Disability-related stigma and discrimination in sub-Saharan Africa and south Asia: a systematic literature review

Research summary

April 2021

Introduction

The Sightsavers Social Inclusion Strategy commits to addressing stigma and discrimination as a key step on the pathway to equitable inclusion for people with disabilities. Despite the strong commitment to social inclusion expressed by the international community, people with disabilities – especially women and girls – across the world continue to experience discrimination and exclusion based on stigma, negative stereotyping and other barriers.

People with disabilities are often excluded from participating in their communities, wider society, and in development interventions; they are also often at increased risk of violence.

Further, people with disabilities are not a homogenous group and many people are subject to discrimination based on their disability status and other intersecting characteristics, such as age, race or gender. People with different impairments also face different barriers and forms of exclusion, which may vary across contexts.

What are stigma and discrimination?

In this review, we define **stigma** as a mark separating individuals from one another based on a socially conferred judgement that some persons or groups are tainted or 'less than'.

Discrimination is defined as the unjust or prejudicial treatment of specific groups of people, often on the grounds of their individual characteristics, such as race, age, sex or presence of an impairment.

A number of systematic and literature reviews have been conducted on stigma and discrimination associated with specific impairment types or health conditions, or among specific sub-populations, such as children.

Our review adds to this body of evidence by focusing specifically on interventions intended to address stigma and discrimination among all population groups and impairment types in sub-Saharan Africa and south Asia.

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The primary focus of this review was to identify studies that describe the effectiveness of interventions to tackle disability-related stigma and discrimination. The secondary focus was to understand the individual, interpersonal, organisational, community and public policy factors that are associated with stigma and discrimination.

We sought to identify the various forms of stigma and discrimination, how they are experienced and the impact on the lives of people affected, and how they may intersect with other individual characteristics and types of stigma or discrimination (such as sexism/racism). Finally, we sought to identify toolkits and good practice guidelines for addressing stigma and discrimination, as well as tools for measuring them.

This study was funded by Irish Aid, under grant number PG10-2021.

A **systematic literature review** is a type of research study that attempts to identify, appraise and synthesise all the evidence that meets pre-specified criteria to answer a specific research question. The findings of a high-quality systematic review can be very valuable as they provide an exhaustive but succinct summary of all available evidence on a particular question.

Why is this issue important for Sightsavers?

Addressing stigma and discrimination directed at people with disabilities in all their diversity, is fundamental to our social inclusion programmes and our Social Inclusion Strategy.

In order to guide our programme design and implementation, it is critical for us to develop a good understanding of why and how stigma and discrimination occurs, as well as effective interventions to mitigate their impact in the contexts of our programmes.

What do the research findings tell us?

Key findings

- Five key drivers of stigma and discrimination were identified: i) poor understanding of disabling conditions/impairments and their causes; ii) not knowing someone with a disability; iii) "othering" people with disabilities; iv) the fear of being "infected"; and v) the fear that people with disabilities are dangerous.

- Four key contextual factors influencing stigma and discrimination were identified: i) religion and traditional beliefs; ii) cultural and social norms; iii) socio-economic environment and availability of services; and iv) accountability and empowerment.

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- Manifestations of stigma and discrimination were organised into four broad categories: i) felt (perceived or anticipated) stigma; ii) enacted (experienced) stigma; iii) internalised stigma; and iv) affiliated (secondary) stigma.

- Limited evidence suggested that younger age, lower socio-economic status and severity of impairment was associated with high levels of internalised stigma, while rural residence, lower socio-economic status and severity of impairment were associated with high levels of enacted stigma.

- 19 studies reported on the effectiveness of interventions to tackle stigma and discrimination, which we organised into five broad categories: i) education and training; ii) education with social contact; iii) communication, persuasion and modelling; iv) alternative models of care; and v) economic empowerment.

Summary

Characteristics of included studies

After excluding duplicates, a total of 7,544 unique records were reviewed against inclusion criteria and a total of 82 papers were identified as eligible. This review looked at 82 peer-reviewed papers. Of these, 71 reported primary data and 11 documents contained guidelines and/or measurement metrics.

Among the 71 sources with primary data, 40 papers described stigma manifestations; 34 papers reported factors leading to stigma (drivers and facilitators); 22 reported stigma and discrimination outcomes; and 19 papers reported interventions, where the effect of the intervention on stigma and/or discrimination outcome was measured and quantified. Among the 71 papers describing primary data, the largest proportion of studies was from India (16), and a third of papers described stigma related to mental health (23). For details about the methodology we used, including how we assessed risk of bias, please see the full report.

Framework for analysis

Stigma as a concept has been extensively studied by social scientists in relation to leprosy, mental health, HIV, and epilepsy, and a number of analytical frameworks of health-related stigma have been developed over the years.

A **framework by Stangl et al** was first developed in the context of HIV/AIDS and later applied to other health conditions, including leprosy, epilepsy, mental health, cancer and obesity/overweight.

The framework articulates the stigmatisation process across multiple scales, from the individual through to the interpersonal, organisational, community and up to public policy level. The framework further breaks the stigmatisation process down into a series of domains, including drivers and facilitators, stigma 'marking' and stigma manifestations. These influence

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a number of outcomes for affected populations and result in a range of negative health and social impacts.

This framework was used to organise and position the findings of this systematic review.

Findings

Factors leading to stigma and discrimination

Among 34 papers that reported factors leading to stigma and discrimination, the majority (17) were qualitative studies, followed by cross-sectional surveys (13), mixed-methods studies (3) and one case-control study. Many studies pointed out the presence of several drivers and contextual factors in their settings. This was particularly common in the studies of conditions such as mental illnesses or HIV/AIDS, and where the levels of stigma were reported to be particularly high.

Five key drivers of stigma and discrimination were identified from studies conducted across 13 different countries. The most common driver identified was **poor understanding of disabling conditions/impairments and their causes**; the other four included: ii) **not knowing someone with a disability**; iii) **"othering" people with disabilities**; iv) **the fear of being "infected"**; and v) **the fear that people with disabilities are dangerous**.

Four key contextual factors influencing stigma and discrimination directed at people with disabilities were reported in studies covering 17 countries. The **most common factor identified was religion and traditional beliefs**. The other three included: ii) (non-religious) cultural and social norms; iii) socio-economic environment and availability of services; and iv) accountability and empowerment. As an example, in Cameroon, the lack of accountability mechanisms to monitor the implementation of anti-discriminatory legislation was identified as a key factor contributing to underreporting and thus, a facilitator of abuse and discrimination of children with disabilities.

Manifestations of stigma and discrimination

Manifestations of stigma and discrimination were organised into **four broad categories** corresponding to different stigma types: i) **felt (perceived or anticipated) stigma**; ii) **enacted (experienced) stigma**; iii) **internalised stigma**; and iv) **affiliated (secondary) stigma**.

Sources of stigma and discrimination included people with disabilities themselves, their immediate social circles, such as families and friends, their local community and broader society. Many studies examined stigma and discrimination from the perspective of more than one group.

Intersectionality and outcomes of stigma and discrimination

Twenty surveys and qualitative studies examined the **intersectionality of disability with other individual characteristics**, namely gender, age, marital status, race, religion, education, occupation, economic status, area of residence and type and severity of impairment. In most studies, evidence on intersectionality was mixed or inconclusive. However, there was some evidence to suggest that younger age, lower socio-economic status and severity of impairment was associated with high levels of internalised stigma, while rural

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residence, lower socio-economic status and severity of impairment were associated with high levels of enacted stigma.

Twenty-two reviewed studies also reported a range of **adverse outcomes** experienced by people with disabilities as a result of stigma and discrimination. These included adverse physical and mental health outcomes, such as physical and psychological trauma, high levels of stress, anxiety and depression and low levels of self-confidence and self-esteem. Studies also reported an adverse impact of stigma and discrimination on educational attainment, employment opportunities, political participation and overall economic wellbeing of people with disabilities.

Interventions and their effectiveness

The review identified 19 studies which reported on the **effectiveness of interventions** to tackle stigma and discrimination. For the purpose of the review, we organised these into five broad categories: **i) education and training**; **ii) education with social contact**; **iii) communication, persuasion and modelling**; **iv) alternative models of care**; **and v) economic empowerment**.

However, most intervention category descriptions were not detailed enough to be able to identify whether they were designed to influence specific drivers or facilitators, and whether they distinguished between stigma and discrimination. Many studies did not specify the type of stigma they addressed and very few described their intervention logic.


The review included a number of studies reporting on education and training interventions.

Education and training interventions were reported in eight studies: two from Nigeria and one each from Ethiopia, Kenya, Tanzania, Malawi, Rwanda and Bangladesh. The studies targeted stigma related to HIV/AIDS (4); epilepsy, mental health, autism and disability in general (conditions unspecified) (1 each).

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The target audiences were medical students, community health workers, hospital workers (medical and non-medical), trainee teachers, patients, church leaders and community healers. All eight papers reported a positive effect of the interventions on all outcomes measured in the studies. However, none of the studies was rated as low risk of bias (high quality). Three studies were medium risk of bias (medium quality), and five studies were high risk of bias (poor quality).

Education with social contact interventions included educational sessions supplemented by contacts involving people with disabilities. One multi-country study implemented in Lesotho, Malawi, South Africa, Swaziland, and Tanzania was included in this category. The study targeted stigma related to HIV/AIDS. It showed a mixed effect of the intervention on stigma-related outcomes and was rated medium risk of bias.

Another set of studies focused on communication, persuasion and modelling.
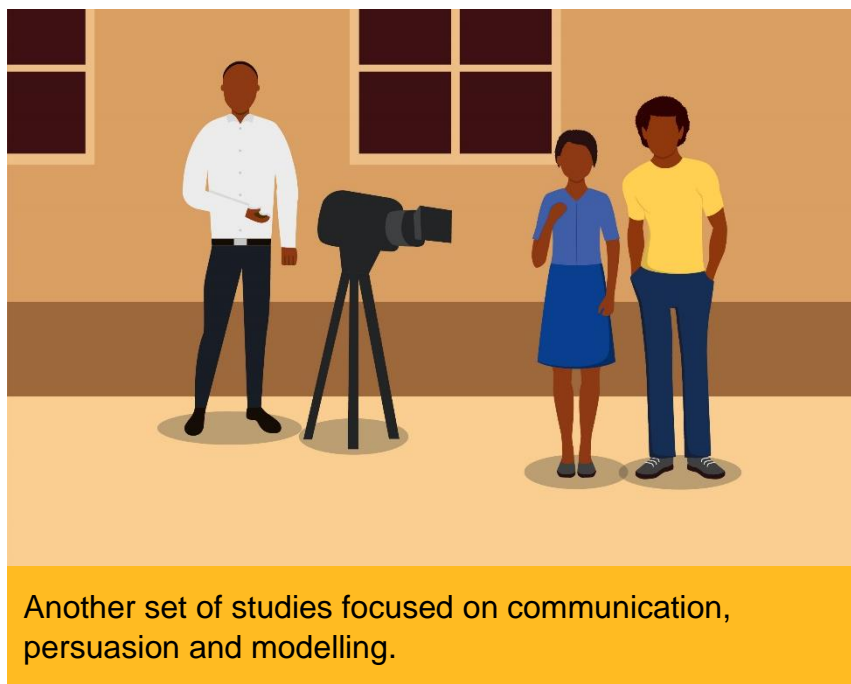
Communication, persuasion and modelling group included five studies from Ethiopia, Malawi, India, Nigeria, and Kenya. The studies addressed stigma related to epilepsy, HIV/AIDS, schizophrenia (1 each) and intellectual impairments (2). Study participants included primarily general population (members of the public/community), both adults and children, although one study from India also targeted people with disabilities themselves.

Four studies reported a positive effect of the intervention and one study had mixed results. Among the studies that showed a positive effect, one study was rated low risk of bias (high quality) and three studies were high risk of bias (poor quality). The study which showed mixed results was rated medium risk of bias.

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Several studies reported on alternative models of care, including home-based and community-based care.

Alternative models of care were piloted in four studies. These included models of care delivered closer to patients, such as integrated primary care services, home-based and community-based care. Two studies focused on stigma associated with HIV/AIDS; one was on stigma associated with schizophrenia and one on stigma of intellectual impairments. One study was conducted in India, one in Kenya, one in Zambia and one in Malawi.

Two studies showed no effect of the intervention; and another two studies reported mixed results. One study was rated high risk of bias (poor quality); two were low risk of bias (high quality); and one was medium risk of bias (medium quality).

Economic empowerment interventions were reported in one study from Nigeria. The study evaluated the impact of a community rehabilitation programme for people with leprosy. The study showed a positive effect of the intervention but was rated high risk of bias (poor quality).

Sightsavers will also be producing a separate summary that describes the findings from the interventions and their effectiveness in more detail.

Toolkits and metrics

Several documents included specific policy provisions, toolkits or guidelines to tackle stigma and discrimination at different levels and a few papers referred to examples of good practices, although without reporting evidence on the effectiveness of the approaches used.

The toolkits and good practice guidelines addressed stigma related to leprosy, HIV/AIDS, lymphatic filariasis, albinism and disability in general. In addition, three studies focused solely on describing and/or comparing tools for measuring stigma. Two of these were disease specific tools (leprosy and tuberculosis and HIV/AIDS) and one was an assessment of a generic tool for 'health-related stigma'.

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Sightsavers will also be producing a separate summary that describes the findings around the measurement tools in more detail.

The review also looked at studies that described or compared tools for measuring stigma.
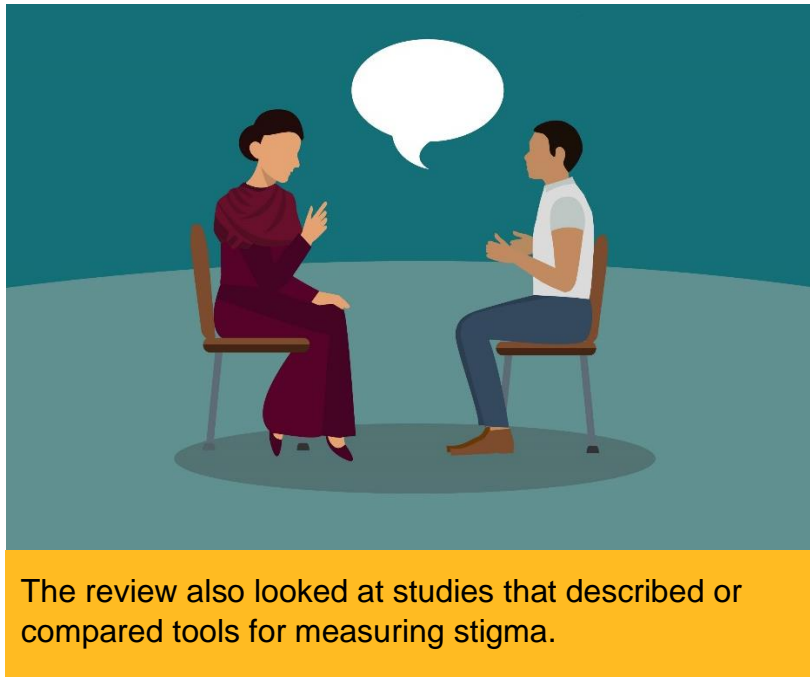
Recommendations for future programming and research

It is important that future programmes which include an aim to tackle disability-related stigma and/or discrimination, are designed, implemented, monitored and evaluated taking into account the findings of this review and other sources of evidence, and specifically:

- involve people with disabilities and their representative organisations in all stages of the design and implementation of interventions aiming to tackle stigma and discrimination, as well as in monitoring, evaluation and operational research.

- do not make assumptions about the magnitude of stigma and discrimination and who it affects, but collect baseline data to guide programme design and advance global knowledge.

- use formative analysis to prioritise contextual factors, drivers, and manifestations of stigma to be addressed in a given context, paying attention to intersectionality of disability with other individual characteristics. The formative analysis and subsequent intervention design should be validated and interrogated by the relevant stakeholders, taking into account the impact of intersectionality.

- use social behaviour change frameworks, for example, the Behaviour Change Wheel to more systematically analyse and influence negative behaviours and social norms which drive stigma and discrimination.

- articulate the type of stigma and/or discrimination the intervention aims to address and the population groups it aims to target. It is vital to clearly articulate intervention types and enabling categories and their aims or intentions to influence a diversity of drivers,

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contextual factors and manifestations of stigma.
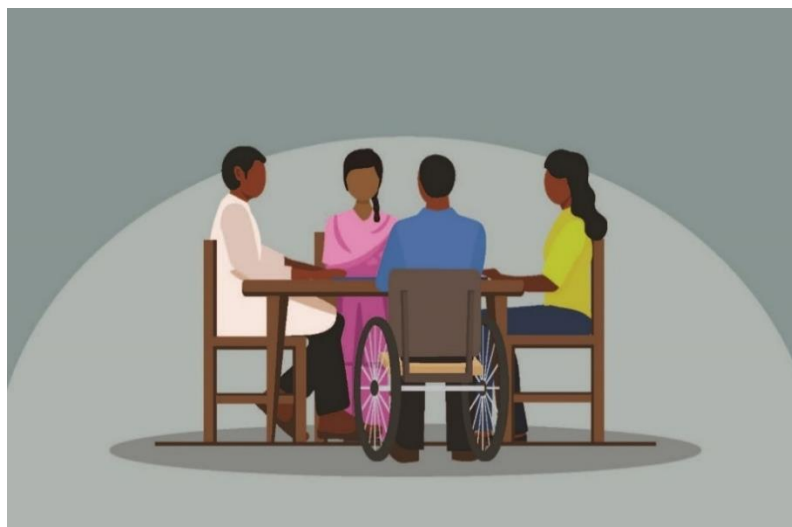
The review has led to a set of recommendations for future social inclusion programmes. This includes using social behaviour change frameworks to more systematically analyse and influence negative behaviours and social norms that drive stigma and discrimination.

- develop a theory of change underpinning the proposed intervention(s) and clearly articulate the intervention logic, for instance, how the proposed interventions are expected to work to tackle specific stigma drivers and contextual factors.

- measure the effectiveness of interventions using rigorous methodologies and validated tools, including sub-analysis of data on the effect for different population subgroups (for example, by sex, age, residency). It can be useful to integrate rigorous methods within different stages of the project cycle, including formative research, baseline measurement, monitoring and evaluation.

- continue to explore how different conceptual and analytical frameworks can help understand and explain disability-related stigma and discrimination as defined by the UNCRPD, and seek to use empirical evidence generated through programmes to review and refine those frameworks, to improve their applicability to the settings in which Sightsavers works.

- share findings widely and encourage others to use standardised tools to measure stigma and discrimination and to share results on the effectiveness of interventions across different settings.

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Learn more about this area of research

- **Read the full report here**
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