



## Family Planning for Women and Girls with Disabilities

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**Query:** 1) What is the evidence on **factors affecting access to and uptake of family planning** for women and girls with disabilities in low and middle income countries, highlighting examples from FP2020 commitment-making countries? 2) What is the **evidence on good practice on increasing full free and informed contraceptive choice** for women and girls with disabilities – from the same countries or elsewhere?

**Purpose:** To support FP2020 and DFID country offices to take forward a greater focus on disability inclusion

**Enquirer:** Jane Hobson, Sexual and Reproductive Health and Rights (SRHR) Team, Human Development Department.

### Contents

1. Overview
2. Methodology
3. Factors affecting access to and uptake of family planning for women and girls with disabilities
4. Good practice on increasing full free and informed contraceptive choice for women and girls with disabilities
5. References

### 1. Overview

**The fundamental right of people to decide, freely and for themselves, whether, when, and how many children to have is central to the vision and goals of FP2020.**<sup>1</sup> In 2017, the Special Rapporteur on the rights of persons with disabilities, Ms Catalina Devandas Aguilar, urged the global community to recognise the needs of women and girls with disabilities to be informed and enabled to make autonomous choices about their own sexual and reproductive health (SRH). This document provides a rapid review of the evidence on factors affecting access to and uptake of family planning for women and girls with disabilities, as well as highlighting examples of good practice.

**The evidence base on family planning for women and girls with disabilities has grown rapidly over the past decade and is assessed to be medium-sized,** according to DFID's (2014) How to Note on Assessing the Strength of Evidence. The most evidence from FP2020 commitment-making countries comes from Ethiopia, Ghana, Nepal, Senegal and Uganda, and evidence tends to focus on challenges faced by women and girls with hearing impairments (see Section 2 for a summary of the evidence base, gaps, and methodology used for this rapid review).

**A summary of the key factors affecting access to and uptake of family planning** is provided in the table below (see Section 3 for further information and examples).

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<sup>1</sup> <https://www.familyplanning2020.org/ayfp>

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

However, there remain considerable gaps in the evidence base on good practice on increasing full free and informed contraceptive choice for women and girls with disabilities. Although there are many organisations and projects working on this issue, interventions are not well evaluated or documented. Given the multiple barriers shown in the table above, most studies and the experts consulted highlight the **need for a multi-component approach** using a range of tailored strategies. Examples of promising practices most frequently mentioned in the literature include:

- Inclusion of women and girls with disabilities in the development of family planning policies and programmes, in line with the principle of 'nothing about us, without us', including actively partnering with local disability service organisations to improve accessibility.
- Peer education to improve the awareness of people with disabilities on FP methods and services.
- Addressing attitudinal barriers with caregivers and communities.
- Tailoring key awareness-raising and educational messages on family planning to the needs of people with disabilities.
- Addressing negative attitudes amongst healthcare workers and ensuring informed contraceptive choice through training
- Engaging family members on family planning interventions to get caregivers' buy-in and create enabling environment to improve access and uptake of family planning.
- Satellite services and sexuality education for people with disabilities.
- Collect data to improve planning of policy and services.
- Ensuring family planning services are accessible to women and girls with disabilities.

## 2. Methodology

This rapid research query has been conducted as systematically as possible within 4.5 days of research time. The methodology is described below.

**Search strategy:** Studies were identified through a variety of search strategies; focusing on FP 2020 commitment-making countries that are also DFID-focus countries (see Annex 1):

- **Google and relevant electronic databases** (PubMed, Science Direct, and Google Scholar) for priority sources using a selection of key search terms.<sup>2</sup>
- **Review of key disability portals and resource centres**, including the Leonard Cheshire Disability and Inclusive Development Centre, Disability Data Portal, Source, International Centre for Evidence in Disability, the Impact Initiative, and Sightsavers Research Centre.
- **Disability-focused journals**, such as Disability & Society, and the Asia Pacific Disability Rehabilitation Journal.
- **Targeted search on the OHCHR database** for the State reports, National Human Rights Institutions (NHRI) reports, and civil society reports submitted to the OHCHR treaty bodies, focusing on Committee on the Rights of Persons with Disabilities (CRPD) reports for FP2020 countries where DFID have bilateral programmes due to time restrictions.
- **Contacted the DFID Disability Inclusive Development Programme consortium partners<sup>3</sup> and experts** for evidence recommendations (see Section 5 for experts who replied).

The review prioritised existing syntheses, evidence reviews, and systematic reviews where possible in order to draw on the fullest range of evidence possible (Horner-Johnson et al, 2018; Carew et al, 2017; Braathen et al, 2017).

**Criteria for inclusion:** To be eligible for inclusion in this rapid review of the literature, studies had to fulfil the following criteria:

- **Focus:** Factors affecting access to and uptake of family planning for women and girls with disabilities, and examples of good practice on increasing full free and informed contraceptive choice.
- **Time period:** 2008<sup>4</sup> – 2019.
- **Language:** English.
- **Publication status:** publicly available – in almost all cases published online.
- **Geographical focus:** low and middle-income countries, highlighting examples from FP2020 commitment making countries (and prioritising DFID focus countries).

**Overall, there is a growing evidence base on family planning for women and girls with disabilities, which is assessed to be medium-sized** according to DFID's (2014) How to Note on Assessing the Strength of Evidence. FP2020 countries with the most evidence include Ethiopia, Ghana, Nepal, Senegal and Uganda. The evidence base tends to focus on challenges faced by

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<sup>2</sup> Key search terms included: family planning, contraception, SRH, condoms AND women, girls, access, uptake AND disabled / disability / disabilities, impairment, deaf, blind, wheelchair AND interventions, programmes, evaluations, reviews, research, study.

<sup>3</sup> The Disability Inclusion Helpdesk is funded under the DID programme. The DID consortium partners are ADD International, BBC Media Action, BRAC, Institute of Development Studies (IDS), International Disability Alliance (IDA), Humanity & Inclusion, Leonard Cheshire Disability, Light for the World, Sense, Sightsavers and Social Development Direct.

<sup>4</sup> Note: The Disability Inclusion Helpdesk reviews evidence from 2008 onwards as this is the year that the Convention on the Rights of Persons with Disabilities and its Optional Protocol came into force.

women and girls with hearing impairments, with comparatively little on people with intellectual disabilities.

**However, the evidence base on good practice on increasing full free and informed contraceptive choice for women and girls with disabilities is limited.** Experts consulted<sup>5</sup> highlighted that although there are many organisations and projects working on this issue, there has not yet been a synthesis of evidence on what strategies have worked (or not) to increase access for women and girls with disabilities. The few relevant systematic reviews and comprehensive evidence reviews point to the scarcity of high quality, rigorous research globally, including in high-income countries (Horner-Johnson et al, 2018; Braathen et al, 2017). Most research has focused on vulnerabilities, rather than emancipatory practices (Carew et al, 2017). Promising programming is often innovative and implemented by smaller disabled persons organisations (DPOs). No evaluations of interventions aimed at increasing access to family planning for women and girls with disabilities were found during this rapid review, possibly because evaluations, particularly impact evaluations, may not be suitable for DPOs' more flexible and adaptable work which is smaller-scale and requires groups to adapt to rapidly changing circumstances.

**Particular gaps in the evidence and therefore priorities for future research** include: lack of systematic examination of how interventions can best address intersecting inequalities such as disability, gender, race/ethnicity, age, caste, sexual orientation, and religion; barriers and good practice for people with psychosocial disabilities<sup>6</sup>; good practice in increasing access to family planning for women and girls with disabilities in humanitarian contexts, although this is noted as a particularly vulnerable group (UNFPA, 2018; Kassa et al, 2016).

### 3. Factors affecting access to and uptake of family planning for women and girls with disabilities

**Available evidence on disability and SRH in low and middle income countries suggests a range of barriers impacting people with disabilities** (Carew et al, 2018; WHO/UNFPA, 2009)<sup>7</sup>. The following section summarises the evidence on the factors affecting access to and uptake of family planning for women with disabilities, based on a framework used by the Disability Inclusion Helpdesk that combines a recognition of **individual factors** that can marginalise people with disabilities (e.g. multiple intersecting factors such as age, gender, impairments) and the **environmental, attitudinal and institutional barriers** that limit or exclude people with impairments.<sup>8</sup>

#### 3.1 Individual factors

**DFID's Strategy for Disability Inclusive Development 2018-23 recognises that people with disabilities face intersecting and compounding forms of discrimination.** Disability intersects with other sources of discrimination or social disadvantage which might limit access to and uptake of family planning such as age, gender, sexuality, ethnicity, impairment type, or economic poverty (Wapling, 2018; DFID, 2018).

Studies have conceptualised the variety of overlapping factors in different ways, for example Ayika and Kikosi (2016) talk about predisposing factors (e.g. age, marital status and education), enabling

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<sup>5</sup> Personal communication with Eva Burke, Reproductive and Sexual Health Specialist (30 December 2018)

<sup>6</sup> Psychosocial disability is an internationally recognised term under the United Nations CRPD, used to describe the experience of people with impairments and participation restrictions related to mental health conditions

<sup>7</sup> Personal communication with Dr Ola Abu Alghaib, Director, Global Influencing and Research, Leonard Cheshire Disability (15 January 2019)

<sup>8</sup> Disability Inclusion Helpdesk helpdesk training by Lorraine Wapling (December 2018)

factors (e.g. access to family planning information, health facilities, geographic location, wealth), and factors influencing the need for contraception (e.g. number of children, fertility intentions). In this paper, we use a **marginalisation framework**<sup>9</sup> to distinguish between individual factors affecting access to and uptake of family planning:

- **Universal factors** (fixed aspects of one's identity regardless of setting), including age, gender, disability and health status.
- **Contextual factors** (more complex and changeable factors that vary by setting), including language, caste, migration and refugee status, poverty and family status.

**Evidence suggests that these multiple factors intersect and create a nuanced picture**, depending on context. For example, research in Senegal found age, disability and gender are associated with different access and uptake barriers that intersect to create multiple vulnerabilities amongst young people with disabilities.<sup>10</sup>

**Barriers can differ depending on the types and severity of impairment and can require different solutions to access and uptake of family planning.** It is important to note that disability is complex and people with disabilities are not a homogenous group. Services and information will therefore need to be tailored, and there is no one-size-fits-all approach to ensure family planning services are accessible to women and girls with disabilities (Plan, 2017). For example, an assessment on the family planning needs of people with disabilities in Addis Ababa, Ethiopia identified a range of barriers depending on impairment type (see box below).

**How access and uptake of family planning varies by type of impairment: Case of Addis Ababa, Ethiopia (FHI 360, USAID, Ministry of Health, 2017)**

152 people with disabilities participated in discussion groups, which revealed different types of barriers depending on impairment types:

- **People with hearing impairments:** Communication barriers, limited access to family planning information, unavailability of sign language interpreters at the health facilities, and media based dissemination of information non-tailored to deaf people. Many deaf people have a negative attitude towards FP and do not support its use, partially caused by rumours and misconceptions on FP methods among deaf people.
- **People with visual and hearing impairments:** No translator at the facilities, negative attitudes of service providers.
- **People with visual impairments:** poor health facility design and infrastructure, poor road conditions that lead to health facilities, lack of guidance at health facilities, and negative experiences in health facilities.
- **People with physical disabilities:** Higher awareness than other groups. Key barriers include disrespectful and mistreatment from health workers and inaccessible health facilities design
- **People with intellectual disabilities:** Mistreatment from some health care workers and other staff at health facilities.

**In most contexts, evidence indicates that adolescents with disabilities face particularly severe challenges**, including difficulties discussing family planning with parents, educators and counsellors, as well as risks of sexual exploitation and discrimination (Plan, 2017; Jones et al, 2018; Burke et al, 2017). Adolescent girls with disabilities are often disadvantaged compared to boys, due to restrictive gender norms (Jones et al, 2018). A 2017 report on sexual and reproductive health and rights by the

<sup>9</sup> As used by DFID's Girls Education Challenge (GEC) programme to understand who is marginalised based on their universal and contextual characteristics (Wapling, 2018)

<sup>10</sup> Expert comments from Eva Burke, Reproductive and Sexual Health Specialist (30 December 2018). See also Burke et al (2017)

Special Rapporteur on the Rights of Persons with Disabilities, Ms Catalina Devandas Aguilar, notes high levels of stigma and abuse of adolescent girls' SRH rights: "the intersection between young age, disability and gender results in both aggravated forms of discrimination and specific human rights violations against girls and young women with disabilities" (p.4).

### 3.2 Environmental factors

**Physical barriers to access:** Examples of the physical inaccessibility of SRH services cited in the literature includes a lack of ramps, adjustable beds, wheelchairs and disability-friendly sanitation facilities in family planning clinics, health facilities and hospitals (Ahumuza et al. 2014). In Nepal, a study of 293 young people aged 15-30 with three types of impairment (visual, hearing or physical) found that only 38% of young people said that they perceived the nearest SRH service centre to be physically accessible and disability-friendly (Sunaulo Pariwar Nepal, 2015).<sup>11</sup> Various State Reports to the CPRD note the challenges with accessibility of health infrastructure, facilities, information and services for persons with disabilities – for example, Ghana (2018), Kenya (2014), Malawi (2016), and Sudan (2015).

**Queues at health facilities** can compound the physical barriers to accessing services. For example, a study in Uganda noted that people with disabilities often had to wait in long queues at health facilities to access family planning, which were partly due to few health workers: "Whereas long queues is a common occurrence especially at public health facilities in Uganda, lack of consideration for persons with physical disability was a hindrance to access of SRH services" (Ahumuza et al. 2014: 7).

**Long and difficult journeys to clinics**, particularly in rural and remote areas, can be a particular barrier to the access and uptake of family planning services (Ahumuza et al., 2014; Mirza, 2015). For example, Malawi's (2016) State Report to the CPRD highlights the mobility challenges from places of residence to health facilities including long distances to health facilities.

**Accessibility of family planning messaging and materials:** Evidence suggests that uptake of family planning materials depends on accessibility of information and SRH education. Various State reports as well as research in Ghana, Kenya and Rwanda have highlighted awareness gaps among people with disabilities, for example people with hearing impairments having difficulty with radio messages or following workshops without sign language interpreters, or people with visual impairments not being provided with Braille materials or television messaging not captioned or translated into sign language (Mprah, 2017; Habinshuti et al, 2017; Tanabe et al, 2015).

### 3.3 Attitudinal factors

**Perceptions that persons having disabilities are perceived to be asexual** can lead to withholding of sexuality information on the assumption that girls and women with disabilities 'won't need it' (Ahumuza et al., 2014; Devandas Aguilar, 2017). Several studies highlight wrongful assumptions that people with disabilities are not sexual beings, leading to a lack of sexual health education, barriers to family planning access and uptake, sexual abuse and exploitation, and risk factors for HIV and other sexually transmitted diseases (Rohleder et al, 2019). It is also worth noting that there can be gender differences in perceptions. For example, research from Uganda observed that family planning was perceived to be a 'female affair' and health workers were not trained to address the contraception

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<sup>11</sup> Characteristics of a physically accessible and disability-friendly include: provision of physical facilities like ramps/ railings/ elevators, suitable toilets, availability of sign language interpreters, provision of written text, IEC in Braille or large text, centres located in ground floor with ample moving space (Sunaulo Pariwar Nepal, 2015).



needs of males with disabilities who “experienced discrimination and marginalization in relation to SRH from service providers and the public” (Ahumuza et al. 2014:8).

**Discrimination from health workers to women and girls with disabilities:** Stigma and negative attitudes by healthcare providers and staff are one of the most commonly cited barriers in the literature (Devkota et al, 2019). These barriers may be compounded for people with disabilities that possess other marginalised identities, such as refugee status.<sup>12</sup> For example, in Uganda, a study of refugees with disabilities observed how negative and disrespectful provider attitudes at health centres and the national referral hospital are ‘the most influential barrier’ deterring refugees with disabilities from accessing family planning services (Tanabe et al, 2015). Given the history (and indeed ongoing practice<sup>13</sup> in some countries) of forced sterilisation of women and girls with disabilities, it is particularly important to address negative attitudes and discrimination and ensure the “full, uncoerced and informed consent of the individual, either alone or with support” (WHO, 2015: 107)<sup>14</sup>. Several studies highlight how girls and young women with disabilities are infantilised, disempowered and lack voice, choice and control to make decisions about their own bodies and sexualities (Plan, 2017; Jones et al, 2018).

**Overprotective attitudes and lack of communication around family planning by parents and caregivers:** For example, a multi-country study from Ethiopia, Uganda and Rwanda observed that discussion on sexuality related matters between parents and young people with disabilities was ‘very low’, with only 22% of respondents having discussed sex and family planning with their parents (Kassa et al, 2016). Conversations about sexuality for younger and unmarried girls may be particularly taboo in culturally conservative contexts, for example research in Jordan with parents of adolescents aged 12-18 with Down’s Syndrome highlighted cultural barriers to discussing masturbation, sexuality and family planning, which were also seen to be more shameful for parents to discuss with girls (Amr et al, 2016).

**Gender-based violence, and particularly intimate partner violence (IPV),** stemming from harmful attitudes, norms and unequal power relations between men and women, can limit access to and uptake of family planning methods. Studies have found that women with disabilities are at least twice as likely as women without disabilities to be victims of rape, sexual abuse and IPV, with the most common perpetrators being their male partners (van der Heijden and Dunkle, 2017). Myths around asexuality can contribute to IPV and other forms of violence going undetected. For example, research conducted in partnership with young people with disabilities in Senegal found high vulnerability to sexual violence and therefore high risk of unintended pregnancies, particularly among young girls with hearing impairments.<sup>15</sup> Research also indicates that women with intellectual impairments are at higher risk, being less likely to receive sexual education, often socialised to be compliant and more reliant on caregivers (Van Der Heijden, 2014; Barger et al, 2009). Perpetration of gender-based violence by healthcare workers in positions of power and authority, including forced sterilisation, can also act as a considerable barrier to family planning for women and girls with disabilities (Bell and Butcher, 2015).

### 3.4 Institutional factors

**Need for national policies to tackle the reproductive rights of women and girls with disabilities:** Despite advances made by several LMICs in ratifying the CRPD, many countries still lack legal

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<sup>12</sup> Personal communication with Dr Ola Abu Alghaib, Director, Global Influencing and Research, Leonard Cheshire Disability (15 January 2019)

<sup>13</sup> For example, the Nepal Shadow Report submitted to the Committee on the Rights of Persons with Disabilities notes that “Forced sterilization of girls and young women with disabilities is still a serious human rights violation in Nepal” (p.4).

<sup>14</sup> See also the interagency statement on eliminating forced, coercive and otherwise involuntary sterilisation: [https://www.who.int/reproductivehealth/publications/gender\\_rights/eliminating-forced-sterilization/en/](https://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/)

<sup>15</sup> Expert comments from Eva Burke, Reproductive and Sexual Health Specialist (30 December 2018)

guarantees and national policies for people with disabilities to have equal rights to health and non-discrimination (Nakray, 2018; Jones et al, 2018). For example, a review of seven major SRH policy and practice documents from Ghana government sources and NGOs concluded that the attention given to the SRH needs of persons with disabilities has been ' cursory', with a need for more guidance and research to ensure disability-friendly services and information (Mprah et al, 2014). Although Ghana's 2016 Adolescent Reproductive Health Policy is more disability inclusive, the policy lacks an understanding of the barriers that adolescents with disabilities face in accessing SRH care and services (Karimu, 2018).<sup>16</sup> The Ghana CRPD State Report (2018) notes: "There are inadequate attempts at tackling maternal health care and reproductive rights of women with disabilities" (p.24) and highlights several challenges including: no provision in the constitution on the right to health; unprofessional attitudes of health professionals towards persons with disabilities; and inaccessible health infrastructure, facilities, information, services and public health campaigns on family planning. Amongst the FP2020 commitment-makers, few examples were identified of policy commitments specifically addressing the needs of young people with disabilities. An example of good practice here is Cameroon who have committed to establishing a budget line to subsidise family planning for the most vulnerable users, including adolescents and youth and women with disabilities.<sup>17</sup>

**Lack of data on access to and uptake of family planning for women and girls with disabilities:**

The lack of age-, gender- and disability-disaggregated data hinders our understanding of the extent of access to and uptake of family planning for persons with disabilities, rendering them invisible (Jones et al, 2018). Similarly, there is a knowledge gap in documented experiences of disability inclusion in family planning and their "needs, experiences and views are not captured in evaluations" (Buchy et al, 2017: 14; see also Section 4 below).

**Lack of technical expertise** around family planning programming from a disability perspective: Various studies have highlighted the lack of comprehensive knowledge about appropriate practices for family planning for women and girls with disabilities (Kassa, 2016; FHI360, 2017).

**High costs to persons with disabilities of accessing family planning services:** Several studies have highlighted the financial barriers to family planning services experienced by people with disabilities, particularly adolescent girls (Tanabe et al, 2015; Arulogun et al, 2013; Ahumuza et al, 2014). For example, a qualitative study<sup>18</sup> with young people aged 18-24 with physical, visual and hearing impairments in Senegal found that financial costs are a key barrier to accessing SRH services, and recommended that "financial or voucher schemes should be introduced for young people with disabilities to access free or subsidised SRH services, including ensuring access to the *cartes d'égalité des chances*<sup>19</sup>" (Burke et al, 2017: 52).

**Lack of confidentiality if help with communication is required**, which is particularly the case for adolescent girls. A study in Ibadan, Nigeria with 167 girls aged 11-24 years with hearing impairments found that over a third (37%) of girls were embarrassed to ask questions in the presence of an interpreter. Where there were no interpreters, 75% of participants were seen in the presence of family members – a breach of privacy. 53% of participants were concerned about the confidentiality of the interactions, and felt excluded from their own healthcare decisions (Arulogun et al, 2013)

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<sup>16</sup> The 2016 policy committed to make SRH information and services accessible for adolescents with disabilities (Karimu, 2018; Expert comments from Eva Burke, Reproductive and Sexual Health Specialist (30 December 2018)

<sup>17</sup> Expert comments from Eva Burke, Reproductive and Sexual Health Specialist (30 December 2018). See <http://www.familyplanning2020.org/sites/default/files/Engagements-FP2020-Cameroun-2014.pdf>

<sup>18</sup> Male and female peer researchers conducted 17 focus group discussions and 50 interviews with young women and men with disabilities in Dakar, Thies and Kaolack in Senegal

<sup>19</sup> 'Cartes d'égalité des chances' are Senegal's 'Equal opportunity cards'



#### 4. Good practice on increasing full, free and informed contraceptive choice for women and girls with disabilities

Several groups are working to increase access to and uptake of family planning for women and girls with disabilities, but to date there is a lack of evidence on good practice, even in high-income countries.<sup>20</sup> For example, a systematic review of the evidence on contraceptive knowledge and use among women with intellectual, physical, or sensory disabilities from high-income countries identified only six intervention studies – five of which reported post-intervention improvements in contraceptive knowledge and use (Horner-Johnson et al, 2018). Methodological challenges include different ways of measuring outcomes, identifying research participants, small sample sizes, and few comparison groups, including with the general population (*Ibid*, 2018; Carew et al, 2017).

A recent scoping study commissioned by DFID found that “people with disabilit[ies] are largely invisible in monitoring and evaluation (M&E) activities” (Buchy et al, 2017: 14), which extends to family planning programming. The study concluded that there was a lack of experience within the monitoring sector for assessing disability inclusion, with many long-running programmes not being designed with inclusion in mind, leading to a lack of visibility of disability in M&E (Buchy et al, 2017; Wapling, 2018).

Given the multiple barriers that women and girls face, the diversity of disabilities and diverse contexts, most studies and the experts consulted highlight the need for a multi-component approach using a range of tailored strategies. Examples of promising practices most frequently mentioned in the literature include:

- **Inclusion of women and girls with disabilities in the development of family planning policies and programmes**, in line with the principle of ‘nothing about us, without us’ (Burke et al, 2017). Programmes should actively partner with DPOs to ensure that strategies are flexible and responsive to the context-specific needs of women and girls with disabilities. An example of promising practice from the Philippines is **peer-facilitated Participatory Action Groups**<sup>21</sup> (PAGs) – structured groups bringing women with disabilities together to discuss sexual and reproductive health issues. A qualitative evaluation of the PAGs revealed positive changes in women’s lives that participants attributed to their participation in the PAGs, including increased knowledge on sexual and reproductive health and rights, enhanced self-confidence, peer support and access to services (see below) (Devine et al, 2017).

##### Changes associated with Participatory Action Groups in the Philippines (Devine et al, 2017: 59)

Women’s prioritisation of change	PAG with women who are Deaf or hard of hearing	PAG with women with vision impairment	PAG with women with mobility impairment	PAGs with women with mobility impairment
1 <sup>st</sup>	Increased knowledge on sexual and reproductive health	Enhanced self-confidence	Increased knowledge on the rights of people with disabilities	Enhanced self-confidence
2 <sup>nd</sup>	Increased understanding on prevention of HIV and STIs more specifically	Increased knowledge on protection from violence for women and children with disabilities	Enhanced self-confidence	Increased knowledge on the rights of people with disabilities
3 <sup>rd</sup>	Increased knowledge on protection from violence for women and children with disabilities	Increased knowledge on the rights of people with disabilities	Increased knowledge on protection from violence for women and children with disabilities	Social inclusion associated with the PAG process and enhanced self-confidence

<sup>20</sup> Based on review of evidence and personal communication with Eva Burke, Reproductive and Sexual Health Specialist (30 December 2018) and Dr Ola Abu Alghaib, Leonard Cheshire Disability (15 January 2019)

<sup>21</sup> As part of the three-year W-DARE project (Women with Disability taking Action on Reproductive and Sexual Health) funded by the Department of Foreign Affairs and Trade, Australian Government.

- **Peer education** to improve the awareness of people with disabilities on family planning methods and services. This review identified several interesting examples of peer educators successfully reaching people with disabilities, particularly people with hearing impairments, for example in DRC (FHI 360, 2015), Nepal (UNFPA, 2018), Uganda (Plan, 2017), and Kenya (Taegtmeier et al., 2009). A study found that exposure to peer educators was ‘highly significantly associated’ with attendance at health services, and peer educators were seen as imparting trustworthy information and using innovative methods developed locally, such as Deaf puppetry, as well as text messaging which is widely used by Deaf persons in Kenya (Taegtmeier et al., 2009). In Nepal, young people with disabilities act as peer educators and ‘pop-up volunteers’ at Marie Stopes youth-friendly service centres to raise awareness and encourage outreach (UNFPA, 2018).
- **Addressing attitudinal barriers with caregivers and communities.** An innovative example of promising practice is the Dance Into Space Foundation in Kenya (funded by AMPLIFY Fund<sup>22</sup>). Contemporary dance performances provide an opportunity for men and women with disabilities to share their stories and address myths around disabilities and sexuality in front of other people with disabilities, their caregivers and community. The project has partnered with local service providers and the dancers become local advisors on SRHR. There are no publically available evaluations of the project, but a report by the Dutch Coalition on Disability and Development (2017) notes that “we observed that people with disabilities were now included in the community’s sexual and reproductive health and rights agenda. Against a hitherto culturally stigmatised environment, community members confessed that the captivating work had enlightened them and changed their perceptions of disability and sex” (p. 24).
- **Tailoring key awareness-raising and educational messages on family planning to the needs of people with disabilities.** For example, in Ghana, the State Report (2018) notes that education on family planning methods are being made accessible using sign language and copies of Behavioural Change Communication (BCC) materials are printed in braille version. Elsewhere, social media and innovative technologies are being piloted, such as the UNFPA-funded *Deaf Elimu*, a web and mobile-based application that targets 800,000 deaf youth users in Kenya who search for SRH information in sign language,<sup>23</sup> and a successful campaign for deaf youth in three Latin American countries using posters with barcodes giving them access to videos in sign language addressing sexuality and sexual health (Plan, 2017). As yet, these initiatives have not been evaluated.
- **Addressing negative attitudes amongst healthcare workers and ensuring informed contraceptive choice through training.** Most of the examples found during this review involve disability sensitisation conferences with Ministries of Health, local NGOs, DPOs and healthcare workers, for example in Kenya and DRC. Resource manuals have also been developed to help build the capacity and interpersonal communication skills of healthcare providers. For example, in Ethiopia, the Resource Manual for Reproductive Health / Family Planning Service Providers on the Inclusion of Persons with Disabilities in Reproductive Health/Family Planning Services provides step-by-step guidance for both mainstreaming disability and developing disability-specific targeted approaches (UNFPA, 2018). In DRC, the C-CHANGE project developed the “Communiquons avec les sourds” or “Let’s Communicate with the Deaf” — an illustrated dictionary (in American Sign Language) of health-related vocabulary associated with human anatomy and sexuality to help improve communication between young people with hearing disabilities and their families, health workers, and educators (FHI 360, 2015).

<sup>22</sup> See AMPLIFY Fund’s Learning Memo 5: <https://amplifychange.org/tools-guides/learning-memos/>

<sup>23</sup> <https://www.deafelimuplus.co.ke/>

- **Engaging family members** on family planning interventions is important to get caregivers' buy-in and create an enabling environment to improve access and uptake of family planning, particularly important in culturally conservative contexts (FHI 360, 2017). An example of promising practice is a project by Leonard Cheshire Disability in Zimbabwe, working with 21 local partner organisations on a variety of SRH activities: training for adolescents with disabilities, peer education, safe spaces, school activities and providing information in accessible formats. A key lesson learnt was the importance of involving parents from the outset to ensure positive outcomes (Dutch Coalition on Disability and Development, 2017).
- **Satellite services and sexuality education** offered through DPOs and special schools for people with disabilities are another approach used. One example is the 'It's my body!' sexuality education, designed by Niketan Foundation and Rutgers Foundation for use at special schools in Bangladesh. The course on sexual and reproductive health aims to empower adolescent girls and boys with intellectual disabilities aged 13-15. Although not yet evaluated, a recent report highlighted lessons learned about breaking taboos while keeping parents on board; and tailoring communication to people with (severe) intellectual disabilities (Dutch Coalition on Disability and Development, 2017).
- **Collect data to generate new knowledge to help improve planning of policy and services** for women and girls with disabilities. For example, as part of the WE DECIDE<sup>24</sup> initiative, UNFPA launched a global study on young people with disabilities (2018) which includes analysis on the situation of the SRHR of young persons with disabilities.
- **Ensure that family planning services are accessible to women and girls with disabilities**, for example, global guidance on 'Family Planning: A Global Handbook for Providers'<sup>25</sup> by the World Health Organisation, USAID and John Hopkins University (2018) recommends facilities are physically accessible (e.g. ramps for wheelchairs, large bathrooms with grab bars), outreach programmes for people in the community with limited mobility, and print materials with simple graphics, large print and Braille, plus information in audio formats. For example, the Straight Talk Foundation in Uganda set up mobile clinics with trained multidisciplinary teams to improve access to SRHR services to girls and young women with disabilities in rural or otherwise isolated areas (cited in Plan, 2017).

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<sup>24</sup> WE DECIDE is a global initiative to promote gender equality and social inclusion of young persons with disabilities and advocate for the end of sexual violence.

<sup>25</sup> See: <https://www.fphandbook.org/sites/default/files/JHU-2018FPHandbook-2018-06-18-1140web.pdf>

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**About Helpdesk reports:** The Disability Inclusion Helpdesk is funded by the UK Department for International Development, contracted through the Disability Inclusion Team (DIT) under the Disability Inclusive Development Programme. Helpdesk reports are based on between 3 and 4.5 days of desk-based research per query and are designed to provide a brief overview of the key issues and expert thinking on issues around disability inclusion. Where referring to documented evidence, Helpdesk teams will seek to understand the methodologies used to generate evidence and will summarise this in Helpdesk outputs, noting any concerns with the robustness of the evidence being presented. For some Helpdesk services, in particular the practical know-how queries, the emphasis will be focused far less on academic validity of evidence and more on the validity of first-hand experience among disabled people and practitioners delivering and monitoring programmes on the ground. All sources will be clearly referenced.

Helpdesk services are provided by a consortium of leading organisations and individual experts on VAWG, including Social Development Direct, Sightsavers, Leonard Cheshire Disability, ADD International, Light for the World, BRAC, BBC Media Action, Sense and the Institute of Development Studies (IDS). Expert advice may be sought from this Group, as well as from the wider academic and practitioner community, and those able to provide input within the short time-frame are acknowledged. Any views or opinions expressed do not necessarily reflect those of DFID, the Disability Inclusion Helpdesk or any of the contributing organisations/experts.

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