

# Disability stigma in the Disability Inclusive Development (DID) programme countries: an overview of the evidence

Brigitte Rohwerder

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This report draws on and expands previous work by Brigitte Rohwerder looking at disability stigma in developing countries (written for K4D) and information on stigma in the situational analyses of the six Disability Inclusive Development (DID)<sup>1</sup> programme countries. It should be noted that specific searches were not made relating to tackling stigma or stigma interventions in each of the countries so the information on tackling stigma in each of the countries is not exhaustive or necessarily representative of what is being undertaken in the countries.

## 1. Disability stigma<sup>2</sup>

Stigma<sup>3</sup> arises when elements of labelling, stereotyping (negative evaluation of a label), and prejudice (endorsement of the negative stereotypes) combine to lead to status loss and discrimination for the stigmatised individual or group, and occur in situations where they are disempowered (Scior, 2016, p. 5; Mostert, 2016, p.6-8; Cross et al, 2011b, p. 65; Stuart et al, 2012, p. 6; Werner et al, 2012, p. 749). Stigma elicits negative attitudes and responses such as

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<sup>1</sup> The Disability Inclusive Development (DID) Programme is a six year (2018 –2024), £29.25m programme implemented in Bangladesh, Kenya, Nigeria, Tanzania, Jordan and Nepal by 11 consortium partners with the aim to impact on the long-term improved well-being and inclusion of people with disabilities in low-and-middle-income countries. The DID programme implements a series of innovative and scale projects in four thematic areas: education, health, livelihoods and negative stereotyping & discrimination.

<sup>2</sup> Expanded and adapted from: Rohwerder, B. (2018). *Disability stigma in developing countries*. K4D Helpdesk Report 312. Brighton, UK: Institute of Development Studies.

<sup>3</sup> There are some who argue that stigma is not a helpful term to use. Stigma is a broad term, which can create ambiguity in its use (Peters, 2015, p. 247). Harris (in Peters, 2015, p. 248) also notes that there is a risk that using the word stigma as synonymous with negative experience could 'contribute to these negative outcomes by validating the perspectives of the stigmatiser; rendering the stigmatised voiceless, subordinate and invisible and denying the possibility of alternative outcomes'. However, Peters (2015, p. 249) argues that the concept of stigma is important for contributing to the reduction of all the negative consequences associated with stigma, although people should be 'more careful how they apply the concept of stigma, write and talk about those affected by stigma in a thoughtful and dignified way and be aware of the role they play in transmitting this message'.

pity, anxiety, avoidance, hostility, withholding help, and even hatred and disgust (Scior, 2016, p. 5; Werner et al, 2012, p. 749).

At the individual level, stigmatisation and discrimination can result in internalised oppression, loss of self-esteem, and feelings of shame as people with disabilities may have to face great challenges in overcoming the negative views of their community or societies to achieve self-acceptance and a sense of pride in their lives (DSPD, 2016, p. 6; Bond DDG, 2017, p. 4). This is known as internalised or self-stigma and can have negative effects on physical and psychological health (Cross et al, 2011b, p. 63, 66-67; Stuart et al, 2012, p. 8). This can increase people's disability (Cross et al, 2011b, p. 65). Fear or anticipation of stigma can lead to non-disclosure avoidance of potential situations of discrimination, which can also have a disruptive impact on people's lives as they live in anticipation of harmful effects (Cross et al, 2011b, p. 66, 69). However, it is important to note that 'individual reactions to stigma vary, ranging from significant loss in self-esteem to righteous anger', or even neither (Werner et al, 2012, p. 750).

Stigma can extend by association to family members, who may experience stress (by feeling shame, guilt, and worry) as a result, which can reduce their reserves and undermine their ability to provide the social supports to their disabled family member (Stuart et al, 2012, p. 6, 11-12).

Organisations working with people with disabilities have found that stigma often lies at the root of the discrimination, exclusion and low status, experienced by people with disabilities and their families in all aspects of their lives in low and middle income countries (Bond DDG, 2017, p. 3; DSPD, 2016, p. 6; Mostert, 2016, p. 5, 11). Combined with poverty and other barriers, stigma and discrimination put people with disabilities' rights at risk (Inguanzo, 2017, p. 7).

## **Factors which contribute to disability stigma**

Lack of understanding and awareness regarding the causes of disabilities and their resulting characteristics is a key factor in the stigma experienced by people with disabilities (Mostert, 2016, p. 9; DSPD, 2016, p. 5; Stone-MacDonald & Butera, 2014, p. 6). Disability is often blamed on misdeeds of ancestors; misdeeds of parents (mainly mothers); misdeeds of the person with disabilities; supernatural forces such as demons/spirits; witchcraft; or punishment or fate from God (DSPD, 2016, p. 5; Aley, 2016; Mostert, 2016). Misconceptions about the cause of disabilities often result from cultural or religious beliefs (Bond DDG, 2017, p. 3). For instance, a literature review looking at journal articles examining cultural beliefs and attitudes about disability in East Africa found that traditional beliefs about the causes of disability continued to be prevalent (Stone-MacDonald & Butera, 2014, p. 5). People often combined different beliefs about causes of disability, for example suggesting a medical explanation in addition to religious understandings (Stone-MacDonald & Butera, 2014, p. 5). Misconceptions about disability are often reinforced by ill-informed and insensitive media coverage that perpetuates negative views of disability (DSPD, 2016, p. 5).

As a result of these beliefs, people with disabilities may be thought to be not quite human or a source of shame, which has serious consequences for how they are treated. Lack of understanding about why their child is born with an impairment and beliefs that it means the family is being punished or under some form of curse or that the child is a non-human spirit has been found to result in the infanticide of new born children with disabilities in some countries

such as Kenya<sup>4</sup>, Guinea, Niger, Sierra Leone, and Togo, and Nepal (Inguanzo, 2017, p. 20, 32, 34; Njelesani et al, 2018, p. 5; Mostert, 2016, p. 9, 12; Parnes et al, 2013, p. 25-26, 33). However, there is no data on the prevalence of infanticide of children with disabilities as it is a very sensitive issue and often occurs in secret (Inguanzo, 2017, p. 20; Njelesani et al, 2018, p. 6). The stigma associated with the birth of a children with disabilities can lead to fathers abandoning the family, with the mother left with the sole responsibility for care (Ditchman et al, 2016, p. 32; Aley, 2016, p. 15; Parnes et al, 2013, p. 26). The stigma faced by children and adults with disabilities mean they face a greater risk of violence, abuse and neglect than their non-disabled peers (Njelesani et al, 2018, p. 4, 6; Parnes et al, 2013, p. 9; Aley, 2016, p. 16). The belief that some people with disabilities weren't human explains why treating people with disabilities in inhumane ways can go uncontested in communities (Aley, 2016, p. 15). Traditional beliefs can result in violent "cures", for example, of practices of forcible ingestion of contaminated water or other substances for psychosocial disability or epilepsy (DSPD, 2016, p. 7).

The low numbers of people with disabilities in national censuses or official statistics is often attributed to stigma around disability, with children with disabilities going unreported and unregistered, affecting their access to services (Inguanzo, 2017, p. 31; Bond DDG, 2017, p. 3; Parnes et al, 2013, p. 25). The stigma around disability can sometimes cause the rejection or ostracism people with disabilities and their whole family (Inguanzo, 2017, p. 20; Parnes et al, 2013, p. 8). When disability is associated with punishment for previous immorality it can be met with strong social disapproval, for example (Aley, 2016, p. 15). As a result people with disabilities may never leave their homes or are sent away to institutions in order to avoid being seen by the community, as the community believes that the family has done something wrong or is under some form of curse (Inguanzo, 2017, p. 20-21, 26).

However, not all cultural beliefs result in negative beliefs about disability and some communities in Africa perceive some disabilities positively, with many families taking good care of their children with disabilities (Mostert, 2016, p. 9, 16; Stone-MacDonald & Butera, 2014, p. 9; Groce & McGeown, 2013, p. 7).

Lack of understanding and awareness about the nature and abilities of people with disabilities, also contribute to the stigmatisation, discrimination and abuses they experience. Stigmatisation of disabled people can occur because of the expectation that people with disabilities are less able to contribute to the good of the family and the community, and the assumption that they are a burden (Mostert, 2016, p. 17; Aley, 2016, p. 15, 18). Low expectations as to the potential abilities of people with disabilities can prevent children with disabilities from attending school (DSPD, 2016, p. 6; Ditchman et al, 2016, p. 34; Parnes et al, 2013, p. 27; Inguanzo, 2017, p. 27; Aley, 2016, p. 17). Being excluded from school in this way curtails children with disabilities' future life chances, which can result in a 'reinforcement of the communities' commonly held beliefs that persons with disabilities are dependent and non-productive' (Aley, 2016, p. 17).

Stigma and beliefs about the nature of disability can also restrict people with disabilities' ability to develop relationships (Franklin et al, 2018, p. 5). Women with disabilities can struggle to access sexual and reproductive health services due to cultural beliefs that they are not sexually active, despite being more likely to be a victim of sexual abuse than their non-disabled peers (Rugoho & Maphosa, 2017, p. 1-2). Disability and gender stereotypes assume that women with disabilities

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<sup>4</sup> For example "there is a big problem in the Maasai community because when a family discover they have a child with a disability, sometimes they end up killing that child, because they fear the stigma of the community, [...] because the community believes the disability is a curse" (Inguanzo, 2017, p. 20).

are 'undesirable, unworthy and incapable of love and sexual expression' (Ando, 2017, p. 4). Sexual abuse is sometimes considered a 'favour' to people with disabilities because it is assumed that it is the only way they will experience sex (Aley, 2016, p. 21, 31). On the other hand, it is reported that some African communities perceive people with disabilities as hypersexual and believe that discussing sexual and reproductive issues with them would trigger their sexual feelings and they would not be able to control their sexual desires (Rugoho & Maphosa, 2017, p. 2). In countries where there is a common folk belief that sex with a virgin can cure HIV, the often incorrect assumption that people with disabilities are sexually inactive, puts them at risk of such rapes (DSPD, 2016, p. 7; Aley, 2016, p. 22). The assumption that people with disabilities will be virgins and therefore free of other sexually transmitted diseases also makes them vulnerable to assailants who assume they are safe sexual partners (Aley, 2016, p. 31). Social attitudes and understanding of disability and sexuality in general were found to be strong influencing factors on the risks that persons with disability face in relation to sexual abuse in East Africa (Aley, 2016, p. 6, 14). Girls with disabilities, especially those with intellectual, communication, or visual impairments, are especially vulnerable as a result of assumptions that they will not be able to tell others about what happened to them and denounce the perpetrators (Inguanzo, 2017, p. 21; Aley, 2016, p. 28-29). The dehumanisation of children with intellectual disabilities and the assumption that they are unable to understand what is happening to them can also make people more willing to accept behaviour that would be impermissible otherwise (Ditchman et al, 2016, p. 33). The stigma and shame associated with sexual abuse in general in some communities can be another factor in underreporting of sexual abuse against persons with disabilities, with discussions about sexual matters combined with disability issues considered particularly uncomfortable or taboo in East Africa for example (Aley, 2016, p. 32-33).

Communities may shun people with disabilities and their families because they believe they will spread their 'ill fortune' to others either intentionally or unintentionally (Groce & McGeown, 2013, p. 5). People with disabilities are sometime avoided by pregnant women out of fear that their unborn child will be contaminated (Njelesani et al, 2018, p. 4). Parents of non-disabled children are reported to sometimes believe that children with disabilities will "infect" the classroom and do not want their children to associate with children with disabilities (Parnes et al, 2013, p. 27).

In some urban areas of Africa, unscrupulous urban practitioners of 'witchcraft' or 'magic'<sup>5</sup> have been reinterpreting traditional links between disability and witchcraft, using practices, which could involve abuse, mutilation or killing of persons with disabilities to obtain body parts for use in rituals, potions or amulets with the promise to help individuals become wealthy, gain social prominence, succeed in love or vanquish rivals (Groce & McGeown, 2013). The links between disability and witchcraft are encouraged by some Pentecostal churches 'where disability is linked to evil spirits or the devil, while 'cure' of disability is linked to virtue and prosperity' (Groce & McGeown, 2013, p. 3, 20). People with disabilities, especially children with autism and people with mental illness, are particular targets of witchcraft accusations, due to their low social status but also because of others' interest in acquiring their property, money or land (Groce & McGeown, 2013, p. 15).

Discriminatory legislation and policies also reinforce prejudice and discrimination, while the segregation of people with disabilities perpetuates negative stereotypes and limits their quality of

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<sup>5</sup> 'These new urban witchdoctors tend to be self-appointed experts, although the amount of training they have varies. Their background is distinct from traditional healers who undergo intensive training in an established body of knowledge and whose practices are situated within the bounds and under the oversight of a coherent cultural tradition' (Groce & McGeown, 2013, p. 9).

life and potential to contribute to society (DSPS, 2016, p. 5; McConkey, 2018, p. 6-7; Scior et al, 2015, p. 101). Stigma can contribute to the lack of adequate services for disabled people, 'resulting in poorer treatment, rejection, and devalued roles within society' (Werner et al, 2012, p. 750).

## **Differences in the extent of stigmatisation**

Attitudes towards disability are not the same within countries, communities, or even families (DSPD, 2016, p. 3; Groce & McGeown, 2013, p. 6). In many cases, negative beliefs about disability differ based on the types of impairment and how/when the disability was acquired (DSPD, 2016, p. 5; Bond DDG, 2017, p. 4). Cultural barriers are usually worse when a child is born with an impairment because of beliefs that the family has done something wrong or that they are under some form of curse (Inguanzo, 2017, p. 26). The degree of stigma also differs between visible and stable disabilities and disabilities that are invisible and variable (Inguanzo, 2017, p. 11). People with intellectual disabilities, severe mental health conditions, albinism, and sensory disabilities are often more stigmatised than people with physical disabilities (Scior, 2016, p. 6; Bond DDG, 2017, p. 4; Parnes et al, 2013, p. 26). People with disabilities who can participate in their communities experience less stigma than those with more severe disabilities (Mostert, 2016, p. 11; Parnes et al, 2013, p. 26; Stone-MacDonald & Butera, 2014, p. 7, 10). For example, Stone-MacDonald and Butera (2014, p. 10) found that in East Africa it 'appears that individuals with disabilities are less likely to experience stigma associated with an obvious physical deformity or a diagnostic label and more likely to face discrimination if they are unable to participate in the daily social and economic activities of the community than their counterparts in the developed world'.

Females who are disabled are doubly disadvantaged, due to the stigma associated with gender as well as disability (Mostert, 2016, p. 10-11; Bond DDG, 2017, p. 4). People with disabilities from minority groups can also face additional discrimination on ethnic grounds (Inguanzo, 2017, p. 27). Socio-economic issues can also affect attitudes towards disability; for example, poorer people with disabilities may face more stigma than more economically advantaged people with disabilities (DSPD, 2016, p. 5). People with disabilities in rural areas may experience more harmful practices than in urban areas (Inguanzo, 2017, p. 34; Njelesani et al, 2018, p. 6).

## **Measuring stigma**

In order to examine the extent and severity of stigma, researchers need accurate measurement tools (Werner, 2016, p. 15). Measurement of stigma is a challenge (Cross et al, 2011b, p. 64). Specific tools for different disabilities are needed because stigma may differ across disabilities, yet the attention paid to the measurement of different disability stigma has not been even (Werner, 2016, p. 15). A lot of existing scales focus on measuring stigma around mental illness (Werner et al, 2012, p. 751). A number of scales measure attitudes (consisting of cognitive, affective, and behavioural components), but these do not capture the entirety of stigma (the chain from stereotypes through prejudice to discrimination) (Werner, 2016, p. 16). Scales can address external (public), self, or family stigma (Werner et al, 2012, p. 751). Most scales have been developed and used predominately in Western countries, and some had their last reported usage a decade ago (Werner, 2016, p. 16; Werner et al, 2012, p. 759).

## **Examples of stigma measures**

Werner et al (2012, p. 753, 760) conducted a systematic review of stigma measures relating to intellectual disability and found that most of the scales reviewed were based on public “attitudes” rather than specifically addressing stigma, while fewer measured self-stigma, and even fewer measured family stigma. Existing scales intended to measure attitudes toward general disability groups include ‘the Semantic Differential Scale (Osgood, Suci, & Tannenbaum, 1957), the Scale of Attitudes toward Disabled Persons (Antonak, 1982, 1988), the Attitudes Toward Persons with Disabilities Scale (Yuker, Block, & Campbell, 1960), the Interaction with Disabled Persons Scale (Gething, 1994), and the Multidimensional Attitudes Scale (MAS, Findler, Vilchinsky, & Werner, 2007)’ and the Attitudes to Disability Scale (ADS; Power, Green, & the WHOQOL-DIS Group, 2010) (Werner et al, 2012, p. 751, 753).

### ***The Attitudes to Disability Scale (ADS)***

The Attitudes to Disability Scale (ADS) was developed in conjunction with focus groups of people with physical and intellectual disabilities and tested in 12 centres throughout the world (Power et al, 2010). The scale can be used with individuals with disabilities (‘personal’ form of the scale) and with the general population to look at attitudes towards disability (‘general’ form of the scale) (Power et al, 2010, p. 872). The scale focuses primarily on four different aspects of disability: issues of inclusion and exclusion and burden on families and on society as a whole; discrimination; positive gains in relation to self and to others; and current and future hopes and prospects and whether or not disability impacts on these hopes (Power et al, 2010, p. 873-874). Werner et al (2012, p. 753) found it to be the most comprehensive scale in their review.

### ***Social distance scales***

Social distance is the willingness of an individual to have social contact with a member of another group, in situations of varying degrees of intimacy (Werner, 2016, p. 21). Many researchers have used some form of social distance scale to measure external stigma (Werner, 2016, p. 21).

### ***The ID Stigma Scale***

The ID stigma scale was developed by Werner and includes 35 items measuring cognitive, affective, and behavioural reactions when meeting a man with an intellectual disability described in a vignette (Werner, 2016, p. 19). The scale consists of three dimensions: stereotypes (including acceptance, low ability, and dangerousness); prejudice (including negative affect and calm affect); and behavioural (including withdrawal, social distance, and helping) (Werner, 2016, p. 19). In order to combat the effects of social desirability, the ID stigma scale had been adapted to an indirect version, where participants are asked to report on the reactions they believe another person would have (Werner, 2016, p. 19). As it is relatively new, the scale has not been used much, although it is based on the widely used Multidimensional Attitudes Scale (Werner et al, 2016, p. 20).

## 2. Disability stigma in Bangladesh<sup>6</sup>

Discrimination, exclusion and neglect of persons with disabilities and their household are still prevalent in Bangladesh, as the laws (including the Disabled Persons Protection and Rights Act 2013) are not being sufficiently enforced (GED 2015). Titumir and Hossain (2005) state that many people in the Bangladesh view disability as a curse and a cause of embarrassment to the family. Persons with disabilities are usually left out of development efforts due to inadequate understanding and awareness among the general public and those who design and manage developmental programs. They are often not aware of the extreme difficulties faced by persons with disabilities and most do not have the skills and knowledge that would enable them to include persons with disabilities and their families in development programs. The neglect that results from this lack of knowledge reinforces and multiplies the effects of the negative attitudes that already exist within families and communities. Most of the time it is not the impairment but rather the attitudinal and environmental factors that a person with disabilities encounters in everyday life that cause his or her exclusion from society (CAMPE 2011). Women with disabilities are particularly vulnerable to social discrimination and neglect. Research by Quinn et al (2016) to document the experiences of 15 women with disabilities in Bangladesh found that they had been subject to oppression due to beliefs regarding traditional gender roles and the common perception that women with disabilities do not need to be educated. Discrimination from their local community was reported by the majority of the women. All of them attributed this to a poor understanding of disability, leading to misconceptions that women with disability were 'cursed' or had committed an offence against God. This form of exclusion was found to impact on their mental health significantly, resulting in reports of depression. Drawing on research by Hosain, Atkinson & Underwood (2002), Kandasamy, Soldatic & Samaratne (2017) explain that in Bangladesh, disability is not the primary disadvantage for women in rural areas, rather, their disability becomes an additional burden in their already marginalised gender position. Ethnicity, social class and race become highly contingent factors that shape women's experience of living with a disability in contexts like Bangladesh. With regards to children with disabilities in Bangladesh, discrimination in the family, the community and the workplace is at the core of most rights violations (UNICEF 2014).

The belief that disability is a curse and a punishment for sinful behaviour permeates all levels of society and affects access to adequate care, health services, education and participation (UNICEF 2014). Negative attitudes of the family, teachers and community are a factor in the lack of school enrolment of children with disabilities (CAMPE 2011). Prejudice and ignorance are among the main barriers to employment for persons with disability in Bangladesh (Danish Bilharziasis Laboratory 2004). Women with disabilities have poor health outcomes within a gender-biased cultural context due to ill-informed attitudes and routine discrimination against them across Bangladeshi society (Quinn et al, 2016). Huq et al (2013) found that distance, cost, and stigma mean that devices such as hearing aids are difficult for rural residents to access.

Examining the views of 2,400 participants, Titumir and Hossain (2005) reported that 55% of respondents accept persons with disabilities well and 20% give extra privilege to them. Most of the participants would be comfortable having friendships with people with disabilities but would never marry them. 63% of respondents do not believe that persons with disabilities are a burden to the family. Most of the people argued that persons with disabilities should get extra assistance

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<sup>6</sup> Taken and adapted from: Thompson, S. (2019). *Bangladesh Situational Analysis*. Disability Inclusive Development.



in society including in the transport, health, and education sectors. A study found that families arranged marriages for their daughters with disabilities with whoever accepted them because of the low expectations they had for them (Ando, 2017, p. 2).

## **Tackling disability stigma**

The Constitution of the People's Republic of Bangladesh prohibits any form of discrimination between various social groups, including due to disability. The 2013 Disabled Persons Protection and Rights Act protects people with disabilities' rights. Amongst other things, this law bans educational institutions, enterprises and other organisations from discriminating against people with disabilities. Organisations and individual will face fines and imprisonment if they discriminate against people with disabilities, for instance by 'creating obstacles to them in getting due share of inherited assets, giving negative impression of them in books, publications and media both directly and indirectly and forgery of identity cards' (GED, 2015).

In Bangladesh, there have been only a few systemic interventions to raise awareness of persons with disabilities at the community level. While progress is slow, changes have been noted due to policy modifications and social mobilisation. For children with disabilities this includes increased access to school and to opportunities for skills development and employment. Now that they are seen as contributors rather than burdens, their status in the family and the community is improving (UNICEF 2014).

## **3. Disability stigma in Jordan<sup>7</sup>**

In Jordan impairment and disability are often linked to stigma and shame. This negative connection may extend to the entire family of the person with a disability (Jalal and Gabel 2014). Men with disabilities are often ridiculed by other men in the community (Pearce 2015). Women with disabilities are also often marginalised, pre-judged, and discriminated against and they may experience more stigma than men. Poor women with disabilities in Jordan suffer greater discrimination than other groups (UN, 2015). Cultural issues may result in people with certain types of disabilities being hidden away (Crock et al 2015). In Jordan, visibility is an important criterion for what constitutes disability and people with physical impairments are more likely to be described as disabled, than people with other impairments (Jalal and Gabel 2014). People with disabilities face discrimination and a lack of accessibility in public places, schools, universities, and streets (Jordan Times, 2015).

Refugees with disabilities may face a heightened risk of exclusion while living in Jordan (Crock et al 2015). They may face discrimination in every day situations, for example when using public transport (Crock et al 2015). Refugee children with disabilities trying to access education may face attitudinal barriers from parents (UNICEF 2015). Stigma was found to be one of the barriers to refugees with disabilities accessing education in Jordan (Culbertson et al 2016). Attitudinal barriers may be keeping refugee children with disabilities out of school as families may fear that other children will not accept a child with disabilities (UNHCR 2013). Inclusive education is vital for refugee children with disabilities, but identification of needs remains a challenge (UNICEF 2013).

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<sup>7</sup> Taken and adapted from: Thompson, S. (2019). *Jordan Situational Analysis*. Disability Inclusive Development.



However, not all attitudes around disability are negative. A study that assessed the views and attitudes of dentists in Jordan towards persons with intellectual disabilities reported highly positive attitudes toward persons with intellectual disabilities (Al-Zboon & Hatmal 2016). A study from 2013 focused on the attitudes of higher education faculty members towards inclusion of students with disabilities at one large public University in Jordan found that the majority of faculty members have positive attitudes toward inclusion of students with disabilities. However, the majority of the faculty members were found to be unfamiliar with the disability legislation in Jordan and not trained to teach students with disabilities (Abu-Hamour, 2013).

## **Tackling disability stigma**

Under the new Disability Law (No. 20) (2017) in order to combat stigma revolving around disability and the role of persons with disabilities in society and local communities, the Law requires media and religious awareness by obliging the Media Commission, Jordanian Press Association and other media and journalistic institutions to the following, amongst others:

- Advocate for the rights of persons with disabilities and use of terminology that is respectful to them;
- Refuse licensing or renewals thereof of any media outlets, including online media presence, unless they are optimised to be accessible for persons with disabilities; and
- Train journalists and persons in the media industry on how to positively address issues pertaining to persons with disabilities and the stereotypes associated with them.

Under the new Law, the Ministry of Awqaf and Islamic Affairs and the Council of Churches are required to promote the rights of persons with disabilities and their acceptance in society as part of the general religious rhetoric. Additionally, religious curricula shall be revised, in coordination with the Ministry of Education, to instil the values of diversity and acceptance (Salaita and Abourah 2017).

## **4. Disability stigma in Kenya<sup>8</sup>**

People with disabilities in Kenya face stigma and discrimination that lead to enduring and humiliating stereotypes and prejudices against people with disabilities as a curse and a burden on society, as well as undermining the human right principals which are key to inclusion (Sightsavers, 2018, p. 4; KNCHR, 2016, p. 16, 21; Kabare, 2018, p. 10). Aley's (2016, p. 14) study<sup>9</sup> in Kenya (and Uganda) found that respondents felt that attitudes to disability in their community were overwhelmingly negative due to 'harmful traditional beliefs and misconceptions about the causes and nature of disability and about what roles and rights persons with disabilities can have in society'. Many communities believed that disability was a curse resulting from transgressions of former generations in the family (Aley, 2016, p. 14). Wrongdoing of ancestors which results in disability is usually placed on the mother's side of the family rather than the fathers (Aley, 2016, p. 15). Many Kenyans believe that disability is the result of taboo activities

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<sup>8</sup> Taken and adapted from: Rohwerder, B. (2019). *Kenya Situational Analysis*. Disability Inclusive Development.

<sup>9</sup> Qualitative participatory action research in Uganda and Kenya with service providers and key responders. Involved 52 individual interviews and 9 focus groups.

such as adultery or incest, or broken taboos by the mother (such as eating eggs during pregnancy or lying on her stomach) (Mostert, 2016, p. 16; McConkey et al, 2016, p. 184; Parnes et al, 2013, p. 24). Within different communities in Kenya some beliefs are more specific, for example, 'among the Nandi, killing an animal without provocation during a wife's pregnancy is believed to cause disability in the new-born child, while among the Abagusii, children born with cleft palates are thought to be the result of parents making fun of someone with a disability' (Mostert, 2016, p. 16; Stone-MacDonald & Butera, 2014, p. 5-6). Some communities believed that people became disabled because they had caused accidents and not been properly cleansed (Aley, 2016, p. 14). Others believe that disability is a curse from a supernatural or mysterious otherworldly force (Mostert, 2016, p. 16; McConkey et al, 2016, p. 184; Parnes et al, 2013, p. 24). Still others believe that disability results from witchcraft spells placed either upon the family or the individual with disabilities (Mostert, 2016, p. 16; McConkey et al, 2016, p. 184; Parnes et al, 2013, p. 24).

However, not all traditional beliefs are negative. For example, the Turkana of Kenya perceive children with disabilities as a gift from God to be well taken care of, or else they risk the wrath of the deity (Mostert, 2016, p. 9; Stone-MacDonald & Butera, 2014, p. 7). Aley (2016, p. 20) found that respondents reported that some community members who would refer to disability in the context of the teachings of their faith and frequently viewed persons with disabilities more positively and as individuals who should be allowed to take their place in the community and be more socially included (although others believe that God imposes disability as a punishment or to prevent them from sinning).

In many communities, families hide away their disabled family member, especially children, due to societal stigma (Kabare, 2018, p. 10; Rodríguez et al, 2018, p. 5). Bunning et al (2017, p. 13) found that the stigma associated with people with disabilities extended to people who helped them, and it was felt that 'the person offering assistance would also ". . . give birth to such a child"'. Stigma excludes people with disabilities from economic and social activities thus trapping them in a cycle of poverty (Jillo, 2018, p. 3; Bunning et al, 2017, p. 15). People with intellectual disabilities, psychosocial disabilities, albinism, as well as women and girls, older persons, children and youth with disabilities, are particularly affected by stigma and discrimination (Sightsavers, 2018, p. 5; Jillo, 2018, p. 3; CRPD, 2015, p. 3-4; KNCHR, 2016, p. 48, 75).

More affluent social classes have the advantage of being able to pay for support and were found to be 'more likely to support their children with disabilities properly and to promote their education and social inclusion, rather than hiding them away or believing in harmful traditional practices' (Aley, 2016, p. 16).

Disability stigma prevents persons with disabilities' full participation in life. Stigmatisation has been identified as a factor in the high dropout rates of children with disabilities from schools (DoE, 2018, p. 11). The main challenges relating to access and equity in the provision of education and training to children with disabilities include, amongst others, cultural prejudice and negative attitudes (DoE, 2012, p. 49; Sightsavers, 2018, p. 8; DoE, 2018, p. 8; KNCHR, 2016, p. 49; Kabare, 2018, p. 10; Kiru, 2019, p. 184-185). Opoku et al (2016, p. 85) suggest that barriers to employment stem 'mainly from the religious, cultural, and medical perceptions of disability, leading to the discrimination and exclusion of persons with disabilities from mainstream activities'. Even people with disabilities with university education have struggled to find employment due to employer attitudes (KNCHR, 2016, p. 87). People with disabilities also experience poor remuneration and discrimination in the workplace (Kingiri et al, 2017, p. 3). Women and men with disabilities encounter barriers to accessing quality healthcare, including reproductive health, as a result of insensitivity and negative attitudes of health care workers

among other factors (KNCHR, 2016, p. 40, 75, 84, 159; Kabia et al, 2018, p. 1). A study in 2014 in Kakuma Refugee Camp also found that refugee women and adolescents with disabilities lacked access to sexual reproductive health services and faced stigmatisation from health workers (KNCHR, 2016, p. 78).

Relationships between people with disabilities or between someone with a disability and someone without a disability were frequently regarded by others with suspicion, mistrust, and ridicule (Aley, 2016, p. 23). Communities may believe that people with disabilities lack the necessary qualities to make successful marriage partners (depending on the disability type), and beliefs around disability being related to bad family spirits can lead to concerns that they will bring evil or misfortune with them if they marry into the family (Aley, 2016, p. 24-25). Sometimes men form sexual relationships with women with disabilities but are unwilling to be seen with them in public due to fear of the community's reaction (Aley, 2016, p. 23). There may be concerns that relationships between people with disabilities and someone without disabilities are not consensual relationships due to the assumption that people with disabilities cannot form their own relationships (Aley, 2016, p. 23). Other myths exist concerning the perceived benefits of having sex with people with disabilities, such as that it will bring good luck (Aley, 2016, p. 22, 31).

Discrimination against persons with disabilities can be enshrined in law. For example, people with visual or hearing impairments cannot become President in Kenya, as the Constitution stipulates that the President should read English and Kiswahili without the use of Braille or sign language (Mostert, 2016, p. 11).

### **Children with disabilities**

Children with disabilities have been abandoned by their families and negative stereotypes against them exist, especially in rural areas (CRPD, 2015, p. 3; Bunning et al, 2017, p. 13; KNCHR, 2016, p. 75; Rodríguez et al, 2018, p. 4). Children with disabilities in rural areas and those among minority communities are particularly inhibited by negative cultural practices such as female genital mutilation and disinheritance of persons with disabilities (Inguanzo, 2017, p. 34).

Children with disabilities are thought to be 'cursed, bewitched, and possessed' and a punishment for the sins of the mother (Rodríguez et al, 2018, p. 4). A recent investigation by Disability Rights International found that parents are even placed under enormous pressure to kill their children with disabilities (Rodríguez et al, 2018, p. 4). '37% of the women surveyed from Nairobi said they were pressured to kill their children with disabilities while 57% of women from the more rural areas felt pressure to kill their children'<sup>10</sup> (Rodríguez et al, 2018, p. 4). Mothers of children with disabilities are sometimes thought to be cursed too and bring shame to their families and communities as a result of their children (Rodríguez et al, 2018, p. 5). Many women who give birth to children with disabilities are rejected by their husbands and wider families, which means they and their children lead lives of social isolation (Rodríguez et al, 2018, p. 5). If they lack support it is very hard for mothers of children with disabilities to survive, which makes infanticide seem like an option (Rodríguez et al, 2018, p. 5).

Children with disabilities who live in orphanages were found to be living in overcrowded and filthy conditions, with children spending lengthy times in restraints and isolation rooms, and an overall

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<sup>10</sup> Approximately 90 mothers were questioned (Rodríguez et al, 2018, p. 4).

lack of staff and untrained staff, neglect, and the withholding of medical care (Rodríguez et al, 2018, p. 6). Disability Rights International has also documented severe neglect, physical and sexual abuse, and torture in Kenya (Rodríguez et al, 2018, p. 6). Many of these children are not actually orphans but the 'belief by families that their children will be better off in institutions – that they will be well-fed, given an education, or have access to rehabilitation for a child with a disability - drive them to give up their children' (Rodríguez et al, 2018, p. 7).

### **Women with disabilities**

Women in Kenya 'face a number of challenges including the fact that they have limited access to and control of resources and other socio-economic opportunities; they have lower literacy levels compared to men; fewer of them enrol in mainstream education; they are generally poorer than men; fewer of them are in formal employment compared to men; where they do work then it is under deplorable conditions; they earn lower incomes; they have poor access to quality healthcare and advice on family planning; and are more vulnerable to gender-based violence' (KNCHR, 2016, p. 39). The situation is even worse for women with disabilities due to the marginalisation, stigma, and double discrimination they experience and the negative cultural practices and attitudes towards disability and gender biases (KNCHR, 2016, p. 39, 156). In addition, traditional and conservative views on the position and the role of women in society 'reinforce the misconception about the ability of women and girls with disabilities to adequately perform their roles as other peers' (KNCHR, 2016, p. 39). Women with disabilities experience high levels of gender-based violence and sexual abuse in both the public and private sphere (KNCHR, 2016, p. 40, 74, 156).

### **Tackling disability stigma**

Existing empowerment programmes targeting these particularly stigmatised groups are insufficient (Sightsavers, 2018, p. 5). However, the government notes that there has been a 'slow but noticeable improvement in public perception towards and treatment of persons with disabilities', including in employment (KNCHR, 2016, p. 21). Respondents in Aley's study (2016, p. 20-21) noted that progressive government policy had helped to gradually change attitudes towards disability. Aley (2016, p. 14, 16) found that respondents reported that attitudes among professionals in Kenya were improving and more progressive ideas about disability are beginning to be accepted, especially amongst educated and economically mobile groups, although they often qualified this observation by stating that it will still take a long time for 'the community' to change their negative attitudes. Teachers, particularly special education teachers, were viewed as being very important in influencing attitudes for the better amongst parents (Aley, 2016, p. 16). Aley (2016, p. 18) found that contact in schools, especially where pupils with disabilities had done well and were positive role models, helped to improve attitudes towards disability.

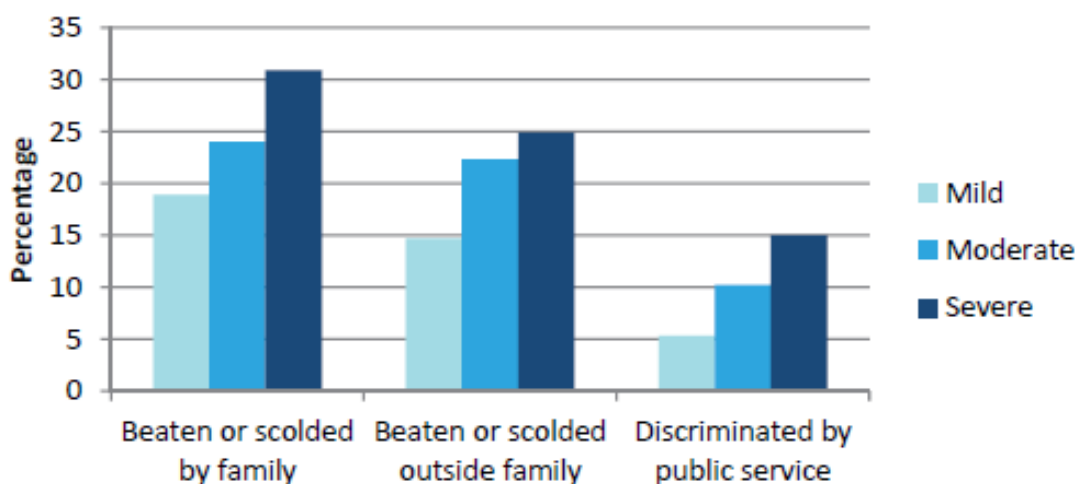
An e-intervention in Kenya and Nigeria in 2016, that involved showing over 1000 participants a 6-minute film designed to increase awareness of intellectual disability and its causes, and to challenge stigmatising beliefs commonly found in African countries, resulted in positive changes in attitudes, while there were no changes amongst participants who had watched the control film (Odukoya & Chenge, 2017). The films used a combination of education and indirect contact to provide factual information about intellectual disability and provide first-hand accounts of the lives of people with intellectual disabilities (Odukoya & Chenge, 2017). Data was collected at three time points (baseline, immediately post-intervention and at one month follow-up) using attitudinal questionnaires (measuring cognition, affect, and behavioural intentions) to measure the impact of the film on attitudes (Odukoya & Chenge, 2017).

The 2010 Constitution of Kenya prohibits direct and indirect discrimination on the grounds of disability (Sightsavers, 2018, p. 2; Kabare, 2018, p. 12). The Persons with Disabilities Act 2003 'prohibits discrimination by both public and private employers in all areas of employment including advertisement, recruitment, classification or abolition of posts; the determination of allocation of wages, salaries, pension, accommodation, leave or other benefits, the choice of persons for posts, training, advancement, apprenticeships, transfers and promotion or retirement' (KNCHR, 2016, p. 87). The Employment Act 2007 recognises disability and outlaw's discrimination on grounds of disability in employment in both the public and private sectors (KNCHR, 2016, p. 35). The Public Officers' Ethics Act 2003 prohibits discrimination of persons with disabilities in employment opportunities (Sightsavers, 2018, p. 9). Section 20 of the 2003 Persons with Disabilities Act mandates the NCPWD to monitor the provision of health care to persons with disabilities to prevent discrimination (KNCHR, 2016, p. 33).

## 5. Disability stigma in Nepal<sup>11</sup>

People with disabilities in Nepal experience stigma and prejudice and many are mistreated and marginalised (Holmes et al, 2018, p. 18; Prasai & Pant, 2018, p. 1, 9, 26; NIDA, NIDWAN & AIPP, 2018, p. 3, 19). The concept of disability is still deeply embedded within superstitions and stigma, making people reluctant to identify as disabled (Poudyal et al, 2018, p. 1, 6). People with disabilities 'face multiple and intersectional forms of discrimination on other grounds such as caste and ethnicity, in particular women and girls with intellectual or psychosocial disabilities, autistic persons, and persons from ethnic, Dalit, Madhesi and Muslim communities' (CRPD, 2018, p. 2). Persons with more severe disabilities experience higher levels of abuse and discrimination – see figure 2 (Eide et al, 2016, 119-120).

Figure 2: Abuse and discrimination by severity of disability



Source: Eide et al, 2016, p. 120 – with permission

A study in rural Nepal found that myths, folklore and misconceptions in culture, tradition and religion about disability are deeply rooted and often cited as the basis for individual beliefs and attitudes (Devkota et al, 2019, p. 1). These beliefs come from many traditions including

<sup>11</sup> Taken and adapted from: Rohwerder, B. (2019). *Nepal Situational Analysis*. Disability Inclusive Development.

Hinduism, Buddhism and Islam (Devkota et al, 2019, p. 10). The stereotypes in Nepal related to disability include 'lack, defect, sins of past deeds', as well as seeing disabled people as tragic figures (NIDA et al, 2018, p. 19; Devkota et al, 2019, p. 10). The belief that disability is a sign of sins in a past life can lead to families hiding family members with disabilities (Holmes et al, 2018, p. 14). Some parents believe that the disability of their child is due to fate and God's will (Inguanzo, 2017, p. 31). This has prevented families from accessing appropriate education or health care for their children because they were ashamed of their children or did not see the benefit of sending them to school (Inguanzo, 2017, p. 31). Derogatory nicknames and pejorative terms which imply they are socially unfit are sometimes still used to describe people with disabilities (Prasai & Pant, 2018, p. 9, 22; Raut, 2018, p. 143; CRPD, 2018, p. 3). Persons with disabilities are sometimes seen as a burden, which can lead to discrimination within the family as their needs are not prioritised (Devkota et al, 2019, p. 10). Stigma can occur both within the family and in wider society (Prasai & Pant, 2018, p. 27). Prasai & Pant (2018, p. 41) also report that people with disabilities can also face discrimination from other people with disabilities. Discrimination, rejection, exclusion and violence against women with disabilities inside and outside their homes was found to be due to insufficient public knowledge about disability leading to inaccurate blanket assumptions (Devkota et al, 2019, p. 1). Exclusion may be expressed through patronising attitudes and questioning by others of the ability of persons with disabilities to exercise their right to make key life decisions (Devkota et al, 2019, p. 10).

Experiences of stigma and discrimination in Nepal differ depending on where people live. In rural areas, children with disabilities and their caregivers reported that they felt more stigma or discrimination towards disability (Holmes et al, 2018, p. 7, 19-20). Fewer people with disabilities in rural areas meant that awareness of their needs was limited, while appropriate and/or adapted services and infrastructure were not available (Holmes et al, 2018, p. 19). Eide et al (2016, p. 11, 16) also found that levels of abuse against people with disabilities were higher in rural areas. Increased awareness and the opportunity for people with disabilities to mix more with their peers was associated with a feeling of less discrimination against them in urban areas, although it still existed (Holmes et al, 2018, p. 7, 19-20).

People with disabilities, especially children with disabilities, are significantly less involved in social life, meaning they are less likely to make and maintain friends, have intimate relationships, and be included in household life and decision-making (Holmes et al, 2018, p. 18, 19, 27). Children with disabilities and their caregivers also reported being picked on and made fun of by their non-disabled peers, extended family, and the wider community (Holmes et al, 2018, p. 19-20; Banks et al, 2019, p. 8). This meant that children who lived away from rural villages for school sometimes preferred to stay there rather than return during the school holidays (Holmes et al, 2018, p. 19). Meeting other children with disabilities helped them to feel better about themselves (Holmes et al, 2018, p. 19). 'Cultural beliefs and poor understanding of disability within the family lead parents to counterproductive behaviours such as overprotection and shame, and even hiding their child, particularly when they have intellectual or multiple unique needs' (USAID, 2017, p. 8). Family support is important for helping people with disabilities overcome stigma (Prasai & Pant, 2018, p. 26-27).

Caregivers reported feeling stressed and anxious about the children they were caring for (Holmes et al, 2018, p. 19). The mobility of children with disabilities is severely limited due to fears that they might get lost, be abused or injure themselves (Holmes et al, 2018, p. 26). Some caregivers of children with learning disabilities lock their children inside (Holmes et al, 2018, p. 26). Caregivers were especially concerned with the safety of girls with disabilities as they felt that they were more vulnerable to abuse and violence than boys (Holmes et al, 2018, p. 19, 21). Cases of sexual harassment and rape have been reported (Holmes et al, 2018, p. 21).

The care of children with disabilities can be a source of tension between spouses, especially in relation to who should care for the child and how should they be cared for (Holmes et al, 2018, p. 21). Husbands sometimes abandon their wives if they have a child with disabilities (Holmes et al, 2018, p. 22). There are reports of children with disabilities being abandoned and exposed to exploitation and abuse as a result (CRPD, 2018, p. 3). The government has some provisions in place for the care of abandoned children, including children with disabilities, and is supposed to establish orphanages and centres for them (Prasai & Pant, 2018, p. 11).

Bullying by fellow students and punishment from teachers for poor performance (corporal punishment is still widespread in schools), as well as negative attitudes about the capability of children with disabilities to learn, are important causes of school drop-out for children with disabilities (Holmes et al, 2018, p. 23; Eide et al, 2016, p. 38-39; Banks et al, 2019, p. 7-8). Levels of bullying by peers and teachers were reported to be higher for children with disabilities (Banks et al, 2019, p. 8). Children with intellectual disabilities and/or behavioural problems are especially affected by the low expectations of guardians and teachers, while children with communication impairments appeared to be particularly vulnerable to bullying (Banks et al, 2019, p. 7-8). People with disabilities may experience stigma and discrimination when it comes to finding employment, and there may be an assumption that they are unable to do anything (Prasai & Pant, 2018, p. 9-10). People with disabilities have experienced rejection from jobs as a result of stigma and discrimination (Prasai & Pant, 2018, p. 19-20; Eide et al, 2016, p. 42). Employers often doubt the capabilities of people with disabilities and refuse to employ them or give them a lower salary compared to others for the same job (Prasai & Pant, 2018, p. 19-20, 40). People with disabilities who managed to find a job reported that they were not respected and they experienced discrimination and harassment at work (Prasai & Pant, 2018, p. 21-22). Stigma means that there can be an assumption that people with disabilities don't need or shouldn't access sexual and reproductive health services (Raut, 2018, p. 144, 148-149; NAWHRD, 2018, p. 18; Devkota et al, 2018, p. 2, 9; ACNS et al, 2017, p. 5-6, 9).

## **Women with disabilities**

Women and girls with disabilities face discrimination both on the grounds of their gender and their disability status (NAWHRD, 2018, p. 18). Disabled women face stigma in relation to marriage and both their ability to get married and whether they should have children is often questioned (Raut, 2018, p. 147-148; Prasai & Pant, 2018, p. 29-30). A study carried out in 2016 by the Nepal Disabled Women Association (NDWA) found that 70% of women with disability were unmarried (NAWHRD, 2018, p. 18). A 2015 study in rural Nepal found 'negative societal attitudes with misconceptions about disability based on negative stereotyping and a prejudiced social environment', especially in relation to marriage and women with disabilities' ability to have and safely raise children (Devkota et al, 2019, p. 1). This also differed depending on the type of disability, with women with intellectual or mental disabilities often presumed to pose a greater risk to the child than women with other types of disability, or where in the country they lived (Devkota et al, 2019, p. 10-11). Some families arranged marriages for daughters with disabilities with whoever accepted them because of the low expectations they had for them (Ando, 2017, p. 2). However, this did not prevent some women with disabilities arranging their own marriages or having children, often in the face of considerable opposition (Devkota et al, 2019, p. 11).

There are reports of a high number of cases of sexual violence and abuse of women and girls with disabilities (CRPD, 2018, p. 2; ACNS et al, 2017, p. 2; Banks et al, 2019, p. 8). Violence and abuse against women with disabilities from both within their family and wider society is often hidden, and 'remains as a result of deep rooted stigma and shame connected to both sexuality



and disability' (NAWHRD, 2018, p. 18; Poudyal et al, 2018, p. 23). Women with disabilities felt that a primary reason for the violence is the dependency they have on the perpetrators of the violence, since most of them are husbands, carers or teachers (ACNS et al, 2017, p. 2). There can be a fear that if they report it, they will be abandoned by their family and community (NIDA, NIDWAN & AIPP, 2018, p. 21). Women with intellectual or psychosocial disabilities from indigenous, Dalit, Madhesi, Muslim and other minorities are reported to have higher prevalence of exploitation and physical, emotional, sexual violence and abuse (NIDA, NIDWAN & AIPP, 2018, p. 16). Women with disabilities also have limited access to justice mechanisms (ACNS et al, 2017, p. 2).

It should be noted however that men with disabilities also experience abuse and were found by a survey in 2014-15<sup>12</sup> to face greater discrimination by public services than women with disabilities (11.8% compared to 7.8%) (Eide et al, 2016, p. 14).

### **Indigenous people with disabilities**

Indigenous people with disabilities are a marginalised population within already marginalised populations as a result of the discrimination they face as a result of being both indigenous and a person with disabilities (NIDA et al, 2018, p. 4). The prejudices and stereotypes associated with indigenous peoples include that they are 'backward, quarrelsome, drunkards, uneducated', which combined with the prejudices and stereotypes about disabled people make it very challenging for indigenous persons with disabilities to counter both (NIDA et al, 2018, p. 19). They are mostly uneducated, unaware about their rights, and have poorer access to public facilities than other people with disabilities (NIDA et al, 2018, p. 4). Indigenous women with disabilities face more marginalisation and discrimination than other people with disabilities because of gender, disability, race, poverty, geographical remoteness (NIDA et al, 2018, p. 9).

### **Tackling disability stigma**

However, negative attitudes to disability are gradually changing and many communities have a mix of attitudes, as a result of 'membership in different ethnic/ minority groups, personal familiarity with disability, education and individual beliefs and temperament' (Devkota et al, 2019, p. 11). The government has also made some budget allocations which include awareness programmes on disability for government officials, health professionals, politicians, and community level officials and some progress has been made in disability awareness, although much more could be done (NIDA, NIDWAN & AIPP, 2018, p. 19-20). The Committee on the Rights of Persons with Disabilities notes that 'current awareness-raising measures are inadequate, given that not even persons with disabilities and their families, let alone the general public and the relevant professionals, are aware of the issues concerning the rights of persons with disabilities' (CRPD, 2018, p. 3).

Article 18 of the Constitution also 'upholds every citizen's right to equality, protects them from any discrimination in application of general laws and otherwise based on gender and/or disability' (ACNS et al, 2017, p. 1). However, most mention is made of people with physical impairments,

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<sup>12</sup> Carried out in 59 districts with representation of all the five development regions of Nepal – eastern, central, western, mid-western and far-western regions. A total of 4000 sampled households (2000 households having persons with disabilities and 2000 households not having persons with disabilities) were included, and 4123 respondents (2123 people with disabilities and 2000 non-persons with disabilities) were interviewed from these households. Used the Washington Group questions to identify persons with disabilities.

rather than persons with disabilities more generally. The 2017 **Rights of Persons with Disabilities Act** also prohibits discrimination<sup>13</sup> and violence based on disability (Holmes et al, 2018, p. 15; Prasai & Pant, 2018, p. 50, 52, 54-56).

## 6. Disability stigma in Nigeria<sup>14</sup>

Within Nigerian society, the common perception is that disability issues are viewed in terms of charity and welfare. This entrenched view has a negative impact on the social inclusion of people with disabilities within the country (Lang & Upah 2008). Persons with disabilities are often regarded as people to be pitied rather than as people who can contribute to the development of Nigeria. They face stigma and discrimination. They lack access to education, rehabilitation and employment. They are not adequately protected by legislation. Even when they have been educated or rehabilitated and meet the necessary requirements for employment, they are often denied employment on the basis of their disability. Consequently, many people with disabilities resort to depending on their family or charities for assistance to sustain themselves as they have no source of income for their livelihood (Ofuani 2011).

Etieyibo & Omiegbe (2016) argue that there a paucity of evidence from Nigeria that focuses on disability and the role that religion, culture and beliefs play in sustaining discriminatory practices against persons with disabilities. Many exclusionary practices are either embedded in or sustained by religion, culture and beliefs about disability. False beliefs about the causes of disability include that is due to ancestral violations of societal norms, it is due to breaking laws and family sins or adultery; it is a curse from God; and it was caused by witches and wizards (DSPD, 2016, p. 5). However, disability is sometimes thought to be due to simple misfortune (DSPD, 2016, p. 5). Traditional negative beliefs about leprosy in Nigeria include that 'leprosy is caused by supernatural forces or as a result of a witchcraft curse pre-empted by the breaking of some form of social taboo (for instance, having sex with a menstruating female)' (Mostert, 2016, p. 14). Mostert (2016, p. 14) finds evidence that the stigma attached to leprosy 'is higher among Nigerian Christians who generally perceive leprosy as a punishment for sin, and lower among Muslims who accept leprosy as being part of God's will'. Negative perceptions about children with disabilities in Nigeria were found to be related to a curse from God (due to gross disobedience to God's commandments); ancestral violation of societal norms (e.g., due to stealing); offenses against gods of the land (e.g., fighting within the society); breaking laws and family sins (e.g., stealing and denying); misfortune (e.g., due to marriage incest); witches and wizards (e.g., society saw them as witches and wizards); adultery (a major abomination); a warning from the gods of the land (due to pollution of water and the land); arguing and fighting with the elders (a societal taboo); misdeed in a previous life (such as stealing); illegal or unapproved marriage by the societal elders (arguing and fighting against the elderly advice in marriage); possession by evil spirits (due to gross societal disobedience); and many others (Eskay et al 2012).

Persons with disabilities are the victims of various discriminatory actions including the trafficking and killing of people with mental illness, oculocutaneous albinism and angular kyphosis; the rape

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<sup>13</sup> However NIDA, NIDWAN & AIPP (2018, p. 11) feel that because people with disabilities from underrepresented marginalised groups were not effectively consulted during the drafting of the disability Act, issues considering multiple and aggravated forms of discrimination were not included.

<sup>14</sup> Taken and adapted from: Thompson, S. (2019). *Nigeria Situational Analysis*. Disability Inclusive Development.

of women with mental illness; and the employment of children with disabilities for alms-begging. Etieyibo & Omiegbe (2016) argue that the Nigerian government needs to introduce legislation that targets cultural and religious practices which are discriminatory against persons with disabilities as well as protecting the interests of persons with disabilities. The Discrimination Against Persons with Disabilities (Prohibition) Act (2018) does make discrimination of persons with disabilities illegal, but it is not yet clear how this law will be enforced and how effective it will be.

Eleweke and Ebenso (2016) found attitudinal barriers existed when individuals with disabilities were applying for admission into schools. Such negative attitudes could be due to misunderstanding of the nature and needs of people with disabilities or due to blatant discrimination. The latter seemed to be the case for those with stigmatised conditions such as leprosy. The attitude of teachers and school administrators was a concern raised by the participants. Persons with disability are especially vulnerable to discrimination and disadvantage in employment in Nigeria, experiencing unequal employment opportunities, limited rights to work and low job security. Most employers are reported to be uncomfortable employing persons with disabilities due to the conviction that they will be unable to perform their roles and/or that it would be too expensive due to fear and stereotyping (Ofuani 2011). Many employers are concerned about productivity and influenced by negative stereotyping (Ofuani 2011). Eleweke and Ebenso (2016) also found that even educated people with disabilities may struggle to secure a job in Nigeria due to people's negative attitudes toward those with disabilities. There were accounts of people with disabilities stereotyped into certain jobs. For instance, large corporations tend to put blind people in call centres regardless of their education and training. People with disabilities were sometimes reported to be employed as token gestures. Some women with disabilities were reported to have been given jobs because of quotas. Eleweke and Ebenso's (2016) study reported that the participants were unanimous that women with disabilities encounter more obstacles than men with disabilities, which could be attributed to gender inequalities in Nigeria.

Drawing on a number of sources, Eskay et al (2012) found that in Nigerian society, children with disabilities have been incorrectly understood, and this misunderstanding has led to their negative perception and treatment. Overcoming negative attitudes and misunderstandings about disability were the basic problems affecting children with disabilities. Public education programmes and information dissemination were undertaken to try and address this challenge. There are several beliefs resulting in the negative attitudes revolving around children with disabilities in Nigeria. These beliefs cut across the Nigerian society and hence have a similar impact on the citizens' attitudes on learners with disabilities

## **Tackling disability stigma**

Some efforts have been made to tackle disability stigma in Nigeria. As mentioned above, an e-intervention in Kenya and Nigeria in 2016, that involved showing over 1000 participants a 6-minute film designed to increase awareness of intellectual disability and its causes, and to challenge stigmatising beliefs commonly found in African countries, resulted in positive changes in attitudes, while there were no changes amongst participants who had watched the control film (Odukoya & Chenge, 2017). The films used a combination of education and indirect contact to provide factual information about intellectual disability and provide first-hand accounts of the lives of people with intellectual disabilities (Odukoya & Chenge, 2017). Data was collected at three time points (baseline, immediately post-intervention and at one month follow-up) using attitudinal questionnaires (measuring cognition, affect, and behavioural intentions) to measure the impact of the film on attitudes (Odukoya & Chenge, 2017).

In January 2019, the Discrimination Against Persons with Disabilities (Prohibition) Act (2018) was signed into law (Ewang 2019).

## 7. Disability stigma in Tanzania<sup>15</sup>

Disability and the abilities and rights of people with disabilities are not well understood in Tanzania (African Initiatives, 2018, p. 7, 24). It is still 'common to find negative community attitudes towards disability, with children being hidden from the community, not placed into schools and perceived as a burden' (African Initiatives, 2018, p. 6, 30; Mrisho et al, 2016, p. 18, 53; Kuper et al, 2016, p. 451). Disability is regarded as a misfortune (African Initiatives, 2018, p. 23). In parts of Tanzania, communities and family members sometimes think the child with disabilities is cursed (Joel et al, 2018; African Initiatives, 2018, p. 23). In some cases, children with disabilities are overprotected by their parents (African Initiatives, 2018, p. 30). There are low expectations of the abilities of people with disabilities (African Initiatives, 2018, p. 24; Mrisho et al, 2016, p. 18). Some families of persons with disabilities in Zanzibar try and hide them and keep information about them a secret (LHRC & ZLSC, 2018, p. 346). Mothers are often blamed when children are born with disabilities (African Initiatives, 2018, p. 5, 24). Research in Kilimanjaro and elsewhere found that having a child with disabilities can weaken family relationships and even lead to fathers abandoning the mother and child with disabilities (Joel et al, 2018; African Initiatives, 2018, p. 24; Mrisho et al, 2016, p. 16). It hard and costly for families to obtain clear information about their family member's disability, and how best to assist and empower them (African Initiatives, 2018, p. 6). Community based parent support groups can help address the isolation and shame some mothers' experience (African Initiatives, 2018, p. 8).

Albinism is often seen as a curse on the family (Mostert, 2016, p. 12; Franklin et al, 2018, p. 4). The characteristics of albinism are believed to be caused by the mother having had an affair with a white person or spirits, having shaken hands with a person with albinism, or having shared a meal with someone with albinism, among others (Mostert, 2016, p. 12; Franklin et al, 2018, p. 4). Other misperceptions hold that persons with albinism are not human, but rather ghosts and they are often regarded as witches or as 'omens of disaster' (Mostert, 2016, p. 12; Franklin et al, 2018, p. 4). They are also often regarded as lazy due to their avoidance of sun to protect their vulnerable skins and the health issues they face may be seen to be a result of a curse (Mostert, 2016, p. 12; Franklin et al, 2016, p. 4).

One recent study found that pejorative terminology about persons with disabilities was being used by officials at the district level (African Initiatives, 2018, p. 23). Negative attitudes from the community can also make it harder for people with disabilities to get married, as people without disabilities are discouraged from marrying them, but positive marital experiences exist (Mrisho et al, 2016, p. 51, 57). On the other hand, young disabled women are sometimes forced into marriage, which often leads to domestic violence (ADD International, 2017, p. 5). A study of people with albinism found that that their partners, if they had one, had problems with their disability and even divorced them because of it (Franklin et al, 2018, p. 5).

In Tanzania there is a belief that families can gain wealth in exchange for the intellect or health of one of their children. This can result in assumptions that a family with a disabled child, particularly a child who is intellectually disabled, is greedy and ruthless, having used witchcraft to

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<sup>15</sup> Taken and adapted from: Rohwerder, B. (2019). Tanzania Situational Analysis. Disability Inclusive Development.

trade their child's intellect for prosperity (Groce & McGeown, 2013, p. 13). Wealthier families appeared to be particularly anxious to hide their children with disabilities as a result (Groce & McGeown, 2013, p. 13-14).

Poor attitudes and discrimination by teachers and peers are one of the barriers children with disabilities can face in attending school (Mrisho et al, 2016, p. 11, 38). Stigma also remains a significant barrier to accessing employment or livelihoods (African Initiatives, 2018, p. 20). This includes cases where people with disabilities have been held back from getting involved in agricultural activities due to concern from their parents about criticism from neighbours (African Initiatives, 2018, p. 20). Discrimination is a major problem for people with disabilities in accessing employment opportunities and workplaces, including agriculture in rural areas (LHRC & ZLSC, 2018, p. 66, 346; African Initiatives, 2018, p. 20; FCS, 2017, p. 62). Women with disabilities face negative attitudes and are 'regarded as people who cannot contribute to anything, dependents and always waiting to be helped', yet are not supported to develop their skills (African Initiatives, 2018, p. 31). Many resort to begging which serves to reinforce the stigma faced by persons with disabilities in Tanzania (FCS, 2017, p. 63). African Initiatives (2018, p. 4) found figures suggesting that the 'exclusion of persons with disabilities from the workplace, either through discrimination or inaccessible work environments, costs Tanzania \$480 million every year - 3.76% of the country's GDP'. Persons with disabilities were found to have limited access to health services as a result of factors including stigma and discrimination (TEPDGHO, 2018, p. 2, 7, 8, 13). About 66% of women with disabilities in a 2018 study reported different forms of verbal abuse or discriminatory practices when attending maternal services (TEPDGHO, 2018, p. 12).

The Human Rights Situation Report for January – June 2018 finds that violence and discrimination against people with disabilities continue to be major challenges, hindering them from fully realising their rights (LHRC & ZLSC, 2018, p. 51). Domestically and within communities, people with disabilities are subject to discrimination and psychological violence (LHRC & ZLSC, 2018, p. 155). People with disabilities are reported to be more vulnerable to violence generally, especially physical and sexual violence, which starts at an early age and continues in one form or another throughout their lives (LHRC & ZLSC, 2018, p. 155, 345; FCS, 2017, p. vi; Mrisho et al, 2016, p. 17; ADD International, 2017, p. 6). Women with disabilities are reported to be sexually exploited, threatened, mistreated, or abandoned, including by their families (Mrisho et al, 2016, p. 17, 52; ADD International, 2017, p. 4, 6). Women and girls with intellectual disabilities are especially vulnerable, with one study finding that 'nine out of ten girls and women with intellectual disabilities were sexually abused, often frequently, without intervention from family or community' (ADD International, 2017, p. 6). Participatory peer research found that 'most violence starts at home and is then carried out into the community', especially if girls with disabilities are seen as a burden and thus treated badly, e.g. calling her names, refusing her food, beating her (ADD International, 2017, p. 4). The research found high levels of abuse from step-mothers, step-siblings, mothers- and sisters-in-law, which may be due to women seeking to assert 'some level of power over perceived weaker family members, especially girls and women with disabilities, to balance against their unequal status compared to men' (ADD International, 2017, p. 5). The violence experienced by women with disabilities was found to be 'predominantly based on gender inequality and severely exacerbated by discriminatory attitudes towards disability' (ADD International, 2017, p. 3). Harmful superstitions, such as the belief that having sex with a person with disability will make you wealthy exist (African Initiatives, 2018, p. 23). Violence against persons with disabilities has extended to the use of excessive force by police against people with disabilities who were peacefully demonstrating in Dar es Salaam's city centre in June 2017 (LHRC & ZLSC, 2018, p. 155).

People with albinism are one of the most vulnerable groups among people with disabilities and continue to live in fear of attacks and killings for their body parts, which are believed to make people rich or give them luck; although no killings were reported in 2017 and the first part of 2018 (LHRC & ZLSC, 2018, p. 51, 155; African Initiatives, 2018, p. 6, 23; Mrisho et al, 2016, p. 15, 47-49; HRW, 2019, p. 9-10). Franklin et al (2018, p. 4) highlight arguments which indicate that it is too simplistic to blame traditional superstitions for the killings of people with albinism, with strong arguments that it is poverty which drives violence towards people with albinism. In some cases, fathers or male relatives have been reported to have killed their children hoping to get rich by selling their body parts (Groce & McGeown, 2013, p. 12). The government set up 'temporary holding shelters', special boarding schools which were supposed to protect and educate children with albinism (HRW, 2019, p. 6). This led to regular schools not accepting children with disabilities and 'had a negative impact on their rights to family life, an adequate standard of living and inclusive education' (HRW, 2019, p. 6). Living in fear of attack has left a psychological impact on those targeted (Mrisho et al, 2016, p. 54). People with albinism interviewed by Human Rights Watch in 2017 experienced stigma and bias in their community, including name calling (HRW, 2019, p. 14). Some have been rejected or even attacked by their own families (HRW, 2019, p. 14). The Tanzania Albino Society, the government and the media have run community sensitisation programmes which have helped to change false and harmful attitudes towards people with albinism, although progress is fragile, especially in rural areas (African Initiatives, 2018, p. 7, 34; HRW, 2019, p. 16). Children with autism are also especially vulnerable as they are believed to be cursed as they look like other children but behave differently, and their treatment means they often die young (African Initiatives, 2018, p. 23). Infanticide has been reported of children with complex disabilities amongst the Maasi (African Initiatives, 2018, p. 23).

## **Tackling disability stigma**

FCS (2017, p. 33) note that it seemed that the prevalence of harmful customs and practices against people with disabilities was decreasing. Focus group discussions it conducted in rural and urban settings mentioned that media awareness, religious teachings, and the work of civil society organisations have contributed to a change in perceptions (FCS, 2017, p. 34). FCS (2017, p. 35) suggests that the positive change of attitudes towards persons with disabilities is due to religious and moral ethics rather than legal standards as the majority of community members, including individual persons with disabilities, some DPOs leaders, local government authority officials, and judicial officers (magistrates and registrar of the high court) were not aware of the existence or contents of the disability laws, especially on part of Tanzania Mainland.

A participatory research project conducted in 2016 found that, despite the negative attitudes persons with disabilities faced, there were examples of self-empowerment and help seeking behaviour among disabled people, showing a strong sense of their own value (Mrisho et al, 2016, p. 57). In addition, they found that the extended family system was more beneficial in supporting persons with disabilities than the nuclear family (Mrisho et al, 2016, p. 58).

The government launched a task force to investigate killings of people with albinism, launched education campaigns, appointed people with albinism to parliament, banned all traditional healers and witchdoctors from practising their trade, made the killing of persons with albinism a capital crime, and worked with police and communities to try and end abuses against people with albinism (DSPD, 2016, p. 12; Mostert, 2016, p. 13; Groce & McGeown, 2013, p. 18).

The **1977 Constitution** prohibits discrimination against people with disabilities, as does the 2010 Persons with Disabilities Act.

## 8. Interventions to reduce disability stigma<sup>16</sup>

False perceptions and beliefs about disability are often difficult to overcome, but they can change and evolve over time, especially when interventions aimed at addressing disability stigma are implemented (DSPD, 2016, p. 5; Groce & McGeown, 2013, p. 8). Interventions aimed at addressing disability stigma in developing countries have been aimed at the intrapersonal and familial level; the interpersonal level; and the structural level. Approaches to stigma reduction can involve contact, protest and education (Stuart et al, 2012, p. 17; NASEM, 2016). However, it should be noted that very few efforts at raising awareness and combatting stigma have been formally evaluated and evidence to support stigma interventions has been found to be sparse and weak (Scior et al, 2015, p. 6; Cross et al, 2011b, p. 63). Multipronged efforts, coordinated across all levels, are likely to be more powerful (Stuart et al, 2012, p. 126; Cross et al, 2011b, p. 68). Tackling disability stigma is also challenging because reactions to it are compounded by other social attitudes (to women, ethnic and religious minorities) and by poverty, which needs to be taken into account (McConkey et al, 2016, p. 180). Approaches also need to be tailored to the variations in understanding and perceptions of disability that exist within and across countries, and to take advantage of local opportunities as they arise (McConkey et al, 2016, p. 180; Stuart et al, 2012, p. 42). One size does not fit all and anti-stigma efforts must also be locally grounded and carefully targeted to build on religious, moral, and social frameworks of the local context (Stuart et al, 2012, p. 126).

Scior et al (2015, p. 6) found that while there was a lot of work aimed at raising awareness about disability generally, 'many of these appeared to be based on the implicit assumption that raising awareness would result in more positive attitudes and a reduction in discriminatory behaviour', rather than actively aimed at changing behaviour. McConkey et al (2016, p. 180) suggest that the biggest challenge in tackling stigma may be in getting beyond changing attitudes to changing behaviour (see also Stuart et al, 2012, p. 17). Efforts to address stigma need to use a combination of methods that address its different component parts: problems of knowledge (ignorance), problems of attitude (prejudice), and problems of behaviour (discrimination) (Cross et al, 2011, p. 73). Stuart et al (2012, p. 128) go beyond this to argue that the need is also to target the social structures, and the power relationships that erect barriers to stigmatised groups full and effective social participation.

### Interventions at the intrapersonal level

'Interventions at the intrapersonal level focus on the persons affected by stigma, and aim to help them overcome the negative consequences of stigmatisation, such as self-stigma' (Werner & Scior, 2016, p. 130). Interventions at the intrapersonal level include self-help, advocacy and support groups, which have generally been found to be effective to some extent (Mostert, 2016, p. 18; Bond DDG, 2017, p. 3, 5). The empowerment of people with disabilities is especially important for overcoming internalised stigma and stigma more generally (DSPD, 2016, p. 8; Stuart et al, 2012, p. 8). Leaders or self-advocates with disabilities 'can, through their work and participation, serve as role models of inclusion, helping other persons with disabilities to overcome internalised stigma and changing negative perceptions that may exist within communities' (DSPD, 2016, p. 8). Thus, stigma reduction efforts could include teaching self-advocacy skills to people with disabilities; providing medical and psychosocial counselling to

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<sup>16</sup> Expanded and adapted from: Rohwerder, B. (2018). *Disability stigma in developing countries*. K4D Helpdesk Report 312. Brighton, UK: Institute of Development Studies.



people with disabilities to increase their self-help and self-advocacy skills; and conducting emancipatory and participatory research, whereby people with disabilities have more prominent roles in the research process (Mostert, 2016, p. 21).

## **Meaningful roles**

As in many cultures one's human status is judged by the extent to which people can participate in valued activities within that society, the participation of people with (intellectual) disabilities in family and community life is important in challenging negative attitudes (McConkey et al, 2016, p. 190). Mostert (2016, p. 23) also suggests that the status of people with disabilities could be improved through efforts at socio-economic rehabilitation which empowers people with disabilities to engage in economic activities that enhances their lives and allows them to provide for themselves and even for others (Mostert, 2016, p. 23). In rural agrarian societies there are many livelihood activities someone with mild to moderate intellectual disabilities could participate in if prepared, for example (McConkey et al, 2016, p. 190). Skills training for people with disabilities is reported to help combat self-stigma and by demonstrating the skills of people with disabilities it can also address negative societal attitudes in the wider community by showing that people with disabilities can sustain themselves and earn money (Bond DDG, 2017, p. 6). Having other meaningful roles, such as being a mother, or a member of a club can also 'help to act as a buffer against the emotional consequences of stigma' (Sheehan & Ali, 2016, p. 104).

## **Interpersonal interventions**

Interpersonal interventions target social interactions between stigmatised and non-stigmatised individuals, and generally involve education (aiming to challenge inaccurate stereotypes by providing factual information) or contact (encouraging positive interactions between the public and persons with disabilities) (Werner & Scior, 2016, p. 132; Mostert, 2016, p. 18). Education interventions were found to have had mixed efficacy, while contact has shown promise as a stigma reduction strategy, especially if it starts at an early age (Mostert, 2016, p. 18; Werner & Scior, 2016, p. 134, 142; McConkey et al, 2016, p. 190). Evidence suggests that it might be most useful to combine contact-based approaches with education (Werner & Scior, 2016, p. 136; Cross et al, 2011b, p. 64; NASEM, 2016, p. 74).

## **Role of families**

Parents and families have been central in improving perceptions of persons with (intellectual) disabilities and in the fight against negative attitudes and discrimination (Werner & Scior, 2016, p. 132). The experiences children with disabilities have within their families can help to 'build the resilience of the child to bolster their identity in the face of stigma' (McConkey et al, 2016, p. 181). However, few reports examine the effects of family-based approaches to tackling stigma (Werner & Scior, 2016, p. 132).

Ways in which families of children with disabilities can tackle stigma include actively nurturing their child's development; including them in the community; spreading information to counter myths and superstitions about disability; and advocating on their behalf (McConkey et al, 2016, p. 185-187). Acceptance within communities depends on the relationships people forge with their peers which is built up through participation in schooling, sports and religious activities, which parents can enable their children's participation in (McConkey et al, 2016, p. 190). Myths and superstitions persist because they go unchallenged which is why many parents' associations place such an emphasis on giving parents information about disabilities so that they in turn can

pass this information onto others, especially in relation to their own child (McConkey, 2016, p. 187).

McConkey et al (2016, p. 186-187, 191) warn that sustaining these actions in the face of rejection and intransigence requires a vast amount of physical and emotional energy from parents and they need allies to maintain their resilience. In Africa, mothers frequently draw on their faith in God to provide them with resolve and resilience, while meeting other parents of children with disabilities also provides much needed emotional support along with informational and practical support (McConkey et al, 2016, p. 186). Families efforts need to be 'reinforced by legal rights, national policies that are enforced and changes in discriminatory practices of professionals and services to name but a few' and families should not be blamed for the stigma their relative experiences (McConkey et al, 2016, p. 190-191).

Parent and friends' associations can be an important strategy for addressing stigma in developing countries (McConkey et al, 2016, p. 188-190). International experience has shown the value of parent associations in changing perceptions within families and communities and providing information to counter ignorance and misrepresentation, as well as providing emotional and practical support (McConkey et al, 2016, p. 188; see also Aley, 2016, p. 18). Associations can be grown with support from sympathetic professionals such as community-based rehabilitation workers and national parent associations (McConkey et al, 2016, p. 188). However, they are not without their difficulties and shortcomings – rural families may struggle to have the time to access them, and professionals have an important role to play in identifying the support that families need, making use of available community resources rather than expensive programmes (McConkey et al, 2016, p. 188-189).

## **Education**

Educational anti-stigma interventions aim to correct misinformation or contradict negative attitudes and beliefs by presenting factual information about the stigmatised condition (NASEM, 2016, p. 69; Werner & Scior, 2016, p. 132). Generally, they are aimed at combating public stigma, however educational interventions have also been found to be helpful in reducing self-stigma when delivered as part of cognitive and behavioural therapy (NASEM, 2016, p. 70). NASEM's (2016, p. 70-71) review of anti-stigma interventions, notes that 'evidence is mixed on the effectiveness of educational interventions in changing public stigma in a significant and lasting way', especially in relation to changes in behaviour.

'Stigma-reduction educational programmes must be carefully matched to the unique culture, community, and mind-set of the population to which it is applied' (Mostert, 2016, p. 20). It has not been enough to simply educate people about the true medical causes of impairments to reduce stigma without taking into account the local social and normative nuances, as stigma is not just a result of ignorance (Mostert, 2016, p. 20; Cross et al, 2011b, p. 65). Sometimes, medically accurate information can have unintended and stigmatising consequences, as has been the case with some mental illness stigma interventions which ended up 'unintentionally drawing attention to the "differentness" of mentally ill people and diverting attention from the possibility of recovery' (NASEM, 2016, p. 71).

DSPD (2016, p. 9) suggests that inclusive and accessible human rights education in schools, which addresses specific harmful beliefs about disability in that culture, can be an important tool for combating stigma and discrimination against people with disabilities.

Werner and Scior (2016, p. 132) question the extent to which efforts to promote inclusion and more positive attitudes through educating through social media and disability organisations' programmes reach audiences who are not already positively inclined towards people with (intellectual) disabilities. Furthermore, their impact on attitude change has rarely been empirically studied.

Other educational interventions that have been more frequently evaluated have attempted to challenge misconceptions and increase knowledge and awareness through brief online films, university based lecture programmes, educational vignettes; aimed especially at students and service provider staff (Werner & Scior, 2016, p. 133). Studies in developing countries have found that while these educational interventions have been useful in increasing knowledge, their impact on (intellectual) disability stigma is frequently short-lived and of limited magnitude (Werner & Scior, 2016, p. 134).

Celebrations of people with disabilities and their contributions to society at the national or local level, for example the International Day of Persons with Disabilities or other relevant days of celebration, such as the International Day of the African Child and the Day for International Albinism Awareness, can also be used to overcome false beliefs (DSPD, 2016, p. 9). It is important however that 'such initiatives serve to counter stereotypes and not create new ones (for example, they should not be used to invoke pity or purely to inspire persons without disabilities)' (DSPD, 2016, p. 9).

## **Contact**

Often people with stigmatised conditions have little meaningful contact with those without these conditions and this lack of contact fosters discomfort, distrust and fear (NASEM, 2016, p. 73). Contact interventions aim to overcome this divide and facilitate positive interaction and connection (NASEM, 2016, p. 73). Researchers have advocated for 'interpersonal contact with members of stigmatised groups as the most effective stigma reduction strategy', especially if it starts at an early age (Werner & Scior, 2016, p. 134, 142; McConkey et al, 2016, p. 190; McConkey, 2018, p. 6; Parnes et al, 2013, p. 30). Contact based interventions are aimed at reducing public stigma but 'have been shown to benefit self-stigma by creating a sense of empowerment and boosting self-esteem' (NASEM, 2016, p. 73).

Contact can be in person or indirectly (e.g. through films or internet) (Werner & Scior, 2016, p. 142; NASEM, 2016, p. 73). Evidence from other fields suggest that exposing people to a variety of individuals who strongly disconfirm stereotypes is likely to be most effective way to challenge stereotypes (Werner & Scior, 2016, p. 142). Involving people with (intellectual) disabilities in delivering attitude change interventions is likely to lead to more positive outcomes (Werner & Scior, 2016, p. 143). 'Contact-based interventions need to be carefully planned to minimise the risk of unintended, adverse consequences' from a negative experience (Werner & Scior, 2016, p. 142).

## **Community level interventions**

At the community level, interventions aim to increase knowledge about impairments and address stigma within specific communities (Mostert, 2016, p. 18). Mostert (2016, p. 18) finds that the literature on community-based rehabilitation, which uses community development to rehabilitate and equalise opportunities for the social integration of people with disabilities, provides 'only vague indications that community-based rehabilitation (CRB) engenders positive outcomes for

people with disabilities'. Reports by NGOs find that CRB efforts in Togo which included communication and educational tools to raise disability awareness, such as training manuals, posters, documentary films and T-shirts, resulted in parents who had previously denied having a child with disabilities acknowledging their child publicly. These efforts also resulted in cases of abuse and discrimination against children with disabilities becoming less common in these targeted communities (Bond DDG, 2017, p. 6; Parnes et al, 2013, p. 33).

Some disabled people's organisations (DPOs) have found that by working within communities they were able to transform negative attitudes and harmful practices in those communities into more positive perceptions (DSPD, 2016, p. 5). For example, a study conducted by the African Child Policy Forum in Ethiopia found that the presence of active DPOs or disability-inclusive NGOs at community level resulted in major positive differences in attitudes towards children with disabilities (DSPD, 2016, p. 9).

Other strategies especially suited to developing countries identified by McConkey et al (2016, p. 188-190) include:

- *Village gatherings*: parents associations and other advocacy groups have made use of village or community gatherings to communicate their messages on intellectual disabilities in a way that harmonises with local cultural values and activities (McConkey et al, 2016, p. 189). They use drama, songs, and speeches from invited dignitaries tailored to their particular culture with the aim of nurturing a pride in disability in families and in local communities (McConkey et al, 2016, p. 189).
- *Support from community leaders*: opinion leaders within communities (such as village chiefs and elders, traditional healers and religious leaders, elected politicians and officials) are key allies for disabled people and their families wishing to bring about change (McConkey et al, 2016, p.189). Building personal relationships seems an effective means of gaining their support, and engaging with leaders who have a relative with a disability can be especially fruitful (McConkey et al, 2016, p. 189). Support from community leaders can be crucial when it comes to removing discriminatory practices (such as school exclusions or charges levied by taxis for transporting people in wheelchairs) (McConkey et al, 2016, p. 189-190).

It is important to note that, although the role of traditional and religious leaders in combatting stigma is important as many families turn to them, they often lack knowledge of the causes of disability and fall back on supernatural explanations (McConkey et al, 2016, p. 190; Mostert, 2016, p. 23). In this case they may actually perpetuate damaging myths, stereotypes and fear of disability, and effort needs to be made to reduce the influence of those who do so (Mostert, 2016, p. 24). If traditional and religious leaders accepted other explanations about the causes and nature of disability, they could instead contribute positively to reducing stigma instead of reinforcing it (McConkey et al, 2016, p. 190).

## **Interventions at the government/institutional level**

'Interventions at the structural level focus on social forces and institutions through legislative action, mass media, governmental and organisational policies that aim to reach a large audience, and service delivery' (Werner & Scior, 2016, p. 138). Interventions at the institutional or organisational level may target individuals in organisations and institutions that have particular relevance to stigmatised people, such as teachers, employers or health-care providers (Cross et al, 2011b, p. 68).

## Legislation and policy

Laws and policy have an important role to play in helping to avoid or remedy harmful cultural beliefs or practices and prevent discrimination against people with disabilities. Under article 8 of the UN Convention on the Rights of Persons with Disabilities, state parties are specifically required to 'undertake awareness-raising activities that address stereotypes, prejudices and harmful practices relating to persons with disabilities' (DSPD, 2016, p. 4, 12). Governments can also seek to directly address harmful practices through national policies or programmes (DSPD, 2016, p. 12).

It is also important to integrate 'disability awareness and disability services into all public institutions (for instance, schools, government departments, the public health sector, and so forth) and services for people' (Mostert, 2016, p. 21).

However, Mostert (2016, p. 20) argues that it is difficult to implement the UNCRPD if disability stigma in society is not also addressed. As a result, it is important for the government to work closely with national and regional disability organisations and NGOs and international organisations working on the frontlines in confronting stigma (Mostert, 2016, p. 20; Scior et al, 2015, p. 104). Mostert (2016, p. 20) was unable to find literature addressing the efficacy of interventions in the legal and policy arenas aimed at reducing discrimination against and enforcing the rights of people with disabilities (see also Werner & Scior, 2016, p. 139).

## Media

Mass media campaigns aimed at tackling disability stigma in Western countries have been found to result in small to medium reductions in stigma, especially when they were provided in several mediums (Werner & Scior, 2016, p. 137). However, media campaigns tend to be blunt instruments, as they cannot be targeted to meet local conditions and they are confined to broad generic messages, for instance (Stuart et al, 2012, p. 128). Stuart et al's (2012, p. 165) research on the lessons learned from fighting mental health stigma suggests that the media can be more useful in efforts to communicate the nature of anti-stigma programmes and ensuring that programme materials reach a wide audience, than in changing attitudes and behaviours of populations.

In general, it is important to have positive reporting criteria around disability as without it the media can serve to cause disability stigma through negatively biased and sensational reports about persons with disabilities (Werner & Scior, 2016, p. 141; Mostert, 2016, p. 21). Encouraging and using non-discriminatory and more positive and accurate language in the media is also important for stigma reduction (Mostert, 2016, p. 21).

McConkey et al (2016, p. 189) identified radio broadcasts as a strategy for reducing (intellectual) disability stigma which is especially suited to developing countries. Wider audiences in developing countries are best reached through radio, and drama and storytelling related to intellectual disability is well suited to radio, while oral communication in local languages is much cheaper than the production of print material (McConkey et al, 2016, p. 189). Mobile phones offer the possibility of phone-in programmes to allow callers to get information and make contact with other likeminded people (McConkey et al, 2016, p. 189).

## **Protest**

Protest strategies are rooted in advancing civil rights agendas and present formal objections to negative representations and experiences of discrimination (NASEM, 2016, p. 76). Protest strategies are generally employed at the grassroots level by those experiencing discrimination and by advocates on their behalf (NASEM, 2016, p. 76). Targets of protest and advocacy campaigns are opinion leaders, such as politicians, journalists, or community officials (NASEM, 2016, p. 76). Their goal is 'typically to suppress negative attitudes or to remove negative representations or content' (NASEM, 2016, p. 76). Protest focusing on legislative reform often aims 'to enhance or enact protections of rights, increase access to social resources, and reduce inequalities' (NASEM, 2016, p. 76). Protest can also serve to increase public awareness and/or policy recognition of issues and concerns of the stigmatised group (NASEM, 2016, p. 76). However, protest can have unintended negative consequences, with negative public opinion sometimes strengthened as a result of the protest (NASEM, 2016, p. 77).

## **Advocacy**

Mostert (2016, p. 23) suggests that enhancing the ability of disability advocates, persons with disabilities themselves, and their organisations to advocate for their unqualified inclusion at all levels of society is the most effective way of enhancing the social status and inclusion of people with disabilities. This can be challenging in contexts where people with disabilities have been socialised into accepting their 'lowly lot in life' although the advocacy movement in Africa is growing and becoming more vocal (Mostert, 2016, p. 21). However, Mostert (2016, p. 19) could find no literature examining the effects of advocacy to promote the rights of persons with disabilities at the national and governmental level by advocating changing laws and policies that are unfavourable to persons with disabilities or the efficacy of protest against stigma.

## **Reporting and documenting of abuses**

Proper reporting and documenting of abuses against people with disabilities is 'essential for bringing little known practices to light and for generating advocacy strategies to combat often deeply-rooted beliefs systems that allow such persecution to continue' (DSPD, 2016, p. 11). This work is already being carried out by some DPOs and human rights organisations and should be undertaken by government bodies too (DSPD, 2016, p. 11). Journalists can also take a role in investigating and publicising abuses experienced by people with disabilities and have benefited from disability awareness training in some countries (DSPD, 2016, p. 11).

## **Designing a stigma intervention**

Stuart et al (2012, p. 126-130, 156) looked at the lessons learned from efforts to fight mental illness stigma and, amongst other things, found that:

- Anti-stigma programme objectives should be made in discussion with those affected and their families.
- Stigma interventions should be targeted at specific groups within the population (those who have a lot of contact with the stigmatised group) and the interventions should be matched to their particular needs, rather than aimed more generally.
- The stigmatised should be active participants and leaders of the anti-stigma programmes.

- Anti-stigma interventions should be tailored to local circumstances and take advantage of local opportunities as they arise.

A working group looking to design guidelines for interventions to reduce stigma created a matrix for cross-checking intervention plans based on previous understandings of stigma and stigma interventions (Cross et al, 2011, p. 77).

Table 1: A matrix for cross-checking intervention plans

Level	Components				
	Labelling	Stereotyping	Separation	Status Loss	Discrimination
<b>Intrapersonal</b>	How does the intervention facilitate the creation and internalisation of a new identity	How does the intervention reverse or alter internalised stereotypes	How does the intervention increase self-respect and reduce self-loathing	How does the intervention increase self-efficacy and provide opportunity for role development	How does the intervention raise self-esteem and self-assurance
<b>Interpersonal</b>	How does the intervention persuade others to acknowledge new identities	How will the intervention change perception from negative to positive stereotype	How will reconciliation between players be facilitated	In what ways will the intervention demonstrate the value of new role to others	What does the intervention do to promote commitment to embrace equality
<b>Organisational/ Institutional</b>	How does the intervention facilitate the sanctioning of changed identities	How does the intervention challenge the process of negative stereotyping	How does the intervention lead to greater participation and inclusion	How will the intervention affect power relationships to positive effect	How will the intervention ensure censure for discriminatory behaviour
<b>Community/ Government</b>	Changing cultural norms: How does the intervention discourage the acceptance and endorsement of stigmatisation (community level) How does the intervention lead to favourable legislation (government level) and commitment to rights				

Source: Cross et al (2011, p. 77)

## Programme evaluation

Evaluation should be a fundamental part of anti-stigma interventions, bringing out the key components of the programme as well as things which have not worked as planned (Stuart et al, 2012, p. 167, 181). However, 'assessing change brought about by an anti-stigma programme can be a complex and difficult task' (Stuart et al, 2012, p. 170). Evaluation of change requires at least two data collection points, one before the intervention and one after, using identical instruments both times (Stuart et al, 2012, p. 171). Stuart et al (2012, p. 172, 175) suggest that the key considerations in assessing (mental health) stigma interventions effects are whether people (with mental illness) have experienced an improvement in their day-to-day lives and



whether they can report fewer stigmatising experiences, rather than measuring changes in the knowledge and attitudes of programme participants.

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