points in collaboration with the MS Mali's Social Marketing Agents (SMAs).
- Increase access to adapted, inclusive SRH services through the provision of high quality reproductive health and family planning services (short, long and permanent methods) free of charge to members of FEMAPH associations by MS Mali's teams.

The Framework and joint agreements facilitated a high degree of ownership and were instrumental in enhancing accountability. They also facilitated appropriate and accurate monitoring and evaluation of the project's performance.

## Principle 5

### Creating opportunities for sustainability

OPDs often experience significant challenges in maintaining their sustainability and have limited capacity to continue their activities without incurring financial hardship. One of the ways that the WISH programme has responded to this challenge is by supporting OPDs to be more visible. The programme has also created strategic opportunities for OPDs to establish themselves more firmly as part of government structures where they are able to contribute more effectively to the disability rights agenda. Opportunities to strengthen the visibility and advocacy power of OPDs do not always need to be cost intensive. Simple yet strategic initiatives can achieve great impact if careful thought is given to networking and linking OPDs to high-level decision-making forums and committees which they can continue to participate in beyond the lifespan of the partnership. These opportunities may provide important gateways to funding and a more sustainable future for OPDs.

## Experience from WISH

### Strategic multi-sectoral partnerships in Cameroon

The International Planned Parenthood Federation's member association, the Cameroon National Association for Family Welfare (CAMNAFAW), serves as the country's leading provider of a complete range of SRH services to populations in the greatest and most urgent need of SRH support, in partnership with government and non-governmental organisations (NGOs).

Through the WISH programme, CAMNAFAW expanded regional SRH service access in the Southern and Western regions of Cameroon by opening two medical centres, in the towns of Ebolowa and Bafoussam. These centres aimed to provide SRH promotion and service delivery, as well as community engagement, to increase access and awareness of available health services. In the context of the WISH programme, where access to services for persons with disabilities is a core component, CAMNAFAW served as an ideal partner in ensuring public sector support for the WISH project objectives in these towns.

Through the WISH programme, CAMNAFAW has secured long-term public sector engagement for SRH services through multi-sectoral partnerships. These partnerships have included close collaboration with the Ministry of Social Affairs, which is responsible for the welfare of persons with disabilities, and the Ministry for the Promotion of Women and Family.

In addition to government collaboration, partnerships have also been established with educational institutions – including schools and technical centres for people living with disabilities, and universities in Douala and Dschang.

Partnerships were established with medical centres in rural communities and connected to educational institutions. Community radio stations were used to ensure that surrounding communities were aware of the locations of new health facilities and the services they provided.

Through these strategic partnerships, CAMNAFAW ensured that various activities were conducted in 2020, including:

- Capacity building and values clarification activities with government departments, with a particular emphasis on gender-based violence – to which persons with disabilities, specifically women with disabilities, are particularly vulnerable.
- A sensitisation campaign in Bafoussam on SRH needs for persons with disabilities, working with disability partners to focus on youth and persons with disabilities.
- Co-facilitation of training with two disability inclusion focused community-based organisations to train service providers on how to ensure access to services for persons with disabilities. It also incorporated Sexual and Gender-Based Violence training for counsellors and referral services to recognise and support vulnerable clients and community populations.

## 3.7 Who benefits when partnership engagement is meaningful?

Striking the right balance so that meaningful participation has mutual benefit is important. Some benefits for both OPDs and health service planners are outlined in the table below.

**Table 2: Who benefits when engagement is meaningful?**
(Source Leonard Cheshire [20])

| OPDs | Implementing partners |
|---|---|
| • An opportunity to address issues related to living with disability<br>• May gain recognition for skills and experiences shared<br>• Provides opportunities to influence policies and programmes which can have an impact<br>• An opportunity to provide the perspective of persons with disabilities and affect decision making<br>• An opportunity to develop personal/organisational strategy/activities<br>• May receive financial recompense for services provided | • Provides credibility and legitimacy that the organisation represents and supports the 'voice' of persons with disabilities<br>• Increases capacity by leveraging on skills and abilities of persons with disabilities<br>• Doing work that is relevant<br>• Decision-making is informed<br>• Easier to identify gaps in approach<br>• Ensures that the work is appropriate and addresses real concerns/issues of persons with disabilities<br>• Adds depth to the organisation's culture, dispelling myths and stereotypes<br>• Should impact staff positively |

# 4

# Strategies and tactics to successfully achieve meaningful partnerships with OPDs

The creation of partnerships often follows a structured process. It generally starts with comprehensive pre-partnership analysis or partnership initiation activities, followed by more specific activities around partnership planning, implementation and evaluation. This section describes the four key development phases for organisations who want to have meaningful partnerships with OPDs.

The four phases are:

1. Pre-partnership assessment
2. Partnership planning
3. Implementation and monitoring
4. Evaluation and lessons learned

A set of tools has been developed for each phase to provide teams with more concrete guidance when working with an OPD partner. The tools are available in the appendix to this resource. They provide a compendium of support and guidance for teams at any partnership phase and can be used sequentially at specific phases of the partnership.

An important component of any enduring partnership is the ability of partners to reflect critically on the merits of the partnership and take corrective action to maximise or improve their collective impact. Active participation of the OPD in all aspects of the project planning and implementation is vital to creating a meaningful partnership.

## Phase 1: Pre-partnership assessment

In general, it is good practice to begin active engagement with OPDs and persons with disabilities as early as possible, rather than merely asking them to comment on work and contribute to policy messaging or 'decisions' that have already been agreed upon. It will help to secure the commitment of all parties involved and can raise the profile and credibility of your organisation with OPDs. This would be especially beneficial if your aim is to build long-term strategic partnerships with OPDs and experts. The Pre-partnership analysis phase should aim to frame the problem that the project is trying to solve for persons with disabilities.

**Example:** Poor knowledge among healthcare workers about barriers to healthcare faced by persons with disabilities hinders access to contraception. The result is that services do not reach vulnerable women with disabilities.

**Possible solution:** A possible solution would be to partner with OPDs to improve the project team's understanding of these barriers and co-create SRH services to improve access to contraception for women with disabilities.

It may be helpful to conduct an internal review of your team's commitment and overall understanding of disability-related matters **(Tool 1 – Part 1 Internal Organisational Assessment)** and identify areas where you may need additional support or training. Thereafter, it may be useful to assess how the OPD's experience and organisational capacity aligns with and supports the project goals **(Tool 1 – Part 2 Assessment of OPDs and need for additional support)**.

## Helpful tips

- Ensure that the aims and objectives of the project are clearly described and the role of the OPD with whom you wish to partner has been described in detail.
- Compile a draft Memorandum of Understanding (MOU) to guide discussions with the OPD.
- Familiarise yourself with the CRPD and the barriers faced by persons with disabilities.
- Visit the International Disability Alliance (IDA) website: **www.internationaldisabilityalliance.org**
- Visit the Leonard Cheshire Website for more information on self-representation: **www.leonardcheshire.org**
- The WHO World Report on Disability outlines the key barriers faced by persons with disabilities: **www.who.int/disabilities/world_report/2011/report.pdf**
- Have formative discussions with potential OPD partners with whom you already have an established relationship, and with those you have not worked with in the past.
- Develop a list of OPDs, networks and ‘experts’ with disabilities that you have worked with or would like to in the future.
- Search for OPDs who have a strong presence in the region/country or local community you wish to work in, and seek advice on the type of expertise and experience you are looking for in a partner.
- When engaging with OPDs for the first time, be aware of the accessibility requirements and the additional costs associated with ensuring that they participate actively throughout the project.
- Set up an OPD Reference Group or Steering/Advisory Group to orientate on the issues and generate interest, as well as identify those with relevant experience. Several pan-disability OPDs have more of a presence with communities with physical disabilities than people with sensory disabilities (Deaf, Blind and/or visually impaired and intellectual disabilities). You will need to reflect on which constituencies they represent and whether this is strongly aligned with the goals of the project and partnership.
- Some OPDs are very good at the national level but won’t necessarily have a strong footprint at the local level. It may be useful to understand an OPD’s influence and presence at the various levels that are relevant to the project.
- OPDs tend to have strong established networks with government and civil society which may prove valuable to the project.
- It may be the case that OPDs do not have experience in a particular area of expertise. Adequate resources and a willingness to provide additional capacity strengthening in this area may be required to optimise the partnership.

## Phase 2: Partnership planning

Partnership planning should aim for partners and stakeholders to have a shared vision of the ultimate aim and purpose of their partnership. When working with OPDs, partnership planning must be viewed from the perspective of the OPD and through a disability inclusion lens. Failure to do so may impact on the ability of OPDs to function optimally. Key elements of partnership planning generally include identifying all stakeholders, defining roles and responsibilities, holding inception and kick-off meetings, defining the partnership scope, reflecting on budgets, timelines and defining a set of priorities, for the lifespan of the partnership.

### Helpful tips

- Sign an MOU/Project Agreement/Project Charter that clearly outlines the roles and responsibilities of all stakeholders.
- Develop an appropriate, sustainable and practical approach to team communication. OPDs are often involved in other activities related to their primary mandate and will likely value being informed of meeting dates well in advance.
- Ensure that your core planning team includes a representative from the OPD partner.
- Be intentional about inclusion during this phase. It is possible that OPDs have limited experience in certain aspects of project planning and may not be comfortable volunteering their opinions.
- Create a schedule for reporting and provide guidance on what is expected of OPDs in terms of their contributions to key reports.
- Provide enough time for OPDs to review documents and provide inputs. This is especially important when drafting budgets.
- Ensure that accessibility remains a key feature of this phase so that OPDs are not left behind in contributing to critical issues.

## Phase 3: Implementation and monitoring

Partnership implementation and monitoring are inextricably linked. There are many important learning points within this phase. In an ideal world, if partnership planning is well executed, the implementation should be smooth sailing. However, the reality is that there is a need for constant monitoring of progress to ensure that the partnership stays on track.

For an OPD, project monitoring provides an important opportunity for evaluating the extent to which the OPD can contribute in the intended way. A good monitoring system must as far as possible involve OPDs through participatory and inclusive methods and should encourage active learning. If done well, partnership monitoring can be an important method of building ownership and accountability and promoting efficiencies and sustainability within OPDs.

### Helpful tips

- Ensure that the partnership is embedded within an operational plan that includes the monitoring framework which all partners are familiar with.
- Partnership monitoring tools should be workshopped if possible. OPDs should be encouraged to make inputs on their limitations around infrastructure and capacity to perform routine monitoring exercises.
- Find opportunities to build capacity in data analysis and reporting with an OPD. The tendency may be to take over the process due to time constraints and other project imperatives. However, time invested at the beginning of the project in building capacity and investing in appropriate infrastructure for OPDs may show dividends beyond the end of a project.
- Invite OPDs to the project kick-off meeting where the global goals of the project can be discussed. Ensure that a member of the OPD is a standing member of the core team.
- OPDs may have members who have specific needs in order to engage with project materials and participate in project meetings. Do not wait for the arrival of your OPD partner at the meeting venue to establish these needs. It is best practice to have these discussions in advance so that there is no risk to their participation.
- Have meetings where all team members are encouraged to join and participate. It is often through opportunities like these that OPDs can build their understand of aspects of project work that they may not be familiar with and vice versa.
- Basic training on disability-related issues may prove invaluable to creating a common understanding of the barriers faced by persons with disabilities.
- Ensure that the OPD is fully aware of any performance-based assessments and provide regular and consistent feedback.
- Prioritise safe spaces for open discussion about the performance of the OPD.

## Phase 4: Evaluation, feedback and lessons learned

Evaluating a partnership means performing a rigorous analysis of completed goals, objectives and activities to determine whether the partnership has produced planned results, delivered expected benefits, and created the desired change. In the context of partnerships with OPDs, the need to evaluate the extent to which OPDs and your organisation have achieved meaningful partnership is an important matter to reflect on.

### Helpful tips

- Dedicate time throughout the partnership for all stakeholders to actively engage in critical aspects about whether all stakeholders are upholding the principles of a meaningful partnership.
- Run learning workshops that are accessible to OPDs so that their perspective on successes, limitations and lessons learnt can be harnessed.
- OPDs often have the potential to provide unique glimpses into contexts that fall outside of the routine or standard practices. Find ways to tap into these experiences and encourage OPDs to take the lead in capturing their experience, and sharing this with the broader team.

# 5

# Key recommendations for implementing partners seeking meaningful partnerships with OPDs

## 5.1 Recommendations: Project design stage

- Give OPDs the chance to be included at the start of any project. This will lay a solid foundation for meaningful partnerships to be formed.
- Disability inclusion and partnerships with OPDs often need more than a willingness to work together towards a common vision. Adequate funding to support inclusion and reasonable accommodation is required. When these are not appropriately budgeted for, the goal of achieving meaningful partnership may be compromised.
- Involve implementation teams, OPDs and beneficiaries from the project design stage onwards. This facilitates ownership of the project objectives and ensures that the aspirations and needs of beneficiaries are taken into account.
- Find strategic opportunities to work closely with the technical departments of ministries and NGOs targeting persons with disabilities.
- When working at a country level, research and aim to understand the respective country's commitments and international mandates as well as the institutional framework adopted when working with persons with disabilities.

## 5.2 Recommendations: Capacity-building

- Invest in becoming disability sensitive as an organisation. Organisations with a high level of disability consciousness can drive the power-shifting agenda because they understand the impact of human rights violations and the importance of supporting disability inclusive health services.
- Carry out an organisational assessment of OPDs. This enables them to better identify gaps to integrate SRHR in their priorities. It may also assist in establishing the strengths of OPDs prior to forming partnerships so that partners can play to their strengths in developing and implementing SRH services for persons with disabilities.
- Where possible, create opportunities for capacity building and power-shifting. This should ideally be identified by the OPD.
- Support OPDs to use good quality evidence in developing their key advocacy messages and selecting their targeted audience. Organisations who adopt evidence-based decision-making practices are more successful in securing support from key stakeholders.

## 5.3 Recommendations: Reflecting on what does and does not work

- Organisations and OPDs should do a routine evaluation to determine what has worked well/what has not so that focused attention can be given to aspects of the partnership that need strengthening. Monthly or quarterly meetings should be encouraged where these critical aspects of partnership can be reviewed and discussed.

- Learning workshops present an ideal opportunity for dedicated time to be spent on reflecting on lessons learnt and how ownership can be enhanced between partners.

## 5.4 Recommendations: Creating decision spaces and highlighting accomplishments and strengths

- Where possible, provide decision spaces to the OPD where they are in true command of a given activity or outcome.

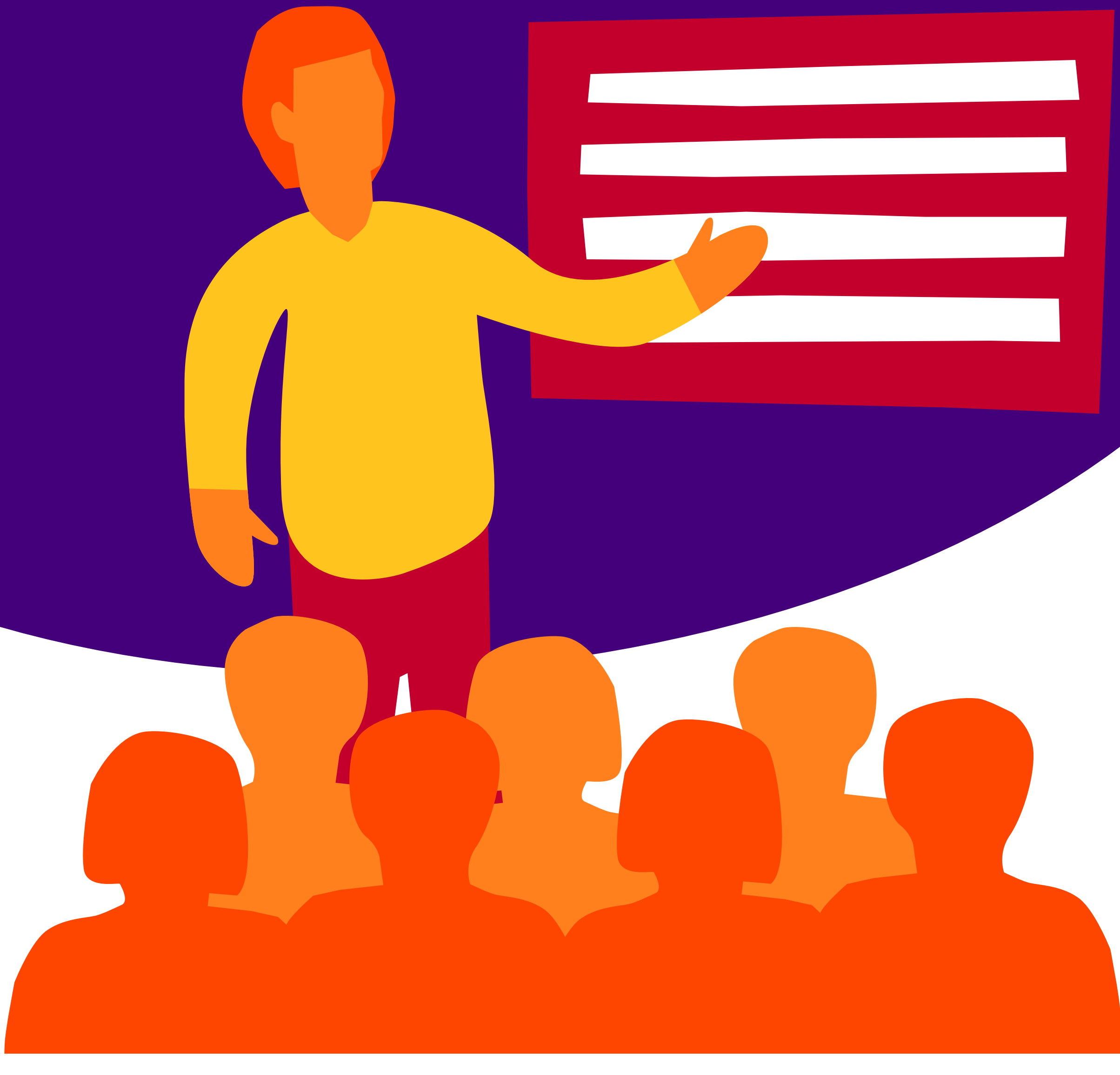
- Find opportunities throughout the partnership to highlight the strengths of the OPD in terms of their strategic networks and influence within government, local municipalities and local communities.

# References

1. World Health Organization, Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA guidance note. 2009, WHO: Geneva.
2. UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution / adopted by the UN General Assembly, Editor. 2008: Geneva.
3. Griffin, S. Literature review on Sexual and Reproductive Health Rights: Universal Access to Services, focussing on East and Southern Africa and South Asia. 2006.
4. Fathalla, M.F., Sexual and Reproductive Health: Overview. The International Encyclopedia of Public Health, 2017. 6: p. pp. 481-490.
5. World Health Organization, Consolidated guideline on sexual and reproductive health and rights of women living with HIV. 2017: Geneva.
6. Fonds, L., Sexual and reproductive health rights. 2019: Netherlands.
7. Fraser, E.a.C., N., Family Planning for Women and Girls with Disabilities in Disability Inclusion Helpdesk Report. 2019, UKaid: London.
8. Griffin, S., Literature review on sexual and reproductive health rights: Universal access to services, focussing on East and Southern Africa and South Asia. 2006.
9. UNFPA, Emerging issues: sexual and reproductive health of persons with disabilities. 2007, UNFPA: New York.
10. Tanabe, M., et al., Intersecting Sexual and Reproductive Health and Disability in Humanitarian Settings: Risks, Needs, and Capacities of Refugees with Disabilities in Kenya, Nepal, and Uganda. Sex Disabil, 2015. 33(4): p. 411-427.
11. Young, R., Reeve, M.,Grills, N., The Functions of Disabled People's Organisations (DPOs) in Low and Middle-income Countries: A Literature Review. Disability, CBR & Inclusive Development, 2016. 27(3).
12. Disability Rights Fund. What is a DPO? 2021 [cited 2021 11 May 2021]; Available from: **disabilityrightsfund.org/faq/what-is-a-dpo**
13. International Disability Alliance. 2021 [cited 2021 3 May 2021]; Available from: **www.internationaldisabilityalliance.org/content/ida-members**

14. United Nations Human Rights Office of the High Commissioner (OHCHR), Convention on the Rights of Persons with Disabilities. General comment on article 4.3 and 33.3 of the convention on the participation with persons with disabilities in the implementation and monitoring of the Convention, in CRPD/C/GC/7, United Nations, Editor. 2018: Geneva.
15. Burke, E., et al., A qualitative study to explore the barriers and enablers for young people with disabilities to access sexual and reproductive health services in Senegal. Reprod Health Matters, 2017. 25(50): p. 43-54.
16. Sharma, S. and M. Sivakami, Sexual and reproductive health concerns of persons with disability in India: An issue of deep rooted silence. J Biosoc Sci, 2019. 51(2): p. 225-243.
17. Alliance, I.D., Increasingly Consulted, but not yet Participating. 2020.
18. Ganle, J.K., et al., Barriers facing persons with disability in accessing sexual and reproductive health services in sub-Saharan Africa: A systematic review. PLoS One, 2020. 15(10): p. e0238585.
19. KPMG, The right to access. Regional Strategic Guidance to increase access to Sexual and Reproductive Health and Rights (SRHR) for Young Persons with Disabilities in East and Southern Africa. 2017, KPMG Services Proprietoary Limited: South Africa.
20. Leonard Cheshire, Effective Influencing: A toolkit for engaging disabled people in our influencing work., Leonard Cheshire, Editor. 2021.

# Appendix
# OPD partnership tool



## A toolkit for implementation teams to establish meaningful partnerships with OPDs

Working in partnership with Organisations of Persons with Disabilities (OPDs) is important for designing and implementing health services that are accessible, appropriate and accessible to persons with disabilities. As healthcare designers and implementers, OPDs are a valuable partner for gaining a better understanding of the needs of persons with disabilities and the specific challenges that they face when trying to access health care and support. This toolkit has been developed by Leonard Cheshire to assist health service implementers to form mutually beneficial and meaningful partnerships in order to improve the quality of and access to healthcare for persons with disabilities. This compendium of tools is based on the insights of implementation teams working on Lot 1 of the WISH Programme who shared valuable lessons learnt after having forged partnerships with OPDs in Sierra Leone, Burkina Faso, Nigeria, DRC and Mali. The Toolkit is designed to support you as you initiate, develop and evaluate your partnership. It provides practical guidance for implementation teams and aims to facilitate a better understanding of persons with disabilities and how OPDs can support the design and implementation of more inclusive health services.

## What is included in the toolkit?

### A two-part pre-partnership assessment tool

**Part 1: Internal organisational assessment**
An inward focussed tool for organisations who wish to assess their readiness to partner with an OPD. The purpose is to facilitate guided self-reflection on precursors to establishing a meaningful partnership with an OPD and raising the level of organisational awareness of disability inclusion. Part 1 is structured as a list of statements that may be used to guide team discussions around readiness to partner with an OPD. It may be helpful in identifying where the knowledge and awareness gaps are within the team.

**Part 2: Assessment of OPD and need for additional support**
A useful tool for organisations who are more advanced in terms of the pre-partnership process. It may be that an OPD has already been identified and approached as a potential partner. This tool will be helpful to guide the organisation in assessing whether the OPD would be a good fit for the project and facilitates a deeper understanding of what support can be offered to the OPD.

### A partnership planning tool

For use by teams who are in the early stages of formalising their partnership with an OPD. Key elements of partnership planning generally include identifying all stakeholders, defining roles and responsibilities, holding inception and kick-off meetings, defining the partnership scope, reflecting on budgets, timelines and defining a set of priorities, for the lifespan of the partnership.

## An implementation and monitoring tool

This tool supports successful project implementation. It provides key questions to guide project teams at an operational level to identify project risks and work through them in a collaborative and meaningful way.

## An evaluation, feedback and lessons learned tool

This tool guides teams to evaluate the extent to which the partnership with the OPD has achieved the desired objectives of the project.

Note that these tools do not all need to be used by every team. They can be used as standalone tools to support partnership development depending on the phase of partnership.

For further guidance on ensuring accessibility, and engaging with OPDs for advocacy please see Leonard Cheshire's effective engagement toolkit: **leonardcheshire.org/our-impact/our-policy-and-research-work/effective-engagement-toolkit**

# Pre-partnership tool

## Part 1: Internal organisational assessment

Name of organisation:

Date:

Project name:

Names of participants filling out the tool:

### How to use this tool

This tool is ideally suited to guide team discussions prior to any discussions with potential OPD partners. As a team, work through each statement of intention in the first column of the table and assess your team's alignment to the statement. Key actions taken by the team can be documented in the **key actions** column with the name of the persons responsible and the date of completion outlined in the respective column. You may benefit from using this tool to guide subsequent discussions and tracking progress against key actions. Should you answer no or unsure for any statement, it would be advisable to document the reasons and the potential risk to the project and the partnership. Where relevant you may seek additional support and advice from disability experts.

| **Statements of intention** | **Self assessment** | | | **Comments / impact or consequence** | **Key action** | **Person responsible** | **Date of completion** |
|---|---|---|---|---|---|---|---|
| | **Yes** | **No** | **Unsure** | | | | |
| 1. Our purpose for partnering with an OPD has a clear rationale. | | | | | | | |
| 2. We are committed to supporting the international and local agenda for disability inclusion. | | | | | | | |
| 3. We are committed to the principles of a meaningful partnership – enabling persons with disabilities to have a voice and facilitating their self-representation in all aspects of the partnership. | | | | | | | |

## **Pre-partnership tool** Part 1: Internal organisational assessment

| **Statements of intention** | **Self assessment** | | | **Comments / impact or consequence** | **Key action** | **Person responsible** | **Date of completion** |
|---|---|---|---|---|---|---|---|
| | **Yes** | **No** | **Unsure** | | | | |
| 4. As an organisation, we are aware of the limitations of our knowledge and understanding of disability related issues. | | | | | | | |
| 5. We are familiar with the barriers faced by persons with disabilities in accessing health services. | | | | | | | |
| 6. We have conducted a situational analysis of existing OPDs operating within the project location (this can be done in partnership with an OPD). | | | | | | | |
| 7. We have conducted a situational analysis of existing OPDs operating within the project location. | | | | | | | |
| 8. We are willing to be supported by an OPD partner so that capacity on disability related issues can be strengthened. | | | | | | | |
| 9. We are willing to support the OPD partner to build its capacity as an organisation to secure its future sustainability. | | | | | | | |

## **Pre-partnership tool** Part 1: Internal organisational assessment

| **Statements of intention** | **Self assessment** | | | **Comments / impact or consequence** | **Key action** | **Person responsible** | **Date of completion** |
|---|---|---|---|---|---|---|---|
| | **Yes** | **No** | **Unsure** | | | | |
| 10. We are committed to facilitating active engagement and participation of OPDs and persons with disabilities. | | | | | | | |
| 11. We understand the additional costs of working with OPDs and are willing to accommodate these costs in our budget. | | | | | | | |
| 12. We have access to or have consulted with a disability expert (contact the local disability umbrella body or academics who specialise in the areas of disability rights). | | | | | | | |

# Pre-partnership tool

## Part 2: Assessment of OPD and need for additional support

Name of organisation:

Date:

Project name:

Names of participants filling out the tool:

### How to use this tool

This tool may be used when an implementation team has a potential partner in mind. The tool can be completed as a team or as a core project group and essentially facilitates an assessment of the potential OPD against criteria outlined in the first column. Key actions taken by the team can be documented in the **key actions** column, with the name of the persons responsible and the date of completion outlined in the respective column. You may benefit from using this tool to guide subsequent discussions and tracking progress against key actions. The comment box may be valuable to record key points made during the discussion and should you wish to at a later stage evaluate your growth and development, these comments could provide a useful baseline.

| Assessment criteria | Current status | | | Comment / possible impact or consequence | Key action | Person responsible | Date of completion |
|---|---|---|---|---|---|---|---|
| | Yes | No | Unsure | | | | |
| 1. Does the OPD represent a constituency of persons with disabilities aligned with the focus of the project? | | | | | | | |
| 2. Does the OPD have a good local/ national and regional presence in the context we are interested in? | | | | | | | |
| 3. Does the OPD have a good track record/reputation within the disability sector and stakeholders we are seeking to influence/ involve? | | | | | | | |

## **Pre-partnership tool** Part 2: Assessment of OPD and need for additional support

| **Assessment criteria** | **Current status** | | | **Comment / possible impact or consequence** | **Key action** | **Person responsible** | **Date of completion** |
|---|---|---|---|---|---|---|---|
| | **Yes** | **No** | **Unsure** | | | | |
| 4. Does the OPD have wide-ranging and useful contacts they are willing to share? | | | | | | | |
| 5. Does the OPD have access to relevant information / resources / experience in the disability sector? | | | | | | | |
| 6. Does the OPD possess skills and competencies relevant to disability inclusion that complement those of our organisation and / or other partners? | | | | | | | |
| 7. Does the OPD possess experience in working in the field of sexual and reproductive health and the barriers faced by persons with disabilities? | | | | | | | |

## Partnership planning tool

Name/s of organisation/s:

Name of OPD:

Date:

Project name:

Names of participants filling out the tool:

### How to use this tool

This tool may be used when you have found your ideal OPD partner(s) and are at the stage of formalising the partnership and working relationship. Partnership planning should aim for partners and stakeholders to have a shared vision of the aim and purpose of their partnership. When working with OPDs, partnership planning must be viewed through a disability sensitive perspective. Failure to do so may impact on the ability of OPDs to function optimally. Key elements of partnership planning generally include identifying all stakeholders, defining roles and responsibilities, holding inception and kick-off meetings, defining the partnership scope, reflecting on budgets, timelines and defining a set of priorities, for the lifespan of the partnership. The tool should ideally be completed by both partners.

The first column on the left interrogates aspects of the partnership that should be in place for a successful and meaningful engagement. Key actions taken by the team can be documented in the **key actions** column with the name of the persons responsible and the date of completion outlined in the respective column. You may benefit from using this tool to guide subsequent discussions and tracking progress against key actions.

| As partners, we have: | Current status | | | Comment / impact or consequence | Key action | Person responsible | Date of completion |
|---|---|---|---|---|---|---|---|
| | Yes | No | Unsure | | | | |
| **Resources** | | | | | | | |
| 1. Defined roles and responsibilities and have circulated a draft MOU. | | | | | | | |
| 2. Consulted with the OPD partner on any budgeting process where they are expected to participate in budget issues prior to finalisation. | | | | | | | |
| 3. Discussed possibilities in terms of reasonable accommodation for meaningful participation of the OPD that can be supported within the available project budget. | | | | | | | |

## Partnership planning tool

| As partners, we have: | Current status | | | Comment / impact or consequence | Key action | Person responsible | Date of completion |
|---|---|---|---|---|---|---|---|
| | Yes | No | Unsure | | | | |
| **Resources** | | | | | | | |
| 4. Planned for disability awareness training for all stakeholders involved in the project. | | | | | | | |
| **Accessibility and accommodation** | | | | | | | |
| 5. Ensured that all venues to be used during the project are accessible and have planned for any additional adaptations (e.g. sign language interpreters, assistants, resources in accessible formats) that may need to be made for the OPD partner. | | | | | | | |
| 6. Discussed what capacity building needs OPDs have in terms of project planning. | | | | | | | |
| 7. Developed a capacity building plan for the OPD to support their sustainability. | | | | | | | |

## Partnership planning tool

| **As partners, we have:** | **Current status** | | | **Comment / impact or consequence** | **Key action** | **Person responsible** | **Date of completion** |
|---|---|---|---|---|---|---|---|
| | **Yes** | **No** | **Unsure** | | | | |
| **Participation and inclusion** | | | | | | | |
| 8. Provided our OPD partner with a seat at the project planning table. | | | | | | | |
| 9. Consulted with our OPD partner about some of their operational weaknesses and made provisions for providing capacity building or additional support. | | | | | | | |
| 10. Ensured that our core planning team includes a representative from the OPD partner. | | | | | | | |
| 11. Developed an appropriate, sustainable, and practical approach to team communication. | | | | | | | |

## Partnership implementation and monitoring tool

Name of organisation:

Name of OPD:

Date:

Project name:

Names of participants filling out the tool:

### How to use this tool

This tool may be used to guide planning for partnership implementation. The implementation team can use this tool to continuously reflect on aspects of inclusion that are important for successful partnership with OPDs. This tool provides key questions to guide partners at an operational level to identify project risks and work through them in a collaborative and meaningful way. A good monitoring system must as far as possible involve OPDs through participatory and inclusive methods and should encourage active learning. If done well, partnership monitoring can be an important method of building ownership and accountability and promoting efficiencies and sustainability within OPDs.

The first column on the left interrogates aspects of the partnership that should be in place for successful and meaningful engagement. Key actions taken by the team can be documented in the **key actions** column, with the name of the persons responsible and the date of completion outlined in the respective column. You may benefit from using this tool to guide subsequent discussions and tracking progress against key actions.

| We are committed to including OPDs in the work we do by: | Current status | | | Comment | Key action | Person responsible | Date of completion |
|---|---|---|---|---|---|---|---|
| | Yes | No | Unsure | | | | |
| 1. Establishing the OPD partner as a valued member of the team. | | | | | | | |
| 2. Identifying and preparing for specific adaptations that may be required for OPDs to participate meaningfully prior to meetings and workshops. | | | | | | | |
| 3. Scheduling regular meetings with our OPD partner throughout the project implementation to ensure that they have opportunity to ask questions and contribute to project discussions. | | | | | | | |

## Partnership implementation and monitoring tool

| We are committed to including OPDs in the work we do by: | Current status | | | Comment | Key action | Person responsible | Date of completion |
|---|---|---|---|---|---|---|---|
| | Yes | No | Unsure | | | | |
| 4. Holding awareness raising workshops on SRH, Disability inclusion and the CRPD with the team so that there is common understanding of key issues relating to persons with disabilities. | | | | | | | |
| 5. Assessing limitations in the OPDs' ability to meet project objectives and addressing these through capacity building / investment in a more efficient system. | | | | | | | |
| 6. Motivating and learning from each other through regular meetings and specific forums where our experience can be shared. | | | | | | | |

## Partnership evaluation, feedback and lessons learned tool

Name of organisation:

Name of OPD:

Date:

Project name:

Names of participants filling out the tool:

### How to use this tool

This tool is designed to assist partners to evaluate the extent to which the partnership has achieved the desired objectives of the project, and whether the partnership has been meaningful in respect of participation, self-representation and power-shifting.

| **Criteria** | **Current status** | | | **Comment** | **Key action** | **Person responsible** | **Date of completion** |
|---|---|---|---|---|---|---|---|
| | **Yes** | **No** | **Unsure** | | | | |
| 1. We have defined the approach to evaluating the impact of the partnership and establishing how partners have contributed to the desired outcomes. | | | | | | | |
| 2. We have approached the OPD about being included in aspects of the evaluation early in the project. | | | | | | | |
| 3. We have created opportunities for the OPD to contribute to stories of change and lessons learnt. | | | | | | | |
| 4. We have supported the OPD in the use of evidence-based decision making to ensure sustainability and capacity. | | | | | | | |

## Partnership evaluation, feedback and lessons learned tool

| Criteria | Current status | | | Comment | Key action | Person responsible | Date of completion |
|---|---|---|---|---|---|---|---|
| | Yes | No | Unsure | | | | |
| 5. We have created opportunities throughout the partnership to engage in active reflection about what is and is not working in terms of designing and implementing inclusive SRH services. | | | | | | | |
| 6. We have responded to feedback that warrants corrective measures that realign the partnership towards power-shifting and a truly meaningful partnership (for example, increased opportunities for input, leadership, budget allocation). | | | | | | | |
| 7. We have ensured the partnership provides for and facilitates a joint evaluation that includes all perspectives, but with joint recommendations that all parties have developed and agreed. | | | | | | | |