



HIV Prevention, Treatment and Care Programming for People with Disabilities

Emma Bell and Nick Corby

28th February 2019

Query: What is the evidence of the effectiveness of inclusive approaches to HIV prevention, treatment and care programming for people with disabilities? What are the key barriers and enabling factors for people with disabilities being able to access HIV prevention, treatment and care programming?

Purpose: To support DFID advisors and inform policy and programming around disability inclusive approaches to integrated HIV prevention, care and treatment.

Enquirer: Juliet Whitley, SRHR Team, DFID

Contents

1. Overview
2. Methodology
3. Evidence of the effectiveness of inclusive approaches to HIV, prevention, treatment and care programming with people with disabilities
4. Barriers for people with disabilities being able to access HIV prevention, treatment and care programming
5. Case studies and lessons learned
6. References

1. Overview

Evidence suggests that there tends to be a higher prevalence of HIV infection in people with disabilities than people without disabilities, which reflects a higher exposure to HIV as well as the presence of disabilities associated with HIV infection¹. (UNAIDS, 2017; UNAIDS, 2014; Banks et al, 2015; Hanass-Hancock, 2009; Beaudrap et al, 2014) A systemic review of the risk of HIV infection among adults with disabilities in Sub-Saharan Africa, found that women with disabilities are at particularly high risk (Beaudrap et al, 2014).

There is often a misconception that people with disabilities are sexually inactive or should be or are unlikely to use drugs or alcohol (UNHR, WHO, UNAIDS, 2009). As a result, people with disabilities tend to be overlooked in HIV and sexual and reproductive health and rights (SRHR) programming and services. People with disabilities tend not to be included in the design and development of HIV services, which would ensure that services are better tailored for their needs. (UNAIDS, 2017; UNAIDS, 2014) Addressing the needs of people living with HIV *and* a disability is particularly pertinent in HIV-endemic

¹ Disabilities associated with HIV infection include: mental health disorders such as depression, anxiety, substance abuse; impairments such as neurocognitive impairments, blindness, deafness, peripheral neuropathy; episodic disabilities - <https://plone.medicusmundi.ch/de/bulletin/mms-bulletin/people-are-still-left-behind/still-left-behind-die-vernachlaessigten-aspekte-der-epidemie/access-to-hiv-and-aids-care-persons-with-disabilities-still-left-behind>

countries where evidence shows a large proportion of people on antiretroviral therapy (ART) may have disabilities, impacting health and ART adherence negatively² (Hanass-Hancock et al, 2015).

The Convention on the Rights of Persons with Disabilities (CRPD) provides a global policy framework to promote equal rights to health for persons with disabilities, including sexual and reproductive health, on a par with those without disabilities. The CRPD expects policies to implement HIV programming for persons with disabilities and programmes to fight against stigma, discrimination and other barriers faced by people with disabilities living with HIV.³ However, there is a lack of research on what works to address HIV prevention for people with disabilities and support those living with both HIV and a disability (UNAIDS, 2017; UNAIDS, 2014; UNAIDS, 2012).

This document provides a rapid review of the evidence on disability inclusive approaches to HIV prevention and response. The purpose of this review is to inform DFID's policy and programming around integrated approaches to HIV, care and treatment. After briefly outlining the methodology in section 2, section 3 provides an overview of the evidence base on disability and HIV programming, and section 4 provides an overview of key barriers to accessing HIV-related services for people with disabilities. Finally, section 5 provides a series of case studies highlighting lessons learned including key enabling factors.

This review finds that overall the evidence base on disability inclusive HIV programming is limited, with the majority of evidence from disability-specific interventions targeted at specific groups of people with different impairments.

Seven evaluations from peer-reviewed journals were identified. Four were of the same initiative and five were from South Africa. All but one evaluation was qualitative. This evidence includes:

- **Positive evidence of the potential for home-based rehabilitation (HBR) interventions to improve the quality of life of people with HIV-associated disabilities.** Qualitative evaluations of a HBR intervention in KwaZulu-Natal, South Africa found a range of benefits for health workers and beneficiaries alike. (Hanass-Hancock and Ali, 2015; Dawad and Jobson, 2011)
- **Promising evidence on an inclusive approach to comprehensive sexuality education to learners with disabilities in South Africa (Breaking the Silence).** (Hanass Hancock et al, 2018)
- **Small but significant evidence supporting peer-led approaches** to improve HIV counselling and testing programme for deaf people in Kenya. (Taegtmeier et al., 2009).
- **Positive evidence of the benefits peer-facilitated Participatory Action Groups (PAGs)** in the Philippines shows that they can lead to a range of positive changes in the lives of women with disabilities. (Devine et al, 2017)

There is scarce evidence to suggest the needs of people with disabilities are being met in mainstream HIV interventions. However, eight case studies were identified of disability specific interventions, that offer results and lessons learned (see section 5).

Key gaps in the evidence include: lack of systematic examination of how interventions address intersecting inequalities such as disability, gender, race/ethnicity, age, caste, sexual orientation, and

² People with disabilities can face significant barriers to accessing lifelong treatment. These can include mobility barriers having to travel frequently to services where treatment is dispensed, understanding treatment-related information about dosage, interaction with other medications and side-effects (this can be compounded when a third person is needed to support treatment) as well as attitudinal barriers such as discrimination among staff in health care settings that can put people with disabilities off accessing services – these barriers are explored further in section 4 of this query.

³ UN Website - <https://www.un.org/development/desa/disabilities/issues/disability-and-hiv.html>

religion; barriers and good practice for people with psychosocial disabilities⁴; good practice in increasing access to HIV prevention, treatment and care programming for people with disabilities in humanitarian contexts; research on addressing HIV and disability in the context of drug use.

A summary of the **key barriers** is provided in the table below (see section 3).

HIV prevention information and education	HIV services and programmes	Enabling environment
<ul style="list-style-type: none"> • A lack of awareness of HIV and related services among people with disabilities. • Inaccessible information and/or exclusion from sexual education and information. • A lack of research on the sexuality of people with disabilities within many LMICs and interventions of what works to prevent HIV or to support people with disabilities living with HIV including treatment and care. 	<ul style="list-style-type: none"> • Physical barriers that present mobility barriers for people with disabilities accessing VCT, SRHR and treatment and care services/programmes and benefitting from them. • A lack of resources for additional costs of access. • Information and communication barriers that hinder HIV-related counselling and advice. • Attitudes and behaviours of staff in health care settings related to HIV and disability. • A lack of HIV policies that include a focus on disability and disability policies that include a focus on HIV and SRHR, As well as poor implementation. 	<ul style="list-style-type: none"> • Violence and fear of violence • HIV and disability-related stigma and discrimination in the community including against care givers. • Socio-economic factors that limit programme / service access such as poverty as well as a lack of legal protection.

Key enabling factors identified and highlighted in case studies in section 6 include:

- Ratification of the UN Convention on the Rights of Persons with Disabilities (UNCRPD)
- Partnerships with and the meaningful involvement of Disabled People’s Organisations (DPOs) at all stages of initiatives
- International and national partnerships that themselves are committed to be inclusive (INGOs, SRHR and HIV organisations / services, DPOs, government departments, community-based organisations (CBOs))
- Government involvement and commitment through policy action and resource allocations.

2. Methodology

Studies were identified through a variety of search strategies.

- Google and relevant electronic databases (PubMed and Google Scholar) for priority sources using a selection of key search terms⁵.

⁴ 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.

⁵ Key search terms used 1. HIV AND disab* / disability. 2. HIV AND disab* / disability AND research. 3. HIV AND disab* / disability AND evaluation

- Review of key disability portals and resource centres, including the Leonard Cheshire Disability and Inclusive Development Centre, Disability Data Portal, Source, the Impact Initiative, and Sightsavers Research Centre.
- Review of disability-focused journals, such as Disability & Society, and the Asia Pacific Disability Rehabilitation Journal.
- The DFID Disability Inclusive Development Programme consortium partners⁶ and relevant experts were contacted for evidence recommendations (see page 17 for experts who responded).

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 HIV testing care and treatment programming, and evidence of effectiveness of inclusive approaches to HIV prevention, treatment and care programming for people with disabilities.
- **Time period:** 2008⁷ – 2019⁸.
- **Language:** English.
- **Publication status:** Publicly available – in almost all cases published online.
- **Geographical focus:** Low and middle-income countries (LMICs).

Where possible peer reviewed articles are featured in this report. However, NGO reports are also included due to the lack of peer-reviewed evaluations.

3. Evidence of the effectiveness of inclusive approaches to HIV prevention, treatment and care programming for people with disabilities

Overall the evidence base on approaches to HIV prevention, treatment and care programming for people with disabilities is limited. In particular, this review identified only a small number of evaluated interventions. A recent scoping study commissioned by DFID found that “*people with disability[ies] are largely invisible in monitoring and evaluation (M&E) activities*” (Buchy et al, 2017: 14). 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 monitoring and evaluation (Buchy et al, 2017). Experts consulted for this review (see page 17) highlight particular challenges securing funding for evaluations on disability and HIV due to perceptions of higher costs. Research on disability involves less people (affecting statistical significance) reached due to the need to spend funds on disability accommodation and outreach.⁹

Only seven evaluations from peer reviewed journals, were found of disability-focused interventions addressing HIV prevention, treatment and care. Four focus on the same initiative; five on initiatives in South Africa. The evidence includes:

- **Positive evidence of the potential for home-based rehabilitation (HBR) interventions to improve the quality of life of people with HIV-associated disabilities.** Qualitative evaluations

⁶ 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.

⁷ 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.

⁸ For a good discussion of barriers that has a wider time period see Rohleder 2017.

⁹ Jill Hanass-Hancock pers comms, 21 February, 2019

of a HBR intervention in KwaZulu-Natal, South Africa found a range of benefits for health workers and beneficiaries alike (Hanass-Hancock and Ali, 2015; Dawad and Jobson, 2011). The intervention included a 16-week HBR intervention to improve the quality of life, functional mobility, and functional capacity of adult people living with HIV on ART. The intervention was carried out by community health care workers under the supervision of a qualified physical therapist. It aimed to address the lack of qualified rehabilitation professionals and the high levels of disability in HIV-epidemic communities by task shifting to community health workers. A randomised control trial (RCT) of the intervention found that while participants in the intervention group showed greater improvements across all outcome measures, differences between groups were nonsignificant. (Cobbing et al 2017a). A qualitative study using semi-structured interviews was also conducted to explore workers' experiences of being involved in carrying out this intervention. Participants reported how their personal development, improvement in their own health and increased feelings of self-worth enabled them to successfully implement the intervention. Skills that need more practical training (e.g. referrals and screening for disability) need to be trained in more detail. The workshop evaluation also revealed that without policy implementation and budget allocations, integrating these aspects would only be limited (Cobbing et al 2017b).

- **There is promising evidence from an inclusive approach to comprehensive sexuality education to learners with disabilities in South Africa (Breaking the Silence)** – this initiative used a curriculum implementation and disability-accommodating approach. Educators conceptualised sexuality education within a risk-protection discourse. A formative evaluation using in-depth interviews with educators from eight “schools for learners with special educational needs” found that educators felt the training and tools enabled them to provide sexuality education in accessible formats, tackle difficult topics such as sexual orientation and masturbation, and improved awareness and assertiveness within their learners. Educators identified the need for a whole-school approach, adjustments to differentiating developmental stages and addressing gender-specific topics. (Hanass Hancock et al, 2018)
- **There is small but significant evidence supporting peer-led approaches to improve HIV counselling and testing programme for deaf persons in Kenya** – voluntary counselling and testing (VCT) services for deaf people were combined with a peer education programme to promote VCT. Peer educators targeted organisations such as churches or learning institutions, seminars and other meetings where deaf people congregate. Univariate and multivariate analyses were used to assess programme impact. 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. However, the authors suggest further innovative strategies to address a subsequent decline in numbers of deaf people accessing VCT (Taegtmeier et al., 2009).

- **Evidence from peer-facilitated Participatory Action Groups (PAGs) in the Philippines shows that they can lead to a range of positive changes in the lives of women with disabilities.** A three-year Women with Disability taking Action on SRH project, funded by the Australian Government, established structured groups bringing women with disabilities together to discuss SRHR issues, including on HIV and STIs prevention. 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 SRHR, 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 st	Increased knowledge on sexual and reproductive health	Enhanced self-confidence	Increased knowledge on the rights of people with disabilities	Enhanced self-confidence
2 nd	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 rd	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

Section five includes eight case studies of best practice from INGOs that feature valuable insights, but do not have external evaluations available.

There remain considerable gaps in the evidence base, in particular:

- A lack of evaluations of interventions to improve access to HIV prevention, treatment and response for people with different types of impairments and with intersecting inequalities.
- No evidence was found on disability inclusion in harm reduction programmes.
- A lack of disaggregated data and disability focused metrics within mainstream HIV prevention, care and treatment interventions, which effectively renders people with disabilities as invisible.
- The sexuality of people with disabilities within many LMICs has received little or no empirical or experimental investigation (beyond a focus on abuse). This could feasibly undermine an approach that supports people with disabilities to live healthy sex lives (Carew et al, 2017).

4. Key barriers for people with disabilities being able to access HIV prevention, treatment and care programming

This rapid review identified a range of barriers affecting people with disabilities’ access to HIV prevention, treatment and care programming. This section focuses on barriers in terms of information and education, accessing and benefitting from HIV prevention, treatment and care programming and health services in general, and in the wider environment.

4.1 HIV prevention information and education

Awareness of HIV, risk and available HIV services: studies from Uganda (Abimanyi-Ochom et al, 2017; Schenk et al, 2017; Chireshe et al, 2010), South Africa (Shisana et al, 2014; Maart and Jelsma, 2010), Ethiopia (Kassa et al, 2016; Mekonnen et al, 2018), Zambia, and Ghana (Schenk et al, 2017) and Nigeria (Aderemi, et al, 2013) found a low level of understanding among people with disabilities of different ways to prevent HIV and a lower perception of risk. The Nigerian study found that knowledge

levels for young people (age 12-19 years old) with mild/moderate intellectual disabilities were lower than those who were not living with a disability. One of the Ethiopian studies did find that perceptions of risk among persons with disabilities were high, 87.6% and 67.2% of respondents in respective studies felt that their disability could increase the risk of contracting HIV. In the same Ethiopian study, 88% of respondents with disabilities had poor knowledge about ways of preventing HIV. Kassa et al (2016) found that only 64.6 % of young people with disabilities were aware of SRH services. Analysis from South Africa revealed that gender and level of education, together with geographical differences, are key predictors for access to information and knowledge about HIV among people with disabilities (Henning Eide, A. et al (2011). Information is often not accessible to people with disabilities (Rohleder, 2017).

Education - Children with disabilities are 2–10 times more likely to be out of school than their peers without disabilities, which could limit their ability to access SRHR and HIV information (UNAIDS, 2017). There can also be specific attitudinal and cultural barriers affecting access to HIV education. A survey questionnaire completed by 34 schools for learners with special education needs in the Western Cape province of South Africa and complimentary data collected through interviews with a total of 21 members of staff at schools for learners with disabilities was conducted by Rohleder et al (2012). Although respondents recognised the importance of providing HIV prevention education for people with disabilities, staff reported some challenges in providing HIV prevention education: barriers to communication; discomfort about issues of sexuality and disability; disagreements among staff about what is appropriate content for sexual health education; and fears of promoting sexual activity.

4.2 HIV services and programmes

The physical/built environment - People with disabilities can face physical barriers related to travelling to and accessing health services in general (Tun et al, 2016; Schenk et al, 2017; Banks et al, 2017; Nixon et al, 2014; Chireshe et al, 2010). Centralisation of available HIV services in urban areas, without accessible, affordable transportation links exacerbates access problems (Banks et al, 2017).

A qualitative study on HIV-related disabilities and challenges in accessing care in Harare, Zimbabwe, found that there was a lack of supplies and equipment in both the HIV and rehabilitation sectors and a lack of disability-inclusive adaptations in health centres, particularly in HIV services (this has implications for physical access and also communications discussed below) (Banks et al, 2017). In a qualitative study conducted by Tun et al (2016 and Schenk et al, 2017) on accessibility of HIV services for people with disabilities living with HIV in Ghana, Uganda and Zambia, one of the most significant barriers to accessing facility-based HIV services and receiving test results was related to physical accessibility. For instance, most health centres in Uganda lack ramps and have narrow doorways that hinder the use of movement devices, such as wheelchairs. Participants of a qualitative study on the perceptions of the availability and effectiveness of HIV/AIDS awareness and intervention programmes in Uganda, found that people with disabilities can be confined to their homes because of issues of mobility further excluding them from key health services (Chireshe et al, 2010). For people living with HIV, HIV treatment is taken for life and involves monitoring, so regular trips to health services are required. Regular trips for treatment can compound access issues for people with disabilities living with HIV.

An additional person may be needed to help a person with disabilities access services (this also has implications for other barriers outlined under resources and communications). Participants of a qualitative study involving people with disabilities and people working in HIV and/or disability in Lusaka, Zambia, described how being reliant on others often jeopardised ARV treatment adherence for people with disabilities. Respondents reported having to miss scheduled appointments when third-party support was not available. Health workers often labelled them as 'defaulters' rather than being allowed to reschedule or given longer courses of ARVs to reduce the number of times they needed to attend

the clinic. Being labelled as ‘defaulters’ required them to have more frequent appointments, limited their supply of medicine, and increased the overall likelihood their treatment would fail. (Nixon et al, 2014; Parsons et al, 2015).

Resources – Additional costs associated with disability for example travel costs, supplementary services and equipment present additional barriers. A case-controlled study at a paediatric ART therapy centre in Lilongwe, Malawi found that the main reported barrier to accessing disability-related services was lack of money for transport (60%), followed by services being too far away (20%), and lack of funds for services/equipment (16%). (Devendra et al, 2013).

Information and communications – Lack of disability inclusive adaptations regarding information on HIV prevention, treatment and care can undermine the ability of people with disabilities to access and benefit from HIV services (Tun et al, 2016 / Schenk et al, 2017; Nixon et al, 2014; Chireshe et al, 2010; Cobbing et al, 2014). Most participants of qualitative studies in Zambia and Uganda, described challenges related to communication for people with visual or hearing impairments seeking HIV-related health services. HIV testing and counselling programmes provide limited counselling in sign language for people with hearing impairments or the counselling given may be incomprehensible to people with intellectual impairments (Nixon et al, 2014; Chireshe et al, 2010). Not having accessible information and advice can also jeopardise a person’s right to informed consent (either directly from themselves or through a caregiver), a fundamental principle of voluntary counselling and testing services.

Often an additional person is needed to help a person living with a disability to understand health advice and treatment provided. The study by Nixon et al (2014) found that many people with disabilities experience a lack of confidentiality when testing for HIV because of communication barriers and the need to involve a third person for interpretation.

The implications of inaccessible information and communications can severely impact on the ability of people with disabilities and living with HIV to ensure continued care in their communities whether by themselves or by others (Cobbing et al 2014). Cobbing et al (2014) state in their qualitative study of physiotherapy rehabilitation in the context of HIV and disability in KwaZulu-Natal, South Africa, that participants showed little understanding of their health conditions, prescribed medication and in some cases therapy. This also speaks to a wider issue of a lack of community health support for people living disabilities, including in the context of HIV. Where rehabilitation services exist, Wazakili et al. (2009) argue that support around sexuality and sexual health can be absent.

Attitudes and behaviours of staff in health care settings related to HIV and disability – People with disabilities can also be put-off from seeking healthcare because of bad treatment by staff working within health care settings (UNAIDS, 2014; Banks et al, 2017; Nixon et al, 2014; Chireshe et al, 2010; Tun et al, 2016 / Schenk et al, 2017). Globally, more than 10% of women and 23% of men living with a disability reported not returning to seek healthcare because they were treated badly during a previous visit (UNAIDS, 2014¹⁰). Bad treatment can manifest itself in a refusal to appreciate the SRHR needs of people with disabilities (Rohleder, 2017). Research is beginning to show that people living with HIV also face violence and discrimination in health services because of their HIV status (See for example, Orza et al, 2015). Devendra et al’s (2013) case-controlled study at a paediatric ART therapy centre in Lilongwe, Malawi highlights that caregivers of people living with disabilities and HIV can also face discrimination. Almost one in ten caregivers reported at least one episode of healthcare staff being unhelpful, discriminatory, not listening or lacking in sufficient training with respect to their child’s disability.

Health workers can lack the necessary knowledge and skills to provide accessible, appropriate services. A qualitative study involving in-depth interviews with 10 healthcare workers in a semi-urban hospital

¹⁰ This study is reported in the UNAIDS Gap report - however, references are not given.

setting in KwaZulu-Natal, South Africa to understand healthcare workers' experiences with disability in the context of HIV, found challenges in dealing with the increased needs of care and support for those people living with HIV who experience HIV-associated disabilities. (Egeraat et al, 2015) Healthcare workers interviewed indicated a limited ability to cope and respond to these needs, primarily relying on additional referrals to manage complex or episodic disabilities. Participants also identified issues such as excessive work load, lack of resources and training and emotional challenges in dealing with disability. This suggests a lack of system-wide support for health care staff.

Policies and implementation – A 2011 review of the national strategic plans for HIV and AIDS in countries in Eastern and Southern Africa highlights a failure in many contexts to integrate issues around disability, with seemingly limited targeted interventions for people with disabilities (Hanass-Hancock et al., 2011). Some countries have included disability in their national HIV strategies, including South Africa, Ethiopia, Namibia, Ghana, Uganda and Senegal and are making progress towards inclusive programming and policies and more accessible programmes and services are beginning to appear¹¹. However, a lack of supportive policies and weak implementation when they do exist limit the ability of health systems to ensure that HIV-related services are fully accessible and affective (UNAIDS, 2017). Key informants in a qualitative study in Harare, Zimbabwe, reported no policies or interventions were in place specifically to address HIV-related disability. This impacts at the service level. While referrals between HIV and rehabilitation providers were not uncommon, no formal mechanisms had been established for collaborating on prevention, identification and management. (Banks et al, 2017). Disability policies may also fail to address HIV. A qualitative study of implementation of the disability policy framework in Namibia highlights that the policies and legal framework failed to address HIV and SRHR and implementation in general was weak (Shumba and Moodley, 2018).

3.4 Environmental factors

Violence against people with disabilities – it is well documented that physical, sexual and psychological violence, including gender-based violence (GBV) and fear of violence, can limit access to HIV, SRH and health services in general for people at risk of HIV and for people living with HIV (see for example, Heise and McGrory, 2016; Orza et al, 2017). This can adversely affect treatment adherence and health outcomes for people living with HIV. Evidence shows that people with disabilities are also subject to high levels of violence during their lives and in multiple settings (Bell, 2017). Children with disabilities are 3.7 times more likely than children without disabilities to be victims of any sort of violence. Children with mental or intellectual impairments are 4.6 times more likely to experience sexual violence than their non-disabled peers (Jones et al, 2012). Violence against adults with disabilities are 1.5 times more likely to be a victim of violence than those without a disability, while those with mental health conditions are nearly four times more likely to experience violence (Hughes et al, 2012).

Stigma, discrimination and exclusion – Stigma and discrimination are major barriers preventing people with disabilities from accessing HIV and SRHR services (Neille and Penn, 2015; Nixon et al; Parsons et al, 2015). Participants of a study of 30 adults with disabilities from Mpumalanga Province, a rural area of South Africa, reported how experiences of discrimination, social exclusion and isolation stopped them from accessing support services (not necessarily HIV-related), underpinned by numerous context-specific experiences, including exposure to violence (Neille and Penn, 2015). A multi-country qualitative research study at urban and rural sites in Uganda, Zambia, and Ghana highlights how multiple overlapping layers of stigma towards people with disabilities (including internalised self-stigma and stigma associated with gender and abuse) have compounded each other to contribute to social isolation and impediments to accessing HIV information and services. (Schenk et al, 2017; Tun et al, 2016). Nixon et al's (2014) qualitative study in Zambia highlights participants' stories of internalised stigma, in some cases resulting in suicidal thoughts. Carers can also face discrimination. In Malawi, 29% of

¹¹ See for example the Avert website - <https://www.avert.org/people-disabilities-hiv-and-aids>

caregivers reported facing stigma or discrimination in the community, at school or in the healthcare sector because of their child's disability (Devendra's et al, 2013).

Internalised stigma can undermine the ability of people with disabilities to negotiate and maintain safe sexual relationships and this can be compounded by an HIV diagnosis. Maart and Jelsma (2010) found that young people with disabilities were less likely than those who were not living with a disability to feel able to protect themselves against contracting HIV. Shakespeare (2000) argues that for many people with disabilities, sexuality has been an arena involving 'distress, and exclusion, and self-doubt' (p. 160) which is likely to influence their sexual behaviour as well as their SRH seeking behaviour.

Economic and social factors – People with disabilities experience a range of social and economic factors that could limit their access to HIV and SRHR services. People with disabilities are often at an increased risk of poor SRHR outcomes including HIV because of poverty, face severely limited access to education and healthcare, and lack the information and resources needed to facilitate safer sex. They also often lack legal protection (UNAIDS, 2014; UNAIDS, 2017; Chireshe et al, 2010, Banks et al, 2017; Nixon et al, 2014).

5. Case Studies

This section provides a services of case studies, which although not externally evaluated, provide insights on enabling factors and lessons learned around best practice.

Case study 1: Specific initiative for deaf women and the integration of sexual violence protection in rural areas of Cambodia

Description: Working in rural communities with deaf women to raise their awareness of HIV, sexual and reproductive health and sexual violence protection was a crucial component of a project on HIV and disability implemented in Cambodia from 2008-2012.

Insights (including enabling factors): A number of key good practices were identified through a participative and longitudinal exercise which included the following: mapping of persons with disabilities and, in particular, deaf people living in target villages; conducting home visits and mobilizing local leaders to encourage community 'buy-in'; close partnership with the Deaf Development Programme (DDP) of Maryknoll; training educated deaf women to become future trainers and awareness-raising facilitators for other deaf women and girls; training deaf women and girls to learn Cambodian sign language before they could learn about HIV and sexual violence prevention; and development of visually-friendly IEC material. Enabling factors included: the common understanding established between the DDP's and Handicap International's management to empower deaf women, for the women to learn sign language and for their needs to be central to the project. (Handicap International, 2014)

Case study 2: Disability-sensitive HIV information and services for persons with visual impairments in Kenya

Description: The project designed information, education and communication (IEC) material that met the communication needs of persons with visual impairments and effectively conveyed HIV-related messages to them, guided by set up a committee of people with disabilities and their DPO representatives.

Insights (including enabling factors): Materials were produced in large print and Braille and audio messaging was used for topics such as: HIV prevention, stigma and the barriers people with disabilities face accessing VCT services and taking their ARVs. Radio talk shows were also organised, supported by community mobilisation and awareness-raising by peer educators with disabilities who also carried out home visits to help people with visual with impairments learn how to use condoms in the privacy of their homes. In total, 8,796 persons with visual impairments were reached with HIV information on

prevention, treatment and care; 23 community discussion sessions were organised; and 3,064 people with visual impairments went for counselling and testing. The involvement of people with disabilities and DPOs in adapting the IEC materials was vital for ensuring more targeted interventions as was the specific funding provided by the Kenyan Government through its National AIDS Council to target people with sensory impairments in its HIV prevention response. (Handicap International, 2014)

Case study 3: Contemporary dance performances by men and women with disabilities to share stories and address myths around disabilities and sexuality

Description: The project was implemented by the Dance into Space Foundation in Kenya (funded by AmplifyChange¹²). The performances were given in front of other people with disabilities, their caregivers and wider community. The project has partnered with local service providers and the dancers became local advisors on SRHR.

Insights (including enabling factors): There are no publicly 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). Facilitating factors included partnering with the community and other existing structures on the ground, for the community to own the project and ensure sustainability. Other like-minded partners included the Ministry of Health, community-based rehabilitation organisations, local disabled people’s organisations and SRHR organisations. (Dutch Coalition on Disability and Development, 2017).

Case study 4: Enhancing accessible and inclusive SRHR information and services by youths with a disability to their peers

Description: Youth Action for Better Health, Zimbabwe aimed to improve the sexual and reproductive health status of youth with disabilities in both rural and urban areas. It was implemented by Leonard Cheshire Disability Zimbabwe (LCDZ) in 2015.

Insights (including enabling factors): Disability-specific organisations were linked to SRHR and HIV-specific organisations for collaboration. Additionally, regular schools, policy makers, parents and caregivers were also involved. The project targeted young men and women equally. Youth with a disability reported that they now practice abstinence or use contraceptives. The project also saw improved access to treatment information, knowledge and awareness for youth with disabilities with HIV. Special counselling teachers played an essential role in addressing SRHR issues and partner disability-organisations established key collaborations with centres specialising in HIV counselling, testing and treatment. An additional lesson learnt was the importance of involving youth with disabilities and parents from the outset to ensure positive outcomes, including addressing negative attitudes of service providers (Dutch Coalition on Disability and Development, 2017).

Case study 5: Strengthening the role of DPOs in the HIV response in Rwanda

Description: This project helped organisations to coordinate with each other in the national response to HIV, mobilise financial resources and increase their institutional credibility in the eyes of donors and government decision-makers.

Insights (including enabling factors): Training on proposal writing and resource mobilisation enabled DPOs and CBOs to plan project proposals ahead of time and in accordance with donors’ requirements. This increased capacity development directly led to two of them receiving funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria. Organisational capacity-building enabled these DPOs and CBOs to better reach out to persons with disabilities on HIV and sexual violence prevention and care.

¹² See AmplifyChange Fund’s Learning Memo 5: <https://amplifychange.org/tools-guides/learning-memos/>

Facilitating factors included: appropriate project planning and budgeting for organisational development from the project design stage; regular re-assessment of partner's organisational capacity and mentoring for organisations; eagerness to learn more about disability on the part of all project stakeholders. (Handicap International, 2014)

Case study 6: Inclusion of disability by mainstream US-funded HIV organisations and implementing partners in Ethiopia

Description: This example involved a series of strategies and activities to mainstream disability issues by US-funded AIDS organisations and projects such as PSI, Population Council as well as the inclusion of disabilities in the Ethiopian National Strategic Plan.

Insights (including enabling factors): The first stage in this process consisted of organising a disability accessibility audit with the organisations' top managers, the results of which provided the starting point for the project. Activities including the Minelik Referral Hospital hiring two sign language counsellors with disabilities at its VCT and ART centres and the VCT data collection tool was updated to include 'type of disability'. More than one thousand people with disabilities benefitted from the improved accessibility. Partners such as PSI and Population Council included disability in their HIV work and people with disabilities were included in the National Strategic Plan. Facilitating factors included: inclusion of people with disabilities in programming; ownership by the steering committee; strong involvement of DPOs and their representatives in governmental posts; buy-in by the PEPFAR Coordinator in Ethiopia; advocacy on the part of the project manager and his team for the inclusion of disability issues in HIV policy and programming. (Handicap International, 2014)

Case study 7: Inclusion of disability into the national AIDS strategic plan in Senegal in 2011

Description: This project focused on strengthening the local HIV and AIDS response for people with disabilities. The project, which started in March 2008 and ended in June 2011, was part of a regional initiative that also involved Mali and Burundi. Its main objectives were to promote access to HIV prevention, treatment, care and support services for people with disabilities and to encourage their participation in HIV and AIDS programming.

Insights (including enabling factors): This was the result of a combination of key programmatic and advocacy activities. Facilitating factors included: financial and technical resources for conducting a seroprevalence and knowledge, attitudes and practices survey among people with disabilities; participation of DPOs in the mobilisation of survey respondents with disabilities; ratification of the UN Convention on the Rights of Persons with Disabilities (UNCRPD); commitment of the programme director and project manager; ownership of and buying-in to the project by main project partners. (Handicap International, 2014)

Case study 8: Disability-inclusive international AIDS conferences (IAC) from 2008 to 2014 –

Description: Joint efforts from the members of the HIV and Disability task group of the International Disability and Development Consortium (IDDC) to ensure the greater inclusion of people with disabilities and coverage of the issue of disability in the IAC including in plenary sessions.

Insights (including enabling factors): The facilitating factors are as follows: representing the voice of many through IDDC and moving forward as a multi-stakeholder alliance; keeping the memory of key events alive via key IDDC HIV and Disability Task Group members over the years; official membership of the International Steering Committee through Handicap International at the International Conference on AIDS and STIs in Africa (ICASA); harnessing the passion of activists and advocates; having an office or members or their partners in the city where meetings and the AIDS conference were taking place; involving local DPOs and their members with experience on the intersection between HIV and disability; getting UNAIDS on board through joint presentations, funding of some of the activities, or co-

organization of skills-building workshops; and involvement of research organisations. (Handicap International, 2014)

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Expert contributors

Janet E Lord, Independent Consultant

Dianne Kingston, Frontline AIDS

Maria Stacey, Equal International

Anton Ofield Kerr, Equal International

Jill Hanass-Hancock, South African Medical Research Council

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 disability, 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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Suggested citation:

Bell, E. and Corby, N. (2019) *HIV prevention, treatment and care programming for people with disabilities*, Disability Inclusion Helpdesk Research Report No. 7. London, UK: Disability Inclusion Helpdesk.