

Women's Integrated Sexual Health (WISH) Programme for Results: independent verification, evidence, and learning

An evidence gap map on 'what works' to ensure persons with disabilities have access to sexual reproductive health services in low and middleincome countries.

April 2020





Preface

The Department for International Development (DFID) has contracted the e-Pact consortium to undertake Third Party Monitoring (TPM) of Women's Integrated Sexual Health (WISH). Oxford Policy Management (OPM) and Itad are jointly implementing this project in collaboration with Forcier, AEDES, and ATR Consulting for in-country support. While TPM is the official name of this project and is used in the contractual documents, in order to better express the nature and dimensions of this work, we are referring to this project as Women's Integrated Sexual Health (WISH) Programme for Results: independent verification, evidence generation, and learning and dissemination for WISH (W4R in short).

This report was drafted by Adrienne Monteath-van Dok with inputs from Mary Lagaay.

We are grateful to everyone who supported with the development of the evidence gap map, and in particular those who made time to provide feedback and share insights on the structure, as well as the WISH Technical Working Group on Disability and Inclusion.

Disclaimer

This report has been prepared by the e-Pact consortium for DFID, for services specified in the Terms of Reference and contract of engagement. The information contained in this report shall not be disclosed to any other party, or used or disclosed in whole or in part without the agreement of the e-Pact consortium. For reports that are formally put into the public domain, any use of the information in this report should include a citation that acknowledges the e-Pact consortium as the author of the report.

This confidentiality clause applies to all pages and information included in this report. This material has been funded by UK aid from the UK government; however, the views expressed do not necessarily reflect the UK government's official policies.

Table of Contents

Pr	eface		2		
Та	ble of Con	tents	3		
Lis	t of abbrev	viations	4		
1	5				
2	Sumr	nary of the methodology	6		
3	Evide	nce gap map	9		
4	Analysis				
	4.1 Overview of the Evidence Gap Map		10		
	4.2 K	nowledge and attitudes	12		
		What evidence exists? 'What works': examples from the EGM	12 12		
	4.3 B	ehaviours	14		
		What evidence exists? 'What works': examples from the EGM	14 15		
		ealth	13		
		What evidence exists?	17		
		'What works': examples from the EGM	18		
	4.5 A	ccess to services	20		
		What evidence exists? 'What works': examples from the EGM	20 20		
	4.6 E	nabling environment	22		
		What evidence exists? 'What works': examples from the EGM	22 23		
5	Conc	usions	26		
	5.1 K	ey examples of 'what works'	27		
6	Reco	nmendations	29		
	6.1 R	ecommendations for future evidence generation	29		
Bib	oliography		30		
An	nex A: De	ailed methodology	33		
Annex B: Questions used in the consultations					
Annex C: Quality assessment questions 42					
An	Annex D: List of interviewees and Technical Working Group members 45				
An	nex E: Lis	of WISH countries	46		
An	nex F: Re	evant Websites	47		

List of abbreviations

CBR	Community Based Rehabilitation
CBR-NE	Community Based Rehabilitation Network Ethiopia
COVAW	Kenya Association of the Intellectually Handicapped and Coalition of Violence against Women
DFID	Department for International Development
DRI	Disability Rights International
DPO	Disabled Persons Organisation
EGM	Evidence Gap Map
FEDWEN-K	Federation for Deaf Women Empowerment Network – Kenya
IRC	International Rescue Committee
LMIC	Low and Middle-Income Countries
MHM	Menstrual Hygiene Management
PAG	Participatory Action Groups
PDF	Pacific Disability Forum
RoB	Risk of Bias
SRH	Sexual Reproductive Health
SRHR	Sexual Reproductive Health and Rights
STI	Sexually Transmitted Infection
TWG	Technical Working Group
UN	United Nations
UNCRPD	UN Convention on the Rights of Persons with Disabilities
VSLA	Village Savings and Loans Associations
WASH	Water, Sanitation and Hygiene
WG	Washington Group
WHO	World Health Organisation
WISH	Women's Integrated Sexual Health
WRC	Women's Refugee Commission

1 Introduction

As part of the Department for International Development's (DFID's) Women's Integrated Sexual Reproductive Health (WISH) programme, an evidence gap map (EGM) has been developed to map interventions on 'what works' to enable access to sexual reproductive health (SRH) services for persons with disabilities in low and middle-income countries (LMICs). EGMs are a user-friendly presentation of the available, relevant evidence for a particular sector, which is systematically gathered and mapped onto a framework, visually highlighting the gaps or concentration of evidence. This EGM aims to support WISH programming by consolidating evidence and identifying tools/approaches which could be brought into the programme. In addition, it aims to identify where evidence is weak and how the WISH programme can contribute to evidence generation.

It is estimated that persons with disabilities make up 15% of the world's population (WHO, 2011). A growing body of evidence shows that persons with disabilities have historically been denied their SRH rights, despite having the same sexual needs as people without disabilities, and continue to face many barriers to accessing SRH services (Carew et al, 2017; Apolot, 2019). The WISH programme (hereafter 'WISH') is a flagship, multi-country SRH initiative that aims to benefit a significant number of women living in LMICs in line with DFID's commitment to 'leave no one behind.' WISH has four key thematic focus areas, one of which is reaching persons with disabilities. As such, the WISH consortium includes several disability-focused partners and the programme works with persons with a disability in a variety of ways.

In 2018, DFID commissioned an EGM to assess the effectiveness of interventions for persons with disabilities in LMICs in relation to education, health, jobs and livelihoods (White, Saran and Kuper, 2018). However, this did not include an in-depth look at the evidence available on access to SRH services. Fraser and Corby (2019) highlighted this in their report 'Family Planning for Women and Girls with Disabilities,' as did Carew et al (2017), stating that '...where there has been some attention to disability and sexual health, it has tended to focus predominantly on vulnerabilities, and we need to know much more about emancipatory practices.' To address this gap and to support WISH countries with their programmes, this EGM focuses on which interventions work.

This report provides a written accompaniment to the EGM to explain the methodology, findings on availability of evidence, and key recommendations. When scoping for this EGM, it was recognised early on that some of the best practices and interventions on 'what works' to support persons with disabilities access SRH services in LMICs are not always empirically tested. Therefore, a decision was made to develop an EGM which includes both peer-reviewed *and* grey literature. This approach diverges from the norm, as EGMs typically only include peer-reviewed literature.

The following chapter explains the methodology behind the creation of this EGM and key decisions in the design process. A detailed methodology can be found in Annex A. Chapter three initially analyses the overall evidence from this EGM, and then drills down into each of the five outcome areas and subcategories that make up the horizonal axis of the EGM. This chapter also shares some examples of 'what works' per outcome area. Chapter five brings together the main conclusions from the EGM, followed by recommendations drawn from the conclusions in chapter six.

2 Summary of the methodology

An EGM on adolescent SRH developed by 3ie¹ in 2017 served as an initial outline for the selection of five key outcome areas and underlying subcategories to be included on the horizontal axis of this EGM. Table 1 describes each of the outcome areas, which were deliberately kept broad to include as many effective interventions as possible. A more detailed description which includes the subcategories within each outcome area can be found in Annex A.

Outcome area		Description
1.	Knowledge and attitudes	This entails interventions linked to both formal and non-formal education, as well as addressing the stigmatisation and negative attitudes persons with disabilities can be subjected to by health workers, the community, family and friends and by persons with disabilities themselves.
2.	Behaviours	This refers to interventions affecting the behaviour of persons with disabilities themselves in relation to a wide range of SRH issues, such as the use of contraception, menstrual hygiene management (MHM), support seeking, as well as sexual pleasure and sexual orientation.
3.	Health	This covers a wide range of SRH interventions with positive health outcomes, such as those relating to pregnancy; maternal health; abortion; HIV and STIs; access to information; being aware of one's rights; and interventions that tackle sexual and gender-based violence. This category also captures positive health outcomes that were unintended by the intervention.
4.	Access to services	This area focuses purely on health services. It distinguishes between access to health services (either physical or remotely); utilising health services for SRH, and the care and after-care received by providers.
5.	Enabling environment	This area is extremely broad and ranges from the role family, friends or the community play in supporting access to SRH services, as well as the role government and donors can play. It also captures interventions concerning livelihoods, confidentiality and the role that data plays.

Following consultation with the WISH Disability and Inclusion Technical Working Group (TWG) the vertical axis of the EGM - which traditionally lists interventions - was replaced with types of impairments. Given the complex heterogeneity of disabilities and the range of interventions that can provide access to SRH services for persons with disabilities, it was deemed useful to create an overview which showed the distinction between different impairments in relation to the interventions being mapped. This resulted in the categories listed in Table 2.

¹ <u>https://gapmaps.3ieimpact.org/evidence-maps/adolescent-sexual-and-reproductive-health-evidence-gap-map</u> (accessed 18 September 2019)

Impairment type	Description
Mobility	People identified as having difficulties with upper and/or lower limb movement and/or manual dexterity
Vision	People identified as having difficulties with complete or partial vision
Auditory	People identified as being completely or partially deaf
Mental health	People identified as experiencing psychiatric problems (this is also known as psychosocial impairment)
Cognition	People identified as experiencing learning difficulties and the ability to concentrate and remember
Communication	People identified as having complete or partial speech difficulties
Pan-disability	Interventions that reached a group of people with a range of impairments

Table 2: Types of impairment included in the EGM

These broad categories allow the mapping of studies which categorise disability using the Washington Group Questions², as well as other forms of identifying persons with disabilities. Therefore, this EGM maps literature which outlines successful interventions to increase access to SRH services for persons with disabilities according to type of intervention and types of impairment. The EGM also contains filters, such as the country the evidence relates to and whether evidence is related to young people, parents/guardians or a disaster/conflict affected area. This should help the user navigate the EGM and select studies related to these specific categories only. These filters were inspired by those used within existing EGMs.

The framework for the EGM was developed in collaboration with the WISH TWG on disability and inclusion, which includes disability partner organisations in the WISH consortium (see Annex D). Input was also sought through six expert consultations, including NGO and DPO representatives, as well as persons with disabilities. The aim of these consultations was to ensure that the EGM is framed in the most useful way for practitioners and includes all necessary categories and filters.

An essential component of an EGM is an assessment of the quality and level of confidence in the evidence mapped. Therefore, the AMSTAR 2³ tool was adjusted and combined with criteria relevant to this EGM, such as having a clear definition of disability and SRH (see Annex C). This resulted in a set of nine questions to be applied to each study in order to assess quality. A colour-coding system was then used to classify the literature in the EGM according to the results. If all the responses to the adjusted AMSTAR questions were positive, a purple label was applied; if a minimum of five questions out of a total of nine were answered positively, an dark green label was applied; and if less than five questions were answered positively, a blue label was applied. Handbooks on SRH interventions are listed in light green and were not part of the quality assessment.

Relevant available evidence was gathered using a number of predefined search terms in Google and a number of academic databases (see Annex A). Search criteria included literature in English with a focus on 'what works' to enable persons with disabilities to access SRH services in LMICs. Due to time constraints, searches in French and Spanish were limited. The initial literature search showed that most research has been conducted in high-

² The Washington Group (WG) Short Set is a set of questions designed to identify (in a census or survey format) people with a disability. See: http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/

³AMSTAR 2 originally created in 2017 is a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both. <u>https://www.bmj.com/content/358/bmj.j4008</u>

income settings, primarily North America and Western Europe and that most studies in LMIC's are needs assessments. Therefore, the search was broadened to include grey literature from 2000 onwards. This increased the volume of evidence included, however, grey literature was commonly found to have a lower level of confidence in the quality rating.

The creation of this EGM did not adopt the stringent review methods commonly found in academic literature (e.g. for a systematic review) but was rather a streamlined scoping exercise conducted within a given timeframe in order to provide timely evidence to support WISH programming. Limitations can be found in Annex A.

3 Evidence gap map

Evidence gap map					
A growing body of evidence shows that people with disabilities have historically been denied their sexual and reproductive health rights, despite having the same sexual and reproductive health needs as people without disabilities, and continue to face many barriers to accessing these lifesaving services. ¹					
 Medium confidence This evidence gap map, developed as part of the UK Department for International Development's Women's Integrated Sexual Low confidence Low confidence Handbook (not rated) for persons with disabilities in low and middle-income countries. 					
Region \checkmark Country \checkmark Methodology \checkmark Other factors \checkmark					
Knowledge and Attitudes Behaviours Health Access to services Enabling environment					
Type of impairment	Education	Stigma: negative attitudes / discrimination from health care workers	Stigma: negative attitudes / discrimination from persons with disability themselves	Stigma: negative attitudes / discrimination from the community	
Auditory	3 0 2	0			
Cognition	22	0 8		2	
Communication		0			
Mental health	0	8		0	
Mobility	22	0			
Vision	3 0 2	000	0	0	
Pan-Disability	0 3 1	0 2 5	0 1	02	

4 Analysis

4.1 Overview of the Evidence Gap Map

This section presents an overall view of the EGM. We first describe the evidence included in the map, followed by the overall trends observed. Sections 4.2 - 4.6 provide more detail on the evidence for each outcome area.

A total of 59 studies were found to be of relevance to this EGM, which resulted in 234 entries across the outcome areas.⁴ The total evidence includes 13 handbooks, 29 items of grey literature and 17 items of peer reviewed evidence. Figure 1 shows the regional distribution of the evidence (excluding the handbooks), which shows that most studies were conducted in relation to interventions in Africa, particularly Sub-Saharan Africa. Most of the studies used qualitative research methods (N = 34) as opposed to quantitative (N = 6) and 3 studies applied mixed methods (the remaining 3 studies were systematic reviews and there were 13 handbooks).



Figure 1: Geographic distribution of evidence

Available evidence (numbers exclude globally applicable studies and handbooks)

Across all five outcome areas, the evidence on 'what works' to support access to SRH services for persons with disabilities in LMICs is limited. Most entries are found in relation to interventions on the outcome areas of health and the enabling environment, followed by outcomes in relation to knowledge and attitudes. Evidence on interventions relating to the outcome areas of behaviour and access to health services show the least number of entries. Notably, when looking across the subcategories under each outcome area, only one has more than ten studies of relevance.

⁴ Many interventions apply to more than one outcome area. For example, a collaboration between Profamilia, Fundamental Colombia, ASDOWN, and PAIIS in Colombia (2015) reports successful outcomes in relation to changing practices of forced sterilisation, countering stigma and advocacy for policy/law changes. Therefore, it is listed under two outcome areas: (i) knowledge/attitudes and (ii) health. In addition, some studies are listed under several types of impairment because an intervention was successful for more than one category - for example, for people with a physical impairment, as well as those with a hearing impairment.

Across the seven impairment types being investigated, the least number of effective interventions are found in relation to communication impairments, followed by mental health. There is only one study that refers to communication impairments and three which refer to mental health impairments.

When looking across all types of impairments, the category of pan-disability has the highest number of entries, followed by interventions in relation to cognition impairments. The higher number of entries under pan-disability can be partly explained by the fact that handbooks are included in the review, many of which often do not specify types of impairments in the interventions they recommend. In these instances, the evidence is classed under the pan-disability category. The remainder of the evidence in this category includes: (i) interventions which are not designed to address a specific type of impairment but are considered applicable across different types of impairments; and (ii) interventions which are specifically aimed at individuals living with multiple impairments.⁵ The fact that this category has the highest number of entries also raises a question with regards to whether persons with disabilities are treated as a homogenous group. A balance is needed to ensure programmes are inclusive across different types of impairments, whilst recognising unique needs that different types of disabilities might require (e.g. sign language). Conversely, taking a less-inclusive approach by targeting one impairment type and excluding others can result in an overly technical / medical focus. Resource constraints can also play a role in relation to delivery of sufficiently differentiated approaches for different impairment types.

More than half of the studies included in the EGM have low levels of confidence based on the quality rating used. Only 14 studies were rated with a high level of confidence (purple), six with medium level of confidence (dark green) and 26 with low levels of confidence (blue)⁶. This is due to the relatively high number of case studies conducted by NGOs included as grey literature, which typically score lower on the quality criteria (for example, grey literature often fails to include a full explanation of the research methods which brings the quality rating down).

The remainder of this chapter explores the EGM in more detail, discussing the findings for each outcome area. The type of available evidence is firstly presented per outcome area, covering the number of studies, regional coverage, level of confidence (i.e. quality of data), whether the data mainly applies to young people or adults, and whether it is applicable to humanitarian settings. References to subcategories within each outcome area are listed in italic throughout the report. Key examples of best practice from the literature included in the EGM are also synthesised, however, this does not represent a full analysis of all literature, which is beyond the scope of this report.

⁵ In this EGM, these two categories come together under 'pan disability' however, future work could consider separating these (i.e. separate categories for interventions which are not designed to address a specific type of impairment but are considered applicable across different types of impairments / interventions which are specifically aimed at individuals living with multiple impairments) as such interventions are likely to employ different programmatic approaches.

⁶ The 13 handbooks included in the EGM were not rated for confidence.

4.2 Knowledge and attitudes

Knowledge and Attitudes: summary of key evidence gaps			
•	Lowest amount of evidence found in relation to interventions which address negative attitudes/ discrimination from people with disabilities. Low amount of evidence found in relation to interventions which address negative attitudes/ discrimination by the community.	 Low amount of evidence found from Asia and Latin America Low amount of evidence found for people with communications impairments. 	
	11	1 4	
Number of studies included in the EGM and level of confidence (red = low confidence, green = high confidence)			

4.2.1 What evidence exists?

Overall, the outcome area of knowledge and attitudes totals 16 studies and 6 handbooks, with 51 entries across the EGM. Most studies (10) were conducted in Africa, whilst only two took place in Asia, and four in Latin America.

In relation to 'what works' for changing knowledge and attitudes, the EGM indicates that the majority of available evidence relates to the subcategories *education* and *changing negative attitudes/discrimination from health workers*. Evidence concerning *education* has more quantitative studies with a high level of confidence than qualitative studies. Conversely, the subcategory *shifting negative attitudes/discrimination from health workers* has just one quantitative study with high confidence, whilst the remaining studies are qualitative and have a lower level of confidence.

There is little available evidence relating to the subcategories of changing negative attitudes/discrimination from people with a disability themselves and changing negative attitudes/discrimination from the community. The existing evidence consists only of qualitative case studies and the quality of evidence in this area is low. This is particularly the case for the subcategory of changing negative attitudes/discrimination from people living with a disability themselves where there are only three interventions listed, both with low levels of confidence.

There is very little evidence in relation to communication impairments, showing a clear evidence gap. When looking at the types of impairments, the evidence shows that most entries are found in relation to visual impairments, followed by cognitive impairments. It is perhaps unsurprising that the evidence included under the subcategory of *education* refers mainly to young people, whereas the other studies describe interventions relating to female adults or both female and male adults.

4.2.2 'What works': examples from the EGM

Example 1: peer-to-peer learning and information sharing can increase knowledge of services

• **Multiplying effect of peer-to-peer learning:** The 'Youth Action for Better Health' intervention implemented in Zimbabwe by Leonard Cheshire reports that peer-to-peer education was found to have a multiplying effect in effectively spreading SRH information. This intervention aimed to improve the SRH health status of young people and included training 357 change agents to become peer-to-peer trainers in sexual

reproductive health and rights (SRHR) for other adolescents with a disability. Some youth became treatment buddies for their peers whilst HIV-positive young women with a disability became community-based facilitators, meeting periodically with peers to discuss issues such as SRHR, HIV/AIDS, sexual violence and child marriage. The programme also included the creation of safe places in schools which acted as meeting points for young people with and without disabilities, where issues of sex and sexuality could be openly discussed. This was proven to be particularly useful in reaching girls with information and services on SRHR (Chivandire, 2017).

Example 2: capacity building for civil society and DPOs may increase knowledge on rights of persons with disabilities

• Seminars to build capacity: The 'Sweeping Barriers' programme in Uruguay used capacity building to tackle stigmatisation and build knowledge amongst civil society and the health sector at a local level. Seminars for DPOs and civil society organisations promoted the rights of persons with disabilities, emphasising SRHR and the right to have a life free of gender-based violence. It included topics such as the social model of disability, the legal framework protecting the rights of persons with disabilities, and violence against persons with disabilities. Importantly, all seminars took place with the direct participation of women and girls with disabilities. As a result of the seminars, government programmes and paperwork were adjusted so that data on persons with disabilities could be tracked. The programme evaluation also reported that after attending the seminars, medical practitioners subsequently demanded training on issues relating to the specific needs of women with disabilities.

Example 3: role models and media representation to increase knowledge on rights of persons with disabilities

- Female role models to empower other women: Evidence collected by DRI (Disability Rights International) in Mexico indicated that "women and men with psychosocial disabilities were experiencing overly frequent hospitalisation in psychiatric institutions and general marginalisation, with the hospital staff treating them as objects rather than respecting them as equal citizens" (DRI and Collectivo Chuhcan, 2015). In response to the realisation that there was no representative group of people with psychosocial (mental health) impairments in Mexico, Collectivo Chucan was established as a self-advocate group. After a few years there were successes advocating for the rights of men, but not for women. Therefore, a women's group was set up to support advocacy for women. A collaboration between DRI and Collectivo Chucan focused on building capacity, with one woman in particular showing an interest in taking on a leadership role. She received intensive training on disability and human rights and was mentored by existing leaders of Collectivo Chucan. The study finds that as her confidence grew, she was able to empower other women, which resulted in a network of peer support amongst women. DRI reported that she became an important role model, which motivated other women (DRI and Collectivo Chuhcan, 2015).
- Media representation to promote a positive image: Role models in the media are discussed in various studies and some highlight that the absence of representation of women with disabilities in the media has an impact on their marginalisation in society. A number of studies referred to media as an important tool for sharing knowledge, particularly television and radio. For example, a study by UNFPA (2009) found that including someone with a visible disability among people shown in a poster or television spot about SRH helps to create a positive image. The media was also reported to be influential in positively affecting social policies and societal attitudes

towards persons with disabilities (UNFPA, 2009).

• Role of the media in obtaining justice for victims of gender-based violence: A case study from the Kenya Association of the Intellectually Handicapped and Coalition of Violence against Women (COVAW) found that the media can play a pivotal role obtaining justice for victims of gender-based violence. An evaluation of the programme found that where previously a person with an intellectual (cognitive) impairment reported abuse would often not be taken seriously, nor offered support, there were now successful prosecutions against perpetrators. In addition, when a court case tended to get stuck in the judicial system, the local media were alerted to report on the issue in order to increase awareness (COVAW, 2015).

4.3 Behaviours

	Behaviours: summary of key evidence gaps				
•	A clear evidence gap was found across the entire outcome area, apart from in relation to the use of contraception/other prevention.	•	No evidence was found on 'what works' to positively change behaviours in relation to SRH in humanitarian settings.		
•	No evidence was found on interventions related to sexual orientation or on sexual pleasure	•	Across the outcome area the quality of the evidence can be considered low.		
	9		2		
	Number of studies included in the EGM and level of confidence (red = low confidence, green = high confidence)				

4.3.1 What evidence exists?

Overall, the outcome area of behaviours totals 12 studies and 4 handbooks, with 20 entries across the EGM. The evidence has a relatively even regional spread, for example four studies come from Asia, two from Latin America and five from Africa. However, all but one of the studies based in Africa were conducted in Kenya, leaving West Africa unrepresented.

The evidence on 'what works' for changing the behaviour of persons with disabilities in relation to SRH practices is amongst the weakest of all outcome areas. After the outcome area of access to services, it has the least amount of evidence, and the existing evidence has the lowest levels of confidence when compared to the other outcome areas.

The best quality evidence is found in relation to the subcategory of menstrual

hygiene. This includes four studies, of which two have a high level of confidence. Notably, three of these studies relate to women and girls with cognitive impairments, and the fourth is rated as pan-disability. The latter study is specifically related to creating accessible WASH facilities in a school in Cambodia. In relation to this issue, whilst there is clear value in providing inclusive hygiene management services in schools, other evidence, such as a study on 'Integrating menstrual health, water, sanitation and hygiene, and sexual and reproductive health in Asia and the Pacific Region' specified that taking menstrual hygiene management (MHM) and SRH services beyond the education setting is critical in reaching the most vulnerable. This study also identifies that there are gaps in understanding 'what works' to support management of menstruation for (young) women living with disabilities, which underscores the findings in this EGM (WaterAid and Marie Stopes International Australia, 2016).

The highest volume of evidence is found in relation to the subcategory of *contraception and other prevention*. However, whilst five items of evidence are relevant to this category, they are all rated with low confidence.

The quality and quantity of evidence is low or non-existent in relation to all other subcategories, including interventions which focus on *sexual behaviour and sexual pleasure, sexual orientation* and *communication and support-seeking.* Within the subcategory of *sexual behaviour and sexual pleasure*, there are two studies with low confidence, both of which focus on sexual behaviour only (i.e. there is no evidence regarding sexual pleasure). In the subcategory of *sexual orientation,* there are no listed studies, highlighting a need for further research in this area.

Most of the studies in this outcome area apply to both young people and adults and some were in relation to children living with disabilities. None of the studies apply to people in emergency situations or refugees. In addition, this outcome area tends to have a relatively high number of studies focused on people living with a cognitive impairment as opposed to other types of impairments.

4.3.2 'What works': examples from the EGM

Example 1: tailoring communication on SRHR for people living with cognitive impairments using culturally appropriate images and dolls

- Raising awareness of SRHR: COVAW in Kenya reports that as a result of their programme to 'break the silence' on sexual and gender-based violence against persons with intellectual impairments, families and communities became increasingly aware of the SRH rights of this group. People with intellectual impairments and their families were counselled around their rights, using self-advocacy groups and images to 'teach what is a good touch, what is a bad touch.' At the same time, local authorities dealing with gender-based violence were sensitised to the rights and needs of people with intellectual disabilities and COVAW developed specific training for the Judiciary Training Institute. COVAW engaged in dialogue with the wider community and community chiefs, who reportedly became much more supportive and engaged. The study reports that persons with an intellectual impairment were now given more choice whether they wanted to get married and sexuality was more openly discussed as a result of changed views within the society. In addition, the study reports that there were successful prosecutions in relation to gender-based violence against people with intellectual impairments (COVAW, 2015).
- Accessible and tailored information: In relation to sexual behaviour, the Niketan Foundation in Bangladesh highlights the need to provide accessible information to people with (severe) intellectual impairments due to the risk of confusion or misinterpretation, which could potentially lead to problematic sexual behaviour. They used culturally appropriate images and dolls to illustrate appropriate behaviour and focused on what was allowed and not allowed (Termoshuizen, 2017). Similarly, Light for the World in collaboration with the Community Based Rehabilitation Network Ethiopia (CBR-NE) implemented a pilot programme, teaching CBR professionals, service providers and parents the skills to reach, teach, inform and discuss the topic of sexuality with girls with intellectual impairments. They emphasise the use of accessible materials and that people with intellectual impairments require repetition to ensure that their new insights are maintained (Boersma, 2017).

Example 2: tailoring communication materials in schools for different types of impairments

Use of learning aids: In Zimbabwe, the study 'Change agents with a disability: youth with a disability in action and collaboration for improved SRH' applies to various types of impairments. It reports an increase in young people with disabilities practicing abstinence or using contraceptives as a result of peer-to-peer education and building on the existing school curricula. The programme created information, education and communication materials in relation to SRH and HIV in braille, sign language and other formats. According to the teachers, the learning materials with graphic illustrations were the best kind of learning aids for young people with an intellectual impairment, whilst young people with a visual impairment preferred to touch contraceptive items (Chivandire, undated).

Example 3: provision of materials and use of dolls/stories to support MHM for women with an intellectual impairment

Dolls to demonstrate behaviour, and provision of 'period packs:' Wilbur's study (2018) on MHM builds on the findings in Altundağ and Çalbayram (2016) which showed that using a doll to teach women with intellectual impairments about MHM is successful. Wilbur's formative research in Nepal, in collaboration with WaterAid, developed the Bishesta campaign, which uses dolls called Bishesta and Perana to demonstrate appropriate behaviour and encourages women to adopt it. The intervention also includes provision of specially designed 'period packs' with two visual stories and a number of items to help with MHM. A large Bishesta doll used in training has removable clothes, a soiled and clean menstrual pad and pain symbols that can be put on parts of the doll's body where menstrual discomfort is experienced. The intervention produced behavioural change for both the young women and their carers, the latter reporting that they felt more comfortable leaving the house with the girls and women with an intellectual impairment (Wilbur, 2018).

Example 4: Participatory action groups and sensitisation training increase confidence, knowledge and support seeking

- Participatory action groups increase confidence: The majority of studies listed in the subcategory of *communication and support seeking* reference the importance of building the confidence of women to encourage them to seek support for SRH. For example, the W-Dare project (Women with disability taking action on reproductive and sexual health) is a three-year participatory action research programme in the Philippines. A report on the programme finds that women gained increased knowledge and confidence as a result of attending Participatory Action Groups (PAGs), which met fortnightly over a period of 20 weeks. All meetings were participatory, strengths-based and comprised a combination of structured activities and interactive methods to facilitate discussion, with a focus on key factors relevant to SRHR and protection from violence. The PAGs resulted in an increase in accessing health centres for SRH services (Devine, 2017).
- **Tailored materials to seek justice:** In most of the studies in the subcategory of *communication and support seeking*, support seeking is also linked to seeking justice. This goes hand-in-hand with teaching people with a disability about their rights, as well as providing training and sensitisation to health workers and law enforcers. For example, the Federation for Deaf Women Empowerment Network - Kenya (FEDWEN-K) has implemented a project called 'Listening to the voice of the voiceless,' funded by AmplifyChange. The project designed and formulated information, education and

communication materials accessible to people with a hearing impairment and created basic Kenyan sign language pamphlets for the community and service providers. The report states: "We provided police and medical officers with training in basic sign language as well as training on disability inclusion. This raised awareness amongst these professionals of the need to involve a qualified interpreter [in court cases]. The training could be used as leverage to gain promotion, which increased the staff's motivation to participate" (Odera, 2017).

4.4 Health

Health: summary of key evidence gaps				
 Lowest amount of evidence found in relation interventions which address pregnancy, birth maternal health, abortion and post abortion of Low amount of evidence found for people wi communication impairments, followed by me health and mobility impairments. 	 and methods. There was an evidence gap in relation to interpretions on HIV/(STI/a conducted outside) 	of		
18	3 6			
Number of studies included in the EGM and level of confidence (red = low confidence, green = high confidence)				

4.4.1 What evidence exists?

The outcome area of health (together with 'enabling environment') contains the most evidence compared to the other outcome areas. It totals 27 studies and 11 handbooks, with 72 entries across the EGM. There is a fairly even regional spread with seven studies conducted in Asia, seven in Latin America, and 12 in Africa, covering both Western and Southern/Eastern Africa. There is also one study which is universally applicable.

The most evidence can be found in the subcategory of access to information⁷, with 27 entries. This is not surprising, as most interventions were found to include components of helping persons with disabilities understand their rights, as well as explaining these to their caretakers and sometimes the community. Many of the studies included in the subcategory were focused on reaching young people and nearly all studies – apart from two – are qualitative with low levels of confidence. A notable study by the Women's Refugee Commission (2015) highlights the importance of interventions which enable access to information through its finding that despite awareness gaps, people with disabilities show much interest in learning about SRH, with no difference across age, sex or impairment group.

The subcategories of *pregnancy and births* and *maternal health*, *abortion and post-abortion care*, contain a low volume of evidence, with only three studies for each subcategory, of which all but two are qualitative. Notably in relation to this area, WHO and UNFPA (2009) state that "women with disabilities are not only less likely to receive general information on sexual and reproductive health and are less likely to have access to family planning services, but should they become pregnant, they are also less likely than their non-disabled peers to have access to prenatal, labour and delivery and post-natal services." Therefore, the need for evidence on 'what works' in this area is clear.

⁷ The complete subcategory reads: Access to information / increased knowledge/awareness of rights.

The subcategory of sexual and intimate partner violence/gender-based violence has 19 entries and most studies have lower or medium confidence levels. Two of the studies in this subcategory refer to refugees/emergency situations and five of the handbooks on this issue are especially designed to ensure SRHR and protection from gender-based violence in humanitarian settings. Interestingly, there are more handbooks which reference working with persons with disabilities in humanitarian situations than the number of effective interventions.

Evidence indicates that sexual violence and the risk of contracting HIV/STIs intersect, whereby persons with disabilities are at greater risk of both. In some contexts, there is a belief that sex with a virgin or person with a (specific) disability is a cure for HIV or other diseases (Groce and Trani, 2004). Persons with disabilities are often more vulnerable resulting in higher levels of gender-based violence with the associated chance of contracting HIV/STIs. As stated in the Report of the Special Rapporteur on the Rights of Persons with Disabilities (2017) "the risk [of gender based violence] is consistently higher in the case of deaf, blind and autistic girls, girls with psychosocial and intellectual disabilities and girls with multiple impairments. Belonging to a racial, religious or sexual minority, or being poor, also increases the risk factor for sexual abuse for girls and young women with disabilities. Humanitarian crises and conflict and post-conflict settings generate additional risks of sexual violence and trafficking that affect girls with disabilities."

The evidence under the subcategory of *HIV/STI testing and incidence prevention* comes mostly from Africa, including studies with high, medium and low levels of confidence. Notably, UNAIDS found that persons with disabilities "represent one of the largest and most underserved populations when it comes to health and HIV services" (UNAIDS, 2014). However, this EGM indicates that there is little evidence on interventions that work to support access to HIV/STI testing. This is also linked to evidence under the subcategory of *access to information / increased knowledge/awareness of rights* which reports that persons with disabilities are often perceived as asexual and therefore SRH information is withheld from them. As a result, this can lead to unsafe sex and an increased chance of contracting HIV or other STIs (Carew et al, 2017; Maart and Jelsma, 2010).

Interestingly, the most reported outcome in the subcategory of other health outcomes was enhanced self-confidence for persons with disabilities (due to an intervention). The subcategory of other health outcomes was included to capture any health outcomes that an intervention did not necessarily set out to achieve. In most cases relevant to this subcategory, interventions referred to an increase in self-confidence amongst persons with disabilities as a consequence of other interventions, such as peer support groups.

4.4.2 'What works': examples from the EGM

Example 1: Increasing knowledge about SRH and disability starts by making people aware of their rights

• Workshops and role play: Multiple studies indicate that successful interventions often start by making participants aware of their rights by increasing access to information, such as through seminars, workshops and provision of accessible information. Goyal (2017) describes how a mindset needs to be created for people with disabilities to start thinking about themselves and their rights: "through my work with girls and women with disabilities in India, I have concluded that, being marginalised in many ways, more often than not girls and women with disabilities are not given the space to think about themselves or express their wishes. A hierarchy of needs is thrust upon them by their parents and society. They are forced to suppress all personal wishes or dreams because

of the pressure, simply to conform to the assumption that they are without desire" (Goyal, 2017). Goyal states that she was able to begin addressing this by asking her workshop participants to share a dream about something they wanted to experience for the first time, followed by various exercises and role play.

Example 2: peer-to-peer learning for people with and without disabilities

• Peer-to-peer learning increases access to services: Marie Stopes in Nepal developed a multi-pronged approach to achieve inclusive SRH, involving schools, health workers, DPOs and the local government. The programme focused on young people, after a study they commissioned found that 90% of young people with disabilities were unaware of all modern methods of contraception and did not visit Marie Stopes clinics. The school-based component of the programme set up peer-to-peer learning groups called 'Rocket and Space Groups', consisting of young people with and without disabilities and youth volunteers, to share SRH knowledge with their peers. The programme also created audio messages and a helpline for people with a visual impairment and the option to live chat with a counsellor for people with a hearing impairment. In 2016 Marie Stopes Nepal reported that they reached 816 young people with a disabilities were also provided with personalised counselling through the client contact centre (Raut et al, 2017).

Example 3: self-advocate groups can increase knowledge about SRHR

Dance and theatre promote inclusion of persons with disabilities in SRH: Dance Into Space is a group of performance artists in Kenya, who are using contemporary dance theatre to increase knowledge of SRHR and HIV for persons with disabilities. No formal evaluation of the programme exists, but the performances aim to target people with disabilities, their caregivers and the community to address the myths around disabilities and sexuality, and provide an alternative narrative. A case study on the intervention states that through discussion, reflection and dialogue around rights and advocacy, participants with disabilities are empowered to become self-advocates. Through exercises and games the case study reports enhancements in concentration, leadership skills and self-confidence. The project also partnered with service providers who carried out HIV counselling and testing during the performances. The case study reports that "after the programme, we observed that people with disabilities were now included in the community's sexual and reproductive health and rights agenda" (Ondiege, 2017).

Example 4: training women with disabilities to be Community Based Rehabilitation (CBR) facilitators improves maternal health and social inclusion

• **Training CBR facilitators**: The Karuna Foundation in Nepal created the Inspire2Care programme, where women with disabilities are trained as CBR facilitators. The CBR facilitator role is to work towards disability inclusion in communities and share information about healthy pregnancies and safe deliveries. A report on the programme states that it is fully planned, implemented and evaluated with and by communities, involving persons with disabilities themselves. The allocation of financial resources from local government and the community ensures sustainability of services. The report concludes that this combination makes inclusive reproductive health, maternal and child health care possible (Rana, 2017).

4.5 Access to services

	Access to services: summary of key evidence gaps			
•	Lowest levels of evidence in relation to service quality/after care. Clear evidence gap in relation to enabling access to SRH services in humanitarian settings.	 No evidence was found on interventions supporting people with communication, mental health or cognition impairments. Across the outcome area the quality of the evidence can be considered low. 		
	7 2	1		
Number of studies included in the EGM and level of confidence (red = low confidence, green = high confidence)				

4.5.1 What evidence exists?

The outcome area of access to services totals 10 studies and 5 handbooks, with 19 entries across the EGM. Four studies were conducted in Africa, two in Asia, two in Latin America, and two studies are universally applicable. All studies in this outcome area were qualitative and the majority have low levels of confidence. The studies have an equal spread relating to young people and adults, and all but one focused on women only.

This outcome area has the least amount of evidence compared to the other outcome areas and there are clear evidence gaps in relation to impairment type. Of the two subcategories reviewed, the majority of evidence is found under access and utilising health services, however, none of this evidence applies to mental health, cognition or communication impairments. Under the subcategory of service quality and after-care, there is only one study of relevance, which is related to auditory impairments.

Only one study on access to services relates to a conflict affected area. This is a case study of Profamalia, an organisation in Colombia that developed mobile health brigades and adolescent-led community education programmes. These have allowed the team to bring SRHR information and services to crisis affected adolescents in some of the communities most impacted by conflict and displacement (Plan International, 2017).

4.5.2 'What works': examples from the EGM

Example 1: Accessibility is defined and addressed in a comprehensive manner

• The need for a comprehensive approach: Evidence indicates that to increase accessibility to SRH services for persons with disabilities, a broad and comprehensive approach should be taken, including, for example, improving the accessibility of entrances to healthcare facilities, appropriate equipment, rest-room facilities and transportation to health care facilities. Ahumuza's (2014) study on access to SRH services for people with physical disabilities in Uganda reports that people with physical impairments (mobility impairment) "face a multitude of challenges in accessing SRH services including negative attitudes of service providers, long queues at health facilities, distant health facilities, high costs of services involved, unfriendly physical structures and the perception from able-bodied people that people with physical impairments should be asexual." Participants in Apolot's study on maternal and new-born health needs for women with walking disabilities in Uganda (2019) highlighted infrastructural requirements, such as lower examination and delivery beds, seats, ramps, and sanitary

facilities. In addition, special maternal and new-born health services require outreach services, shorter waiting times, and responsive health services (Apolot, 2019).

Example 2: Include persons with disabilities in the design and implementation of interventions

- Understanding the needs of persons with disabilities is key to formulating interventions that support them: A recent workshop hosted by SightSavers focused on practical approaches to disability inclusion in healthcare with participants from Humanity & Inclusion, Catholic Relief Services, Light for the World and the National Forum of Women with Disabilities Pakistan. A report on recommendations from the workshop stresses the importance of including persons with disabilities in policy and infrastructure decision-making to ensure accessibility of SRH services (Pregel, 2019). It is recognised that persons with disabilities have historically been left out of development initiatives, and states that services will be improved if they are more inclusive with voices of persons with disabilities are at the core. This approach was central to the development of an accessibility standards and audit pack which aims to help establish national accessibility standards, provide tools to assess existing health infrastructure and provide guidance for the development of new health facilities in LMICS (see Annex F).
- The importance of raising awareness amongst health workers: When persons with disabilities are able to access services, they may have very different experiences in relation to the quality of care they receive. In addition to the experience of physical barriers, quality of care is also linked to the subcategory of *stigma, negative attitudes and discrimination by health care workers* (listed as a subcategory in the outcome area of knowledge and attitudes, see section 4.2). Studies discussing negative attitudes from health workers cited awareness raising through workshops, seminars and peer-to-peer learning as effective ways of positively changing behaviour and as a, result improving quality of care (Chivandire, 2017; Raut, 2015).

Example 3: Using technology to improve access to SRH services

• Mobile trackers to increase access: Karuna's maternal and new-born health programme 'Best Wishes' in Nepal developed a mobile tracker in response to the low level of antenatal checks accessed by women with and without disabilities. The tracker automatically registers and generates a reminder SMS to a nominated female community health volunteer when it is time for a pregnant woman to visit health facilities for antenatal care, institutional delivery and postnatal check-ups. The volunteer can assist women with disabilities to go to the health facility in order to increase attendance and provide additional care when required. The system went live in 2017 and a case study was documented in the same year, which reports 503 women with disabilities being registered of whom five had a safe delivery (Rana, 2017).

Example 4: Sign language training for health workers to address communication barriers

• **Teaching health workers sign language increases access:** VSO implemented a programme in Rwanda in 2018 which aimed to increase access to SRH services for young people with an auditory impairment. Basic sign language training was offered to nurses and community health workers to break the communication barrier in relation to family planning and general SRH services. Their evaluation reports that "Health care

workers said that the training had helped them to overcome their fears and inhibitions and increased their confidence to work with deaf clients and their parents. Some also talked about how the training had challenged their preconceptions about deaf people and increased their awareness of deaf people in the community" (VSO, 2018). Through awareness raising sessions on SRH issues with young people with an auditory impairment, the case study reported that young people found it easier to access nurses without the need for an interpreter when it had previously been challenging for them to do so (VSO, 2018). VSO (2018) also reported the challenge of accessing young people with auditory impairments who did not speak any sign language, stressing the need for visual materials. Last, it should be noted that training health care workers in the use of sign language, will only support communication at a basic level; complex health information and needs will still have to supported by visual aids and interpreters.

4.6 Enabling environment

Enabling environment: summary of key evidence gaps				
 Significant evidence gaps in the subcategories of ensuring confidentiality and improving livelihoods for persons with disabilities. 	 Evidence gap on interventions in humanitarian settings. Evidence gap for mental health and communication impairments. 			
17 4	6			
Number of studies included in the EGM and level of confidence (red = low confidence, green = high confidence)				

4.6.1 What evidence exists?

The outcome area of enabling environment totals 27 studies and 3 handbooks, with 72 entries across the EGM. Nearly half of the studies (14) were conducted in Africa, of which the majority are from Southern and Eastern Africa. Six studies were conducted in Latin America, and six in Asia, with one that is universally applicable. Just two of all studies in this outcome area apply to humanitarian settings/refugees and eight are applicable to young people.

The EGM provides a mixed picture in terms of evidence quality (level of confidence). The higher levels of confidence are mainly in the subcategories of *marital status* and of *caregivers/family*, whilst lower levels of confidence can be found in the *laws/policy* and *donors/government* subcategories. The evidence shows the importance of the supportive role of family and how marital status can make a difference in terms of accessing SRH services.

There are significant evidence gaps in the subcategories of confidentiality and *livelihoods/costs*. In relation to livelihoods, just three studies referenced successful interventions which is in line with findings by White et al (2018) within their EGM of studies assessing the effectiveness of interventions for persons with disabilities. In relation to confidentiality, just one study referenced what works, indicating a clear evidence gap. The sub category of confidentiality is important given that some people with disabilities (particularly those with more severe impairments) live at home or in institutions, which means they can be completely dependent on others. This can result in denial of their autonomy and privacy, whether intentional or not (UN Special Rapporteur on the Rights of Persons with Disabilities, 2017) which in turn affects their confidentiality in accessing SRH services.

Five studies referred to the role of marital status and how being married could positively affect access to SRH services. The studies which referenced this were conducted in Uganda, Ethiopia, Kenya and Nepal, and one of the studies referred to women in a humanitarian setting (refugees). Whilst marriage obviously cannot be seen as an effective intervention to increase access to SRH services, it is important to be aware of the different experiences for married and unmarried women with disabilities for programmatic purposes. Evidence indicates that unmarried women with disabilities can face a higher degree of marginalisation compared to their married peers (Women's Refugee Commission, 2015; Apolot, 2019)⁸.

There are also gaps in relation to interventions for different types of impairment, most notably in the subcategories of *disaggregated data* and *donors / government*. Five interventions included in this EGM highlighted the relevance of disaggregated data, four of which are not related to a specific type of impairment (falling under category of pandisability). The subcategory of *disaggregated data* refers to studies which reference the use of data that is broken down into different types of impairments. Evidence states that it is best practice to collect and use disaggregated data instead of collecting or using data for one particular type of impairment (WHO, 2011). Collection of disaggregated data recognises that needs may differ for people with different or multiple impairments and allows appropriate alteration to programmes. A similar point can be made for donors and governments who provide support for persons with disabilities to access SRH services: support is needed across all types of impairments. Donors can also play a role in enabling access to SRH services by commissioning inclusive evidence and programmes. Six studies are included in this EGM which how governments were successfully engaged in changes laws, policies and practice to enable persons with disabilities access to sexual reproductive health services.

4.6.2 'What works': examples from the EGM

Example 1: Family and friends play important roles to increase access to SRH services or information

The role of family is critical: Positive outcomes are reported through the role of family, friends and the community in a number of studies (FHI 360 Ethiopia, 2017; Raut, 2015). Many of these refer to the support persons with disabilities receive from family both emotionally and practically (the latter being critical in rural areas where SRH services are often far away). Counselling, sensitisation and peer-to-peer learning have proved effective ways to increase the supportive role family and friends can play to support access to SRH services and information (see 4.2.2 and 4.3.2). Ways of encouraging this support are important given the fact that families are sometimes amongst those who stigmatise people with disabilities, leading to further isolation, and they can also be the perpetrators of violence (WHO, 2011). Evidence also indicates that marital status can affect how family and community treat people with disabilities. For example, in Ghana it was noted that "most women with disabilities who were not married reported limited support from family and

⁸ It is worth noting that evidence also indicates specific risks for married women with disabilities. For example, Gartrell (2017) states that "by marrying, women with disabilities fulfil a socio-cultural norm that brings them status as wives and mothers alongside their non-disabled peers. However, whilst a spouse can be a source of support, love and care, they can also be abusive and unsupportive." In addition, an article based on ethnographic research in a village in North China explores the social aspects of sexuality and marriage for women with an intellectual disability. It reports that "the socioeconomic context of rural society makes marriage for women with an intellectual disability possible primarily because of their female body and biological attributes of reproduction. Being socially constructed as the embodiment of reproduction, women with an intellectual disability lose their autonomy and face multiple risks in their experience of sexuality and marriage" (Pan and Ye, 2011).

community members" (Ganle et al. 2016).

Example 2: Peer support networks and village saving and loan schemes help to address the socio-economic barriers to accessing SRH services

Using peer support networks to address gender-based violence: Women with • disabilities face particular barriers to their economic, social and political participation and are more likely to live in poverty than their non-disabled counterparts or men with disabilities (Gartell, 2017). Socio-economic inequality can also affect access to reproductive health services (Trani et al, 2011). In response to this, IRC (International Rescue Committee) and WRC (Women's Refugee Committee) in Burundi designed a multi-pronged approach for urban refugees, including refugees with disabilities, building on their existing Women's Protection and Empowerment Programme. Urban refugees in Burundi receive support to access limited health care services, but all other needs (shelter, safety, education, food etc.) must be met by the refugees themselves. This reportedly leads to exploitation whereby refugees are used as cheap labour and experience sexual exploitation and abuse. The IRC / WRC programme was twofold in addressing gender-based violence through counselling, case management and access to healthcare on the one hand, and through social and economic empowerment programmes on the other hand. In relation to the latter, IRC created social protection networks through peer support groups and worked to increase access to income generating opportunities through a Village Savings and Loans Associations (VSLA) scheme.

However, IRC field staff indicated that they had been hesitant to work with women with disabilities, because they assumed they needed specialist skills to work effectively with them and their assessment tools did not include or track women with disabilities. To change this, IRC and WRC firstly set up group discussions with female refugees with disabilities and female healthcare staff to identify gender-based violence needs and capacities, as well as to identify barriers and enablers to facilitate access and inclusion in activities. Subsequently, peer support networks consisting of female refugees with disabilities and/or caregivers were set up. The groups were supported by a community mobiliser from IRC, who facilitated the group dynamics and supported a series of discussions on GBV, which included husbands. The participating female refugees with disabilities reported a positive change in their perception and daily outlook and said that the counselling and savings groups supported their empowerment. The IRC staff received training from Handicap International (currently known as Humanity & Inclusion) on the CRPD and the accessibility measures, which they said was vital in being able to change their practice. They also started to employ women with disabilities.

Example 3: Participatory research raises community awareness

• Participatory research to raise community awareness: Advantage Africa in their justice for survivors of sexual abuse programme explain that the participatory nature of their research into gender-based violence against persons with disabilities contributed to the establishment of an improved community response system for people with disabilities who experienced (sexual) abuse. It is reported that through participation, awareness was raised amongst the community.

Example 4: Relevance of networks and partnerships

- Using donor networks to improve partnerships: A study on sexual violence against people with intellectual (cognitive) impairments by COVAW (2015) in Kenya reports successful outcomes as a result of improving partnerships through the utilisation of donor networks. Particularly when they decided to develop a programme to tackle gender-based violence, they were able with support from their donor to partner with the right technical experts in this area (COVAW, 2015).
- Relevance of networks and partnerships to strengthen programmes and raise awareness: Pacific Disability Forum (PDF) is a Fiji based federation of Disabled People's Organisations (DPOs) that represents persons with disabilities across the Pacific. They developed a programme that specifically addressed violence against women with disabilities. The programme had three phases, firstly to increase knowledge and raise awareness amongst a select group of DPO representatives, family members, caretakers and community workers, who subsequently collected relevant data in their communities. The second phase was the analysis of that data and creation of a toolkit to address violence against women with disabilities in Fiji. This was shared at a four-day workshop with a wide range of organisations with the goal to improve the toolkit and raise awareness. Phase three involved a round of consultations to raise awareness amongst key interested groups about the toolkit, as well as a workshop with stakeholders from the government to pilot the toolkit. The varied nature of the organisations PDF involved meant that a broad base of support for issues around violence against women and girls with disabilities was created. This for example led to The National Task Force on Ending Violence Against Women in Fiji to agree to include a representative from the disability movement in its committee discussions (Pacific Disability Forum, 2015).

5 Conclusions

The EGM shows that across all outcome areas, there is a low amount of evidence in relation to 'what works' to ensure persons with disabilities have access to SRH services in LMICS. The UN Convention on the Rights of Persons with Disabilities (UNCRPD) guarantees persons with disabilities the right to access "the same range, quality and standard of free or affordable health care and programs as provided to other persons, including those in the area of sexual and reproductive health and population-based public health programmes" (UNCRPD, 2008). It also specifies that persons with disabilities have legal capacity on an equal basis with others (Article 12), have the right to marry and found a family, retain their fertility (Article 23), and have access to SRH care (Article 25). Yet, inequality for persons with disabilities persists. Prejudice that persons with disabilities are asexual or that they should have their sexuality and fertility controlled continues to be prevalent in many contexts. Studies have shown repeatedly that persons with disabilities face multiple barriers that are often intersecting. Albert and Hurst (2005) attribute people with disabilities' inability to access health services to a complex web of discrimination made up of negative social attitudes and cultural assumptions, as well as environmental barriers including policies, laws, structures and services which result in marginalisation and social exclusion. Access to SRH services for persons with disabilities is also hampered by inaccessible health facilities, long queues, insensitivity of health care providers, limited knowledge on disability from health care providers, and limited information tailored to their health needs.

Most evidence on was found under the outcome areas of health and knowledge and attitudes, whilst behaviour and access to services showed significant gaps. However, the picture becomes more nuanced when looking at subcategories under each outcome area. The following nine subcategories showed significant evidence gaps (four studies or less, excluding handbooks):

	Subcategories with biggest evidence gaps				
•	 Stigma/negative attitudes and discrimination from persons with disability themselves 	•	Pregnancy and births and maternal health		
		•	Abortion and post abortion care		
٠	Sexual behaviour and sexual pleasure	•	Providers/service quality and after care		
•	Sexual orientation	•	Livelihoods/costs		
•	Communication and support seeking	•	Confidentiality		

Table 3: Subcategories with biggest evidence gaps

Overall, the EGM shows that most studies relate to women and girls. This is perhaps unsurprising given the topic, however, SRH should not be seen as a women's issue alone, but should include both men and women, again highlighting a gap.

More studies on effective interventions for young people with a disability are needed. The outcome area of knowledge and attitudes included the most interventions focused on young people; particularly the subcategory of *education*. However, this was not consistent across all categories and particularly the outcome area of enabling environment could benefit from more evidence about 'what works' to enable young people's access to SRH services. In addition, the evidence is weak in understanding how age (e.g. being young) can intersect with disability in creating additional barriers to access SRH services. For example, Burke (2017) found that 'young people with disabilities focused more on barriers and challenges related to being young than on living with a disability' highlighting how this group face multiple barriers to accessing services.

SRH issues in humanitarian settings do not stop or diminish during an emergency. In fact, they may become greater (Barot, 2017). Yet, little evidence included in this EGM refers to humanitarian settings and refugees. UNFPA (2009) states that "the positive outcome of past experiences in emergency situations reveals that in most cases, the needs of women with disabilities can be covered when they have access to mainstream health services. Although sometimes more specialist care may be required, enormous progress is made when women with disabilities are recognised as part of the community and are given access to the same resources as other victims in the situation" (UNFPA, 2009). Yet little evidence shows successful interventions in relation to how this can be achieved. Interestingly, many handbooks do provide specific guidance for persons with disabilities in humanitarian settings, however, the evidence-base behind such guidance is not always clear.

There are evidence gaps in relation to individual countries, as well as regional evidence gaps, such as in Latin America, Asia and Western and Northern Africa. The map on page 10 shows that the majority of studies were conducted in relation to interventions in Africa and in particular Eastern and Southern Africa, highlighting a particular evidence gap in relation to studies from Northern and Western Africa. Conducting a more extensive search in Spanish and French was beyond the possibilities of this assignment and doing so could potentially fill some of these gaps (e.g. in relation to Latin America and Western Africa). The evidence that exists from the Asia region comes mainly from Nepal.

Due to the lack of evidence it is difficult to draw any conclusive trends in relation to 'what works' across interventions. Whilst interventions should be understood in their context, some of the interventions did show similar attributes (discussed below). However, since confidence in data quality was often low, care should be taken when implementing these.

5.1 Key examples of 'what works'

There is a clear need for a multi-component approach to programmes, as well as data collection, due to the multiple barriers that persons with disabilities face, the diversity of types of impairment, and the contexts people live in. As Braathen (2016) aptly explained on the topic of disability and HIV "it is crucial to consider the interconnectedness of the challenges faced by an individual and a household. Issues of health (physical and mental), disability, employment, education, infrastructure (transport/terrain) and poverty are all related and interconnected, and should be addressed as a whole in order to secure equity in health." A number of interventions included in this EGM have shown how this was done successfully.

Key example 1: Address environmental, institutional and attitudinal barriers

• Programmes should focus on the different barriers persons with disabilities face in accessing SRH services. As such they should aim to address institutional or systemic barriers, whilst at the same time tackle the underlying inequalities faced by persons with disabilities. For example, by developing skills and increasing livelihood opportunities. Programmes should tackle the environmental barriers persons with disabilities face and advocate for their rights. For example, Profamilia in Colombia addressed the needs of women and girls with intellectual (cognitive) disabilities, who

experienced forced sterilisation, but simultaneously challenged the system that allowed this to happen by tackling the legal framework. They also created awareness amongst communities' healthcare workers and caretakers about the rights of persons with disabilities and successfully advocated for change of this practice (Profamilia, Fundamental Colombia, ASDOWN, and PAIIS, 2015).

Key example 2: Working in partnership

- Working in partnership can help create stronger programmes at an individual level, but at the same time provide a network and stronger voice to advocate for systemic change. As persons with disabilities can face intersecting challenges, for example, of increased gender-based violence and the threat of contracting HIV or other STIs, partnerships can be an important way of achieving change. This is demonstrated, for example, by the IRC and WRC in Burundi, where their collaboration allowed the exchange of technical knowledge, the creation of networks and began to break down barriers and previously held assumptions (IRC and WRC, 2015).
- Partnerships will have to be context specific, but can help to provide the necessary technical knowledge when dealing with intersectionality and as such increase overall impact. This is demonstrated by the Advantage Africa and Kibwezi Disabled Person's Organisation's (KDPO) case study (2015) which describes how: "The engagement of KDPO in research with Advantage Africa helped them to develop as an organisation. Not only did they learn new research skills, but they also established links with a much wider range of stakeholders."
- Donors can support this by sharing their network and helping to establish connections, as was demonstrated by COWAV in Kenya. Donors can also influence the need for data collection and the importance of obtaining data disaggregated by types of impairments. They should be explicit about definitions and expectations in relation to disability and inclusion (COWAV, 2015).

Key example 3: Persons with disabilities need to be involved and have leading roles in research, programme development, policy creation and evaluation.

- Most importantly, persons with disabilities need to be involved and have leading roles in research, programme development, policy and toolkit development and evaluation. For example, role models were mentioned by Goyal in relation to the workshops she conducted in India (2017) and how this can help shift negative societal attitudes. Another example is found from Disability Rights International and Collectivo Chuhcan (2015) in Mexico, where a female leader with a psychosocial (mental) impairment positively influenced the involvement and self-advocacy of other women with psychosocial impairments.
- Peer-to-peer learning examples in Nepal, Zimbabwe and Uganda (Women's Refugee Commission, 2015) showed how groups of mixed abilities resulted in some of the most successful interventions. Marie Stopes Nepal also set up peer-to-peer learning groups called Rockets and Space Groups, consisting of young people with and without disabilities and youth volunteers who share SRH knowledge with their peers. Their evaluation showed a huge increase in the use of their services by young people with disabilities. As such, it remains that the maxim 'nothing about us, without us' should be key to all interventions.

6 Recommendations

6.1 Recommendations for future evidence generation

Despite a growing body of evidence, this EGM reveals a number of significant evidence gaps regarding what interventions are effective in ensuring persons with disabilities have access to SRH services. It is important that these are acknowledged and addressed. It is therefore recommended that:

Research institutes, NGOs and DPOs generate further evidence on 'what works.' This should focus on the key evidence gaps highlighted in Table 3. Where possible it is recommended that evidence should be quantitative, or apply mixed methods, as this EGM showed that the majority of existing evidence on 'what works' is qualitative. Further quantitative evidence would be particularly useful for showing change created by programmes at scale (whereas qualitative evidence provides and in-depth look at what works and why).

Research institutes, NGOs and DPOs share what does not work to enable access to sexual reproductive health services for persons with disabilities. We recognise that it is not easy to discuss and share failings, but 'learning from failure' could prevent other organisations making similar mistakes and ensure that funds can be better allocated in future.

Persons with disabilities should form part of research/evaluation teams and/or validate the research findings. Ideally they should be involved in all stages of generating data on enabling access to SRH services for persons with disabilities using a peer research approach, but as a minimum they should have the ability to validate the research findings.

Research/evaluation institutes should continue and increase working in close collaboration with DPOs and NGOs, as well as other organisations working to enable persons with disabilities to have access to SRH services. Working in partnership will ensure knowledge exchange, capacity building, increased access for persons with disabilities and an improved platform to share learning. The EGM also highlighted that some of the evidence has lower levels of confidence in the quality of the evidence, collaboration between research institutes and DPOs and NGOs could help address this.

Commissioners of research and evaluation should be explicit about definitions and expectations in relation to disability and inclusion and ensure it is non-discriminatory when they commission data/evidence. For example, SRH should be defined inclusively and encompass both women and men. Data should be disaggregated by Sex, Age and types of impairment using the Washington Group Questions. Requests should be made for the research process, as well as research teams to be inclusive.

Service delivery organisations to incorporate disaggregation by types of impairment into existing MIS systems so that client profiles are strengthened, and in turn help analysis around health seeking behaviours by people with disabilities.

Bibliography

Note the references below refer only to those used for this report in addition to those listed in the EGM. The full overview of articles included in the EGM can be found in the EGM itself.

Atwebembeire, J. (2011) Access to and Utilization of Reproductive Health Services by Women with Disabilities in Rural Uganda, International Statistical Institute: Proceedings of 58th World Statistical Congress, 2011, Dublin (Session CPS069) p.5662. http://2011.isiproceedings.org/papers/950492.pdf

Ahumuza, S. et al (2014) *Challenges in accessing sexual and reproductive health services by people with physical disabilities in Kampala, Uganda*, Reproductive Health, Volume 11, Article Number 59.

https://reproductive-health-journal.biomedcentral.com/articles/10.1186/1742-4755-11-59

Barot, S. (2017) *In a State of Crisis: Meeting the Sexual and Reproductive Health Needs of Women in Humanitarian Situations*, Guttmacher Policy Review, Volume 20. <u>https://www.guttmacher.org/gpr/2017/02/state-crisis-meeting-sexual-and-reproductive-health-needs-women-humanitarian-situations</u>

Bill, A. and Hurst, R. (2005) *Disability and a human rights approach to development: Briefing Paper*, Norwich: Knowledge and Research (KaR), pp.1-16. https://pdfs.semanticscholar.org/bd51/f5ecf571cf152b45c8cf6195eaa66242eb89.pdf

Buchy, M., Resch, E., Wapling, L., Jones, S. and Singh, P. (2017) *Scoping Study: Donor Support for Disability Inclusive Country Led Evaluation Systems and Processes.* Synthesis Report, Oxford: Oxford Policy Management.

https://assets.publishing.service.gov.uk/media/5a29174740f0b659d45200ae/8Sept17NoTrac kDisability inclusive evaluation systems executive summary Final.pdf

Burke, E. et al (2017) *Qualitative study to explore the barriers and enablers for young people with disabilities to access sexual and reproductive health services in Senegal,* Reproductive Health Matters, Volume 25, Issue 50: Disability and sexuality: claiming sexual and reproductive rights.

https://www.ncbi.nlm.nih.gov/pubmed/28784062

Carew, M. et al (2017). The sexual lives of people with disabilities within low- and middleincome countries: a scoping study of studies published in English, Global Health Action, Volume 10.

https://www.tandfonline.com/doi/full/10.1080/16549716.2017.1337342

Devkota, H.R., Murray, E., Kett, M. et al (2017) *Healthcare provider's attitude towards disability and experience of women with disabilities in the use of maternal healthcare service in rural Nepal.* Reproductive Health, Volume 14, Issue 79. https://reproductive-health-journal.biomedcentral.com/articles/10.1186/s12978-017-0330-5

FHI 360 (2017) Assessment on Family Planning Needs of People Living with Disabilities: Case of Addis Ababa, Ethiopia. USAID, FHI 360, Ministry of Health. https://www.fhi360.org/sites/default/files/media/documents/resource-disability-report.pdf

Fraser and Corby (2019) *Family Planning for Women and Girls with Disabilities.* Disability Inclusion Helpdesk Report. UK AID

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_da ta/file/818118/query-2-family-planning.pdf

Groce, N. and Trasi, R. (2004) *Rape of individuals with disability: AIDS and the folk belief of virgin cleansing,* The Lancet, 363, pp.1663-4 https://www.ncbi.nlm.nih.gov/pubmed/15158626

Isomi M. Miake-Lye et al. (2016) *What is an evidence map? A systematic review of published evidence maps and their definitions, methods, and product, Systematic Reviews* Volume 5, Article Number 28.

https://systematicreviewsjournal.biomedcentral.com/articles/10.1186/s13643-016-0204-x

Plan (2017) Let me decide and thrive: Global discrimination and exclusion of girls and young women with disabilities, Woking: Plan International. https://plan-international.org/publications/let-me-decide-thrive-srhr-disability

Pregel, A. (2019) 12 tips to make health programmes inclusive for people with disabilities, Sightsavers.

https://www.sightsavers.org/blogs/2019/06/12-tips-to-make-health-programmes-inclusive/

Pan, L., Ye, J. Sexuality and Marriage of Women with Intellectual Disability in Male-Squeezed Rural China. Sex Disabil 30, 149–160 (2012). <u>https://doi.org/10.1007/s11195-011-9232-6</u>

Sightsavers website: <u>https://www.sightsavers.org/blogs/2019/06/12-tips-to-make-health-programmes-inclusive/</u> (accessed December 2019).

Snilstveit, B. et al (2013) *Evidence Gap Maps: Tool for Promoting Evidence-Informed Policy and Prioritizing Future Research*, The World Bank. <u>https://www.researchgate.net/publication/259582146_Evidence_Gap_Maps_A_Tool_for_Promoting_Evidence-Informed_Policy_and_Prioritizing_Future_Research</u>

Taegtmeyer M. et al (2009) *A peer-led HIV counselling and testing programme for the deaf in Kenya*, Disability and Rehabilitation, 31, pp.508-514. https://www.ncbi.nlm.nih.gov/pubmed/18608420

Trani, J. et al (2011) Access to health care, reproductive health and disability: A large scale survey in Sierra Leone, Social Science & Medicine, Volume 73, Issue 10, pp.1477-1489. https://www.ncbi.nlm.nih.gov/pubmed/22014873

WaterAid and Marie Stopes International Australia (2016) Integrating Menstrual Health, Water, Sanitation and Hygiene, and Sexual and Reproductive Health in Asia and the Pacific Region A Discussion Paper, Australia: WaterAid and Marie Stopes International. https://washmatters.wateraid.org/sites/g/files/jkxoof256/files/Integrating%20Menstrual%20He alth%2C%20Water%2C%20Sanitation%20and%20Hygiene%2C%20and%20Sexual%20and %20Reproductive%20Health%20in%20Asia%20and%20the%20Pacific%20Region.pdf

White, H., Saran, A. and Kuper, H., (2018) *Evidence and Gap Map of Studies assessing the Effectiveness of Interventions for people with Disabilities*, London: CEDIL Inception Paper 12.

https://assets.publishing.service.gov.uk/media/5baa3c32ed915d2e2bf779fd/Disability_Evide nce_Gap_Map_report.pdf

World Health Organisation (2011). *World Report on Disability*. <u>https://www.who.int/disabilities/world_report/2011/report.pdf</u>

3ie website. <u>https://www.3ieimpact.org/evidence-hub/evidence-gap-maps</u> (accessed September 2019)

UNAIDS (2014) *The Gap Report: People with Disabilities*. Switzerland: UNAIDS. <u>https://www.unaids.org/sites/default/files/media_asset/UNAIDS_Gap_report_en.pdf</u>

UN Special Rapporteur on the Rights of Persons with Disabilities (2017) Sexual and health and rights of young women and girls with disabilities. United Nations. https://digitallibrary.un.org/record/1301518?In=en ATTITUDES OF HEALTH PROFESSIONALS TOWARD

PERSONS WITH DISABILITIES IN

Annex A: Detailed methodology

1. Introduction

Evidence gap maps (EGMs) have emerged in the last decade to consolidate research that already exists; they aim to avoid duplication of work and visually show existing research gaps to support more strategic research funding. There is a growing body of evidence about the inequalities that persons with disabilities face compared to their non-disabled peers. In 2018, DFID commissioned an EGM to assess the effectiveness of interventions for persons with disabilities in LMICs in relation to education, health, jobs and livelihoods (White, Saran and Kuper, 2018). However, this did not include an in-depth look at the evidence available on their access to SRH services. Fraser and Corby (2019) highlighted this in their report 'Family Planning for Women and Girls with Disabilities', as did Carew et al (2017), stating that '...where there has been some attention to disability and sexual health, it has tended to focus predominantly on vulnerabilities, and we need to know much more about emancipatory practices.'

To address this gap and to support WISH countries with their programmes, this EGM focuses on which interventions work. When scoping for this EGM, it was recognised early on that some of the best practices and interventions on 'what works' to support people with disabilities' access to SRH services in LMICs are not always empirically tested. Therefore, a decision was made to develop an EGM which includes both peer-reviewed and grey literature. This approach diverges from the norm, as EGMs typically only include peer-reviewed literature. To our knowledge, the inclusion of grey literature has not been done before, hence the development of this EGM has been exploratory in nature. This Annex sets out the development of the EGM; firstly, the creation of the framework, followed by the data collection, the design and its limitations.

What is an evidence gap map?

An EGM is a visual, user-friendly presentation of the available, relevant evidence for a particular sector. Relevance is defined in relation to the scope of the map. Evidence is systematically gathered and mapped onto a framework, visually highlighting the gaps or concentration of evidence. The evidence included in an EGM may be global or for a particular region(s). It may also cover different types of evidence, such as systematic reviews or impact evaluations. An EGM provides an overview of what relevant evidence is available, but it does not summarise the findings (White et al, 2018; Isomi M. Miake-Lye et al, 2016; 3ie, 2019; Snilstveit et al, 2013). EGM's offer a unique opportunity to showcase the strengths and gaps in the availability of systematic reviews and impact evaluations across a range of pre-defined topic areas.

2. Development of the EGM framework

2.2.1 Examination of existing frameworks

Existing methodologies for the development of EGMs were firstly examined. In 2017 3ie developed an EGM on Adolescent Sexual and Reproductive Health Evidence Gaps.⁹ This

⁹ <u>https://gapmaps.3ieimpact.org/evidence-maps/adolescent-sexual-and-reproductive-health-evidence-gap-map</u> (accessed 18 September 2019)

map served as an initial outline for the selection of five key outcome areas and underlying subcategories to be included on the horizontal axis of this EGM, as shown in table 4.

Table 4: Outcome areas included in the EGM

Outcome areas and subcategories

1. Knowledge and attitudes:

This entails interventions linked to both formal and non-formal education, as well as addressing the stigmatisation and negative attitudes persons with disabilities can be subjected to by health workers, the community and by persons with disabilities themselves.

- 1.1. Education
- 1.2. Stigma / negative attitudes: discrimination from health care workers
- 1.3. Stigma / negative attitudes: discrimination from persons with disability themselves
- 1.4. Stigma / negative attitudes: discrimination from the community

2. Behaviours:

This refers to interventions affecting the behaviour of persons with disabilities themselves in relation to a wide range of SRH issues, such as the use of contraception, menstrual hygiene management, support seeking, as well as sexual pleasure and sexual orientation.

- 2.1. Sexual behaviour, sexual pleasure
- 2.2. Sexual Orientation
- 2.3. Contraception and other prevention
- 2.4. Menstrual hygiene
- 2.5. Communication and support-seeking
- 2.6. Sexual behaviour, sexual pleasure

3. Health:

Health covers a wide range of SRH interventions with positive health outcomes, such as those in relation to pregnancy; maternal health; abortion; HIV and STIs; access to information; being aware of one's rights; as well as interventions that tackle sexual and gender-based violence. This category also captures positive health outcomes that were unintended by the intervention.

- 3.1. Pregnancy and births and maternal health
- 3.2. Access to information
- 3.3. Abortion and post abortion care
- 3.4. HIV/STI testing and incidence
- 3.5. Sexual and intimate partner violence
- 3.6. Other health outcomes

4. Access to services:

This area focusses purely on access to health services (either physical or remotely. It distinguishes between utilising health services for SRH and the care and after care received by providers.

- 4.1. Accessing and utilising services
- 4.2. Providers and service quality and after care

5. Enabling environment:

This area is extremely broad and ranges from the role family, friends or the community play in supporting access to SRH services, as well as the role government and donors can play. It also captures interventions on livelihoods, confidentiality and role that data plays.

- 5.1. Livelihoods/ costs
- 5.2. Marital status/long term partner
- 5.3. Caregivers and family
- 5.4. Community, CBOs and DPOs
- 5.5. Disaggregated data
- 5.6. Laws and policy
- 5.7. Confidentiality
- 5.8. Donors / government

Following consultation with the WISH Disability and Inclusion Technical Working Group (TWG) the vertical axis of the EGM - which traditionally lists interventions - was replaced with types of impairments. Given the complex heterogeneity of disabilities and the range of interventions that can provide access to SRH services for people with disabilities, it was deemed useful to create an overview which showed the distinction between different impairments in relation to the interventions being mapped. For example, if a certain intervention was created for people living with hearing impairments and this was not tested for people living with a physical impairment (who might require a different type of intervention), a framework listing the intervention on the Y-axis would not immediately show this distinction. This resulted in the categories listed in Table 5.

Impairment type	Description		
Mobility	People identified as having difficulties with upper and/or lower limb movement and/or manual dexterity		
Vision	People identified as having difficulties with complete or partial vision		
Auditory	People identified as being completely or partially deaf		
Mental health	People identified as experiencing psychiatric problems (this is also known as psychosocial impairment)		
Cognition	People identified as experiencing learning difficulties and the ability to concentrate and remember		
Communication	People identified as having complete or partial speech difficulties		
Pan-disability	Interventions that reached a group of people with a range of impairments		

Table 5: Types of impairment included in the EGM

These broad categories allow the mapping of studies which categorise disability using the Washington Group Questions, as well as other forms of identifying people with disabilities. Therefore, this EGM maps literature which outlines successful interventions to increase access to SRH services for persons with disabilities according to type of intervention and types of impairment. The EGM also contains filters, such as country, young people, parents/guardians, and disaster/conflict affected area. This should help the user navigate the EGM and select studies related to these specific categories only. These filters were inspired by those used within existing EGMs.

This framework was discussed with a small subset of the WISH Disability and Inclusion TWG; after which minor iterations were made. Subsequently feedback was sought from the wider TWG, both on the EGM framework, as well as its scope, quality criteria and proposed filters.

2.2.3 Consultations with key experts, NGO and DPO representatives

Development of the framework was followed by six consultations with key experts (NGO and DPO representatives) including persons living with disabilities, in order to further enhance the framework, the quality criteria and the filters. The selection of organisations / experts was purposive, and in order to reach the widest number of stakeholders, snowball sampling was applied by asking participants to recommend other experts to consult. The consultations took place mostly via phone, but some were in person and one was via email. After every consultation the framework was refined. The consultations were semi-structured using a set of guiding questions, and notes were taken during each conversation. A list of those consulted can be found in Annex D and the interview questions in Annex B.

As a result of the consultations, the following adjustments were made:

- The framework was adjusted to include elements such as sexual orientation, post abortion care, forced sterilization, disaggregated data, long term partner, sexual pleasure and gender-based violence.
- The 'stigma' subcategory was further broken down into different groups (e.g. parents, health care workers, community).
- Feedback on the filters suggested replacing fragile states with countries affected by disasters and countries affected by conflict. The reason being that when a country is affected by conflict some services might still be available, whilst during disasters all services are likely to be unavailable. However, when populating the EGM, a decision was made to group disaster and conflict affected countries and to also include refugees in this category - as very little literature exists in relation to successful interventions for access to SRH services for disabled women in countries affected by conflict / disasters.
- The Y axis on types of impairments went through various iterations before landing on the seven broad categories. Firstly, a suggestion was made to list the impairments in relation to the Washington Group's (WG) short set of questions. However, as stated on their website 'the [short] questions were not designed to measure all aspects of difficulty in functioning that people may experience, but rather those domains of functioning that are likely to identify a majority of people at risk of participation restrictions. [...] The WG Short Set will identify most, but not all, people with disabilities.'¹⁰ After consultation with the WISH Disability and Inclusion TWG the seven broad categories were decided upon: Mobility, Vision, Auditory, Mental Health, Cognition, Communication and a category listing Pan-Disability.

3. Development of quality criteria

One of the biggest challenges with including grey literature in an EGM is deciding upon the quality of work. This is particularly important, as promising interventions might not have been thoroughly tested, which could potentially lead to untested interventions being replicated on the basis of being included in the EGM.

To develop a set of quality criteria specific to this EGM, the criteria used in other EGM's was initially explored. This process provided useful insights, but these did not seem fully applicable to an EGM that includes grey literature. For example, rigorous criteria such as 'did the authors perform the study selection in duplicate,' don't commonly apply to evaluations conducted by NGO's, which are often conducted under budget constraints. The AMSTAR 2¹¹ tool, created in 2017 is a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions or both. This tool was adjusted and combined with criteria relevant to this EGM, such as having a clear definition of disability, whether the study disaggregated types of disabilities and if a clear definition of sexual reproductive health is provided by the authors.

This resulted in a set of nine questions to be applied to each study in order to assess quality. A colour-coding system was then used to classify the literature in the EGM according to the results. If all the responses to the adjusted AMSTAR 2 questions were positive, a green label was applied; if a minimum of five questions out of a total of nine were answered positively,

¹⁰ <u>http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/</u> (accessed 12th of December)

¹¹ <u>https://www.bmj.com/content/358/bmj.j4008</u> (accessed 23 November 2019)

an amber label was applied; and if less than five questions were answered positively, a red label was applied. Handbooks on SRH Interventions are listed in light green and were not part of the quality assessment.

All studies with an amber label were also classified independently by another researcher using the same tool. Random spot checks were provided on the literature with green and red labels by a second researcher.

Handbooks on SRH Interventions, including interventions for people with disabilities, are listed in light green and were not part of the quality assessment, because assessing these would require high levels of technical knowledge, preferably conducted by a review committee.

4. Design of filters

The EGM can be navigated using filters. For example, if someone would like to look at a specific country, this can be selected in the filter. Or if someone would like to search for a country and interventions related to parents / guardians / caretakers, these filters can be applied and only studies in relation to these filters will show in the EGM. The filters in this EGM were inspired by other EGMs and after consultations the following filters were included:

Search terms

- Type of study
- Female / Male
- Young People
- Parents / Guardians / Caretakers
- Countries / Region
- Lower Income country/ Upper-Middle Income Country and Lower-Middle Income Country
- Conflict/Disaster affected countries and/or Refugees
- Type of intervention

Including 'Rural and Urban' was discussed as a potential filter, however, due to time limitations this was left out, because most studies referred to specific locations, which would have meant manual assessment of the rural and urban filter.

5. Literature scoping

Whilst the refinement of the framework took place, the search for literature started on the basis of the following criteria:

- 1 Topic in relation to access to reproductive health services for those living with a disability
- 2 Primary research from low-and middle-income countries (as per World Bank Atlas Method)
- 3 Literature starting from 2000 onwards
- 4 Inclusion of grey literature
- 5 Literature to be either in English, French or Spanish
- 6 Literature to present 'what works', not just the issue at hand

As this EGM aims to support the WISH programme, as well as the sector at large, an emphasis was placed on the 27 WISH countries.¹² The search started with an extensive search on google using the search terms below. The last four included a specific search involving the WISH countries.

Search terms
 sexual reproductive health systems + disability sexual reproductive health services + disabilities sexual reproductive health + disabilities persons with disabilities and access to reproductive health
 persons with disabilities and maternal health persons with disabilities and maternal health in Africa persons with disabilities and maternal health in Asia
 sexual reproductive health + disability + [country] sexual reproductive health systems + disability + [country] sexual reproductive health + disabilities + [country]

- sexual reproductive health services + disabilities + [country]
- sexual reproductive health + [outcomes listed on z-axis]

In addition, a call for documents was sent to various network groups including: International Disability, Development Consortium and CORE Group Disability Inclusive Health TAG, as well as the WISH Disability and Inclusion TWG.

Academic searches using similar search terms as listed above, were conducted in CambridgeCore, EBSCO educational, JSTOR, OECD, Emerald Insight, Sage Journals and Project Muse. Reference mining was also applied to check no vital documents were missed. Literature that described a needs assessment instead of an intervention was not included in the EGM, unless it also included elements of what works. Digital tools sourced as part of the literature scoping are not included in the EGM, however, these are listed in Annex F.

6. Designing and populating the Evidence Gap Map

The framework was created using Excel and subsequently designed digitally. Types of impairments are listed on the Y-axis and the outcomes on the Z-axis. When a study addressed various topics and/or applied to different types of impairments the study would be listed in all relevant 'cells.' This means that one study can appear in various tabs in the EGM. The excel document includes links to each study and highlights where a paywall exists.

7. Limitations

There are a few key limitations to the methodology used for this study to be kept in mind when reviewing the EGM.

¹² Democratic Republic of the Congo (DRC), Nigeria, Burkina Faso, Mali, Niger, Senegal, Sierra Leone, Chad, Mauritania, Cote D'Ivoire, Cameroon, Afghanistan, Bangladesh, Burundi, Ethiopia, Madagascar, Malawi, Mozambique, Pakistan, Rwanda, Somalia, South Sudan, Sudan, Tanzania, Uganda, Zambia, Zimbabwe.

- Firstly, due to time restrictions, an extensive search in French and Spanish was not possible. In addition, the focus of the search was on literature related to WISH programme countries, which exclude Latin America, it is therefore likely that studies from this region are currently underrepresented.
- Secondly, some of the studies included in the EGM did not disaggregate by types of impairments. Whilst these have been listed under the 'pan-disability' category, this might be an incorrect assumption due to the lack of information for this particular study.
- Finally, including grey and qualitative literature in the EGM meant searching through vast amounts of data, most of which are focused on vulnerabilities and needs of people with disabilities. As a consequence, the grey literature reviewed is unlikely to have been exhaustive. However, we are confident that all key literature has been captured.

Annex B: Questions used in the consultations

Introduction

As part of the DFID Women's Integrated Sexual Health (WISH) programme, Itad is leading a workstream on evidence generation; learning what works; and dissemination of evidence. This work will include the production of an **evidence gap map** which reviews the evidence base of people with disabilities' access to Sexual and Reproductive Health Services (SRH) in Low-and Middle-Income Countries (LMICs). I have been asked to lead on this piece of work and I would like to ask you a few questions in relation to the framework that I emailed you earlier, as well as the scope and quality criteria for this evidence gap map.

Consent

This conversation will only be used to inform the evidence gap map (EGM), but with your permission I would like to mention that I've spoken to you in the report that will accompany the EGM (e.g. with name, title and organisation). Would you be comfortable with that? If not, this conversation can be completely confidential, and we can omit your name, title and organisation from the report.

The interview is expected to take no more than 30 minutes, but we can stop at any time you wish. Are you happy to proceed?

Questions

- 1. Have you used an evidence gap map before? If so, what was your experience?
- 2. Would an Evidence Gap Map on 'what works' for reaching persons with disabilities with SRH services be useful for your organisation?
- 3. When looking at the framework I've emailed you, do you feel this structure makes sense?
- 4. Do you think anything is missing from the structure?
- 5. You might have noticed several filters, in your experience, do you feel these are the right filters? Should we be adding any filters?
- 6. In terms of the scope of this evidence gap map, we would like to move away from looking at impact studies only and would like to include grey literature. What do you think of this?
- Did you have a chance to look at the scope we identified for the Evidence Gap Map? Is so, what do you think of this? If not, the scope identified is as follows:
 - 1) Topics in relation to access to reproductive health services for those living with a disability
 - 2) Include primary research from low and middle income countries
 - 3) Literature starting from 2000 onwards

- 4) Include grey literature in the analysis
- 5) Literature to be either in English, French and Spanish
- 6) Literature to present 'what works' not just the issue at hand

We will try to include 'what works in crisis situations' depending on how much we find and the time

- 7) available.
- 8. As we would like to include grey literature in the scope of this study, would you have any suggestions on the quality criteria for the literature/reports?

To date we have identified the following quality criteria:

- 1) Clear definition of disability
- 2) Sound research methodology
- 3) Sample size
- 9. Would you be able or willing to share any relevant reports/literature that we can include in the Evidence Gap Map?
- 10. The evidence gap map and its accompanying report will be finalised in the beginning of 2020 would you like to receive a copy from the report and the Evidence Gap Map? Yes/No

Can we keep your records on file in order to do so?

Yes/No

Can I mention in the accompanying report that I have spoken to you?

Yes/No

11. DFID have asked us to ensure that our consultations on this EGM include people living with a disability. Are you happy to disclose whether you consider yourself to have a disability?

Name	
Title	
Organisation	
Location	

12. Thank you so much for taking time to talk to me today. It is greatly appreciated. Is there anything else you would like to add?

Thank you once again for taking part!

Annex C: Quality assessment questions

Classification Criteria for the Evidence Gap Map on 'what works' to ensure persons with disabilities have access to sexual reproductive health services in low and middle-income countries.

This classification tool is based on AMSTAR 2: a critical appraisal tool for systematic reviews that include randomized or non-randomised studies of healthcare interventions or both created in 2017 (Shea, BJ et all). As the Evidence Gap Map includes literature beyond systematic reviews and randomised studies, this tool was adjusted to support with the classification of literature in the Evidence Gap Map on 'what works' to ensure persons with disabilities have access to sexual reproductive health services in low and middle-income countries.

If all the responses to the questions below are positive and question 2 is either answered with Yes or with the first No, a green label is applied; if as minimum five questions were answered with Yes an orange label was applied and if less than five questions were answered with Yes, a red label was applied.

1. Did the authors set out a clear definition of disability?

- Yes
- □ No

For Yes: Persons with disabilities include "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (UN Convention on the Rights of Persons with Disabilities, Article 1)."

2. Did the authors disaggregate by types of disability?

- Yes
- No, because the research was testing an intervention with individuals with multiple disabilities. (e.g. literature did not specify what the multiple impairments consisted of)
- 🗆 No

For Yes: Did they use the Washington Group questions or clearly set out how this disaggregation of types of disability happened

3. Did the authors clearly define sexual and reproductive health?

- Yes
- □ No

For Yes: Sexual and Reproductive Health is described by the United Nations Population Fund as "Good sexual and reproductive health is a state of complete physical, mental and social well-being in all matters relating to the reproductive system. It implies that people are able to have a satisfying and safe sex life, the capability to reproduce, and the freedom to decide if, when, and how often to do so."

4. Did the authors explain their study design?

- Yes
- □ No

- 5. Did the research report contain an explicit statement that the review methods were established prior to the study and were independently verified and did the report justify any significant deviations from the protocol?
- Yes
- Partial Yes
- □ No

For Partial Yes: The authors state that they had a written protocol or guide that included ALL the following:

- □ Review question (s)
- □ A search strategy
- □ A risk bias assessment

For Yes: All of the Partial Yes, plus the protocol should have a dated submission to a research office or research ethics board.

6. Did the authors use a comprehensive literature search strategy?

- Yes
- Partial Yes
- 🗆 No

For Partial Yes:

- □ Searched at least 2 databases (relevant to the research question)
- □ Provided key word and or/ search strategy
- □ Justified publication restrictions (e.g. language)

For Yes should also have all of the following:

- □ Search the reference list / bibliographies of included studies
- □ Searched trial/study registries
- □ Included/consulted content experts in the field
- □ Where relevant, searched for grey literature
- □ Conducted search within 24 months of completion of the review
- 7. Did the authors report on sources of funding for the studies included in the review?
- Yes
- □ No
- 8. Have authors taken account of risk of bias (RoB) when summarizing and interpreting the results?
- Yes
- 🗆 No

For Yes: did the authors carry out an adequate investigation for example confounding; sample selection bias; bias in measurement of exposures and outcomes; selective reporting of outcomes and analyses; publication bias and discuss its likely impact on the results of the review?

9. Did the authors report any potential sources of conflict of interest, including any funding they received for conducting the review?

- Yes
- □ No

For Yes:

- □ The authors reported no competing interest OR
- The authors described their funding sources and how they managed potential conflicts of interest.

Annex D: List of interviewees and Technical Working Group members

The following people were consulted as part of the development of the EGM framework. All interviewees provided consent to be listed below and we would like to thank them for their time and insights.

Consultations:

No	Name	Title	Organisation
1	Faraz, A	Technical Gender expert	War Child
2	Groce, N.	Professor and Director	UCL International Disability Research Centre
3	Hameed, S.	Research Fellow	London School of Hygiene and Tropical Medicine, International Center for Evidence in Disability
4	Leavy, A.	Inclusion Specialist	Plan International
5	Kayastha, S.	Consultant	Independent consultant in Nepal
6	Shakespeare, T.	Professor	London School of Hygiene and Tropical Medicine, International Center for Evidence in Disability

Disability and inclusion technical working group members consulted:

No	Name	Organisation
1	Mark Carew	Leonard Cheshire
2	Kaitlin Keane	MSI
4	Megan McLaren	MSI
5	Musa Muga	IPPF
7	Sarah Palmer	MSI and Leonard Cheshire
8	Ricardo Pla Cordero	International Rescue
10	Tharcisse Mulindwa	Humanity and Inclusion
11	Ellie Hukin	Options
12	Kate Grey	IPPF
13	Sandra Mudhune	IPPF

Annex E: List of WISH countries

- 1. Democratic Republic of the Congo (DRC)
- 2. Nigeria
- 3. Burkina Faso
- 4. Mali
- 5. Niger
- 6. Senegal
- 7. Sierra Leone
- 8. Chad
- 9. Mauritania
- 10. Cote D'Ivoire
- 11. Cameroon
- 12. Afghanistan
- 13. Bangladesh
- 14. Burundi
- 15. Ethiopia
- 16. Madagascar
- 17. Malawi
- 18. Mozambique
- 19. Pakistan
- 20. Rwanda
- 21. Somalia
- 22. South Sudan
- 23. Sudan
- 24. Tanzania
- 25. Uganda
- 26. Zambia
- 27. Zimbabwe

Annex F: Relevant Websites

Accessibility standards and audit pack to assess existing health infrastructure and guide the development of new health facilities by Sightsavers https://www.sightsavers.org/disability/health/accessibility-standards/

https://www.youtube.com/watch?v=KE5HcO4ws90&feature=youtu.be

Deaf Elimu

https://www.deafelimuplus.co.ke/

Dance into Space Foundation

https://www.disabilityartsinternational.org/artists/profiles/dance-into-space-foundation/ and https://danceintospace.org/

Rockets and Space groups in Nepal

https://www.sdgsforall.net/index.php/archive-search/project-articles/225-nepal-youths-makesexual-health-services-more-accessible http://myhealthrightsfuture.com/assets/day-2%2C-msi--integrating-srh-needs-of-youngpeople-with-disability-within-youth-friendly-srh-service.pdf

Sexuality and Disability

https://sexualityanddisability.org/

We decide initiative for young persons with disability

https://www.msh.org/resources/we-decide-initiative-for-young-persons-with-disabilities-infographic

Disability Portals or other relevant websites:

- <u>https://www.disabilitydataportal.com/</u>
- <u>www.asksource.info</u>
- <u>https://research.sightsavers.org/publications/</u>
- <u>https://www.leonardcheshire.org/our-impact/our-policy-influencing-and-research/our-publications</u>
- <u>https://www.lshtm.ac.uk/research/centres/international-centre-evidence-disability</u>
- <u>https://www.theimpactinitiative.net/</u>
- <u>http://www.sddirect.org.uk/our-work/disability-inclusion-helpdesk/</u>