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Disability stigma in developing countries

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9 May 2018

Question

What are the core drivers behind stereotypes, prejudice (including pity/shame etc), and harmful practices against persons with disabilities in developing countries and what promising strategies/pathways for addressing these drivers have been identified?

Contents

1. Overview

Across the world stereotypes, prejudice, and stigma contribute to the discrimination and exclusion experienced by people with disabilities and their families in all aspects of their lives. This rapid review looks at available evidence on the drivers of disability stigma in developing countries, and promising strategies for addressing these.

Most of the available evidence uncovered by this rapid review comes from Sub-Saharan Africa, and is from a mix of academic and grey literature. Evidence gaps remain, with Mostert (2016, p. 22) for example, noting that there is need for more empirical research around disability stigma in every African country, although pockets of fairly deep research do exist. The available literature has focused more on studying the victims of stigmatisation than the stigmatisers (Mostert, 2016, p. 22).

Key findings about the drivers of disability stigma include:

- 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.

- Misconceptions about the cause of disabilities often result from cultural or religious beliefs. Disability is often blamed on: misdeeds of ancestors; misdeeds of parents; misdeeds of the person with disabilities; supernatural forces such as demons/spirits; witchcraft; or punishment or fate from God.

- As a result 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.

- Misconceptions about the nature and abilities of people with disabilities, including that they are unable to contribute financially; that they are not able to have a normal relationship; that they will be unable to report sexual abuse; that their disability is contagious or they bring bad luck; that their bodies have magical powers; or that they are witches, also contribute to the stigma, discrimination and abuses they experience.

- Discriminatory legislation and policies reinforce prejudice and discrimination, while the segregation of people with disabilities perpetuates negative stereotypes.

Attitudes towards disability are not the same within countries, communities, or even families.

- Different types of impairments carry different levels of stigma, as does the severity of the impairment and how it was acquired. People with intellectual disabilities, severe mental health conditions, albinism, and sensory disabilities are often more stigmatised than people with physical disabilities.

- People with disabilities who can participate in their communities experience less stigma than those with more severe disabilities.

- Females who are disabled are doubly disadvantaged, due to the stigma associated with gender as well as disability.

- Socio-economic status can affect attitudes towards disability.

- People with disabilities in rural areas may experience more harmful practices than in urban areas.

Tools to measure disability stigma are needed. Those that exist have been developed in Western countries and tend to measure attitudes rather than the entirety of stigma (the chain from stereotypes through prejudice to discrimination).

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. Much of the available information on promising strategies for addressing disability stigma appears to focus on efforts to reduce the stigma experienced by people with intellectual disabilities but is applicable more widely.

- Interventions at the intrapersonal and familial level include self-help, advocacy and support groups, which have generally been found to be effective to some extent. The empowerment of people with disabilities is especially important for overcoming internalised stigma and stigma more generally.

- It is important for families of children with disabilities to actively nurture their child's development; to include them in the community; spread information to counter myths and superstitions about disability; and advocate on their behalf.

- Parent and friends associations can be an important strategy for addressing stigma in developing countries.

- Interpersonal interventions generally involve education (aiming to challenge inaccurate stereotypes by providing factual information) or contact (encouraging positive interactions between the public and persons with disabilities). Education interventions are reported to have had mixed efficacy, while contact has shown a lot of promise as a stigma reduction strategy, especially if it starts at an early age. It might be most useful to combine contact based approaches with education.

- Community based rehabilitation; village gatherings to communicate messages on disabilities in a way that harmonises with local cultural values and activities; and support from community leaders have been suggested as strategies especially suited to reducing disability stigma in developing countries.

- Interventions at the governmental/structural level including legislation to tackle disability discrimination; mass media campaigns; reporting and documenting of abuses; and advocacy are important for tackling disability sigma.

Tacking disability stigma is 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. Approaches also need to be tailored to the variations in understanding and perceptions of disability that exist within and across countries.

Interventions have tended to focus on raising awareness rather than actively aimed at changing behaviour. It is suggested that to be effective, 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).

The available evidence base on disability stigma interventions is weak. Werner & Scior (2016), found that despite numerous reported interventions across the world aimed at tackling disability stigma, there has been little evaluation of their utility (and interventions which have been tested and showed promising results have not resulted in wider implementation). In addition, the studies which have been conducted have had methodological and conceptual limitations (Werner &

Scior, 2016, p. 139-140). They suggest that greater collaboration between those delivering interventions and researchers is needed to develop a stronger evidence base (Werner & Scior, 2016, p. 140). Mostert (2016, p. 22) also suggests that 'there needs to be an emphasis on a holistic research approach to stigma reduction which incorporates relevant theoretical, behavioural, psychosocial, and cultural models as a means of providing a comprehensive framework for deeper investigations' using both quantitative and qualitative approaches.

2. Drivers of stigma

Across the world people with disabilities face attitudinal barriers including prejudice, stereotypes, and low expectations (DSPD, 2016, p. 3). These negative attitudes and inaccurate beliefs about disability can result in stigma[1] (an attribute possessed by a person or group that is regarded as undesirable or discrediting) (DSPD, 2016, p. 6). Stigma 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). Stigma elicits negative responses such as pity, anxiety, avoidance, hostility, and even hatred and disgust (Scior, 2016, p. 5).

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 puts people with disabilities' rights at risk (Inguanzo, 2017, p. 7). At the individual level, stigma and discrimination can result in internalised oppression 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).

Factors which contribute to disability stigma in developing countries include:

Misconceptions about the causes of disability: Cultural and religious beliefs

Mostert (2016, p. 9) suggests that the considerable 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 in Africa (see also DSPD, 2016, p. 5Stone-MacDonald & Butera, 2014, p. 6). Aley's (2016, p. 14) study[2] in Uganda and Kenya also 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'. Such misconceptions

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[1] Stigma has been theorised as both a social construction and in evolutionary terms. Scior (2016, p. 6-7) suggests that the experiences of people with intellectual disabilities indicate that both types of theories should be borne in mind to advance understanding of (intellectual) disability stigma.

[2] Qualitative participatory action research in Uganda and Kenya with service providers and key responders. Involved 52 individual interviews and 9 focus groups.

are often reinforced by ill-informed and insensitive media coverage that perpetuates negative views (DSPD, 2016, p. 5).

Cultural or religious beliefs about the causes of disability often underpin stigma (Bond DDG, 2017, p. 3). 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). Traditional animism included beliefs that disabilities are punishments for bad deeds or the result of witchcraft exercised by other people (Stone-MacDonald & Butera, 2014, p. 5). Christian fatalism beliefs revolved around notions that disability results as an act of God's will (Stone-MacDonald & Butera, 2014, p. 5). Medical determinist beliefs accepted the explanations of modern medicine as to the cause of disabilities (Stone-MacDonald & Butera, 2014, p. 5). People often combined different beliefs about causes of disability, for example suggesting a medical explanation in addition to traditional animism (Stone-MacDonald & Butera, 2014, p. 5).

More broadly in developing countries, examples of negative cultural and religious beliefs about the causes of disability relate to[3]:

- *Ancestors*: Research in Cameroon, Ethiopia, Senegal, Uganda and Zambia indicates that beliefs about the causes of disability include that it is an ancestral curse (DSPD, 2016, p. 5; see also: Mostert, 2016, p. 9; Aley, 2016, p. 15; Parnes et al, 2013, p. 24; Groce & McGeown, 2013, p. 4). Another study in Uganda and Kenya found that many communities believed that disability was a curse resulting from transgressions of former generations in the family (Aley, 2016, p. 14). In Nigeria false beliefs about the causes of disability include that is due to ancestral violations of societal norms (DSPD, 2016, p. 5). In Uganda and Kenya wrong doing 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).

- *Actions of parents (mainly mothers)*: Research indicates that beliefs about the causes of disability in Cameroon, Ethiopia, Senegal, Uganda and Zambia include that it is due to the sin or promiscuity of the mother (DSPD, 2016, p. 5; see also: Mostert, 2016, p. 9; Aley, 2016, p. 15; Parnes et al, 2013, p. 24; Groce & McGeown, 2013, p. 4). In Nigeria false beliefs about the causes of disability include that it is due to breaking laws and family sins or adultery (DSPD, 2016, p. 5). Disability has also been attributed to the breaking of social taboos (for instance, having sexual intercourse during pregnancy), (Mostert, 2016, p. 9; Stone-MacDonald & Butera, 2014, p. 5; Groce & McGeown, 2013, p. 4, 7). A study[4] of children with disabilities in West Africa found common beliefs were that disabilities were caused by 'a "bad" act of a family member (Parnes et al, 2013, p. 24). Many Kenyans believe that a disability is the result of taboo activities 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 newborn 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).

- *Actions of the disabled person*: A study in Uganda and Kenya found that some communities believed that people became disabled because they had caused accidents and not been properly cleansed (Aley, 2016, p. 14). In Nigeria disability is sometimes thought to be due to simple misfortune (DSPD, 2016, p. 5).

- *Supernatural – demons/spirits*: Research indicates that beliefs about the causes of disability in Cameroon, Ethiopia, Senegal, Uganda and Zambia include that it is due to demonic possession and that people with disabilities are not really human (DSPD, 2016, p. 5; see also: Mostert, 2016, p. 9; Aley, 2016, p. 15; Parnes et al, 2013, p. 24; Groce & McGeown, 2013, p. 4). Disability has also been attributed to a general sense of evil or otherworldly powers meting out disability as punishment for some perceived wrong (Mostert, 2016, p. 9; Stone-MacDonald & Butera, 2014, p. 5; Groce & McGeown, 2013, p. 4, 7). Many Kenyans believe that a 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). A study in West Africa found that a common belief was that children with disabilities were inflicted due to a "bad spirit" (Parnes et al, 2013, p. 24).

- *Witchcraft*: Disability has also been attributed to witchcraft and magic (Mostert, 2016, p. 9; Stone-MacDonald & Butera, 2014, p. 5; Groce & McGeown, 2013, p. 4, 7). In Nigeria false beliefs about the causes of disability include that it was caused by witches and wizards (DSPD, 2016, p. 5). Many Kenyans believe that a 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).

- *God – punishment/fate*: In Nigeria false beliefs about the causes of disability include that it is a curse from God (DSPD, 2016, p. 5). Research in West Africa also found common beliefs about the causes of disability were that it was a curse from God or was the child's "fate" (Parnes et al, 2013, p. 24). In Nepal, some parents believe that the disability of their child is due to fate and God's will (Inguanzo, 2017, p. 31).

These different understanding of the causes of disability can have serious consequences for the lives of people with disabilities, including:

- *Infanticide*: 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 resulted in the infanticide of new born children with disabilities in some countries such as Kenya[5], 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).

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[5] 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).

- *Paternal abandonment*: 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).

- *Lack of registration*: The low numbers of people with disabilities in national censes or official statistics is often attributed to stigma around disability, with children with disabilities going unreported (Inguanzo, 2017, p. 31; Bond DDG, 2017, p. 3; Parnes et al, 2013, p. 25).

- *Violence and abuse*: Such negative beliefs and the stigma associated with disability contribute to children with disabilities being seen as unworthy and means they face a greater risk of violence than their non-disabled peers (Njelesani et al, 2018, p. 6; Parnes et al, 2013, p. 9). A study[6] looking at violence against children with disabilities in Guinea, Niger, Sierra Leone, and Togo found that perpetrators often made reference to the child's disability when teasing, bullying, restricting food access, and physically punishing them[7] (Njelesani et al, 2018, p. 4; see also Franklin et al, 2018, p. 4; Parnes et al, 2013, p. 7, 24). Mocking and bullying in relation to disabilities can extend into adulthood (Aley, 2016, p. 16). Prejudice and stigma can also result in less direct violence with widespread maltreatment of children with disabilities in the form of child neglect or malnutrition (Njelesani et al, 2018, p. 4; Inguanzo, 2017, p. 26). 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).

- *Violent "cures"*: 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 in Ethiopia and Sierra Leone, while some people with some serious mental health conditions in Somalia have been thrown into a pit with one or more hyenas that have been starved of food on the basis that the hyenas will scare away the djinns, or evil spirits, that inhabit the person (DSPD, 2016, p. 7, 11; DSPD, 2016, p. 7).

- *Restricted participation*: These beliefs can also result in some families stigmatising their relative with disabilities (Bond DDG, 2017, p. 4; Parnes et al, 2013, p. 25). Surveys conducted in Cameroon, Ethiopia, Senegal, Uganda and Zambia found that 38% of respondent caregivers of children with disabilities reported hiding them away, or forbidding them to take part in social activities owing to stigma and shame, or in order to protect them from perceptions and stigmas (DSPD, 2016, p. 6; Mostert, 2016, p. 9). Beliefs that disability of their child was due to fate and God's will prevented families in Nepal 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).

- *Ostracism*: 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

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[6] A qualitative study with a total of 419 children, community members, and disability stakeholders selected using purposive sampling.

[7] For example, children stated: 'They will beat us just because of our disability' (child with a disability, Guinea, male) and 'The other children berate me and say that I am only a half-person' (child with a disability, Guinea, female) (Njelesani et al, 2018, p. 4).

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). People with disabilities and their families are sometimes isolated and shunned, sent away from their communities or denied traditional funeral rites (DSPD, 2016, p. 7; Aley, 2016, p. 18; Parnes et al, 2013, p. 25; Groce & McGeown, 2013, p. 5).

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). For example 'among the Chagga in East Africa, those with physical handicaps are seen as pacifiers of evil spirits; in Benin those with physical handicaps are often selected as law enforcement personnel; 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 in Uganda and Kenya 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).

DSPD (2016, p. 5) suggests that in some cases respectful attitudes towards people with disabilities held by some traditional societies in Africa 'gave way to more negative views and beliefs as a result of colonialism and the introduction of medical or charity models of disability by outside actors'.

Misconceptions about the nature of disability

Lack of understanding and awareness about the nature of disability and people with disabilities abilities is another factor in the stigma, discrimination and abuses they experience. Some common beliefs include:

Misconception: People with disabilities are unable to contribute

Stigma of disabled people can also 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). In West Africa for example, children with disabilities were not believed to be capable of living independent lives and were expected to require constant help from nondisabled people (Parnes et al, 2013, p. 24). As a result they are not only seen as a 'financial and resource liability internally, but also by the larger community, resulting in the shaming of the family with a member with disabilities' (Mostert, 2016, p. 17).

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). For example, advocates in Gabon report that children who are deaf are considered incapable of pursuing an education (DSPD, 2016, p. 6). 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).

People with disabilities can struggle to find work and when in work often face 'discrimination, abuse and marginalisation by nondisabled colleagues and managers who believe that the employee with a disability is automatically less capable and less productive than nondisabled workers' (Mostert, 2016, p. 11).

Misconception: people with disabilities cannot have normal relationships/are sexually inactive

Stigma and beliefs about the nature of disability can also restrict people with disabilities' ability to develop relationships (Franklin et al, 2018, p. 5). Respondents in Uganda and Kenya reported that 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 with bring evil or misfortune with them if they marry into the family (Aley, 2016, p. 24-25). A study in Bangladesh, India, and Nepal, found that families arranged marriages for daughters with disabilities with whoever accepted them because of the low expectations they had for them (Ando, 2017, p. 2). A study in Tanzania of people with albinism found that that their partners, if they had one, had problems and even divorced them because of it (Franklin et al, 2018, p. 5). Sometimes men form sexual relationships with women with disabilities but are unwilling to be seen with them in public due 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).

Women with disabilities can also 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 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 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). Respondents in Uganda and Kenya note that 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).

Misconception: people with disabilities will not be able to report sexual abuse

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).

Stigma towards people with disability among police and judiciary staff also contributes to the impunity experienced by those perpetrating violence against people with disabilities (Inguanzo, 2017, p. 25; Aley, 2016, p. 36). 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).

Misconception: people with disabilities are contagious or bring bad luck

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).

Misconception: the bodies of people with disabilities have 'magical' properties

Groce & McGeown's (2013, p. 4) research focused specifically on witchcraft and reported that in some urban areas of Africa, unscrupulous[8] urban practitioners of 'witchcraft' or 'magic' were reinterpreting traditional links between disability and witchcraft[9]. They used 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. These beliefs were increasingly reported among educated urban populations, and it was unclear whether traditional beliefs about disability have been brought from rural to urban areas with urban migrants, whether these beliefs reflect new urban myths, or a combination of the two (Groce & McGeown, 2013, p. 5). The links between

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[8] '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).

[9] Historically witchcraft has been linked to tensions in African social structures; responses to social instability; or as psychological responses in individuals suffering from sickness or lack of autonomy (Groce & McGeown, 2013, p. 5-6). 'Recent studies have documented an evolving belief system, now linking traditional beliefs with personal striving for prosperity, interest in achieving personal and family goals, or as a way to address personal disputes, class tensions and political strife' (Groce & McGeown, 2013, p. 6).

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). Existing stigma and prejudice against persons with disabilities can make their lives of less value and therefore the rational for some engaged in these practices is that the death of a disabled person would be a lesser loss than a nondisabled person if human sacrifice is needed for these rituals (Groce & McGeown, 2013, p. 11).

In countries such as Tanzania, Zambia and Uganda, 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 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).

Misconception: people with disabilities are witches

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

Law and policies can sometimes affirm harmful beliefs about disability and reinforce prejudice and fears (DSPD, 2016, p. 5). Countries can have laws and policies that perpetuate stigma and discrimination against people with disabilities (DSPD, 2016, p. 12). For example, in Kenya people with visual or hearing impairments cannot become President, as the Constitution stipulates that the President should read English and Kiswahili without the use of Braille or sign language (Mostert, 2016, p. 11).

Lack of contact and segregated services

As contact (see below) is an important factor in combatting stigma, McConkey (2018, p. 6-7) points out that the segregation of services solely for persons with disabilities (where they exist) has probably perpetuated stigmatisation despite the other benefits special schools, centres and residential homes may have brought to other facets of their life. The exclusion and segregation of people with disabilities limits their quality of life and potential to contribute to society and perpetuates negative stereotypes (Scior et al, 2015, p. 101).

Factors contributing to different levels of stigma

Attitudes towards disability are not always the same across a region or within a country (DSPD, 2016, p. 3; Groce & McGeown, 2013, p. 6). In addition, 'different groups or individuals may have beliefs about disability that vary from those held by wider society and beliefs may vary even within small communities and within families' (DSPD, 2016, p. 3; Groce & McGeown, 2013, p. 7). 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).

Type of impairment

Different types of impairments carry different levels of stigma, as does the severity of the impairment (Al-Ghaib et al, 2017, p. 13; Parnes et al, 2013, p. 9). Prejudices and stigma against children with disabilities and negative treatment towards them has been found to differ depending on whether children were born with an impairment or acquired it later on, and on the impairment type, for instance (Inguanzo, 2017, p. 26; Njelesani et al, 2018, p. 5; Parnes et al, 2013, p. 26). Inguanzo[10] (2017, p. 26) found that cultural barriers were 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. 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 and people with severe mental health problems are generally more stigmatised than people with physical or sensory disabilities, although there are also reports that people with sensory disabilities are also among the most discriminated against (Scior, 2016, p. 6; Bond DDG, 2017, p. 4; Parnes et al, 2013, p. 26). Children in the study in Guinea, Niger, Sierra Leone, and Togo with visual, communicative, and cognitive impairments experienced the most violence because 'their disability is considered like a contagion' or because children with physical impairments were thought to have more economic potential (Njelesani et al, 2018, p. 5).

Ability to participate

Acceptance may depend on how well people with disabilities are able to conform to 'the behavioural and ritualistic norms of the community, with more acceptance being granted to less impaired individuals and less acceptance being shown to persons with more severe disabilities' (Mostert, 2016, p. 11; Parnes et al, 2013, p. 26; Stone-MacDonald & Butera, 2014, p. 7, 10). 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'. Children with physical impairments who had less participation restrictions, for example they can independently access their environment with the use of a mobility aid, were thought to experience less violence in Guinea, Niger, Sierra Leone, and Togo (Njelesani et al, 2018, p. 5). This difference in treatment was attributed by some to be the result of their greater participation in society, such as going to school (Njelesani et al, 2018, p. 5).

Gender and ethnicity

Mostert (2016, p. 10) notes that as stigma is not only associated with disability but gender in many African countries, females who are disabled are doubly disadvantaged. Females with obvious disabilities are more likely to be abandoned or killed at birth, and in many places they have higher mortality rates than their male counterparts (Mostert, 2016, p. 11). In general, across the world, organisations working on disability find that girls and women with disabilities are most

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[10] Study involved an extensive review of academic literature and relevant legal, as well as questionnaires and semi-structured interviews with indigenous people with disabilities activists and experts on indigenous people with disabilities.

affected by stigma and discrimination, experiencing it both as a result of their disability and their gender (Bond DDG, 2017, p. 4; Ando, 2017, p. 2; Parnes et al, 2013, p. 9, 26-27).

Children with disabilities from minority groups can face additional discrimination on ethnic grounds (Inguanzo, 2017, p. 27).

Socio-economic status

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). More affluent social classes have the advantage of being able to pay for support and were found in Uganda and Kenya 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). On the other hand, there are reports from Rwanda of wealthier families hiding away their children with disabilities because of concerns over potential witchcraft accusations against them (Groce & McGeown, 2013, p. 14-15).

Location

In Kenya, 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 born with impairments in rural areas or small villages in Guinea, Niger, Sierra Leone, and Togo where more likely to be ritually killed than in cities, where detection of the killings by officials is more likely to occur (Njelesani et al, 2018, p. 6).

Stigma specific to different impairment types

A number of different disabilities appear to be focused on slightly more in the available literature. They include:

Albinism

People with albinism, most of whom live with some kind or degree of visual impairment, are reported to be 'regularly singled out and subjected to torture, cruel, inhuman and degrading treatment or killings because of cultural beliefs and witchcraft' in countries such as Tanzania, Kenya, Burundi, and Malawi[11] (Inguanzo, 2017, p. 20, 34; DSPD, 2016, p. 7; Mostert, 2016, p. 12; Franklin et al, 2018, p. 1; Groce & McGeown, 2013, p. 12). Their body parts are believed to bring good luck, wealth and medical cures, as well as success in elections (DSPD, 2016, p. 7; Groce & McGeown, 2013, p. 12). Their existing marginalisation and exclusion made them easier targets of mutilation and killing (Mostert, 2016, p. 13). Parents have been forced to escort their

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[11] Mostert and Weich (2017, p. 102) note that a recent report indicated that in 25 African countries, there had been 185 killings and 297 survived attacks. African countries known to be involved in the trafficking of albino parts include Tanzania, Burundi, Kenya, the Democratic Republic of the Congo (DRC), Mozambique, Malawi, South Africa and Swaziland. Further isolated reports of killings and attacks have come from Benin, Botswana, Burkina Faso, Burundi, Cameroon, Côte d'Ivoire, the DRC, Egypt, Ghana, Guinea, Kenya, Lesotho, Malawi, Mali, Mozambique, Namibia, Niger, Nigeria, Rwanda, Senegal, South Africa and Swaziland.

children to school or hide them at home, while others sent them away to boarding schools, camps or relatives in safer areas (Franklin et al, 2018, p. 4).

The sociocultural risks for people with albinism are 'particularly serious in areas that associate albinism with legend and folklore, leading to stigmatisation and discrimination' (Franklin et al, 2018, p. 1, 4). In many places in Africa, including Tanzania, 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; Aley, 2016, p. 15). 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).

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). Mostert and Weich (2017) propose a conceptual framework linking underlying interrelated vectors (including stigma, traditional and cultural beliefs, and economic factors) that combine to drive severe exploitation of persons with albinism.

Intellectual disability

People with intellectual disabilities face social exclusion, marginalisation, and abuse as a result of stigma (Ditchman et al, 2016, p. 31; Scior et al, 2015, p. 39). They have 'been ostracised throughout history and across cultures, and are one of the most marginalised and excluded (social) groups around the world' (Scior et al, 2015, p. 7). There are indications that stigma results in people with intellectual disabilities facing some of the most difficult living conditions in the world, although more research is needed (Ditchman et al, 2016, p. 40; Scior et al, 2015, p. 7). The stigmatisation of people with intellectual disabilities can also be expressed by people with other disabling conditions, such as physical or sensory impairments, who might not want to associate with people with intellectual disabilities for fear that they will be assumed to be intellectually impaired as well as physically disabled (McConkey, 2018, p. 6).

A comprehensive global study[12] into attitudes to intellectual disability found that in 'low and lower-middle income countries in Africa, Asia, Southern and Central America and in Russia, there is often still an active desire to segregate people with intellectual disabilities from society due to deep rooted prejudices or stigmatising beliefs about the causes of intellectual disability' (Scior et al, 2015, p. 5, 40-41). The derogatory terms such as retard', 'downey', 'moron', 'mongol' and 'fool' used in many countries reflect the fundamental disrespect of people with intellectual disabilities (Scior et al, 2015, p. 5).

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[12] Involving 667 experts from 88 countries.

In their research on the experiences of people with intellectual disabilities, McConkey et al (2016, p. 181) highlight the very important role families in developing countries play in perpetuating and also in reducing stigmatising attitudes to people with disabilities, especially as they may stay in their families during adulthood because of their ongoing need for support. Research in South Africa, Ghana, Tanzania, Namibia and Pakistan indicates that intellectual disability brings shame on families which often leads to families hiding their family member with intellectual disabilities from the community (McConkey et al, 2016, p. 183). This further reinforces the shamefulness associated with this disability, which is often interpreted as a misfortune that has befallen the family because of their misdeeds (McConkey et al, 2016, p. 183). Families may also hide their children or adults with intellectual disabilities because of physical deformities or behavioural challenges (McConkey et al, 2016, p. 183). McConkey et al (2016, p. 185) point out that such reactive responses by the family only serve to perpetuate negative perceptions and misunderstandings about disability. However, they also point out that families can be a stimulus for change – see below for more detail (McConkey et al, 2016, p. 185).

Leprosy

People with leprosy experience very high levels of stigma (Mostert, 2016, p. 13). The fear of leprosy tends to be related to visible deformities; perceived incurability; perceived infectiousness; and perceived 'bad origin of the disease' (Mostert, 2016, p. 14). The literature indicates that this stigma persists despite a high level of understanding of the real causes of and treatment for leprosy (Mostert, 2016, p. 13).

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'.

Measuring stigma

In order to examine the extent and severity of stigma, researchers need accurate measurement tools (Werner, 2016, p. 15). Specific tools for different disabilities are needed because stigma may differ across disabilities, yet the attention paid to the measurement of different disability stigma, such as intellectual disability stigma, has not been even (Werner, 2016, p. 15). 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). Most scales have been developed and used predominately in Western countries (Werner, 2016, p. 16).

Werner (2016, p. 15- 24) describes the most widely used intellectual disability stigma scales, although as mentioned, most seem to have been used in higher income countries, and concludes that the field of intellectual disability stigma measurement is still in its infancy.

3. Addressing disability stigma

It is important to note that while false perceptions and beliefs about disability are often difficult to overcome, beliefs can change and evolve over time (DSPD, 2016, p. 5). Aley (2016, p. 14, 16)

found that respondents reported that attitudes among professionals in Uganda and 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). Scior et al (2015, p. 101) found that in many countries attitudes towards people with intellectual disabilities are becoming more positive, although more so in some high and middle countries. Groce & McGeown (2013, p. 8) note that some research found that some 'traditional beliefs are receding in the face of significant efforts in many countries by disability advocates, government and civil society to dispel such negative attitudes and practices'.

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. Much of the available information focuses on efforts to reduce the stigma experienced by people with intellectual disabilities but is applicable more widely. It should be noted that very few efforts at raising awareness and combatting stigma have been formally evaluated (Scior et al, 2015, p. 6).

Interventions at the intrapersonal and familial 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). While the literature on self-help, advocacy and support groups to develop positive self-identity, self-esteem, and an array of coping skills among people with disabilities is limited, Mostert (2016, p. 18) notes that it generally tends to indicate that these interventions are effective, at least to some extent. NGOs report success in reducing and eliminating stigma by offering information and support through self-help groups, peer support and training groups, and parent support and training groups (Bond DDG, 2017, p. 3, 5). Such groups can help dispel myths, for example that people with disabilities can never earn a living, and offer people with disabilities and their families new hope and confidence (Bond DDG, 2017, p. 5; DSPD, 2016, p. 10).

The empowerment of people with disabilities is especially important for overcoming internalised stigma and stigma more generally (DSPD, 2016, 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). The Leonard Cheshire Disability Young Voices programme, for example, reported that young campaigners with disabilities from Zimbabwe who went on a speaking tour of six secondary schools, reaching over 12,000 school children, were able to change the way the school children and their teachers saw disability (DSPD, 2016, p. 8).

Thus, stigma reduction efforts could include teaching self-advocacy skills to people with disabilities; providing medical and psychosocial counselling to people with disabilities to increase their self-help and self-advocacy skills; and conducting emancipatory research, whereby people with disabilities have more prominent roles in the research process (Mostert, 2016, p. 21).

The role of families

Parents 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).

McConkey et al (2016, p. 185-187) have looked at the role of family in tackling intellectual disability stigma in developing countries and have found four main strategies that have proved effective in challenging negative perceptions of intellectual disability. They include:

- *Nurturing development*: actively nurturing their child's development, taking their child outside the home and participating in family and community events, despite criticism from others (McConkey et al, 2016, p. 185). 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). Parents associations can play a crucial role in making families proactive change agents for their children.

- *Inclusion*: not hiding away the child with disabilities gives them the opportunity to gain from interacting with others, and others from interacting with the child (McConkey, 2016, p. 186). Acceptance within communities depends on the relationships people forge with their peers which is built up through participation in schooling, sports and religious activities (McConkey et al, 2016, p. 190), It is especially important for children with intellectual disabilities to have the opportunity to join in formal and informal education, although this is especially challenging for rural communities where these services are often far away (McConkey, 2016, p. 186).

- *Information*: 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).

- *Advocacy*: Parental advocacy has played an important role in bringing the needs and rights of people with intellectual disabilities to the attention of politicians and officials and ensured that they have got a fair deal when it comes to the provision of support services (McConkey et al, 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. 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 are a strategy for addressing stigma that McConkey et al (2016, p. 188-190) identify as being especially suited to developing countries. 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).

Productive work

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).

Interventions at the interpersonal level

'Interpersonal-level interventions (beyond the familial level) target social interactions between stigmatised and non-stigmatised individuals' and have tended to fall under two broad types: education or contact (Werner & Scior, 2016, p. 132). Mostert (2016, p. 18) finds that the literature reveals mixed efficacy in relation to the variety of education interventions. The limited literature on contact (encouraging positive interactions between the public and persons with disabilities at the point of contact to reduce the stigma attached to disability) shows some positive findings, while also noting that there are some dangers involved (Mostert, 2016, p. 18).

Education

Educational interventions aim to challenge inaccurate stereotypes by providing factual information (Werner & Scior, 2016, p. 132). '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 (Mostert, 2016, p. 20).

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 educations 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

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). 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 in Uganda and Kenya.

Contact can be in person or indirectly (e.g. through films) (Werner & Scior, 2016, p. 142). 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). Some studies have suggested that it is most useful to combine contact based approaches with education (Werner & Scior, 2016, p. 136).

For example, an e-intervention in Kenya and Nigeria in 2016 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 (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). Attitudes in both countries were found to be more favourable after the film intervention, while there were no changes amongst participants who had watched the control film (Odukoya & Chenge, 2017).

Community level interventions

At the community level, interventions aim to increase knowledge about impairments and address stigma with in 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/structural 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). The UN Convention on the Rights of Persons with Disabilities (UNCRPD)[13] and national disability legislation fall under such efforts (Werner & Scior, 2016, p. 138-139).

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). For example the governments of Tanzania and Malawi have launched task forces 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). However, across sub-Saharan Africa people with albinism are still vulnerable to attack[14].

Respondents in Kenya and Uganda noted that progressive government policy had helped to gradually change attitudes towards disability (Aley, 2016, p. 20-21). 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[15] 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).

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[13] Ratified by 177 countries as of beginning of May 2018:
https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

[14] http://www.latimes.com/world/africa/la-fg-malawi-albinos-hunted-2017-story.html

[15] See Price, R.A. (2018). *Strategies for implementing and monitoring the UNCRPD in developing countries.* K4D Helpdesk Report 299. Brighton, UK: Institute of Development Studies. for more information about implementation on the UNCRPD in developing countries.

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 a number of mediums (Werner & Scior, 2016, p. 137). 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 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 story-telling 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).

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).

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 stigmas.

Challenges to tackling disability stigma

McConkey et al (2016, p. 180) warn that tackling (intellectual) disability stigma is challenging because reactions to it are compounded by other social attitudes (to women, ethnic and religious minorities) and by poverty, and efforts to counter disability discrimination need to take these other factors into account. In addition there are variations in public understanding and perceptions of disability within and between countries and a range of approaches may be needed to be tailored to these 'sub-cultures' (McConkey et al, 2016, p. 180).

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. 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).

Questions to consider when designing a stigma intervention

A working group looking to design guidelines for interventions to reduce stigma created a matrix for cross-checking intervention plans based on previous understands 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
Intrapersonal	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
Interpersonal	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
Organisational/ Institutional	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
Community/ Government	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)

4. References

Aley, R. (2016). *An Assessment of the Social, Cultural and Institutional Factors that Contribute to the Sexual Abuse of Persons with Disabilities in East Africa*. Advantage Africa. https://www.advantageafrica.org/file/advantage-africa-full-research-report-sexual-abuse-of-persons-with-disabilities-pdf

Al-Ghaib, O.A., Andrae, K., & Gondwe, R. (2017). *Still left behind: Pathways to inclusive education for girls with disabilities.* Leonard Cheshire Disability. http://www.ungei.org/Still_Left_Behind_Full_Report.PDF

Ando, M. (2017). *The right to sexual and reproductive health rights of girls with disabilities: Response by the Asian-Pacific Resource and Research Centre for Women (ARROW)*. ARROW. http://www.ohchr.org/Documents/Issues/Disability/ReproductiveHealthRights/NGOS/Asian-PacificResourceandResearchCentreforWomen.docx

Bond Disability and Development group (DDG). (2017). *Stigma, disability and development.* Bond. https://www.bond.org.uk/sites/default/files/resource-documents/stigma_disability_and_development.pdf

Cross, H.A., Heijnders, M., Dalal, A., Sermrittirong, S., & Mak, S. (2011). Interventions for Stigma Reduction–Part 2: Practical Applications. *Disability, CBR & Inclusive Development*, 22:3, 71-80. http://doi.org/10.5463/DCID.v22i3.72

Ditchman, N., Kosyluk, K., Lee, E-J., & Jones, N. (2016). How Stigma Affects the Lives of People with Intellectual Disabilities: An Overview. In K. Scior & S. Werner (eds.). *Intellectual Disability and Stigma: Stepping Out from the Margins*. Palgrave Macmillan.

Division for Social Policy and Development (DSPD). (2016). *Toolkit on Disability for Africa – Culture, Beliefs and Disability*. UN. http://www.un.org/esa/socdev/documents/disability/Toolkit/Cultures-Beliefs-Disability.pdf

Franklin, A., Lund, P., Bradbury-Jones, C., & Taylor, J. (2018). Children with albinism in African regions: their rights to 'being' and 'doing'. *BMC International Health and Human Rights*, 18:2, 1-8. http://doi.org/10.1186/s12914-018-0144-8

Groce, N., & McGeown, J. (2013). *Witchcraft, Wealth and Disability: Reinterpretation of a folk belief in contemporary urban Africa* (Working Paper Series: No. 30). Leonard Cheshire Disability and Inclusive Development Centre, UCL. https://www.ucl.ac.uk/iehc/research/epidemiology-public-health/research/leonard-cheshire-research/research/publications/documents/working-papers/wp-30.pdf

Inguanzo, I. (2017). *The situation of indigenous children with disabilities*. Policy Department, Directorate-General for External Policies, European Union. http://www.europarl.europa.eu/RegData/etudes/STUD/2017/603837/EXPO_STU(2017)603837_EN.pdf

McConkey, R. (2018). *Citizenship and people with intellectual disabilities: An international imperative?* In B. Watermeyer, J. Mckenzie & L. Swartz (eds). Palgrave Handbook of Disability and Citizenship in the Global South. Palgrave Macmillan.

McConkey, R., Kahonde, C., & McKenzie, J. (2016). Tackling Stigma in Developing Countries: The Key Role of Families. In K. Scior & S. Werner (eds.)*. Intellectual Disability and Stigma: Stepping Out from the Margins*. Palgrave Macmillan.

Mostert, M.P. (2016). Stigma as a barrier to the implementation of the Convention on the Rights of Persons with Disabilities in Africa. *African Disability Rights Yearbook*, 2-24. http://www.adry.up.ac.za/images/adry/volume4_2016/adry_2016_4_chapter1.pdf

Mostert, M.P., & Weich, M.M. (2017). Albinism in Africa: A proposed conceptual framework to understand and effectively address a continental crisis. *African Disability Rights Yearbook,* 5, 101-117. http://doi.org/10.29053/2413-7138/2017/v5n1a6

Njelesani, J., Hashemi, G., Cameron, C., Cameron, D., Richard, D., & Parnes, P. (2018). From the day they are born: a qualitative study exploring violence against children with disabilities in West Africa. *BMC Public Health,* 18:153. http://doi.org/10.1186/s12889-018-5057-x

Odukoya, D., & Chenge, W. (2017). *The Era of Digital Interventions: Combating intellectual Disability Stigma in Africa*. UCL blog. https://blogs.ucl.ac.uk/stigma-research/2017/07/21/the-era-of-digital-interventions-combating-intellectual-disability-stigma-in-africa-by-deborah-odukoya-and-winnie-chege-ucl/

Parnes, P., Hashemi, G., Njelesani, D., Njelesani, J., Richard, D., Cameron, C., & Keachie, H. (2013). *Outside the Circle - A research initiative by Plan International into the rights of children with disabilities to education and protection in West Africa*. Plan International. https://plan-international.org/publications/outside-circle#download-options

Rugoho, T., & Maphosa, F. (2017). Challenges faced by women with disabilities in accessing sexual and reproductive health in Zimbabwe: The case of Chitungwiza town. *African Journal of Disability*, 6, a252. https://doi.org/10.4102/ajod.v6i0.252

Scior, K. (2016). Towards Understanding Intellectual Disability Stigma: Introduction. In K. Scior & S. Werner (eds.)*. Intellectual Disability and Stigma: Stepping Out from the Margins.* Palgrave Macmillan.

Scior, K., Hamid, A., Hastings, R., Werner, S., Belton, C., Laniyan, A., Patel, M., & Kett, M. (2015). *Intellectual Disabilities: Raising Awareness and Combating Stigma- a Global Review*. University College London. https://www.ucl.ac.uk/ciddr/documents/Global_ID_Stigma_Report_Final_July_15.pdf

Stone-MacDonald, A., & Butera, G. (2014). Cultural Beliefs and Attitudes about Disability in East Africa. *Review of Disability Studies*, 8:1, 1-19. http://www.rdsjournal.org/index.php/journal/article/viewFile/110/367

Werner, S. (2016). Measurement Methods to Assess Intellectual Disability Stigma. In K. Scior & S. Werner (eds.)*. Intellectual Disability and Stigma: Stepping Out from the Margins.* Palgrave Macmillan.

Werner, S. & Scior, K. (2016). Interventions Aimed at Tackling Intellectual Disability Stigma: What Works and What Still Needs to Be Done. In K. Scior & S. Werner (eds.)*. Intellectual Disability and Stigma: Stepping Out from the Margins*. Palgrave Macmillan.

Acknowledgements

We thank the following experts who voluntarily provided suggestions for relevant literature or other advice to the author to support the preparation of this report. The content of the report does not necessarily reflect the opinions of any of the experts consulted.

- Katrina Scior, University College London
- Mark Mostert, Regent University
- Roy McConkey, University of Ulster
- Callista Kahonde, Stellenbosch University
- Penny Parnes, University of Toronto
- Shirli Werner, The Hebrew University of Jerusalem
- Angi Stone-MacDonald, University of Massachusetts
- Hillary Lane, Afrinead

Suggested citation

About this report