



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

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Executive summary

Introduction

Sightsavers is an international non-governmental organisation (INGO) working to eliminate avoidable blindness and promote equal opportunities for people with disabilities. Addressing stigma and discrimination directed at people with disabilities 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 interventions to mitigate their impact in the contexts of our programmes.

This report presents a systematic literature review undertaken to understand the extent, quality and findings of published and unpublished literature on interventions designed to tackle disability-related stigma and discrimination in sub-Saharan Africa and south Asia.

For the purpose of this review we follow the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and define persons with disabilities as “those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.⁽¹⁾

In academic literature, stigma is described as an “attribute that is deeply discrediting”⁽²⁾ and as a mark separating individuals from one another based on a socially conferred judgement that some persons or groups are tainted and “less than”.⁽³⁾ For discrimination, we follow Rohwerder’s definition of 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.⁽⁴⁾

The Sightsavers’ Social Inclusion Strategy refers to addressing stigma and discrimination as a key step on the pathway to equitable inclusion for people with disabilities. In our programmatic work, we target both stigma and discrimination and often use the two terms together. However, we recognise that stigma and discrimination are two associated but distinct concepts that can feed and reinforce each other.⁽⁵⁾ Commonly, stigma is often described through negative attitudes and stereotypes, while discrimination refers to unjust treatment. However, stigma can also refer to negative behaviours and practices (either anticipated or experienced), and in this sense is closely related to the term “discrimination”. In addition, some literature distinguishes between discriminatory practices, which fall within the purview of the law (referring to these as discrimination) and those that are outside the legal purview (referring to these as experienced stigma).

A number of systematic and literature reviews have recently been conducted on stigma and discrimination associated with specific types of impairments or health conditions, or among specific sub-populations, such as children.^(4, 6, 7) 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 specific countries.

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 set of objectives focused on understanding the individual, interpersonal, organisational, community and public policy factors that are associated with stigma and discrimination. We sought to identify the various ways in which stigma and discrimination have been reported to manifest, the extent and range of their outcomes on the lives of people affected, and how they may intersect with other individual characteristics and types of stigma. Finally, we sought to identify toolkits and good practice guidelines for addressing stigma and discrimination, as well as validated tools and metrics for measuring them.

Methods

We searched for peer-reviewed literature from a wide range of electronic databases and supplemented these with screening references and grey literature searched through websites of bilateral and multilateral agencies, INGOs, organisations of people with disabilities (OPDs), and academic institutions. Driven by the context of Sightsavers' programmatic work, for the purpose of the review, we focused on evidence from any country of sub-Saharan Africa and three countries in south Asia, India, Bangladesh, and Pakistan.

Two reviewers independently reviewed the sources we identified against a list of pre-defined inclusion criteria. This was followed by the extraction of data and assessment of the quality of the papers that met the inclusion criteria. The quality appraisal checklist was developed based on the Critical Appraisal Skills Programme (CASP) checklists for different study design⁽⁸⁾.

We synthesised the findings narratively, using an analytical framework based on a number of earlier frameworks described in the literature, specifically by Stangl et al;⁽⁹⁾ Weiss;⁽¹⁰⁾ and van Brakel et al.⁽¹¹⁾ In this review, we distinguish between two groups involved in stigma related interactions: those who are stigmatised and those who are stigmatisers, recognising that some people may belong to both groups. We also differentiate between stigma, which is felt (perceived or anticipated), stigma that is enacted (or experienced), internalised (self) stigma, associated (secondary) stigma, and compound stigma arising from intersectionality of disability with other individual characteristics.

Results

The database search yielded a total of 412 records, and an additional 7,193 records were identified through other searches. After excluding duplicates, a total of 7,544 unique records were included in sifting against inclusion criteria (p.19) and a total of 82 papers were eligible for inclusion in the review.

Characteristics of included studies

Out of 82 included papers, 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 outcomes was measured and quantified. Among the 71 papers describing primary data, the largest proportion of studies was from India (n=16, 22.5%), and a third of papers described stigma related to mental health (n=23, 32.4%). Thirty-four (47.9%) studies were found to be at high risk of bias, implying significant methodological flaws. Twenty (28.2%) were at medium risk of bias, and only 17 (23.9%) were at low risk of bias.

Factors leading to stigma and discrimination

Among 34 papers that reported factors leading to stigma and discrimination, the majority (n=17/34, 50%) were qualitative studies followed by cross-sectional surveys (n=13/34, 38.2%), mixed methods studies (n=3/34, 8.8%), and one case-control study (2.9%). 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. These were reported in studies 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 of people with disabilities due to perceived dangerousness.

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) cultural and social norms; iii) socio-economic environment and availability of services; and iv) accountability and empowerment.

Manifestations of stigma and discrimination

For the purpose of the review, 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. The 40 papers that described these manifestations referred to different types and sources of stigma and mainly used qualitative methods (n=19/40, 47.5%).

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 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. But 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 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.

A broad range of study designs was used to evaluate the effectiveness of interventions described. The largest proportion of studies that tested the effectiveness of stigma related interventions were: before and after design with no control group (n=6/19, 31.6%), or quantitative, qualitative or mixed method cross sectional studies (n=6; 31.6%). Other designs were control trial – four randomised, one non-randomised (total n=5; 26.3%); one prospective cohort (5.3%); and one case study (5.3%).

Education and training interventions were reported in eight studies from Nigeria (n=2), Ethiopia (n=1), Kenya (n=1), Tanzania (n=1), Malawi (n=1), Rwanda (n=1), and Bangladesh (n=1). The studies targeted stigma related to HIV/AIDS (n=4), epilepsy (n=1), mental health (n=1), autism (n=1), and disability in general (conditions unspecified) (n=1). 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.

Communication, persuasion and modelling group included five studies from Ethiopia (n=1), Malawi (n=1), India (n=1), Nigeria (n=1), and Kenya (n=1). The studies addressed stigma related to epilepsy (n=1), HIV/AIDS (n=1), schizophrenia (n=1), and intellectual impairments (n=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 the positive effect of the intervention and one study had mixed results. Among the studies that showed 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 medium risk of bias.

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).

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. These documents had either a global focus or looked at specific countries, including Uganda, Mozambique, Ethiopia, Zambia, Tanzania, Togo, Bangladesh, and India. 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’. The paper focused on comparing and testing the validity and reliability of several scales related to different aspects of stigma, for example, the Participation Scale, the General Self-Efficacy Scale, Internalised Scale of Mental Illness, Berger Stigma Scale, Social Distance Scale, and others.

Conclusion

Despite the methodological limitations of the studies identified in the literature and other sources, this systematic review has a number of implications for Sightsavers’ programme design and for the global disability research community more broadly. First, the review provides an overview of what is currently known about stigma related interventions and where the knowledge gaps are, highlighting the scope and focus for future research. Second, the review presents frameworks for understanding stigma drivers that need to be addressed, when developing projects to tackle stigma and discrimination. Third, the review identifies a range of tools and approaches for measuring different aspects of stigma and its outcomes, providing a useful basis for evaluation studies. Finally, the review confirms the

complexity and heterogeneity that surrounds stigma and discrimination, which provides a useful basis for furthermore nuanced research into linkages between different types of stigma (for example, internalised, felt and enacted), as well as the complex relationships between the stigmatisers and those who are stigmatised.

This review can help to inform the design of future social inclusion programmes. We have made a number of recommendations that need to be taken into account in the design, implementation and monitoring and evaluation of future programmes, which aim to tackle disability related stigma and discrimination:

- 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.
- Articulate the type of stigma and/or discrimination the intervention aims to address and the population groups it aims to target.
- 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; and ensure that the formative analysis and subsequent intervention design is validated and interrogated by the relevant stakeholders, taking into account the impact of intersectionality.
- Use Social Behaviour Change (SBC) frameworks, for example, the **Behaviour Change Wheel**, to more systematically analyse and influence negative behaviours and social norms which drive stigma and discrimination.
- Clearly articulate intervention types and enabling categories and their aims or intentions to influence a diversity of drivers, contextual factors, and manifestations of stigma.
- Develop a theory of change underpinning the proposed intervention(s) and clearly articulate the intervention logic, such as 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); and integrate rigorous methods within different stages of the project cycle, including formative research, baseline measurement, monitoring and evaluation.
- 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.

Introduction

Sightsavers is an international non-governmental organisation (INGO) working to eliminate avoidable blindness and promote equal opportunities for people with disabilities. We work in sub-Saharan Africa and south Asia, in partnership with governments, civil society and other stakeholders to deliver effective, efficient and equitable development programmes.

Addressing stigma and discrimination directed at people with disabilities is fundamental to our social inclusion programmes and is one of three pathways in the Theory of Change of our Social Inclusion Strategy.⁽¹²⁾ In order to guide our programme design and implementation, it is critical for us to develop a good understanding of factors that lead to the stigmatisation of and discrimination towards people with disabilities in the contexts of our work.

Research and evidence are key aspects of Sightsavers' approach to delivering effective advocacy and programmes and we consider it critical to collect and appraise evidence relevant to what we do. It is particularly important for us to understand the evidence on practices and interventions, which have shown to be effective in reducing disability related stigma and discrimination at individual, family, community and institutional levels. Rather than re-invent the wheel, we try to understand what has worked in addressing stigma and discrimination and why and conversely, what approaches have failed and why.

This report presents a systematic literature review undertaken to understand the extent, quality and findings of published and unpublished literature on interventions designed to address disability related stigma and discrimination in sub-Saharan Africa and south Asia. The evidence presented will inform recommendations for the design, monitoring and evaluation of Sightsavers' programmes for improving the social inclusion of people with disabilities in sub-Saharan Africa and south Asia.

Concept of disability

Disability is a complex phenomenon understood and defined differently in different settings. For the purpose of this review, “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.⁽¹⁾

The World Health Organization (WHO) estimates that in 2010, approximately 15 per cent of the global population lived with some form of disability; the prevalence of disability is higher among women, older people and those living in low and middle income countries (LMICs).⁽¹³⁾

Evidence from primary research consistently shows that persons with disabilities experience disadvantages in terms of poorer health outcomes, limited access to essential services, and exposure to stigmatising attitudes and discriminatory practices.^(13, 14)

Because of the diverse conceptualisations and definitions of disability within the literature, for the purpose of this review we sought to engage an inclusive definition that would allow us to draw on as broad a range of experiences as possible. As well as searching for studies related to ‘disability’ and physical, intellectual, or sensory impairments, we also sought to

include studies focusing on health conditions that can be disabling, including any mental health or neurological conditions, HIV/AIDS, leprosy, epilepsy, cerebral palsy, and albinism.

Concept of stigma and discrimination

The concept of stigma is not consistently described in the literature, reflecting its complex and diverse nature across settings.^(10, 15) The Cambridge English Dictionary defines stigma as a bad opinion of a person or a group of people arising from a strong feeling of social disapproval⁽¹⁶⁾. In academic literature, stigma is described as an “attribute that is deeply discrediting”⁽²⁾ and as a mark separating individuals from one another based on a socially conferred judgement that some persons or groups are tainted and “less than”.⁽³⁾ Stigma often leads to negative beliefs (such as stereotypes), the endorsement of those negative stereotypes as real (prejudice), and a desire to avoid or exclude persons who hold stigmatised statuses (discrimination).⁽¹⁷⁾ Stigma is related to problems of knowledge (ignorance), attitudes (prejudice), and behaviour (discrimination)⁽⁵⁾. It exists when labelling, stereotyping, separating, status loss, and discrimination occur together in a social, economic and political power situation that allows them.⁽¹⁵⁾

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.⁽⁴⁾ The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), a legal framework which defends and reinforces the human rights of persons with disabilities, defines disability related discrimination as “any distinction, exclusion or restriction on the basis of disability, which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field”.⁽¹⁾ To date, 175 countries had signed the CRPD and 160 of these have ratified it, equating the convention rulings with national law.⁽¹⁸⁾

The Sightsavers’ Social Inclusion Strategy recognises that negative stereotyping and stigma lead to discrimination, and understanding and influencing the root causes of these negative behaviours is critical to ensure greater inclusion and sustainable positive change for people with disabilities. The above definitions highlight that stigma and discrimination are distinct but strongly associated concepts that can feed and reinforce each other.

Analytical frameworks of disability-related stigma and discrimination

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

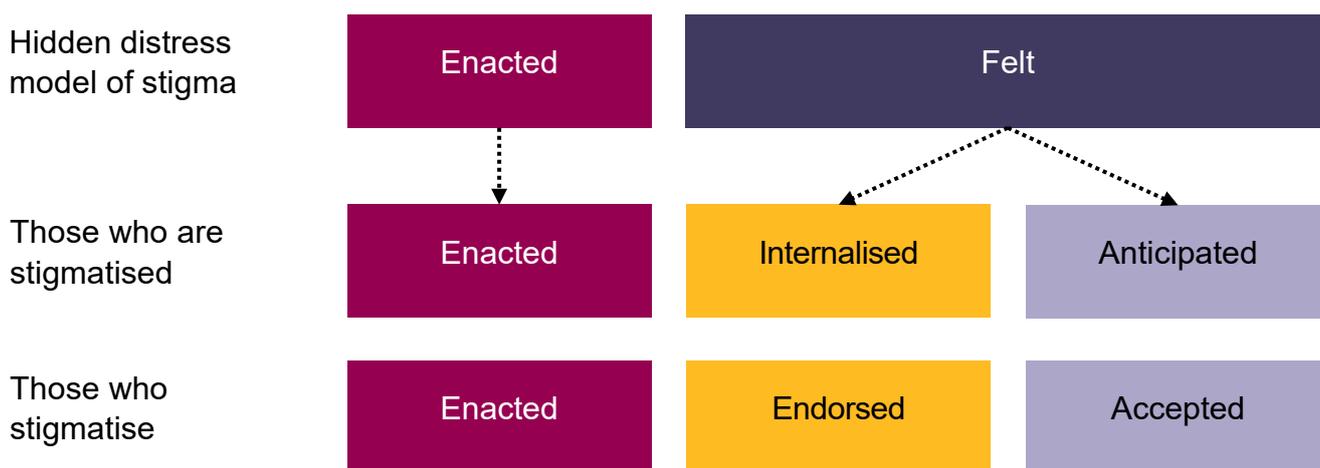
Some of the earliest studies of health-related stigma from the 1950s were among patients living with leprosy in Africa, Asia, the Pacific Islands, and the United States. These studies described the mistreatment of people with leprosy, highlighting misinformation that sparked fear and superstitious beliefs about the disease.⁽¹⁹⁾ Some of these early studies also ascribed this observed stigma to the limited abilities of science to adequately challenge

prevalent misconceptions and associations of the disease with poverty and social disadvantage.^(20, 21)

In the 1960s, the sociologist Erving Goffman, developed a theory of stigma centred on social interaction and exclusion, and the notion of deviance. Goffman distinguished between felt and enacted stigma – the former is the feeling of being discriminated against and the latter is the act of stigmatisation through discrimination.⁽²⁾ Goffman’s ideas were taken further by Graham Scambler in his studies of epilepsy. Scambler developed the ‘Hidden Distress Model’ and argued that felt stigma is typically more disruptive to the lives of people with epilepsy than enacted stigma.⁽²²⁻²⁴⁾

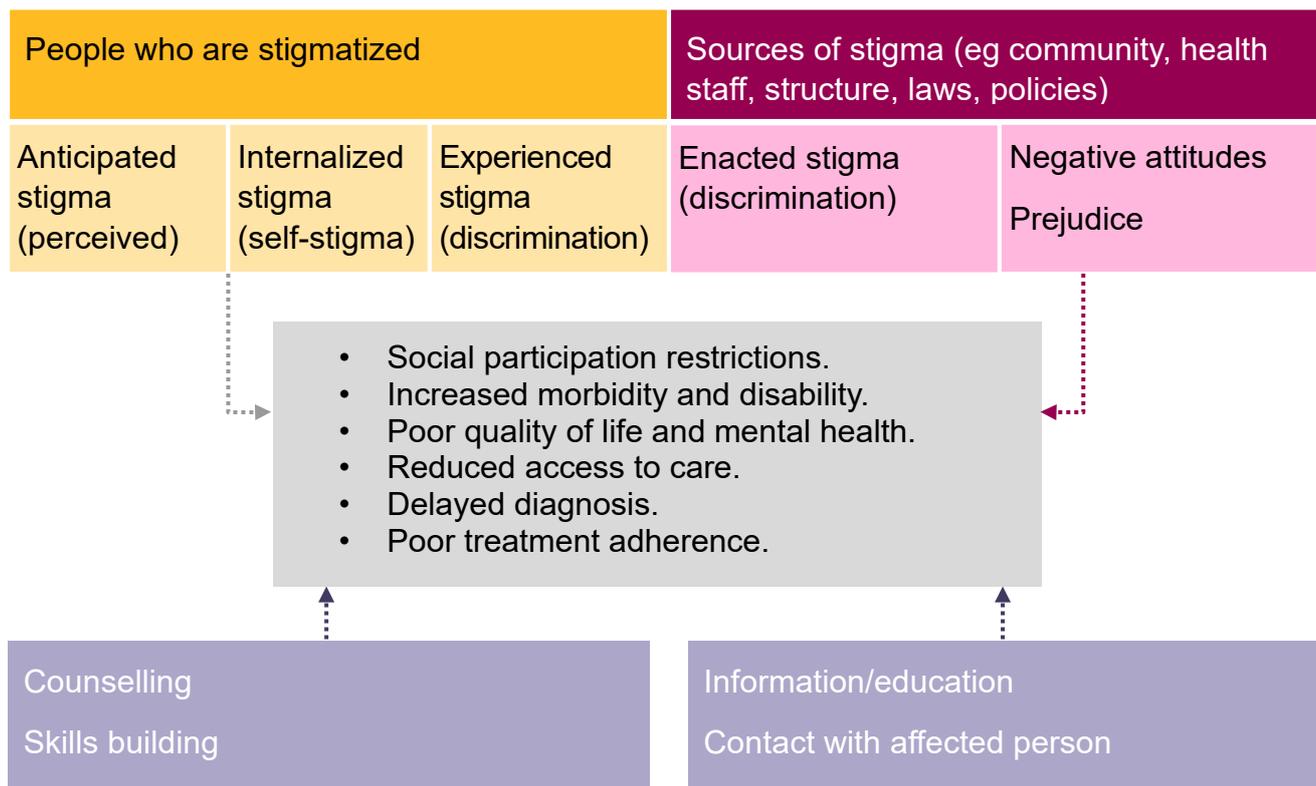
Scambler’s model was modified by Weiss in studies of stigma related to neglected tropical diseases (NTDs).⁽¹⁰⁾ In this model, the distinction between enacted and felt stigma has been further elaborated by differentiating anticipated stigma, for instance, regarded as unjustified but likely and internalised stigma. The latter refers to a process in which a person with a stigmatised condition internalises the stigma and associated social exclusion. The model differentiates two types of disability-related stigma: that of the person who is stigmatised, felt, or perceived stigma; and that of those who stigmatise, enacted stigma (Figure 1).

Figure 1: Extending Scambler’s Hidden Distress Model of stigma⁽¹⁰⁾



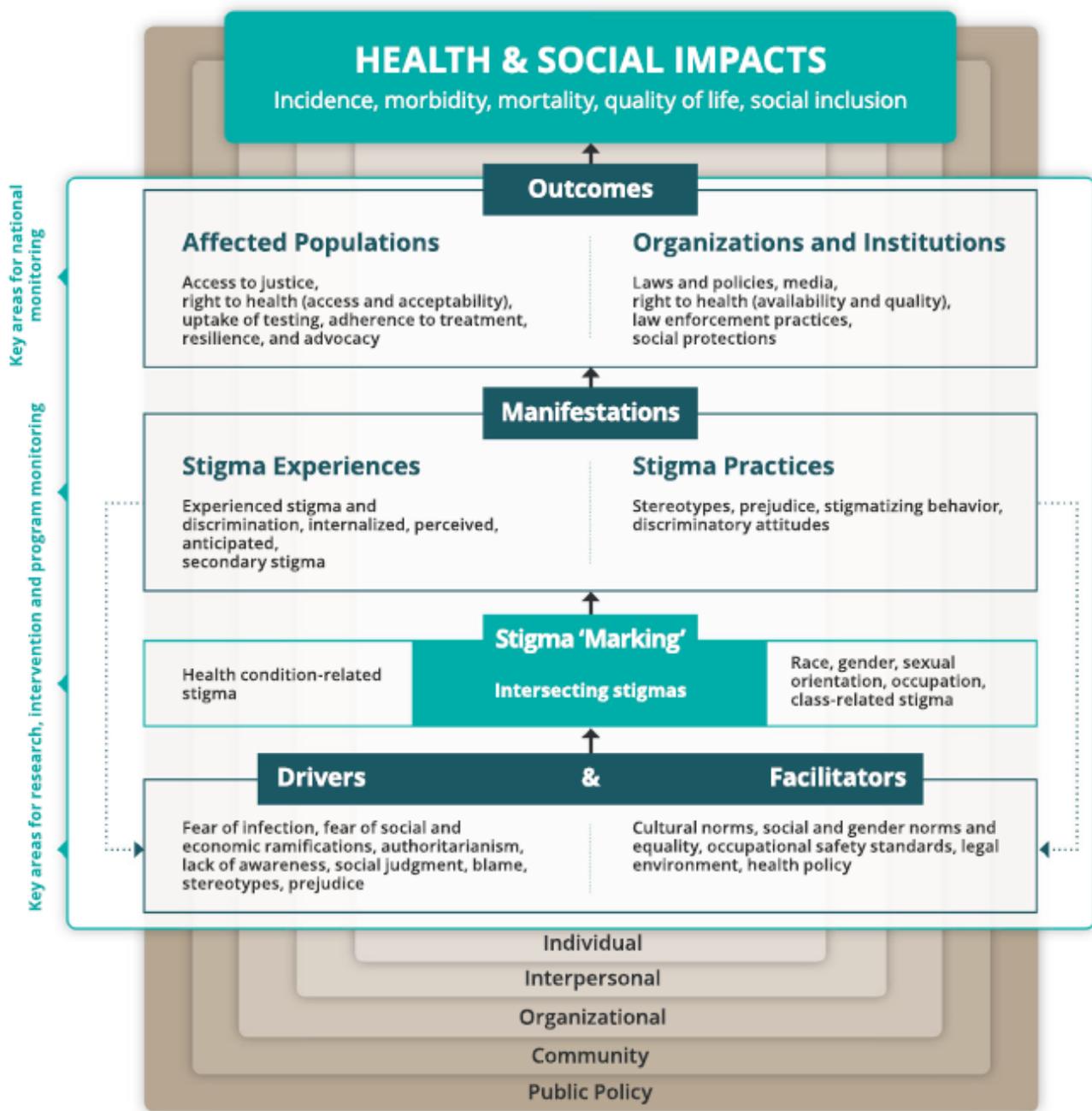
The model by Weiss has been further modified by van Brakel et al,⁽¹¹⁾ who demonstrated the cross-cutting nature of health-related stigma using data from studies of leprosy, HIV/AIDS, tuberculosis, mental illness, inflammatory bowel disease, obesity, cancer, and disability more broadly, which refers to limitations resulting from complex interactions between an impairment (often unspecified) and inaccessible environment. This model also differentiates the two perspectives – that of persons who are being stigmatised, and that of those who stigmatise – and further recognises that people may belong to both categories (Figure 2). This model describes different types of stigma (anticipated, internalised, attitudinal, experienced, and enacted), and defines ‘discrimination’ as a type of stigma, which is either experienced or enacted.

Figure 2: Stigma-related model modified from Weiss.⁽¹¹⁾ (Image reproduced under the Creative Commons License <https://creativecommons.org/licenses/by/4.0/>.)



Another recently developed 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.⁽⁹⁾ The framework articulates the stigmatisation process across the socio-ecological spectrum, from the individual through 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 a range of outcomes for affected populations and result in a range of negative health and social impacts (Figure 3).

Figure 3: Health stigma and discrimination framework.⁽⁹⁾ (Image reproduced under the Creative Commons License [https://creativecommons.org/licenses/by/4.0/.](https://creativecommons.org/licenses/by/4.0/))



For the purpose of this review, we use the following definitions of stigma related concepts:

- Factors leading to stigma** refer to drivers and facilitators of stigma articulated in the Stangl et al framework.⁽⁹⁾ Drivers are inherently negative beliefs and emotions about disability that can result in negative attitudes and stigmatising and discriminatory behaviours. Facilitators are contextual factors, which can be both positive and negative and can either facilitate or mitigate the adoption of these attitudes and behaviours. We do, however, acknowledge that the distinction between the two types of factors in many studies and in real life settings can be blurred.

- **Stigma manifestations** refer to a range of feelings, beliefs and attitudes (felt/perceived/anticipated realities) and shown or experienced behaviours and practices (lived realities). In the context of this review:
 - **Felt or perceived stigma** refers to perceptions about how stigmatised groups are treated in a given context, which can be expressed by stigmatisers and those who are stigmatised.
 - **Enacted (or experienced) stigma** refers to how stigma is experienced by people subject to stigmatising or discriminatory attitudes and behaviours.
 - **Internalised or ‘self-stigma’** refers to a stigmatised person’s own adoption of negative beliefs and feelings related to their disability, as well as the social devaluation associated with their stigmatised status.
 - **Secondary or ‘associated’ stigma** refers to the experience of stigma by those close to people with disabilities, which may include family members, friends or health care providers.
- **Stigma outcomes** refer to adverse effects of stigma on the health and quality of life of affected individuals, as well as their social relationships, and access to resources, services, and economic opportunities.
- **Intersecting stigma** occurs when people are ‘marked’ with multiple stigmas.⁽²⁵⁾

Previous reviews

To the best of our knowledge, no systematic reviews have previously examined stigma and discrimination in relation to disability broadly and across all population groups. However, a number of systematic and literature reviews have been conducted on stigma and discrimination associated with specific types of impairments or health conditions, or among specific sub-populations.

In 2020, Smythe et al published a systematic review of interventions to reduce stigma and discrimination towards children with disabilities and their families in LMICs,⁽⁶⁾ which included 20 studies. About 63% of all reported interventions targeted enacted stigma and the most common approach was education/training (63%). About 54% of interventions were delivered at the organisational/intuitional level and only four studies targeted more than one level. The most common condition targeted was epilepsy, followed by intellectual impairments. There was some evidence of the effectiveness of interventions in reducing stigma; however, most included studies were rated as poor quality.

A recent rapid literature review of disability-related stigma in developing countries by Rohwerder focused on drivers of stigma.⁽⁴⁾ The included studies were mainly from sub-Saharan Africa and reported three main groups of drivers: i) lack of understanding of causes of disability; ii) misconceptions about the nature of disability and capacities of people with disabilities; and iii) discriminatory legislation and policies.

Another systematic review conducted in 2017 was a meta-review of 98 systematic reviews, which focused on stigma towards people with HIV/AIDS, mental health conditions, and

physical impairments.⁽⁷⁾ This review showed that the majority of systematic reviews were disease specific and the largest proportion focused on mental health (61%, n=60), followed by HIV/AIDS (34%, n=34), with only three reviews conducted on stigma related to other physical impairments (3%). One review (1%) looked at stigma across several health conditions, including leprosy, tuberculosis, and epilepsy. Nearly half (47%) of the reviews discussed more than one stigma type. Across all health conditions, 78.5% of the reviews examined intrapersonal stigma, 48% looked at interpersonal stigma, and 3% focused on stigma at the organisational or public policy levels.

Primary studies included in the reviews were from 60 different countries with all continents represented, except Antarctica. Mental health reviews were predominantly from high-income settings with 10 reviews focusing on Africa and Asia. Sixteen out of seventeen HIV/AIDS related reviews included primary studies conducted in Africa and Asia. Among three physical impairment related reviews, one included primary studies conducted in Africa. Interventions to manage, reduce or prevent stigma were included in 36% (n=35) of the reviews. These primarily targeted mental health-related stigma (74%, n=26), followed by stigma related to HIV/AIDS (23%, n=8) and physical impairments (3%, n=1). Most reviews reported behavioural interventions with psychoeducation, information sharing and/or social contact the most common approaches.

Other identified reviews examined stigma and discrimination related to individual factors (for example, among sex workers, or men who have sex with men); characteristics or specific health conditions and included broad scoping reviews; theory development; reviews of definitions and metrics; evaluations of interventions; and reviews of the economic impact of stigma and discrimination.⁽²⁶⁻³¹⁾

A report by InterAction published in June 2020 looked at how stigma experienced by people with intersecting vulnerabilities, arising from racial, ethnic, religious or disability characteristics, affected their ability to access health services during the COVID-19 pandemic and led to further marginalisation and discrimination.^(32, 33) The report recommends anticipation and mitigation of stigma in COVID-19 response and other humanitarian efforts.

Study objectives

The aim of this systematic review was to identify, appraise and synthesise evidence on interventions to address disability related stigma and discrimination in sub-Saharan Africa and south Asia. In south Asia, we focused on evidence from the three countries where Sightsavers implements social inclusion programmes: India, Bangladesh, and Pakistan.

The primary focus of this review was on interventions to tackle disability related stigma and discrimination and their effectiveness. The secondary set of objectives focused on factors leading to stigma and discrimination, stigma manifestations and stigma measurement and metrics.

Research questions

The specific research questions this review sought to answer are defined below:

1. What are the factors leading to disability-related stigma and discrimination, and which can be characterised as drivers, and which as contextual facilitators?
2. What interventions to reduce disability-related stigma and discrimination have been identified and evaluated, and were they effective?

As a result of answering the above, the authors used the identified data to answer the additional following questions:

1. How do disability-related stigma and discriminatory behaviours manifest in the reviewed studies?
2. What other types of stigma have intersected with disability-related stigma to produce a unique experience for those individuals?
3. What are the outcomes of disability-related stigma and discrimination?
4. What toolkits exist to tackle stigma?
5. What tools and approaches exist to measure and monitor change in disability stigma and discrimination?

Methods

Search strategy

We searched for peer-reviewed literature from electronic databases, including EBSCO, CINAHL, EMBASE, PsycINFO, ProQuest, PubMed, the Campbell Collaboration, IDEA and ELDIS from inception to November 2019. We supplemented this data with grey literature through a search of relevant websites, including the International Centre for Evidence in Disability; Make Every Woman Count; different Organisations of People with Disabilities (OPDs) and networks; and different INGOs, including Sightsavers, Humanity and Inclusion, Leonard Cheshire Disability, Sense International, CBM, ADD International and others. We also contacted authors/experts in the field for further relevant studies, and screened references of included studies and existing systematic reviews. We did not restrict searches by language, study setting, date of publication, or publication status. The full description of our search strategies can be found in Appendix 1.

Sifting and selection

Full-text articles were reviewed by two authors independently against the inclusion criteria listed below. Disagreements around eligibility for inclusion were resolved through discussions. Studies selected for inclusion met all of the following criteria:

- Contained primary data relevant to our primary research questions and/or guidelines on how to reduce disability-related stigma and discrimination or how to measure it.

- Focused on people with physical, intellectual, or sensory impairments or disabling health conditions, including any mental health or neurological conditions, HIV/AIDS, leprosy, epilepsy, cerebral palsy, albinism.
- Conducted in any country of sub-Saharan Africa and/or in India, Pakistan, and Bangladesh.
- Published after 2006, as this is the year when the UNCRPD was adopted and when many governments formally undertook a commitment to focus on equality and non-discrimination.
- Written in English, French or Portuguese. These were the languages accessible to the review team.

Data extraction and quality assessment

Two reviewers independently extracted data and assessed the quality of the papers that met the inclusion criteria. The data extraction and quality appraisal tools were developed by the authors to suit the needs of this review, based on existing tools. The quality appraisal checklist was developed based on the Critical Appraisal Skills Programme (CASP) checklists. The CASP checklists are available for eight different study designs. Our review used those for qualitative research, randomised control trials, surveys, case control studies and cohort studies⁽⁶⁾ to ensure each study was appraised on appropriate merits.

The CASP checklists do not produce directly comparable quality assessments across all study designs, and thus we adapted our quality appraisal checklist and developed an overall measure of study quality, or risk of bias (methodology available from the authors). The overall measure scoring system is shown in Table 1. The critical appraisal tools were piloted with three studies by two reviewers independently to ensure validity and reliability. Methodological quality was only assessed for studies containing primary data. Documents, which included information on how to measure stigma/discrimination and guidelines on how to address it were not assessed for quality.

The data extraction form was organised according to our research questions and piloted with three papers by two reviewers, independently. The form included information about the study, its design, participants, interventions, changes in stigma or discrimination, stigma manifestations, and/or impact and factors leading to or associated with it. Among studies reporting interventions, as per Smythe et al,⁽⁶⁾ we classified intervention effectiveness as 'positive' (evidence of statistically significant improvement in all stigma/discrimination-related outcomes), negative (evidence of statistically significant deterioration in all stigma/discrimination-related outcomes), 'null' (no statistically significant changes), or mixed (a mix of 'positive' and 'negative'/'null' changes).

Table 1: Overall risk of bias assessment criteria for included studies

Overall risk of bias assessment	Scoring profile
Low risk of bias	8+ 'yes' answers
Medium risk of bias	6-7 'yes' answers
High risk of bias	5 or less 'yes' answers

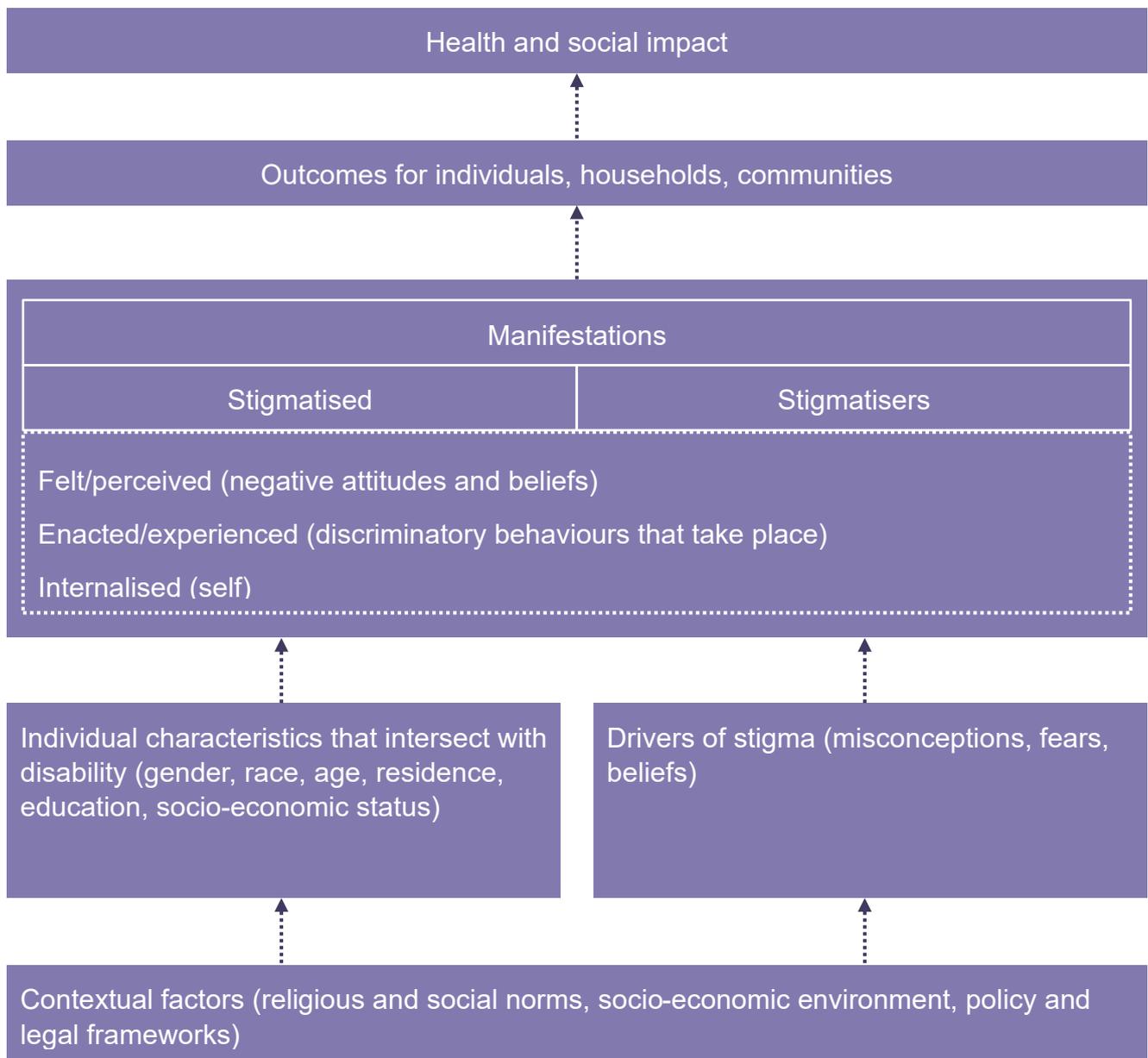
Data synthesis and analytical framework of the review

Findings of included data sources were synthesised narratively. For the purpose of this review, we drew on the health-related stigma analytical framework discussed above, developed by Stangl et al⁽⁹⁾ and Weiss,⁽¹⁰⁾ with adaptations from van Brakel et al.⁽¹¹⁾

We distinguish between factors leading to stigma, manifestations of stigma, and stigma outcomes and effectiveness of interventions designed to reduce stigma. We also distinguish between two groups involved in stigma-related interactions: those who are stigmatised and those who are stigmatisers, recognising that some people and groups (including people with disabilities themselves) may belong to both categories. We also differentiate between stigma, which is felt (perceived or anticipated) and stigma that is enacted (or experienced).

There is also internalised (self) stigma, associated (or secondary) stigma, and compound stigma arising from intersectionality of disability with other individual characteristics to produce a compound effect (Figure 4).

Figure 4: Analytical framework used in this study

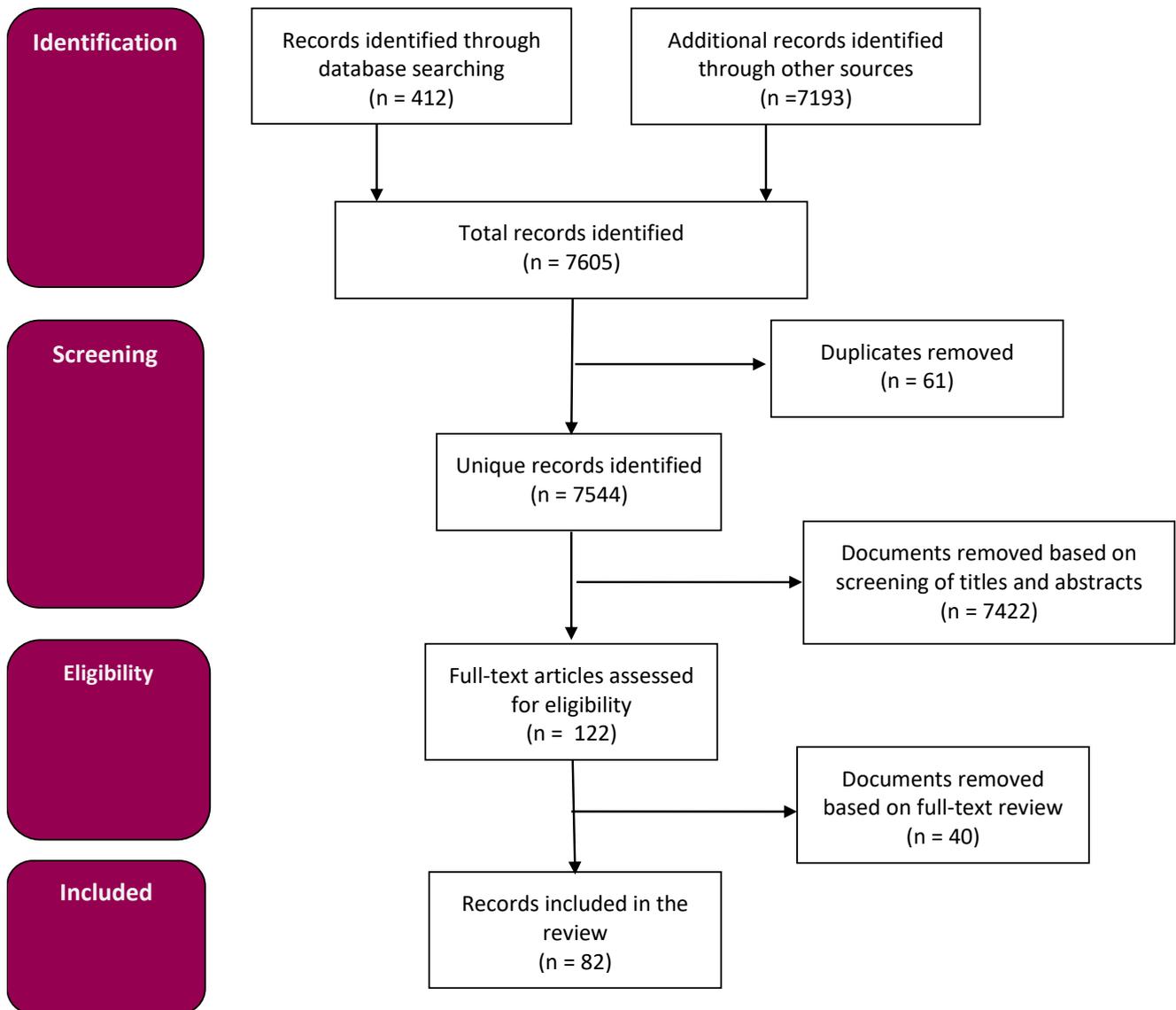


Results

The database search yielded a total of 412 records, and an additional 7,193 records were identified through other searches. After excluding duplicates, a total of 7,544 unique records were taken for sifting. After screening the titles and abstracts, 7,422 documents were removed, leaving 122 eligible for full text review. Following full text review, 40 documents were removed, leaving a total of 82 papers eligible for inclusion in the review (Figure 5). The main reasons for exclusion were i) outcomes of stigma and discrimination related to the study focus area were not addressed by the document; ii) it was published before 2006; iii)

conducted in settings other than sub-Saharan Africa, India, Bangladesh, and Pakistan. No studies were identified in languages other than English.

Figure 5: A flow diagram of the sifting process



Characteristics of included studies

Out of 82 papers included in the review, 71 included primary data and 11 documents contained toolkits and/or measurement metrics with no primary data reported.

Among the 71 sources reporting primary data, 34 documents reported factors which contributed to stigma; 40 documents described stigma manifestations; 22 reported stigma and discrimination outcomes; 20 papers documented intersecting stigmas, and 19 papers reported the effect of interventions to reduce stigma or discrimination (non-exclusive

categories).

Study design

A broad range of study designs were used to evaluate the effectiveness of different interventions designed to reduce stigma or discrimination; not all may be appropriate for such an aim. The largest proportion of studies that tested the effectiveness of stigma-related interventions were before and after design with no control group (n=6/19, 31.6%), or quantitative, qualitative or mixed method cross sectional studies (n=6; 31.6%). Other designs were control trials: four randomised, one non-randomised (total n=5; 26.3%); one prospective cohort (5.3%); and one case study (5.3%).

Studies that reported stigma manifestations were mainly of qualitative design (n=19/40, 47.5%), cross-sectional surveys (n=12/40, 30%) and mixed methods studies (5/40, 12.5%). Other designs were case-control studies (n=2); before and after (no control) studies (n=1); and a randomised control trial (n=1).

Papers that reported factors leading to disability stigma included qualitative studies (n=17/34, 50%); cross-sectional surveys (n=13/34, 38.2%) and mixed methods studies (n=3/34, 9.8%); and one case control study (n=1/34; 2.9%)

Study settings

The largest proportion of papers reported data from India (n=16), followed by South Africa (n=8); Malawi (n=7); Ethiopia (n=6); Nigeria (n=6); Bangladesh (n=4); Kenya (n=4); Tanzania (n=4); Uganda (n=3); Ghana (n=2); Sierra-Leone (n=1); Cameroon (n=1); Rwanda (n=1); and Zambia (n=1). A further seven studies reported multi-country studies: Kenya and Nigeria; two reports from Togo, Sierra Leone, Niger and Guinea; Lesotho, Malawi, South Africa, Swaziland, Tanzania; Kenya, Pakistan, Rwanda, (Indonesia, Brazil, Turkey); Ethiopia, India, Nepal, Nigeria, South Africa, Uganda; and, Cameroon, Ethiopia, Senegal, Uganda, Zambia.

Study populations

The largest proportion of studies with primary data described stigma and discrimination related to mental health (n=23, 32.4%). In many studies, mental health conditions were not specified; in those where they were, the majority was on schizophrenia. The second most common disability-related health condition studied was HIV/AIDS (n=15), followed by leprosy (n=6), epilepsy (n=5), and intellectual disability (n=4). Other health conditions explored included albinism, autism, cerebral palsy, spina bifida and hydrocephalus, and stroke. Eight papers referred to either different impairments or disability in general.

Quality assessment

A total of 71 studies included primary data and thus were eligible for quality assessment. Based on methodology described in the papers, the majority of studies were judged to be of high risk of bias, or poor quality. Among studies that described manifestations of stigma, 11

were deemed to be at low risk of bias, or high quality, 10 were medium risk of bias (medium quality) and 19 were high risk of bias (low quality). Among papers that described factors contributing to stigma, 12 were deemed to exhibit low risk of bias, six were at medium risk of bias and 16 were at high risk of bias. Among studies that described interventions, three were low risk of bias, six were medium and ten were high risk of bias (Table 2, some studies report primary data in multiple categories).

One of the reasons for attributing high risk of bias, or poor quality, was the lack of methodological detail provided by authors (for example, on sampling, recruitment of participants, tools, and so on). Other studies reported themselves significant limitations with regards to their chosen study design, for example, with regards to sampling (such as recruitment or allocation of participants) or control for counterfactual (where applicable), which impacted on the validity of their findings. These limitations were often acknowledged by the authors and noted as issues that were beyond their control.

Table 2: Overall quality of studies which contained primary data

	Interventions	Factors contributing to stigma	Manifestations of stigma
Low risk of bias, high quality	3	12	11
Medium risk of bias	6	6	10
High risk of bias, poor quality	10	16	19
Total	19	34	40

Factors leading to stigma and discrimination

A total of 34 papers provided information on factors leading to stigma. Out of these, 27 documents reported drivers of stigma – that is, negative emotions and beliefs about disability leading to negative attitudes and behaviours; and 27 documents reported on contextual factors, which influenced the adoption of such attitudes and behaviours. The majority of papers⁽¹²⁾ addressed stigma related to mental health; six each were on HIV/AIDS and ‘disability’ generally; three were on epilepsy; two each on leprosy and albinism; and one each on cerebral palsy, developmental disorders and post-stroke impairments.

Drivers of stigma and discrimination

Five main drivers of stigma and discrimination were reported across 27 studies, with a significant degree of interrelations between them. These were i) poor understanding of impairments and their causes; ii) not knowing someone with a disability; iii) othering people with disabilities; and two types of fears: iv) the fear of being “infected” and v) the fear of people with disabilities due to perceived unpredictability or danger. The studies reported data

from 14 countries.

Poor understanding and misconceptions about the causes of impairments

Poor understanding of impairments and their causes, and misconceptions and myths were the key drivers of stigma reported in the studies reviewed.⁽³⁴⁻⁴¹⁾ Interestingly, although the knowledge and understanding of impairments was linked to stigma in many papers, the relationship between them was nuanced and varied depending on the setting, the type of impairment and the studied group.

In many studies, a significant proportion of participants (both people with disabilities and the general public) were aware of specific health conditions or impairments and the ways to manage them. Yet, a significant proportion would report misconceptions (rooted in beliefs about sin, spirits or the supernatural) related primarily to their causes. For example, a study of epilepsy-related stigma in Delhi, India, showed that the knowledge of the disease among people with epilepsy was high: 94% of participants had heard about the disease; over 91% knew that it could be treated with modern medicines; and over 97% would take a person experiencing an epileptic seizure to hospital. About 55% of respondents correctly referred to the disease as a brain disorder. The proportion of respondents who related epilepsy to supernatural causes was smaller but considerable: one in five thought that the disease was caused by ancestors' sins and the same proportion believed that the disease could be treated by traditional healers.⁽⁴²⁾

Another study of epilepsy-related stigma in India was conducted among secondary school students in Bareilly district of Uttar Pradesh. In this study, over 63% of respondents said that epilepsy was a brain disorder and less than 5% believed that it was caused by an evil. However, nearly half of the respondents (49%) thought the disease was due to eating pork or non-vegetarian food.⁽⁴³⁾

A study of mental health-related stigma among community members in rural Nigeria showed that although nearly 90% of participants knew that mental illnesses could not be transmitted from one person to another; about 48% believed that the conditions were due to smoking Indian hemp or taking drugs; and 29% thought the causes were supernatural.⁽⁴⁴⁾

A study of eye-related conditions conducted by Sightsavers in Sierra Leone showed that 75% of community members knew that blindness could be prevented, and 82% knew that it could be treated (82%). Just under half of study participants related blindness to eye diseases (48%) or injuries (43%), while just under a third explained it by supernatural causes or witchcraft (29%).⁽⁴⁵⁾

Several studies showed that better knowledge of impairments was associated with lower levels of stigma. For example, a study of leprosy-related stigma among community members in India found that only 1.2% of the sample answered correctly all five questions about the disease, and less than 5% answered four out of five questions correctly. The questions answered incorrectly referred primarily to the route of transmission and cause of leprosy. The crude correlation between leprosy-specific knowledge and community stigma was not strong, but yet statistically significant, and indicated that an increase in leprosy-related knowledge was associated with a lower level of stigma.⁽⁴⁶⁾ Similarly, a qualitative study of

HIV/AIDS stigma in Uganda showed that increased knowledge of HIV/AIDS improved attitudes towards people living with HIV/AIDS among faith-based organisations (FBOs) and their members.⁽⁴⁷⁾

In Ethiopia, community members, who gave psychosocial or biological explanations for mental health conditions demonstrated lower levels of stigma of people with mental illnesses. Interestingly, in the same study, those who gave supernatural explanations also showed lower levels of stigma, but mainly if they were not exposed to mental illnesses within their own family. The authors explained it largely by the feelings of sympathy to people with mental health conditions among those with strong religious beliefs, but mainly if these conditions were outside their immediate family.⁽⁴⁸⁾

A study among caregivers of people with schizophrenia in India examined associations between the knowledge of the disease and affiliated stigma, but found no statistically significant associations.⁽⁴⁹⁾ However, a study among community members in urban and rural areas of India found that the belief that mental illness was caused by spirits was associated with higher levels of stigma.⁽⁵⁰⁾

Knowledge of disability-related policies or organisations of people with disabilities (OPDs) was examined in one study in Sierra Leone. Only just over 28% of community members had heard about the national Disability Act and the same proportion had heard about OPDs. The study, however, did not examine whether community levels of stigma were associated with the knowledge of disability legislation or OPDs.⁽⁴⁵⁾

Not knowing people with disabilities

Several studies examined the role of knowing someone with a disability. The findings varied greatly by the setting and the type of impairment. In Sierra Leone, 78% of survey respondents recruited from the community reported that they personally knew someone with a disability, usually a relative, a friend or an acquaintance.⁽⁴⁵⁾ In Nigeria, the survey asked about the knowledge of someone with a mental illness and the proportion of those who responded positively was considerably lower: only 15% of participants had a family member with a mental illness, and less than 10% reported knowing someone as a friend.⁽⁴⁴⁾ In Ethiopia, only 1.7% of community members reported that they themselves had a history of mental health problems, and less than 10% had a relative with a mental illness.⁽⁴⁸⁾ In India, a survey of secondary school children about epilepsy found that over 36% of respondents knew personally someone with epilepsy but only one in 10 had ever witnessed a seizure.⁽⁴³⁾

A number of studies explored the relationship between personal knowledge of the impairment or family history and stigma. A qualitative study from Malawi reported that stigma of children with albinism was more common, when other children did not know them personally; in more familiar social circles, children with albinism were 'treated with respect and dignity like anyone else'.⁽⁵¹⁾ In Tanzania, a case study of a 28-year-old woman with albinism showed that the awareness of her family and family history led to more positive attitudes towards her condition among her relatives and community. Participants from this ethnographic study explained that in their community "individuals with albinism were easily accepted within their family, if there were already persons with the condition among their kin relatives and/or if the grandfather affirmed in front of all the relatives that the child belonged to the family and resembled other family members".⁽⁵²⁾

In a study of stroke survivors in Ghana, not having anyone with the history of stroke in the family was the only predictor of stroke related to self-stigma.⁽⁵³⁾ In Sierra Leone, community members with the history of disability in the family were 60% more likely to say that they will employ someone with a disability than those without such history (OR=0.1.6, p=0.012).⁽⁴⁵⁾ In contrast, in a community-based survey in India, knowing someone with leprosy was associated with higher levels of enacted stigma (p=0.03).⁽⁴⁶⁾

Othering of people with disabilities

Perception of people with disabilities as “different” or “others” was another driver of stigma described in the studies reviewed.

In Ethiopia, people with schizophrenia were described as ‘insignificant or lacking usual needs’; they were also believed not to feel pain or bleed from bruises in the same way as other people.⁽⁵⁴⁾ In India, fewer than 41% of secondary school children believed that “an epileptic patient can live like others” in society.⁽⁴³⁾

In South Africa, people with psychiatric conditions were described as “not quite human”.⁽⁵⁵⁾ Similarly, in Malawi, people with albinism were not considered to be human with some people referring to them as “ghosts”, who “do not die”.⁽⁵¹⁾

Fear of being ‘infected’

Several studies reported fear of being ‘infected’ as a driver of stigma and discrimination.^(37, 56-58) These studies were qualitative and related to either people with HIV/AIDS or leprosy.

For example, in Bangladesh, the research showed that although most family members, hospital staff and community members were aware that HIV could not be transmitted through casual contact, they were hesitant to share glasses, utensils or even sit next to people with HIV/AIDS.⁽⁵⁶⁾

In Ghana, study participants described a community, “where people believed leprosy to be highly contagious, creating fear and discrimination”.⁽³⁷⁾ As a result, “patients with leprosy were excluded from social interaction by being denied physical contact and closeness”.⁽³⁷⁾

The fear of “being infected” was not common in the studies of non-infectious health conditions. For example, in a study of families of children with developmental delays in Ethiopia, 93% of parents said their child’s condition was not contagious and 88% agreed that others in the community had similar views.⁽⁵⁷⁾

Fear of people with disabilities due to perceived social dangerousness

This type of fear primarily drove stigma related to people with mental health conditions and was reported in a number of settings.

In a study in South Africa, a lay councillor interviewed explained how she was “scared to work” with people with mental illnesses because they were in her view, “crazy people” and “aggressive people”.⁽³⁸⁾

In Ethiopia, one caregiver explained how in severe cases, a person with schizophrenia would start “fire in a neighbour’s house” or “fire in a house made of grass”; and this was perceived to be “a big danger” and therefore communities would “take it seriously” and protect

themselves by isolating or restraining the ill person.⁽⁵⁴⁾ Another caregiver in the same study described how her husband diagnosed with schizophrenia would threaten to “kill people”, and how she would not go “to sleep before hiding a knife in the house”.

Fears of people with epilepsy were also reported in a study among secondary school children in India, where over 37% of survey respondents considered an epileptic patient to be dangerous.⁽⁴³⁾

Contextual facilitators of stigma and discrimination

A total of 27 studies included information on contextual factors that influenced the adoption of stigmatising attitudes and practices. For the purpose of this review, we organised them in four categories: i) religion and supernatural beliefs; ii) cultural and social norms; iii) socio-economic environment and availability of services; and iv) accountability and empowerment.

Religion and traditional beliefs

Religious and traditional beliefs as a contextual factor facilitating the adoption of disability-related stigma were reported in multiple studies. In these contexts, impairment was believed to be a punishment from God, a consequence of an undesirable act or sin, or a result of a curse, witchcraft, bad spirits or reincarnation.^(34, 37, 38, 48, 57, 59-61)

In many contexts, more than one traditional belief was reported to be prevalent, and often such beliefs co-existed alongside knowledge of biological causes of impairments or medical treatments available. For example, in a study of schizophrenia-related stigma in India, schizophrenia was reported to be related to karma, black magic, punishment of God and evil spirits; and although over 95% of study participants knew the disease required treatment “by a doctor”, about half also believed that it could be cured by “visiting a temple or other religious places”.⁽⁴⁹⁾ In Malawi, while 76% of study respondents said that mental illnesses were caused by traumatic events or shocks; nearly 83% also believed that they were caused by evil spirits, although only 22% thought mental illnesses were a punishment of God.⁽⁴⁰⁾

Traditional beliefs were common, irrespective of the type of impairment, but were particularly strong for severe health conditions, such as mental illnesses or HIV/AIDS.^(36, 42, 51, 56, 58, 62)

Furthermore, in the context of strong religious or traditional beliefs about disability and association of impairments with sins and wrongdoings, stigma was often observed to lead to abusive physical practices, as these were perceived to be essential for “cure”.^(60, 63) For example, in Cameroon and Ethiopia, a child born with an impairment was believed to be a punishment for crimes committed by his or her ancestors; and punishing such a child was thought to assist their growth and development.

Some studies, however, argued that building an alliance with faith-based organisations (FBOs) and religious leaders could be effective in addressing stigma and discrimination. For example, in Uganda, although FBOs were thought to be influential in instigating feelings of blame and shame of people living with HIV/AIDS in the early stages of the epidemic, their increasing support over time played a significant role in shaping up more positive attitudes towards HIV/AIDS in local communities.⁽⁴⁷⁾ It was particularly noticed that FBOs had a comparative advantage in their ability to address stigma through their existing social mobilisation channels and to influence the cultural norms of their congregations.

Cultural and social norms

Although cultural and social norms were strongly linked to the religious beliefs in most settings, there were additional attributes of culture and social norms that facilitated the adoption of social stigma.

In Bangladesh, since HIV infection was associated with sexual behaviours, people with HIV/AIDS were often stigmatised for “immoral” activities, infidelity or “unconventional” sexual practices. Punishment and isolation of people with HIV/AIDS in this context was interpreted as acceptable and justifiable.⁽⁵⁶⁾ Also, in South Africa, stigma of people living with HIV/AIDS was influenced by dominant sexual moralities of abstinence and expectations of strict control over women’s and young people’s sexual behaviour.⁽⁵⁸⁾

A study in Malawi reported that a common name used locally for someone with albinism was ‘mzungu’ or ‘azungu’ (plural of mzungu) – the same name that had been historically used in relation to white people of Western origin. The authors further explained how in the context, where the overwhelming majority of the population was dark-skinned, the meaning of the word had inevitably led to representation of someone with albinism as “different” from everyone else in society.⁽⁶⁴⁾

Another important cultural norm discussed in the papers was prioritising of male needs over female needs and legitimising the lower social status of women. This social factor reported in many contexts was linked to higher levels of stigma and discriminatory practices against girls and women with disabilities. For example, in Cameroon, women in general, as well as women with disabilities, were thought to be “good [only] for the home”, and were disadvantaged in accessing education and employment. Women with disabilities were also perceived to be weak and defenceless and therefore extremely vulnerable to physical and sexual abuse from men, who wanted “to prove their masculinity”.⁽⁶⁰⁾ Gender norms and expectations also shaped the experiences of disability by men and women and their perception of self. In India, for example, men with disabilities were primarily concerned about their ability to work and be self-sufficient. Women with disabilities were concerned about the effect of their health condition on their marriageability and suitability as mothers.⁽³⁹⁾

Socio-economic environment and availability of services

Several studies explored how poor socio-economic circumstances in which people lived facilitated adoption of negative social attitudes and practices towards people with disabilities. In some contexts of extreme poverty and hardship, people with disabilities were perceived to be unable to contribute to society and therefore be of low economic and social value. In these environments, people with disabilities and particularly children, were reported to be denied access to food, education, health care and other essential services.^(39-41, 59) In Cameroon, many households with children with disabilities were reported to live in poverty, where parents could not take care of their children or send them to school; as a result, many children with disabilities were forced into child labour or prostitution. It was further reported that many parents of children with disabilities felt stressed and frustrated about their inability to provide appropriate care, which often resulted in high consumption of alcohol and led to more physical abuse of their children with disabilities.⁽⁶⁰⁾

In most contexts, poverty also meant the lack of environmental adjustments necessary for people with disabilities to participate equally in society. In Malawi, women with physical

impairments said that “they had problems doing simple daily activities such as carrying water on their heads, cooking, lifting heavy things, taking care of small children”.⁽⁶⁴⁾ A blind woman from the same study described how “she needed someone to assist her... when she went to the market, but she could not afford to pay for this”.

In a number of settings, stigma of people with disabilities was exacerbated by the lack of accessible and affordable health care services, therapies, or rehabilitation. For example, in South Africa, stigma of people living with HIV/AIDS was reported to be compounded by the lack of adequate HIV/AIDS management services.⁽⁵⁸⁾ However, the relationship between the availability of services and stigma seemed to be nuanced and dependent on where the services were provided, as well as their quality and responsiveness to the needs of people with disabilities. For example, in south India, people with HIV/AIDS accessing antiretroviral treatment (ART) reported higher levels of personal stigma compared to those, who were not on ART, reflecting most likely people’s fear of risk of being exposed to the local community while attending the ART services.⁽⁶⁵⁾ Similarly, in South Africa, people with mental illnesses were reported to be reluctant to use local primary care centres, first because of the lack of medication and psychosocial rehabilitation services in these facilities, and second, because of the fears of having their health condition exposed and subsequently stigmatised by their local communities.⁽³⁸⁾

Access to medication was also a major contextual factor highlighted in the studies. In Ethiopia, people with schizophrenia were reported to have severe attacks leading to the practices of restraint, often when they did not have access to medication or hospital treatment.⁽⁵⁴⁾ Similarly, in Tanzania, the majority of children with epilepsy did not have access to antiepileptic drugs.⁽³⁵⁾ Authors of this study reported that out of 112 children with epilepsy identified by them in the studied community, 98 children required regular antiepileptic treatment to manage seizures, but only less than a third (n=30) received their medicines daily. The main reasons for not accessing medicines were: inability of local health centres to diagnose the disease and prescribe timely treatment; patients’ difficulties in travelling to distant tertiary hospitals to take up referrals; and prohibitively high cost of antiepileptic drugs. It was further reported that poor management of epilepsy had adverse effects on children’s educational opportunities and academic achievements. Half the children participating in the study did not attend school on a regular basis because schools could not manage their seizures and could not address their learning difficulties and behavioural problems. In another study in Tanzania, a woman with albinism described how as a child, she went to school and was “part of a large class crowded into a single classroom, and since she had no glasses, she had tremendous trouble seeing the blackboard from a distance”. She received poor academic grades and since it was too expensive for her parents to pay for private secondary education, she had to drop out after primary school.⁽⁵²⁾

Accountability and empowerment

A number of studies also reported a variety of social and community factors related to empowerment, social capital and the rule of law.

A study among mental health stakeholders in six LMICs, including five countries included in this review (Ethiopia, India, Nigeria, South Africa, and Uganda) pointed out the poor governance and accountability; poor implementation of mental health laws; the lack of transparency; and the lack of inclusion of mental health service users in decision-making as

the key factors influencing the widespread stigma of mental health conditions and people affected by them.⁽⁶⁶⁾

In South Africa, the lack of a social dialogue about HIV/AIDS was thought to instigate HIV/AIDS-related stigma.⁽⁵⁸⁾ Another South African study examined the relationship of social capital and stigma.⁽⁶⁷⁾ It showed that people with HIV/AIDS, who displayed higher levels of empowerment and control over their lives, reported lower levels of personal stigma, while those who felt trust and safety in their community were less likely to think that their community would have negative and hateful attitudes towards their disease.

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 facilitating abuse and discrimination of children with disabilities.⁽⁶⁰⁾ Study participants argued that many caregivers of children with disabilities were unaware of their rights or where to report abuses. The process of reporting to the police and other authorities was described as long, cumbersome and expensive. Many families could not afford to go back and forth with lengthy administrative procedures or hire a lawyer to follow up on their behalf. In addition, in many instances, even when the cases of abuse were pursued, “the abusers used their influence and money to corrupt the officials” or “threaten the children” and the cases were dropped, undermining the system of justice and discouraging other families to report abuse.

Impact of multiple drivers and contextual factors

Many studies pointed out the presence of several drivers and contextual factors of stigma and discrimination in their settings. This was particularly common in the studies of severe disabling conditions, such as mental illnesses or HIV/AIDS, and where the levels of stigma were reported to be particularly high.

For example, a qualitative study in South Africa reported that HIV/AIDS-related stigma was driven by a complex interaction between the lack of HIV-related information and services, misconceptions about HIV transmission, community fears and cultural norms about sexuality.⁽⁵⁸⁾ Similarly, in Bangladesh, health care workers’ attitudes towards people with HIV/AIDS were determined by their fears of being infected, their own religious beliefs and anticipated stigma by others, as helping someone with HIV/AIDS was perceived to be a sin in their community.⁽⁵⁶⁾

In Malawi, albinism-related stigma was driven by poor understanding and misconceptions about the condition, compounded by not knowing people with albinism, and associations of the condition with wrongdoings and witchcraft.⁽⁵¹⁾

In India, epilepsy-related stigma was linked to the lack of knowledge, misconceptions about the disease and associations of epilepsy with sins.⁽⁴²⁾

Manifestations of stigma and discrimination

A total of 40 studies examined different manifestations of stigma and/or discrimination. These studies reported manifestations of both felt (perceived) and enacted (or experienced) stigma. Most of these papers related to mental health and behavioural disorders (n=15), including four studies on schizophrenia, and one on bipolar disorder. Six documents referred to disability generally where the type of impairment was not specified. Four documents related to epilepsy; three each were on HIV/AIDS and leprosy, with another one paper researching both conditions in the same study. Other studies related to albinism (n=2); intellectual disability (n=2); autism (n=1); cerebral palsy (n=1); spina bifida and hydrocephalus (n=1); and post-stroke impairments (n=1).

The papers referred to different types and sources of stigma described previously in health-related stigma and discrimination frameworks.^(9, 10) The sources of stigma reported were persons with disabilities themselves; their immediate social circles, such as families and friends; their local community; and broader society. Many studies examined stigma from the perspective of more than one group.

Reviewed papers reported stigma and discrimination across many different settings, but the types of stigma and its manifestations varied by context, the type of impairment and population sub-group. Surveys used different approaches and tools to measure stigma across different domains. People with disabilities and their caregivers were asked about their personal feelings about the impairment, their willingness to disclose it to others, their perceptions of social attitudes, and actual behaviour they experienced. Those in the general population or specific groups (like service providers) were asked about their attitudes towards people with disabilities, their intended behaviour, for example, working with someone with a disability or living nearby, maintaining close relationship or accepting marriage, as well as their views on people with disabilities' rights and entitlements.

For the purpose of this review, we organised our findings on manifestations of stigma into four broad categories corresponding to different types of stigma: i) felt (perceived or anticipated) stigma; ii) enacted (experienced) stigma; iii) internalised stigma; and iv) affiliated (secondary) stigma. (Appendix 3)

Felt (perceived) stigma

This stigma refers to negative feelings, attitudes and beliefs about disability, which were expressed by both the stigmatisers and the stigmatised. The stigmatisers directed such negative emotions towards health conditions leading to disability and towards people affected by them. For the stigmatised, these described their own perceptions of social attitudes and beliefs about disability, as well as their feelings about themselves. The latter was more commonly referred to as internalised or self-stigma, which is described in sections below.

One of the key manifestations of felt stigma reported in the papers was the perception of people with disabilities as being different from others in the community and broader society. This perception was reported in many studies across both Africa and Asia, although the reasons underpinning such perceptions varied by context and the type of impairment.

People with mental health conditions were often perceived by others in the community as aggressive, dangerous or unpredictable.⁽⁶⁸⁾ These social attitudes were found in the studies in Malawi, Ethiopia, South Africa, and Nigeria.^(38, 54, 69)

In South Africa, people with psychiatric illnesses were described as “crazy” or “abnormal”.⁽⁵⁵⁾ In Ethiopia, people with schizophrenia were compared to “a dog needing to be restrained”.⁽⁵⁴⁾ In Nigeria, 73% of community respondents perceived people with mental illnesses to be violent.⁽⁴⁴⁾ In Malawi, 63% of patients and caregivers attending a general tertiary hospital reported to be afraid to have a conversation with a person with a mental illness.⁽⁴⁰⁾ In Ethiopia, the highest levels of community stigma were reported on the items: “families who have a member with mental illness ought to be treated differently” (score 2.81 ± 1.23) and “people should keep their family member with mental illness behind locked doors” (2.24 ± 1.05).⁽⁴⁸⁾

The reviewed studies further reported how negative social attitudes and fears led to the desire of social distancing from people with disabilities, as they were perceived to be different and therefore socially undesirable.^(39, 55) Close personal contacts seemed to be more affected than formal or professional relationships, although there were variations by context, the nature of relationship, and the type of impairment. In Malawi, 66% of people attending a tertiary hospital said that they would work with someone with a mental illness; 60% would be willing to share a room; 68% would maintain friendship; but only 18% would marry someone with a mental illness.⁽⁴⁰⁾ In rural Nigeria, fewer than 17% of community members would share a house with a person with a mental health condition; fewer than 10% would have them as a friend; and only 12% would agree to marry them.⁽⁴⁴⁾ In Sierra Leone, while about 80% of the community would accept that their child makes friends with a child with a physical or sensory impairment, only 14% would accept friendship with a child with a mental illness.⁽⁴⁵⁾ Similarly, while 39% of community members would agree to marry a person with a physical impairment; 33% would marry someone with a sensory impairment, but only 4% would marry a person with a mental illness. In India, two-thirds of study participants would not permit a person with leprosy to take care of their child, and only 7% would permit a marriage with one.⁽⁴⁶⁾

A number of studies of mental health-related stigma also reported that although people with mental illnesses were viewed to be different from others in the community, they were also perceived to be dishonest or cunning about their impairment. In South Africa, there were beliefs that people with mental health conditions were “pretending to be sick and were deliberately acting out the symptoms of mental illness”.⁽³⁸⁾ In Malawi, mothers of children with intellectual impairments were accused of performing “rituals” on their children for wealth.⁽⁷⁰⁾ In Ethiopia, children with intellectual disabilities were not to be believed when reporting violence.⁽⁶³⁾

In many contexts, disability-related stigma was also instigated by feelings of social dislike, largely because of associations of impairments with wrongdoings, witchcraft, or punishment of God. In South Africa, Malawi and Nigeria, people with mental illnesses were described as “bewitched” and “possessed by devil”.^(38, 44, 51) In south India, schizophrenia was thought to be related to karma and evil spirits.⁽⁴⁹⁾ In Tanzania, 55% of church attendees from three congregations (protestants, catholic, Lutheran) believed people with HIV/AIDS should be ashamed and 53% thought they were punished by God.⁽³⁶⁾

Another common social belief reported in the studies was that people with disabilities were contagious. This was mainly reported in relation to people with HIV/AIDS and leprosy. In

India, 94% of community members in Uttar Pradesh expressed negative attitudes towards people with leprosy; and 75% said that they would hide the disease from their community.⁽⁴⁶⁾

In some settings, people with disabilities were also perceived to be less capable and therefore of lower value to society compared to others. For example, in India, over 40% of survey respondents recruited from secondary schools believed that people with epilepsy had on average lower IQ than non-disabled people.⁽⁴³⁾ In a study in South Africa, people with HIV/AIDS were stigmatised because they were perceived to be ill and unable to contribute economically to their community.⁽⁵⁸⁾ In Malawi, women with disabilities were less valued, as they were thought to be unsuitable for marriage, motherhood and household chores.⁽⁶⁴⁾

A study in Nigeria among the general population, found negative and patronising attitudes, including pity, sadness and being moved by people with moderate and severe levels of intellectual disability.⁽⁷¹⁾

A four-country study among children with disabilities in West Africa identified several issues, including being identified by their impairment, rather than name, and negative language generally.⁽³⁴⁾ Being neglected and marginalised within their households was common, and in rare cases having their existence hidden, or being concealed, was discussed.

Very few studies asked about participants' attitudes towards disability inclusion policies. In Sierra Leone, 86% of community members agreed that the government should do everything in their power to promote equal opportunities for people with disabilities, although the opinions about the type of support varied.⁽⁴⁵⁾ Over 65% of respondents believed that the role of the government and society is to provide elms; other views included provision of home care and services (40%); provision of education (22%); and provision of employment (15%).

Enacted stigma

This type of stigma refers to practices and behaviours projected on and experienced by people with disabilities.

Reviewed studies described a wide range of discriminatory behaviours and practices experienced by people with disabilities at different levels: within their family, their community and broader society.

Family

Relationships within the family were found to be complex, as families were often a source of stigma and a source of major support for people with disabilities. As shown later in this report, families were also found to be a subject of disability stigma and discrimination projected on them by the community and society.

In South Africa, family members of people with mental illnesses were reported to deny food, laugh at their relatives, and beat them.⁽³⁸⁾ In India, and in a multi-country study in Kenya, Pakistan and Rwanda, family members showed little support and used derogative and abusive language towards their relatives with mental illnesses.^(39, 72) In Bangladesh, two thirds of participants with HIV/AIDS reported that their partners threatened to leave them, and nearly half reported abuse by a family member or a friend.⁽⁵⁶⁾ In Cameroon, children with disabilities were reported to be kept out of school, not fed, or given food last.⁽⁶⁰⁾ In Ethiopia,

family members of people with schizophrenia described how they had to tie up or chain their relatives because they feared their aggressive and violent attacks, although in many cases, the restraint was also used to administer medication or take their relative to hospital, or to protect them from self-harm.⁽⁵⁴⁾

In a number of studies, however, families of people with disabilities were regarded to be the most important source of support, which played a critical role in maintaining the wellbeing of people with disabilities. In India, patients with mental health conditions reported that they relied on their families for care, emotional support and financial help.⁽³⁹⁾ Among 23 women with disabilities participating in a qualitative study in Malawi, only one woman with multiple physical disabilities said that she “had been abandoned by both parents very early on in her life and was left to grow up with her grandmother”.⁽⁶⁴⁾ All other women said that: “they were looked after and treated just like other children in the family... They received the same amount of food and were scolded just like the rest of the family”.

Community

Discriminatory practices at the community level were reported in many settings. Studies in India, Uganda, Nigeria, South Africa, and Malawi reported the use of abusive language, labelling, whispering, being spat at, and mocking as people with mental illnesses were walking the streets.^(40, 41, 44, 51, 55, 62, 73) Similar practices were described in Tanzania in relation to people with albinism, who were often labelled as ‘ghost’, ‘white person’, or ‘deal’ (referring to the illegal trade of human body parts).⁽⁵²⁾

A number of studies reported discriminatory behaviours in relation to children with disabilities. In Tanzania, children with epilepsy were reported as being persistently isolated and rejected by friends and the wider community.⁽³⁵⁾ Similarly, in Kenya, children with autism often experienced social exclusion and non-acceptance by their peers, family and friends.^(35, 74) A multi-country study in Africa explored the prevalence of reported violence against children with disabilities and reported that 100% of the sample in Zambia, 87% in Uganda, 68% in Ethiopia, and 60% in Senegal experienced at least one form of physical violence in their childhood. The most common type of violence was being beaten, followed by the denial of food and forced work for the benefit of others.⁽⁶³⁾ Over 60% of trainee teachers in a Nigerian study were found to have negative attitudes towards people with epilepsy.⁽⁷⁵⁾ In West Africa, a study found that parents of other children did not want their children interacting with children with disabilities.⁽³⁴⁾ Among teachers and education leaders, education was only regarded as feasible for those with physical disabilities.

In the studies among people with disabilities themselves or their caregivers, the opinions on the levels of community stigma and discrimination varied. In Uganda, while 55% of parents of children with spina bifida and hydrocephalus reported that their children were treated well, 45% reported name calling, gossiping, and exclusion from social activities.⁽⁷⁶⁾ In a study among patients with schizophrenia and their caregivers in India, 42% of participants said that they experienced community discrimination in at least one of the twenty domains measured in the study.⁽⁷³⁾ Around 20% experienced discrimination in one social domain; 11% in two or three domains; and 10% in more than four domains. The most frequent type of discrimination was by neighbours (reported by 17% of participants), and 11% reported discrimination by friends. In a study among patients with schizophrenia in South Africa, 65% of respondents said they were discriminated against within their community; 42% said that they experienced

name calling; 40% were verbally abused and 26% were physically abused because of their mental health condition.⁽³⁸⁾

In another South African study among patients with HIV/AIDS, about half of men and women participating in the study said that they were discriminated against in their communities.⁽⁵⁸⁾ A study in south India compared discrimination experiences of people with leprosy and people with HIV/AIDS, and found that people with HIV/AIDS had significantly higher levels of community stigma (mean score 21.8 vs 15.1, $p < 0.001$).⁽⁷⁷⁾ In this study, around 30% of people with HIV/AIDS said that they did not receive the “same respect” as their peers, compared to 10% of people with leprosy ($p < 0.001$).

Institutions and broader society

Overall, stigma and discrimination by those who were close to people with disabilities (such as neighbours and friends) was reported more frequently than stigma and discrimination by institutions. For example, in India 6% of people with schizophrenia and their caregivers said that they were discriminated against by education institutions; 5% by the police; and 2% by religious organisations.⁽⁷³⁾

Opinions about stigma and discrimination in health care facilities varied by context and type of impairment. In South Africa, a qualitative study among people with mental illnesses showed that while some health service users were treated well at the clinics, others were “beaten, shouted at, being made fun of or simply ignored”.⁽³⁸⁾ In another South African study, 16% of people with schizophrenia said that it was difficult for them to attend health clinics because of stigma.⁽⁶⁹⁾

In Bangladesh, both private and government health facilities were reported to have refused admissions of people with HIV/AIDS, although discrimination by government facilities was reported more frequently and when in hospitals, people with HIV/AIDS were “neglected” or “experienced delays in receiving treatment”.⁽⁵⁶⁾

The role of media in stigma was examined in a study in South Africa, where 29% of patients with schizophrenia believed that media messages were responsible for facilitating stigmatising attitudes in society.⁽⁶⁹⁾

Affiliated stigma

Affiliated stigma refers to negative attitudes and behaviours towards people associated with people with disabilities. These can include their family members and friends, as well as those who provide services to people with disabilities.

As shown in the previous section, family members can be a source of negative attitudes and discriminatory practices against people with disabilities. But evidence from many countries also shows that family members themselves are subjected to disability stigma and discrimination. Affiliated stigma was reported in studies in different settings and in relation to different types of impairments.

In India, 21% ($n=59$) of caregivers of people with schizophrenia reported high levels of stigma, while 83% said that they had experienced at least one aspect of stigma in the past 12 months.⁽⁷⁸⁾ About 45% of caregivers in this study felt uncomfortable about the disclosure

of the disease of their relative to others in the community, although 48% said it was not an issue for them. For those, who did not want to disclose, the main concern was that this might affect their relative's prospect of marriage (expressed by 44% of respondents) and their relationship with neighbours (40%). About a third of caregivers also reported feeling ashamed or embarrassed about the disease of their relative, while one in five felt that the disease was their fault. About a quarter of caregivers worried that others in the community would blame them for the disease.⁽⁷³⁾

Qualitative data from the same study also showed that the main concern about community attitudes among caregivers was being blamed; and the anticipated blame was two-fold: being responsible for the disease (particularly common among mothers of people with schizophrenia), but also “not taking care... properly”, “not marrying him/her off”, or “making sure... [they have] work”. Among negative community practices described by the caregivers the key ones were being “alone”, “excluded from social interactions”, “labelled”, “being looked down”, and “not respected.” Despite the prevalence of such negative reactions from the communities, many caregivers in the study also reported ‘supportive’ attitudes, including “financial help”, “advice”, “practical help”, and “reassurance”.⁽⁷³⁾

Similarly, caregivers of children with cerebral palsy in Bangladesh described that while some individual members of their family and neighbours “loved their child” and expressed “sympathetic and caring” attitudes, others created an atmosphere of “isolation” and lack of support by not talking “about their child’s condition within the family”.⁽⁶¹⁾

In Ethiopia, 43% of families of people with mental illnesses said that they were treated differently by their community; 45% said that they were ashamed of their relative’s condition; and 26% would prefer to keep it secret.⁽⁴⁸⁾

In South Africa, caregivers of people with HIV/AIDS were reported to be so ashamed of the positive status of their relatives that they would hide them away; deny their access to health care; refuse to collect their bodies from the mortuary; and not refer to HIV/AIDS by name.⁽⁵⁸⁾

Women with disabilities participating in a study in Malawi explained how their families felt about their impairment and how it affected them. They described how their “parents were shocked and... saddened by their children’s impairments and some found it hard to acknowledge that their child had become disabled and felt ashamed to talk about it and show off their disabled child”; and only when time passed “they were able to accept and learn to live with the disability”.⁽⁶⁴⁾

Parents of children with intellectual difficulties in Kenya described how, due to disruptive and aggressive behaviours of their children, their families were evicted from their houses by landlords. Women were particularly vulnerable within their community and within their own families, as they were often “accused of giving birth to a disabled child”, and in some cases their husbands would divorce them because of this.⁽⁷⁹⁾

Leprosy was also reported to be highly stigmatised. In Ghana, nurses working in leprosy clinics reported they were often a subject of negative remarks from their peers, who feared that due to frequent contacts with leprosy patients, the nurses themselves were contagious and dangerous.⁽³⁷⁾

Internalised stigma

Internalised stigma refers to self-stigma among persons with disabilities. Health-related stigma frameworks^(9, 10) suggest that self-stigma can be originated in two ways. First, people with disabilities come from the same social context as their community, and therefore may share prevalent community attitudes and beliefs about disability. Second, frequently experienced stigma and discrimination may lead to deeper feelings of self as inferior to others and a subsequent loss of status and self-esteem.

Internalised stigma was reported across many different context and conditions. In South Africa, 60% of people diagnosed with schizophrenia admitted that they themselves perceived people with mental illnesses to be violent; 56% felt disappointed about their disease and 46% felt inferior to people without mental illnesses.⁽⁶⁹⁾ Further, 45% of respondents “felt out of place in the world” because of their illness; and nearly a quarter believed that people with mental illnesses should not get married.

A survey of people with epilepsy in India showed that although 90% of respondents agreed that people with epilepsy should have an opportunity to marry, work and have children, less than 60% said that they would disclose the disease of their child before their marriage.⁽⁴²⁾ In Bangladesh, approximately half the leprosy patients involved in a study exhibited internalised self-stigma.⁽⁸⁰⁾

In another study in India, around 28% of people with bipolar disorder reported moderate to high levels of internalised stigma.⁽⁸¹⁾ Participants scored particularly high on the feelings of alienation (mean score 2.21) and social withdrawal (mean score 2.23). The authors of the paper also argued that self-stigma reported in India was higher than in the studies in European countries, and attributed it to the prevalent self-devaluation and severe impact of perceived compromises in matrimonial and employment prospects. Another study in India, this time among patients with schizophrenia, found that at least 60% believed in at least one non-biomedical cause for their illness: karma 32%; black magic 24%; evil spirits 29%; punishment by God 35%.⁽⁴⁹⁾

In Ghana, a study among stroke survivors showed that internalised stigma in this population was stronger than the stigma from the family or the community.⁽⁵³⁾ Only one in five study participants said that they had never experienced self-stigma. Although the majority of participants reported low to moderate levels of self-stigma, 10% ‘always’ felt embarrassed about their condition, and 13% ‘always’ felt embarrassed about their physical limitations.

In another study from Ghana, nurses reported that patients with leprosy felt ashamed of their disease and feared to disclose it to their relatives, asking the nurses to lie about the name of the hospital or the name of the ward they were admitted to.⁽³⁷⁾

In Cameroon, study participants reported that children with disabilities often felt inferior in the company of other children because they could not run or play in the same way as their peers.⁽⁶⁰⁾ Many tended to avoid social activities and self-isolate. Low levels of self-esteem were reported to be one of the reasons why children with disabilities dropped out of school.

In south India, a study sought to identify the differences and commonalities around internalised stigma among persons with leprosy and people with HIV/AIDS.⁽⁷⁷⁾ About 60% of respondents with either condition felt embarrassed; and over 70% felt disappointed with their

illness; 45% of people with HIV/AIDS and 60% of those with leprosy also reported feeling inferior to those without the conditions. Overall, self-stigma was slightly stronger among people with HIV/AIDS and particularly on the beliefs that "affected people should not marry" and "stay away from social situations to protect family".

Intersectionality of disability with other individual characteristics

Twenty surveys and qualitative studies reported intersectionality between the presence of an impairment and other individual characteristics, such as gender, age, education, occupation or area of residence, and how they together resulted in the compound disability stigma and discrimination.

Gender

Several studies in both Africa and Asia examined how gender intersected with an impairment and social context; the findings of the studies were mixed and varied by context and type of impairment.

A qualitative study in Malawi explored experiences of women with disabilities of "being a woman and living with a disability".⁽⁶⁴⁾ The study highlighted various aspects of life, where gender intersected with impairments. One woman discussed that men with disabilities were more respected and accepted in their families and society than women with disabilities. She further explained that in her community, a man would not take his wife with a disability out, but a man with a disability could go out with his wife. It was further highlighted that in this setting, women could "speak freely in a group composed solely of women", but were "often afraid to speak their minds" in the presence of men. Another important topic that was brought up in almost half the interviews was the issue of women with disabilities being "tricked" into marriage and being "used" as wives. It was further explained that some men were known to "seduce women and propose marriage in order to have sex with them, but as soon as the women became pregnant, the men disappeared". This was a well-known phenomenon to all informants and as many as eight women had experienced it themselves.

In a multi-country qualitative study in West Africa, girls with disabilities were reported less likely than boys with disabilities to come out of the house or go to school because they were perceived to be "at greater risk of mistreatment, abuse and rape".⁽³⁴⁾ Also in Cameroon, girls and young women with disabilities were more frequently reported to be exposed to sexual and physical abuse and have a history of neglect and emotional stress than boys and men with disabilities.⁽⁶⁰⁾

Quantitative data from cross-sectional surveys showed a more mixed picture. For example, a study of HIV/AIDS-related stigma in South Africa found that a greater proportion of men than women, reported adverse social reactions to their HIV status, including being treated differently by friends and family (40% vs 31%), or losing a job (27% vs 18%) ($p < 0.05$). In addition, internalised stigma was also more common among men, who were more likely than women to report feeling "dirty" (33% vs 23%), "guilty" (47% vs 37%), or "ashamed" (43% vs

35%), although the impact of stigma measured by depression scores was higher among women than men.⁽⁸²⁾

Also in another study in South Africa, men with schizophrenia were more likely to report physical abuse than women.⁽⁶⁹⁾ Similarly, in the two studies of schizophrenia patients in India, enacted and internalised stigmas were higher among men compared to women.⁽⁴⁹⁾

In a study of leprosy in Ghana, nurses argued that due to high levels of social stigma, patients with leprosy were reluctant to seek care. However, women tended “to seek care more often and at an earlier stage compared with men, resulting in women barely having any deformities, while deformities were common among men”.^(37, 78)

Several studies showed a neutral effect of gender on disability-related stigma. In Ethiopia, the levels of stigma reported by caregivers of children with developmental disorders did not have an association with the child’s sex.⁽⁵⁷⁾ In the studies in north India, there was no effect of gender on either leprosy or HIV or bipolar disorder-related stigmas;^(65, 81) and in Ghana, no association was found between gender and internalised stigma among stroke survivors.⁽⁵³⁾

In a community-based survey in Sierra Leone, there were no gender differences in respondents’ opinions on whether they keep disability in the family secret; care for someone with disability; or support a disabled child to school. However, men were 40% more likely to say that they would employ someone with disability than women (OR=1.4, p=0.035).⁽⁴⁵⁾

Age

Only a few studies examined the effect of age on the levels of enacted or internalised stigma, and the evidence of association was mixed, but there are suggestions that younger people with disabilities or their caregivers may experience higher levels of internalised, enacted and affiliated stigma than those of older age.

In India, caregivers of younger people with schizophrenia showed higher levels of stigma than other caregivers (p=0.003).⁽⁷³⁾ In another Indian study, younger patients with bipolar disorder experienced higher levels of overall stigma (p<0.05) and stigma in the domains of stereotype endorsement (p<0.01); discrimination experience (p<0.01); and social withdrawal (p<0.05).⁽⁸¹⁾ However, in Ethiopia, stigma reported by parents of children with developmental disorders did not depend on the child’s age or on the age of the caregiver.⁽⁵⁷⁾

Race

The intersection between race, discrimination and mental health conditions was examined in a study in South Africa, which showed some presence of an association, but only for acute racial discrimination and only among people diagnosed with substance use conditions. For those who experienced other mental health conditions, such as mood or anxiety, the impact of non-racial discrimination on mental health was stronger – suggesting limited evidence of intersectionality of disability and race.⁽⁸³⁾

Religion

Although the role of religious beliefs as a contextual factor was discussed in most papers included in the reviews, only a few studies used statistical tests to examine an association

between stigma and a particular religion as an individual characteristic. In Ethiopia, being an Orthodox Christian was associated with higher levels of stigma reported by caregivers of children with developmental disorders ($p=0.028$).⁽⁵⁷⁾ In India, those who followed Hinduism showed higher levels of stigma related to distancing from people with leprosy compared to those who followed Islam ($p=0.01$) or Buddhism ($p=0.04$).⁽⁴⁶⁾ However, in a study of patients with bipolar disorder in north India, there was no association between religion and levels of internalised or felt stigma.⁽⁸¹⁾

Marital status

Three studies reported on the effect of marital status or family situation on stigma and discrimination of people with disabilities, with most evidence suggesting no apparent association. For example, in a study of patients with schizophrenia in South Africa, there was no association between marital status or living arrangements and reported levels of internalised or enacted stigma.⁽⁶⁹⁾ Similarly, in Ghana, no association was found between marital status and internalised stigma among stroke survivors.⁽⁵³⁾

In a study of patients with bipolar disorder in north India, there was no association between marital status and levels of internalised or felt stigma. However, patients belonging to extended/joint family reported a greater level of felt stigma.⁽⁸¹⁾

Education

Several studies addressed how individual levels of education interacted with stigma. The findings were mixed.

In India, community members with higher levels of education demonstrated lower levels of stigma of people with leprosy, although the relationship was not linear. The magnitude of association between education and stigma was the strongest for those with primary education compared to those without any formal education ($p=0.01$). It was weaker but yet statistically significant for those with secondary education ($p=0.05$), and even weaker for those with higher education ($p=0.06$). In Ethiopia, higher levels of education were associated with lower levels of mental health-related stigma ($p<0.01$), particularly among people with a high level of exposure to people with mental illnesses.⁽⁴⁸⁾

Findings from the studies among people with disabilities and their caregivers were also mixed. For example, a qualitative study in Malawi provided some insights into how higher levels of education among people with disabilities led to higher levels of self-esteem, and lower levels of internalised and enacted stigma. One woman with a hearing impairment in this study was educated as a special educational needs teacher. She was proud of her job and felt that education made her more self-confident. Similarly, a blind woman who worked as a teacher said “people have changed their attitude” towards her because of what she had accomplished.⁽⁶⁴⁾ However, a study in north India did not find any relationship between education and various domains of stigma among people with bipolar disorder.⁽⁸¹⁾ Similarly, in Ethiopia, no association was found between education and stigma reported by parents of children with developmental disorders.⁽⁵⁷⁾

A study of people living with HIV/AIDS in south India found that people with lower levels of education (primary level or less) were more likely to report stigma compared to those who

studied up to high school and above ($p < 0.01$).⁽⁶⁵⁾ In contrast, in another study in south India, literacy was associated with higher levels of stigma experienced by people with schizophrenia and their caregivers.⁽⁴⁹⁾ Similarly, another study in south India found the highest level of education at the household level (secondary education) was associated with higher levels of stigma reported by caregivers of people with schizophrenia.⁽⁷⁸⁾

Occupation

Occupation as an explanatory variable for stigma was reported in two studies. In a study of leprosy-related stigma in India, government employees expressed higher levels of stigma than other professions ($p = 0.03$). However, when asked about social distancing from people with leprosy, significantly higher social distancing scores were found among housewives compared to other participants ($p = 0.01$).⁽⁴⁶⁾ In Ghana, no association was found between the skills or employment of stroke survivors and the levels of their internalised stigma.⁽⁵³⁾

Economic status

A few studies reported on the effect of socio-economic background on stigma. Findings of cross-sectional surveys were mixed.

In a survey of community members in Ethiopia, the levels of stigma of people with mental illnesses were higher among respondents with higher levels of income at both medium ($p < 0.01$) and low education ($p < 0.001$) levels.⁽⁴⁸⁾ In Sierra Leone, there was a linear relationship between survey participants' relative wealth and their willingness to look after a family member with a disability, with those in the wealthiest economic quintile being 14 times more likely to agree to such care than those in the poorest quintile ($OR = 14.4$, $p = 0.001$).⁽⁴⁵⁾ Wealthier participants would also be more likely to be willing to employ someone with a disability ($OR = 3.3$, $p = 0.002$). However, they would also be more likely to keep disability in the family secret, compared to the poorer households ($OR = 4.4$, $p = 0.004$).

In a survey of people with bipolar disorder in India, those with lower incomes experienced greater levels of overall stigma and stigma in the domains of alienation, stereotype endorsement, discrimination experience, and social withdrawal.⁽⁸¹⁾ A qualitative study from Uganda provided some insights into how disability and poverty intersected in the lives of people with mental illnesses.⁽⁶²⁾ Key informants from this study pointed out that people with mental health disorders from poor socio-economic backgrounds were more likely to experience stigma and other unfavourable consequences of mental illness than their better off counterparts. Participants further explained that if someone was mentally ill but came from "a good family", the family would "take care of [them]... take [them] abroad" or to a psychiatric hospital; while those who were poor were ostracised and rejected – they could not "access any help... [and] just wait until [they]... die".

Area of residence

A number of studies examined stigma by geographical area. The majority of these studies were conducted in India and most studies were on stigma related to mental health. The findings were mixed, although some evidence suggests that disability-related stigma may be higher in rural communities.

In a study conducted in Goa, Tamil Nadu and Satara in south India, internalised stigma was higher among patients with schizophrenia living in rural areas than those in urban areas.⁽⁷⁸⁾ Also, caregivers of people with schizophrenia from Goa showed higher levels of associated stigma than those in Tamil Nadu or Satara ($p=0.03$), although there were no further explanations of the differences between these three areas.

A study among community members in Kanpur district of Uttar Pradesh in India also showed that the overall stigma scores were higher in rural areas and particularly in manual labourers.⁽⁵⁰⁾ The authors further explained that individuals living in rural areas were more likely to adopt punitive attitudes towards the severely mentally ill, while urban residents expressed more liberal and sympathetic views. For example, study participants in urban areas were more likely to believe that others in the community could help people with mental illnesses to adjust and prevent relapse, whereas individuals in rural communities were more likely to say that they would call the police in the case of an acute mental illness episode. Similarly, in Ethiopia, higher levels of stigma of people with mental illnesses were found among community members living in rural areas ($P < 0.001$).⁽⁴⁸⁾

In a study in Vellore in India, rural residence was associated with stigma scores of the relatives of people with mental illnesses, but not the scores of people with mental illnesses themselves.⁽⁴⁹⁾ In a study of patients with bipolar disorder in north India, there was no association between locality and the levels of internalised or felt stigma.⁽⁸¹⁾ Similarly, there was no association between rural/urban location and internalised stigma among stroke survivors in Ghana.⁽⁵³⁾

Health status and severity of impairment

Several studies examined the role of health and impairment in stigma and discrimination. A qualitative study in West Africa found that the type and severity of impairment had an impact on how stigma and discrimination was experienced. The authors argued that children with physical impairments, and “especially those still able to move around”, were “the least discriminated against”. These children were “more accepted in society”, as they were “perceived to be potentially independent, especially when there... [was] access to mobility aids”. In Sierra Leone specifically, there was “greater acceptance of those who have become physically impaired through war injuries”, as people in the community believed that “this type of impairment was not the fault of the individual”. On the other hand, “children with sensory (especially deafness), intellectual and mental disabilities” were “discriminated against”. In Sierra Leone, children who were deaf were described as “the group most vulnerable to abuse, as they could not easily tell of their abuse”. Across all countries included in the study, children with severe mental illnesses or multiple disabilities suffered “the strongest forms of discrimination”, as they “rarely attended school and... [were] often kept hidden in their homes”.⁽³⁴⁾

In another qualitative study in West Africa, participants also spoke of how violent experiences and social participation varied by type of impairment.⁽⁵⁹⁾ The study argued that children with visual, communication, and cognitive impairments experienced the most violence. For example, one study participant from Niger said: “The greatest discrimination is towards those with mental deficiencies, the blind, the epileptic. Their disability is considered like a contagion.” It was further noted that children with the impairments that did not

significantly limit their physical or cognitive function could participate in community life and education. This is how one participant from Togo explained the situation in his country: “When the child has no difficulty with mobility, he can be enrolled in school, when he does not suffer from speech impairments or from serious mental disorders, he can be enrolled in school”.

Findings from cross-sectional surveys were more mixed. In India, higher levels of associated stigma among caregivers of people with schizophrenia were correlated with higher levels of schizophrenia symptoms ($p=0.003$) and severity of disability ($p=0.04$).⁽⁷⁸⁾

In a study of patients with bipolar disorder in north India, higher levels of stigma were associated with shorter duration of remission, duration of depressive episodes, severity of depressive symptoms, and current level of functioning.⁽⁸¹⁾ However, the number of lifetime depressive, manic or hypomanic episodes, or the number of lifetime hospitalisations, did not correlate with either the total stigma score or any of the components of the stigma scale.

In Ghana, the study among stroke survivors found no association between internalised stigma and severity of stroke or other aspects of participants’ health (such as cognitive and eco-social functions and physical and psychological health).⁽⁵³⁾ Similarly, in a study among parents of children with developmental disorders in Ethiopia, there was no association between the levels of stigma and the type of developmental disorder.⁽⁵⁷⁾

Outcomes of stigma and discrimination

Twenty-two studies reported a range of adverse outcomes experienced by people with disabilities as a result of stigma and discrimination.

Several studies report the effect of stigma on physical and mental health of children and adults with disabilities and their caregivers. These included physical and psychological trauma;^(34, 60, 63) high levels of stress, anxiety and depression;^(35, 61, 79) and low self-confidence and self-esteem.^(38, 70, 72, 74, 78) In a study of families of children with developmental delays in Ethiopia, nearly 70% of caregivers reported feeling grief or being depressed.⁽⁴⁹⁾ In a study of HIV/AIDS-related stigma in India, people who reported high levels of stigma were two to three times more likely to experience severe depression ($p<0.05$) than those who did not report stigma.⁽⁷⁷⁾ In Ghana, stroke survivors who did not experience self-stigma had a higher quality of life than those who experienced it.⁽⁵³⁾

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. In the studies in Cameroon, Tanzania, Uganda and Ethiopia, children with disabilities were reported to not attend school regularly and be at risk of school dropout due to stigma.^(34, 35, 49, 62, 64) In Malawi and Tanzania, people with albinism reported frequent closures of businesses and difficulties in obtaining jobs.^(51, 52) In Uganda, Nigeria and South Africa, stigma played a significant role in reduced political participation and increased risk of poverty among people with severe mental illnesses.^(44, 62, 69, 73) In a study among people with mental illnesses in India, multidimensional poverty was strongly associated with stigma, with those who reported family exclusion being 2.6 times more likely to experience multidimensional poverty than those who did not report family stigma.⁽⁸⁴⁾ The

effect was particularly strong for women and people from scheduled castes, scheduled tribes, or other backward castes.

Interventions and their impact

We identified 19 studies which reported on interventions to tackle stigma and discrimination, and assessed their impact (Appendix 4). For the purpose of this review, we organised them into five broad categories: i) education and training; ii) education with social contact; iii) communication, persuasion and modelling; iv) alternative models of care; and iv) economic empowerment.

Each study was assigned a category based on the driving force of the interventions. However, under each of these categories there is a diverse range of intervention types which aim to influence the capability, opportunity and motivation of a range of stakeholders, with the aim of changing their attitudes and actions and to reduce stigma and discrimination towards people with disabilities.⁽⁸⁵⁾ The intervention studies and their results are described in more detail in Appendix 4.

Education and training

Eight studies reported interventions which included education or training. The studies were conducted in Nigeria (n=2); Ethiopia (n=1); Kenya (n=1); Tanzania (n=1); Malawi (n=1); Rwanda (n=1); and Bangladesh (n=1); and targeted stigma related to HIV/AIDS (n=4), epilepsy (n=1), mental health (n=1), autism (n=1), and disability in general (conditions unspecified) (n=1). Study participants included 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, no studies were 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).

HIV/AIDS

A **non-randomised controlled trial in Rwanda** assessed the effectiveness of a peer-led HIV/AIDS prevention intervention in secondary schools (years 2 and 5) aimed at reducing sexual risk behaviours and increasing the use of sexual reproductive health services.⁽⁸⁶⁾ The study was integrated in a sexual and reproductive health programme, which, among other things, targeted enacted stigma measured by asking i) if a child would refuse to be taught by an HIV-positive teacher; and ii) if HIV-positive students should be expelled from school. The intervention was based on an integrated theoretical framework, which included some aspects of the Theory of Reasoned Action, the Social Learning Theory, the Diffusion of Innovations Theory, and the Health Belief Model.⁽⁸⁷⁻⁹²⁾

The study involved 14 (eight intervention and six control) schools in two districts of Rwanda, where students (n=1,950) completed three surveys (baseline, six months and twelve months follow-up).

The intervention consisted of a six-day training for peer educators (five students and one teacher per school). The **education and training** consisted of information on the Red Cross

and its main principles, HIV/AIDS, sexually transmitted diseases, family planning and pregnancies, the role of the peer educator (what is expected of a peer educator and what is the de-ontology of a peer educator), and teaching methods (how to best approach students and how to transmit messages and counsel).

School principals also attended a half-day information session. During the course of the intervention, the peer educators were tasked with teaching their fellow students how to adopt positive and responsible sexual behaviours. This was done through group and individual counselling and feedback mechanisms, drama performances, songs, and other interactive methods.

At the 12-month follow-up, the knowledge of HIV/AIDS increased in both intervention and control groups. The level of enacted stigma at baseline was high, especially in the intervention group (mean=0.35 vs. 0.18). Stigma scores in the intervention group reduced significantly, particularly at the six-month follow-up (mean=0.19). Respondents with high sexual self-concept were more likely to be sexually active and less likely to report enacted stigma. The study was judged to be at high risk of bias.

A **before and after study in Malawi** evaluated the effects of a peer-group intervention on HIV/AIDS knowledge, attitudes and behaviours of urban hospital workers.⁽⁹³⁾ This study used an adapted version of an earlier intervention implemented effectively with women in urban areas of Botswana and with primary school teachers in Malawi.

The intervention, called Mazke ndi Mazke (Friend to Friend), consisted of six **education** sessions giving knowledge on human sexuality; sexually transmitted infections; HIV epidemic; stigma; HIV prevention; testing; partner negotiation; and condom use. Four additional **training** sessions were developed specifically for health workers, and included information on HIV treatment and management; universal precautions; helping individuals and families with HIV prevention; and ethical issues related to HIV. Each session included guided discussions; role play; return demonstrations with corrective feedback (**modelling**); and an assignment to practise skills. Sessions lasted between 90 and 120 minutes. Space was provided for peer groups to have discussion and ongoing guidance by trainers to build **self-efficacy** and **confidence** in performing HIV prevention behaviours (**enablement**).

HIV-related stigma was examined by asking i) whether the health worker believed a person living with HIV should be blamed because of past behaviour; and ii) whether contact with persons living with HIV should be permitted.

Following the intervention, authors reported that blaming attitudes towards people with HIV/AIDS among nurses significantly reduced (no data reported). The acceptance of contacts with HIV positive people was already high at baseline (2.97 out of maximum 3), and did not change after the intervention. The study was judged to be at high risk of bias.

Another **before and after study from Bangladesh** measured the effect of **education** and **training** of health care providers (doctors, paramedics, nurses and counsellors) on reducing HIV/AIDS-related stigma.⁽⁹⁴⁾ The training was conducted over two days, and alongside other topics, included a 90-minute session on stigma which covered (1) definitions of sex, gender, and sexuality; (2) vulnerability of young girls; (3) the impact of stigma on access to health services; and (4) approaches to dealing with stigma and discrimination in the health care system to increase self-awareness and skills in language and barriers for young people.

Training included **persuasive** techniques to engage an emotional response from trainees to change attitudes.

A self-administered questionnaire was administered to a cohort of 300 participants before the training. The first follow-up survey was conducted six months after the training. The survey was followed by an additional one-day's training on stigma related to cultural and moral beliefs, with the reflection on participants' personal values around sexuality. A third survey of participants was administered six months later. In addition, a cross-sectional survey of clients aged 15-24 years old was conducted before and after the second stigma training to assess client satisfaction with services. Lastly, service providers were asked a series of questions to explore their experiences of working with people with HIV/AIDS, as well as workplace and personal drivers of stigma and discrimination.

Results showed that among service providers, there was a decrease in the proportion of respondents who thought that "people with HIV should be ashamed of themselves" (from 35.3% at baseline to 19.7%, and 16.3% at two follow-ups; $p < 0.001$); and that young people and men who have sex with men (MSM) engage in "immoral behaviour" (reduced from 50.3%, to 36.0% and 21.7% $p < 0.001$ for youth; and from 49.3% to 38.0% and 24.0%; $p < 0.001$ for MSM, respectively). Among clients, there was an increase in the overall satisfaction with services (from 63.5% to 97.6%; $p < 0.001$). Also, after the second training, none of the clients felt that the health care provider acted in a negative way, compared to 4.1% before the training ($p < 0.01$). The study was rated medium risk of bias.

A **qualitative study in Tanzania** evaluated the training of 15 church leaders, including pastors, evangelists, heads of women's groups and Bible study groups.⁽⁹⁵⁾ The **education** and **training** was conducted through gender-segregated sessions, where one was on HIV/AIDS and the second one was on reproductive health, gender, and the role of the church. The training used religious script and the notion of 'being a good Christian' as an **incentive** to influence behaviours.

Focus group discussions conducted three to five months after the training showed that stigma was not raised by participants as a barrier to HIV prevention. Church leaders who initiated home visits of families affected by HIV/AIDS reported that their initiative was received positively by the community; it improved attitudes towards people with HIV/AIDS and allowed them to confront their own fears and prejudices. The study was judged to be at high risk of bias.

Epilepsy

A **before and after study in Nigeria** tackled epilepsy-related stigma among trainee teachers ($n=226$ at baseline and $n=216$ at follow-up) who were given a 1.5 hour lecture (**education**) on epilepsy, which included an audio-visual presentation, followed by a discussion.⁽⁷⁵⁾ The lecture covered biological and psychosocial aspects of epilepsy, including key definitions, the burden carried by the patient, risk factors, triggers, manifestations and management of an epileptic seizure. The aim was to improve knowledge and attitudes towards students with epilepsy.

At baseline, 44% of respondents reported poor knowledge of epilepsy and 62% had negative attitudes towards the disease. At the 12-week follow-up, the proportion of respondents with poor knowledge and negative attitudes decreased by 15.5% ($p < 0.0001$) and 16.4%

($p < 0.0001$), respectively, while the proportion of those with correct knowledge and good first aid management skills increased by 29.6% ($p < 0.0001$) and 25.0% ($p < 0.0001$), respectively. The study was medium risk of bias.

Mental health and developmental disorders

A **before and after study in Nigeria** used an educational intervention to tackle mental health-related stigma among medical ($n=39$) and nursing ($n=43$) students (96) through a change in attitudes and beliefs. The intervention was a four-day review of basic **education** on mental illness and psychiatric treatment based on the World Health Organization Mental Health Gap Action Programme Intervention Guide (mhGAPIG). Each course day included five interactive **training** sessions, lasting one hour each. The sessions covered participants' general understanding of mental illness and their personal interactions with people they perceived to have mental illness. To engage participants, there were also two role play sessions focused on interviewing a "psychotic patient" and a "depressed patient", which involved student volunteers and a modelling faculty. These **persuasive** techniques help participants reflect on previous engagement with mental illness and how they might adjust their behaviours.

The Community Attitudes to Mental Illness (CAMI) questionnaire was used to measure changes in social stigma. The greatest changes in attitudes were found on the items favouring normalisation of the lives of people with mental illness ($p=0.0002$), socialising with the mentally ill ($p=0.01$), and biopsychosocial perspectives on mental illness ($p=0.01$). The study was high risk of bias.

In **Ethiopia, an experimental, three-arm post-intervention study** evaluated the impact of Health **Education** and **Training** (HEAT) programme on autism-related stigma among rural health extension workers.⁽⁹⁷⁾ The two intervention arms included two types of the HEAT programme to improve participants' attitudes, beliefs and expectations towards mental illness. In the HEAT arm, health extension workers (HEWs, $n=104$) completed a basic mental health training module, which covered topics on maternal and child health, family planning and sexual health, environmental hygiene and communicable and non-communicable diseases. Those in the second intervention arm (the HEAT+ group) ($n=97$) received enhanced training, comprised of basic HEAT, as well as video-based training on developmental disorders and **modelling** of skills, counselling and problem-solving skills. Resources included a mental health pocket **guide** covering a range of topics on adult and child mental health and specifically, autism and intellectual impairments.

HEWs in the control group ($n=108$) did not receive any intervention.

Autism-related stigma was assessed through measures of beliefs, expectations and social distancing towards children with autism, using a questionnaire and a vignette. Findings show that HEWs in the HEAT ($p=0.004$) and HEAT+ ($p < 0.001$) groups reported fewer negative beliefs than the control group; and the HEAT+ group in turn displayed fewer negative beliefs than the HEAT group ($p < 0.001$). Similarly, both the HEAT ($p < 0.001$) and the HEAT+ group ($p < 0.001$) showed decreased social distance towards children with autism; and the HEAT+ group displayed a smaller preferred social distance than the HEAT group ($p=0.017$). However, the HEAT+ trained group was less likely to have positive expectations about children with autism than the untrained HEWs. Authors note that this may be due to the

exposure of health extension workers in rural Ethiopia to predominantly severe cases of autism, as well as the focus of the training materials on severe symptoms. The study was rated medium risk of bias.

Disability (unspecified).

In **Kenya**, a **before and after study** evaluated the effectiveness of training workshops with local leaders (church leaders and pastors, traditional healers, government officials) and families affected by disability.⁽⁹⁸⁾

The workshops aimed to change cultural perceptions of childhood disability (conditions unspecified). The workshops were delivered for different groups of participants separately and used a range of techniques for each group to **educate, train, persuade, incentivise** and **enable** space for discussion on childhood disability.

Community leader workshops drew on participants' beliefs and experiences of disability and guided them through the process of developing compassionate, inclusive responses based on the bible and tailored to their communities' unique needs. Traditional healer workshops facilitated discussions about common traditional practices that can be harmful, as well as timely referrals of children with disabilities to local health facilities. Government official workshops encouraged multisectoral collaboration between government departments to address multiple needs of children with disabilities. Workshops for families affected by disability involved sharing experiences of caring for a child with a disability; information about specific impairments; home-based care and communication strategies to improve a child's quality of life. Parents were also encouraged to come together to start parent support groups, learn sign language, and advocate for new or improved special needs facilities in their communities. Each workshop included participatory presentations and discussions.

Overall, 603 participants participated in the workshops. All were asked to complete a survey before and after the workshops. In addition, participants' actions after the workshops were monitored and recorded, including identification of children with disabilities; referrals to health and education facilities; sharing information; setting up support groups; providing food and equipment; and constructing facilities for children with special needs.

Prior to the workshops, 73% of all participants believed in supernatural causes of disability. After the workshops, this proportion dropped to 29%. The reduction was observed in all participant groups: from 80% to 20% among pastors; from 100% to 50% among traditional healers; from 90% to 50% among families of children with disabilities; and from 20% to 0 among government officials. Authors also suggested that the subsequent actions of workshop participants reached 37,950 people in their communities and improved the quality of life of 3,795 children with disabilities. However, no data underpinning these estimates were provided in the paper. The study was judged to be at high risk of bias.

Education with social contact

One study reported an intervention, which included an educational session supplemented by direct contact with people with disabilities, in this case with HIV/AIDS. It was a multi-country study implemented in five sub-Saharan African counties (Lesotho, Malawi, South Africa, Swaziland, and Tanzania).

HIV/AIDS

The **multi-country before and after study** in **Lesotho, Malawi, South Africa, Swaziland** and Tanzania assessed the impact of an intervention, which in each setting, brought together a team of nurses and people living with HIV/AIDS. **Education** and **training** activities included sharing information on the impact of stigma, joint planning and implementation of stigma reduction activities, and developing examples of people to aspire to or imitate through the self-designed project and direct engagement with the affected group [**modelling**].⁽⁹⁹⁾ The aim was to increase tolerance, increase willingness to engage with people living with HIV/AIDS and improving coping strategies for dealing with stigma. The study used Goffman's definition of stigma⁽²⁾, which is an undesirable or discrediting attribute that an individual possesses, which affects the person's status in society. The study used a model of the HIV/AIDS stigma process, which emphasises the importance of internal stigma stemming from the person's own negative perceptions of themselves based on their HIV status.

Across the settings, the intervention involved different numbers of participants ranging from 14 (seven nurses and seven people with HIV/AIDS) in Lesotho to 20 (10 nurses and 10 people with HIV/AIDS) in Tanzania. To measure stigma, the study used four instruments: i) HIV/AIDS Stigma Instrument-Nurse, a 19-item tool examining nurses as stigmatisers and the stigmatised; ii) HIV/AIDS Stigma Instrument-person with HIV/AIDS, a 33-item instrument that measures total perceived stigma and HIV-related stigma across six domains (verbal abuse, negative self-perception, health care neglect, social isolation, fear of contagion and workplace stigma); iii) Generalized Self-Efficacy Scale, a 10-item tool to measure self-beliefs of individuals to cope with a variety of difficult demands in life; and iv) Self-Esteem Scale, a 10-item instrument to measure global self-esteem.

Results were reported for all five countries cumulatively. After the intervention, people with HIV/AIDS reported significant reduction in overall perceived stigma ($p=0.003$), workplace stigma ($p=0.015$), and self-stigma ($p=0.001$). In the nurses' group, there were no changes in stigma, self-esteem, or self-efficacy, but by the end of the project, a significantly higher proportion of nurses reported having been tested for HIV ($p<0.001$). The study was rated medium risk of bias.

Communication, persuasion and modelling

Five studies reported interventions, which were grouped under communication, persuasion and modelling category. The papers reported studies from Ethiopia ($n=1$), Malawi ($n=1$), India ($n=1$), Nigeria ($n=1$) and Kenya ($n=1$). The studies addressed stigma related to epilepsy ($n=1$), HIV/AIDS ($n=1$), schizophrenia ($n=1$) and intellectual impairments ($n=2$). 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 positive effect of the intervention, and one study had mixed results. Among the studies that showed 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 medium risk of bias (medium quality).

Epilepsy

A **before and after study in Ethiopia** targeted attitudes and beliefs related to epilepsy among school children (age or year not specified), by providing them with a comic book.⁽¹⁰⁰⁾ The study used the developed **communication** tool (the comic book) to **persuade** and **model** through emotional connections with characters and impactful messages. The book also aimed at providing **education** on understanding of epilepsy, stigma and exclusion, and addressed myths and misconceptions about the disease.

Following the intervention, the knowledge of epilepsy increased and the attitudes towards people with epilepsy improved in both urban and rural schools. For example, before the intervention, half of the urban school students did not know whether epilepsy was contagious, while 41% of rural students believed that it was. After reading the comic, 71% and 87% of rural and urban students, respectively, agreed that epilepsy was not contagious ($p=0.001$). Also, before the intervention, about 41% of urban participants and 43% of rural participants were not sure whether they would allow their sibling to marry someone with epilepsy. After reading the comic, 82% and 86% of respondents in urban and rural schools, respectively, said that they would allow such marriage ($p=0.001$). The study was judged to be at high risk of bias.

HIV/AIDS

In **Malawi, a three-group between-subject post-test-only study** evaluated the effect of a **social marketing** intervention, which aimed to tackle HIV/AIDS-related stigma using 'radio diaries' programme featuring people with HIV/AIDS telling stories about their everyday lives.⁽¹⁰¹⁾ Two diarists (one male and one female) narrated 10-minute segments in their own words about issues and key events in their lives, such as interpersonal relations, experiences with health services and coming to terms with their condition (**modelling** and **persuasion**). Segments were purposely chosen for each specific group to target male and female audiences accordingly.

The study used a three-group experimental design, including one "radio diary" arm (RD), where participants listened to 20 minutes of diary segments from one diarist; one "radio diary+ discussion" arm (RD + D), where participants listened to the segments followed by a 20-30 minute group discussion and one control arm, where participants listened to an unrelated radio programme of equivalent length on child labour. Study participants were residents of thirty villages, with 10 participants each and a total sample of 300 people. The villages were randomly allocated to the study arms. A post-intervention survey assessed four stigma outcomes: i) fear of casual contact; ii) shame; iii) blame and judgment; and iv) willingness to disclose HIV status.

Fear of casual contact was significantly lower in the RD group compared to the control group (64% vs 80%, OR=0.44, 95% CI=0.22, 0.89), but there were no significant differences between the RD + D and control groups (67% vs 80%, OR=0.51, 95% CI=0.23, 1.1). There were no significant interactions with other variables and no significant difference between the RD and RD + D groups.

Similarly, shame was significantly lower in the RD group compared to the control group (22% vs 45%, OR=0.34, 95% CI=0.17, 0.71) but there was no significant difference between the RD + D and control groups (41% vs 45%, OR=0.85, 95% CI=0.48, 1.5). The RD + D group

reported significantly higher levels of shame than the RD group ($p=0.008$); and there was a main effect of knowing someone with HIV on shame: participants who knew someone with HIV were overall less likely to report shame than those who did not (27% vs 41%, $OR=0.26$, $95\% CI=0.11, 0.58$). The reduction in shame in the RD group compared to the control group was greater for those who did not know someone with HIV; for those who did know someone with HIV, there was no significant effect of the intervention. There was also an interaction between study group and prior exposure to the RD programme. A reduction in shame in the RD group compared to the control group was reported only for those who had prior exposure to the programme.

Blame/judgement did not differ between the RD and control groups, but it was significantly lower in the RD + D group than the control group ($p<0.05$). There was no significant difference between the RD and RD + D groups, but there were significant interactions between study arm and sex and between study arm and age. The RD and RD + D groups reported lower levels of blame than the control group, but only for men; for women, the three study arms reported the same levels of blame. Also, the RD group reported lower blame than the control group for youth, but not for older people; while the RD + D group reported lower blame than the control group for older people, but not for youth. Youth in the RD + D group reported higher blame than youth in the RD group; there was no significant difference in blame between the RD and RD + D groups for older participants.

Willingness to disclose potential HIV status did not differ between the three groups and there were no significant interactions found. The study was rated medium risk of bias.

Intellectual impairments

Both studies that tackled stigma related to intellectual impairments evaluated a film-based **communications** intervention.

An **RCT in Nigeria** recruited a total of 571 participants, who were randomly allocated to watch either the intervention ($n=291$) or control film ($n=280$).⁽⁷¹⁾ All participants were recruited through social media advertising, in partnership with influential online figures and university platforms. However, the study had a significant loss to follow up, as only 198 participants completed the study.

The stigma film was six minutes long and aimed to improve attitudes through showing first-hand accounts by persons with intellectual disabilities describing their life experiences and social stigma they faced (**modelling**), using emotional hooks to describe their capabilities, humanity, sense of humour and contributions to society (**persuasion**); mixed with facts and **education** on the definition of intellectual impairments, causes, management and impact. The control group watched a film of similar length, but it was unrelated to intellectual impairments and focused on the current state of education in Nigeria.

Data was collected at three time points: baseline, immediately post intervention and at a one-month follow-up. Stigma was assessed through five types of attitudes across three attitudinal components: affect, cognition and behaviour. The affect component measured feelings of discomfort and sensitivity/tenderness. The cognition component included knowledge of causes and knowledge of capacity and rights. The behaviour component focused on interactions with people with intellectual impairments. In addition, the study used

a number of items from the Intellectual Disabilities Literacy Scale, which assessed causal beliefs about intellectual impairments.

Study findings showed a significant increase in positive attitudes of the intervention group in discomfort ($p=0.006$) and sensitivity ($p=0.001$) domains immediately after the intervention. At the one-month follow-up, these positive attitudes significantly decreased compared to post-intervention (Discomfort: $p=0.001$; Sensitivity: $p=0.020$) but were still significantly more positive compared to baseline (Discomfort: $p=0.003$; Sensitivity: $p=0.02$). Looking at group effects, there was a significant difference between intervention and control groups post intervention (time point two) for both Discomfort ($p<0.001$) and Sensitivity ($p<0.001$), but no difference at one-month follow-up (time point three).

Similarly, for the Interactions component, positive attitudes in the intervention group significantly increased immediately post-film ($p<0.001$). At the one-month follow-up, the effect of the intervention decreased ($p<0.001$), but the attitudes stayed significantly more positive compared to baseline ($p<0.001$). With regards to between group effect, the attitudes in the intervention group were significantly more positive than in the control group post-film ($p<0.001$), and the effect was maintained at the one-month follow-up.

On the knowledge of rights component, the intervention group showed an increase in positive attitudes immediately after the intervention ($p<0.001$), but a decrease over time with no significant differences between the two groups at the one-month follow-up. For the knowledge of capacity component, positive attitudes in the intervention group increased significantly immediately post-film ($p<0.001$), and remained notably more positive at the one-month follow-up compared to baseline ($p=0.003$). Attitudes in the intervention group compared to the control group were significantly more positive at both post-intervention and follow-up ($p<0.001$).

With regards to superstitious beliefs about intellectual impairments, both intervention and control groups reported a significant decrease in such beliefs post film ($p<0.001$). However, the decrease was maintained in the intervention group only ($p<0.001$); and the difference between the two groups at the one-month follow-up was statistically significant ($p<0.001$). The study was rated low risk of bias.

An **RCT in Kenya** was conducted by the same group of authors, who evaluated the effect of a similar six-minute **film** on stigma of intellectual impairments. Findings were compared with the Nigeria study in a short unpublished paper by Odukoya and Chege.⁽¹⁰²⁾ The intervention and the evaluation in Kenya followed the same design as in Nigeria described above. The paper, however, provided little detail of the Kenya data and only reported that the intervention had a significant effect on positive attitudes towards intellectual impairments in the intervention group across all attitudinal domains: cognition, effect and behaviour. In contrast to Nigeria, however, in Kenya, the film had little effect on superstitious beliefs. Based on the information about the study methodology described in the paper, the study in Kenya was rated high risk of bias.

Schizophrenia

A **mixed methods study from India** was a case study of a family, who participated in a stage model community-based intervention as part of their treatment for schizophrenia.⁽¹⁰³⁾ The case study included four patients diagnosed with chronic schizophrenia – all of them

were members of the same family (mother, a son and two daughters) and experienced the same symptoms. The family was referred to a psychiatric hospital by a voluntary organisation for an assessment and initiation of treatment. In addition to acute treatment using medication, the social work team provided home visits, one-to-one interactions, and collaborative work with local governing bodies for the family. Community-based **education** and a **persuasive** programme in the family's village allowed space and discussion of myths and misconceptions on mental illness through street play, experience sharing by a person affected by mental illness (**modelling**), a display and distribution of IEC material, interactive sessions and community oath taking by community members (**incentivisation**).

Data on stigma was collected using the Family Burden Scale and Stigma Questionnaire from the last sibling in the family, who was not ill. Overall, there were 14 items, including the need to hide the patients' mental illness status, feeling shame and embarrassment, and avoidance of social gatherings and friendships. Authors reported that based on the baseline assessment, the family was facing significant discrimination in the village; neighbours did not attend their home, children threw stones at their house, and the community believed that they were 'under attack' of evil spirits. All family members reported being deprived of their basic needs like food, water, and social living. At baseline, the caregiver (the remaining sibling) scored 40 out of 50 on the Family Burden scale, and 31 out of 40 on the Stigma scale, indicating high levels of stigma and discrimination faced by the family. Post-intervention, authors reported a positive effect of the intervention. The family reported lower levels of stigma and discrimination, being less concerned with neighbours treating them differently or avoiding them and experiencing better acceptance in the community. The family noted that they were able to build-up and maintain adequate interpersonal relationships with the neighbours. But there was no quantitative follow-up data reported in the paper. The study was rated high risk of bias.

Alternative models of care

Four studies piloted new models of care and evaluated their impact on stigma and discrimination of people with disabilities. Alongside piloting models of alternative care, each study shows a diverse range of supporting activities that aimed at reducing stigma surrounding the new service.

Two studies focused on stigma of HIV/AIDS; one on stigma of 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; and another two studies reported mixed results. Two studies were low risk of bias (high quality), one was medium risk of bias (medium quality) and one was high risk of bias (low quality).

HIV/AIDS

A **before and after study in Kenya** evaluated a new approach to **integrate HIV/AIDS care with primary health care services**.⁽¹⁰⁴⁾ The aim of the activities was to improve patient satisfaction and reduce perceptions of stigma by people living with HIV/AIDS.

Integration of services meant that people with HIV/AIDS could be seen by a health care provider on any day of the week instead of specific days separately from other patients. As

part of the intervention, integrated health **education** was provided for all patients, regardless of HIV status in a single shared waiting bay, which was seen as a way of reducing stigma and broadening health education reach. This **environmental restructuring** changed the patient flow, supply chain network and laboratory testing: drugs were supplied from the same pharmacy, HIV and non-HIV tests were performed by the same laboratory facilities. In addition, clinical mentorship and **training**, and on-the-job **mentorship** was provided to all clinical officers and nurses on HIV and non-HIV-related topics.

At baseline, data was collected from adult patients (18+ years old), who were HIV-positive and already enrolled in HIV care. Follow-up data was collected from patients in HIV care and those accessing general outpatient services. There were two follow-up time points: at three months and 12 months after the integration. The data collection tool was a self-administered questionnaire on service satisfaction and perceived stigma. A consecutive convenience sampling approach was used to recruit 58 participants at baseline, 104 at the three-month follow-up, and 133 at the 12-month follow-up.

The levels of satisfaction with the services were very high at baseline (98.2% of patients were very satisfied or satisfied with the service). Satisfaction remained high at the 12-month follow-up (98.8%). On specific areas of care, 12 months after the integration, respondents had higher odds of being very satisfied with reception services (aOR 2.71, 95% CI 1.32-5.56), HIV education (aOR 3.28, 95% CI 1.92-6.83), and wait time (aOR 1.97, 95% CI 1.03-3.76). Women rated clinician performance more favourably at both the three-month ($p < 0.001$) and 12-month ($p = 0.007$) follow-ups compared to baseline.

Perceived stigma was measured by three stigma-related questions: i) whether people with HIV/AIDS were treated in the same way as other patients; ii) whether the services protected patient privacy and confidentiality; and iii) whether patients felt uncomfortable about receiving care at the facility. At the 12-month follow up, study participants were more likely to agree that people with HIV/AIDS were treated in the same way as other patients compared to baseline, but statistically significant differences were reported for men only (aOR 17.81, 95% CI 1.83-173.12). The views on privacy and confidentiality did not change between the baseline and either three- or 12-month follow-up. Feelings of discomfort about receiving care at the facility differed between men and women. Men were less likely to feel uncomfortable after the integration, although statistically significant differences were observed at the three-month follow-ups only. Women, however, were more likely to express feelings of discomfort after the integration and the differences were statistically significant at both the three-month (aOR 2.65, 95% CI 1.01-6.99) and 12-month (aOR 3.37, 95% CI 1.33-8.52) follow-up. Authors did not provide any explanation for this change or for the gender differences observed. The study was rated as medium risk of bias.

An **RCT in Zambia** assessed the effects of a **new home-based voluntary counselling and testing (VCT)** on HIV/AIDS-related stigma.⁽¹⁰⁵⁾ The study used a cluster RCT design, where the intervention was offered to all adults in 18 intervention villages by lay counsellors specifically trained for testing and counselling in the home setting. The control arm had access to clinic-based HIV testing and counselling, which is the standard of care. This type of testing was also available to the intervention arm. Home-based VCT was supplemented

by a community mobilisation process, including discussions and in-depth interviews with traditional leaders. **Marketing** about the trial and interviews with individuals who had been tested through home-based VCT (**modelling**) were broadcast on the **local radio** channel in all villages – reaching both intervention and control clusters.

Structured questionnaires were used to assess changes in stigma, which was one of the secondary outcomes of the trial. The tool contained eight stigma items from a validated stigma scale by Genberg et al,⁽¹⁰⁶⁾ including i) people living with HIV/AIDS should not be ashamed; ii) a person with HIV/AIDS should be allowed to work with other people; iii) people who have HIV/AIDS deserve compassion and support; iv) people who have HIV/AIDS should be treated the same as everyone else; v) people living with HIV/AIDS should be treated similarly by health care professionals as people with other illnesses; vi) people living with HIV/AIDS face neglect or rejection from their homes by their family; vii) most people would not buy vegetables from a shopkeeper or food-seller that they knew had AIDS; viii) people living with HIV/AIDS face verbal abuse or rejection from their peers. A total of 732 individuals in the intervention arm and 768 individuals in the control arm completed stigma questions at baseline. Stigma responses from both baseline and follow-up surveys were available for 560 individuals in the intervention arm and 547 individuals in the control arm.

Between baseline and follow up, authors reported reductions of stigma for six out of eight stigma items, but statistically significant differences were observed for four items. Three of these items related to equality of care. For the items related to perceived discrimination, statistically significant differences were observed for one item only. In addition, the observed reductions took place in both intervention and control arms. The study did not find statistically significant differences between intervention and control arms at either baseline or follow-up ($p=0.432$), leading to the conclusion that home-based VCT did not have an impact on reducing HIV-related stigma. The study was rated low risk of bias, although the authors note that as reduction of stigma was a secondary outcome, the study was not sufficiently powered to measure the difference.

Schizophrenia

A three-site RCT in Tamil Nadu, Goa and Satara in south India tested community care models for people with schizophrenia and compared the effectiveness of a **new collaborative community-based intervention** with standard facility-based care.⁽¹⁰⁷⁾ The collaborative community-based intervention was designed to promote collaboration between the person with schizophrenia, their caregivers, and the treatment team to deliver a flexible, individualised, and needs-based care. The intervention was delivered by community health workers who had at least 10 years' of schooling and good interpersonal skills. Stigma- and discrimination-related components of the intervention included specific **training** for participants and caregivers to deal with stigma and discrimination, linkages to self-help groups; networks with community agencies to address social issues; access to legal benefits; and employment opportunities. A **manual** was developed for community health workers for three phases of visit.

A total of 282 patients with schizophrenia were randomly allocated to receive collaborative community-based care plus facility-based care ($n=187$) and facility-based care alone ($n=95$).

Out of them, 253 patients completed a 12-month follow-up. Changes in the experiences of stigma and discrimination were one of the two secondary outcomes, measured using items from several existing tools, such as the discrimination and stigma scale; the internalised stigma of mental illness scale; the burden assessment schedule; the knowledge about schizophrenia interview schedule; and others.⁽¹⁰⁸⁻¹¹¹⁾

Findings show that at 12 months post-intervention, there were no statistically significant differences in the levels of stigma reported by intervention and control groups in either alienation domain (aOR 1.15, 95% CI 0.66-2.02), reported stigma (aOR 1.35, 95% CI 0.72-2.53), negative discrimination (aOR 1.02, 95% CI 0.54-1.92) or anticipated discrimination (aOR 1.31 95% CI 0.66-2.60). Furthermore, the intervention did not have an effect on either the knowledge about schizophrenia (adjusted mean difference 0.34, 95% CI 0.28 to 0.96), or burden (-0.04; 95% CI 0.18 to 0.11), or willingness of families to disclose their relative's illness (aOR 1.43, 95% CI 0.80-2.53). In fact, people with schizophrenia in the intervention group were nearly three times more likely to be unwilling to disclose their disease than in the control group (aOR 2.77 95% CI 1.65-4.67). The study was rated low risk of bias.

Intellectual impairments

A **post-intervention survey in Malawi** evaluated a **new community-based rehabilitation (CBR) model** and explored the role of non-professional local women recruited as community home visitors (CHVs) to assist trained professionals in supporting parents of children with intellectual impairments in educating them in their home environment.⁽¹¹²⁾ A total of four CHVs were trained by the Child Development Centre (CDC) Portage centre trainers, who specialise in home-visiting educational service for early years children with disabilities, over 17 days, including one week of intensive training and one day-a-week over four weeks of supplemental training. The **training** included sessions on carrying out home visits; completing a development checklist, activity chart and behavioural log; and helping parents with physiotherapy, occupational and sensory exercises. Monthly in-service training sessions (of eight days) included curriculum planning and implementation; parental involvement; normal versus delayed child development; alternate learning strategies; the needs of the entire community; and general hygiene. Portage centre staff supervised the CHVs through weekly meetings, video observations, and fortnightly home visits. The programme supported a total of 39 families across four communities. The CHVs travelled from between 1.5 and 5km to support their families once a week for one hour and the focus was on parent perceptions and satisfaction with the new service.

Study participants included three CDC trainers, four recruited CHVs and 10 parents selected by convenience sampling. Three questionnaires (one for the Portage staff (13 questions), one for CHVs (19 questions), and one for the parents (36 questions)) were used to collect data. Interviews to complete the questionnaires took place nine months after the pilot programme was implemented. Two out of six themes related specifically to stigma: community inclusion; and participation of fathers, siblings, and neighbours in supporting the child.

Overall, seven out of ten parents reported more participation of other members of the family or neighbours in supporting the child since the home visits started. Six parents reported the involvement of the father or an extended family member; and indicated that siblings were involved in providing support. Participants' comments suggest that fathers and siblings

gained a deeper understanding of the nature and causes of the impairment and “learned practical activities to assist in the child’s development”. These efforts helped to bring the family closer together and had the effect of normalising the child’s difficulties within the family. With regards to neighbours, only four out of 10 parents reported that they experienced more support; and “there was still reluctance or maybe a fear among some neighbours in the village to engage or assist”. CHVs also reported some challenges which included stigma, social exclusion of families, and a lack of community knowledge on how to help children with disabilities. Findings also showed that extending the child’s learning environment into the community presented more challenges for the CHVs. One prohibiting factor was dealing with the cultural attitudes associated with having a child with a disability which affected the integration of the child and family at a social level. The quality of the study was rated high risk of bias.

Economic empowerment

One study reported interventions, which aimed at economic empowerment of people with disabilities. The study was conducted in Nigeria and addressed leprosy-related stigma.

Leprosy

A **mixed methods study in Nigeria** examined the effect of **socio-economic rehabilitation (SER) intervention** on leprosy-related stigma.⁽¹¹³⁾ The SER programme undertaken in northern Nigeria aimed to improve livelihoods of people with leprosy and included both community and individual level interventions. Community interventions included the provision of water boreholes and electricity, and the construction of markets and schools. Individual interventions included housing projects; scholarship schemes for education; micro-credit loans schemes; and vocational training. The study evaluated the effect of individual level interventions.

Data was collected from 20 randomly selected SER participants using a participation scale questionnaire (the P-scale), supplemented by semi-structured interviews and focus group discussions. The P-scale was used once throughout the programme and data could not be compared over time. At the time of the assessment, four out of 20 participants reported severe limitations in social participation (score >12). Qualitative findings showed that 14 out of 20 participants claimed they became independent following SER interventions (for instance, the ability to meet family needs); 13 reported increased accessibility to hospitals, schools, places of worship and ceremonies following their participation in micro-credit loans; and 15 participants reported increased participation in family activities, mainly through financial contributions. Furthermore, 15 participants (nine men and six women) reported improved family relationships; and 13 (eight men and five women) reported improved community attitudes. Improvements in attitudes were described as honour, respect, dignity, recognition, reduced verbal abuse, inclusion in activities and increased access to information. The study was rated high risk of bias.

Toolkits and guidelines to tackle stigma

This section reports on the toolkits, guidelines, specific policies or examples of good practices to tackle stigma and/or discrimination. These papers, however, reported no evidence of the impact of the described policies and/or interventions on stigma related outcomes. Therefore, they were included in this separate section rather than in the intervention section.

Legal and policy provisions

Several documents referred to legal and policy provisions put in place worldwide to tackle stigma and discrimination against people with disabilities. For example, the aspiration of the 2030 Agenda for Sustainable Development to leave no one behind requires a cross-sectoral, multi-stakeholders approach, and the active mobilisation of a broad range of stakeholders – although the degree to which stakeholders are able to participate meaningfully in the national formulation and the implementation of sustainable policy may vary.⁽¹¹⁴⁾

Article 6 of the UNCRPD was created in response to the lack of recognition on the rights of women and girls with disabilities.⁽¹¹⁵⁾ It reinforces the non-discriminatory approach of the Convention, in particular in respect of women and girls. It requires that State parties go beyond refraining from taking discriminatory actions to adopting measures aimed at the development, advancement and empowerment of women and girls with disabilities and the promotion of measures to empower them by recognizing that they are distinct rights holders, providing channels to have their voices heard and to exercise agency, raising their self-confidence and increasing their power and authority to take decisions in all areas affecting their lives. Article 6 should guide States to comply with their Convention related responsibilities to promote, protect and fulfil the human rights of women and girls with disabilities, from a human rights-based approach and a development perspective.⁽¹¹⁵⁾

Toolkits

With regards to the toolkits, two specific toolkits were identified in the reviewed literature: one on stigma related to leprosy and the other one to HIV/AIDS.

Leprosy toolkit

The leprosy-related toolkit was created specifically for civil society organisations (CSOs) in India, including self-help groups, OPDs and NGOs working at grassroots level to facilitate the inclusion of people affected by leprosy and other disabling conditions.⁽¹¹⁶⁾ It uses a human rights-based approach, so that field workers and CSOs can use guiding principles to promote a socially inclusive community response to the stigmatisation of people affected by leprosy, including:

- **Awareness** of leprosy and negative social and personal impacts of stigma and discrimination.
- **Participation** of people affected by leprosy.

- **Empowerment** of people with leprosy by understanding power dynamics in their life and developing skills and capacity to gain control and make informed choices.
- **Non-discrimination and equality** – rights based.
- **Comprehensive accessibility** – barriers to participation in community processes, justice, services, and facilities are identified and addressed.

The guidelines focus on 10 steps to stop discrimination by helping participants:

1. Have a safe environment in which to talk.
2. Name the problem in different contexts.
3. Own the problems of stigma and discrimination and recognise they are part of the problem in words, attitudes and actions.
4. See the effects of stigma and discrimination.
5. Analyse the root causes of stigma, such as fear and misunderstanding.
6. Address fears and misconceptions and build technical knowledge.
7. Challenge the values that underlie stigma and discrimination.
8. Build commitment to changing attitudes.
9. Learn attitudes and skills to support and care people affected by leprosy.
10. Develop strategies and plans for action.

The toolkit was pilot tested at two workshops with field workers and CSOs in Andhra Pradesh and Uttar Pradesh. However, no presentations of findings on the effectiveness of the toolkit in changing stigma and discrimination was reported in the paper.

HIV/AIDS toolkit

The second toolkit was developed out of a three-country research project on HIV/AIDS-related stigma in Ethiopia, Tanzania and Zambia.⁽¹¹⁷⁾ At the start of the research project, workshops were organised for research assistants and HIV/AIDS NGOs to familiarise them with HIV/AIDS-related stigma, and build support for action against stigma. Participants liked the participatory exercises created for these workshops and asked for copies so they could use them in their programmes. Out of this grew the idea of creating a “toolkit” of participatory training materials on HIV/AIDS stigma.

The toolkit was designed to be used by policy makers to influence their approaches and policies on stigma. The toolkit is a set of flexible and participatory educational exercises for raising awareness and promoting action to challenge HIV/AIDS stigma. The toolkit targets frontline workers to work with community groups and to raise their own understanding of stigma – what it means, why it is an important issue, what its root causes are – and to develop strategies to challenge stigma and discrimination. Exercises can be picked out and used to suit the group.

The toolkit identifies five critical elements that programmes aiming to tackle stigma need to address:

- Create greater recognition of stigma and discrimination.
- Foster in-depth, applied knowledge about all aspects of HIV/AIDS through a participatory and interactive process.
- Provide safe spaces to discuss the values and beliefs about sex, morality and death that underlie stigma.
- Find common language to talk about stigma.
- Ensure a central, contextually appropriate and ethically responsible role for people with HIV/AIDS.

The toolkit recommends specific individuals and groups as target groups, who play a key role in reducing stigma:

Families caring for people living with HIV and AIDS: programmes can help families both to cope with the burden of care and also to recognise and modify their own stigmatising behaviour.

NGOs and other community-based organisations: NGOs can train their own staff to recognise and deal with stigma, incorporate ways to reduce stigma in all activities, and critically examine their communication methods and materials.

Religious and faith-based organisations: these can be supportive of people living with HIV and AIDS in their role as religious leaders, and can incorporate ways to reduce stigma in their community service activities.

Health-care institutions: medical training can include issues of stigma for both new and experienced providers, while at the same time risks faced by providers need to be acknowledged and minimised.

Media: media professionals can examine and modify their language to be non-stigmatising, provide accurate, up-to-date information on HIV, and limit misperceptions and incorrect information about HIV and people living with HIV and AIDs.

The toolkit was designed to get participants learning through sharing feelings, concerns, and experience, discussing and analysing issues, solving problems, planning and taking action. The exercises build awareness about and action against stigma – so help participants move to action.

Guidelines

One of the reviewed documents outlines guidance on different techniques and approaches for counselling people affected by stigma.⁽¹¹⁸⁾ The guidelines target “lay counsellors” who do not have a professional or clinical qualification but are working with people affected by stigma. They may be health workers, fieldworkers, health educators or social workers. Counselling is defined as a helping relationship that involves working with a person to address the feelings (emotions), thoughts and beliefs, behaviours and relationships that are associated with the diagnosis and with the ongoing process of living with a stigmatising condition. Authors note that an effective counsellor should have empathy towards the patients, a non-judgemental attitude, respect, and an intent to empower and build self-

awareness. Essential skills include communication skills, such as listening and observing, and skills to deal and handle emotions. It is emphasised that for counselling to have any measurable effect in stigma reduction, the ongoing development of attitudes, skills and knowledge of the counsellor are critical. In addition, change will only occur for the individual if the conditions for safety and confidentiality are met. It is also necessary that the counsellor allocates the time necessary for such work.

Examples of good practices

One document reported on several examples from the programmes supported by different NGOs to address stigma and discrimination in the settings of their work.⁽¹¹⁹⁾ Self-help groups, peer support and training groups, ran by an organisation called Motivation, tackled stigma by offering information and support to people with disabilities and the parents of children with disabilities. These helped dispel myths, demonstrate that people with disabilities can earn a living, and offer people with disabilities and their families new hope and confidence.

In India, Bangladesh and Mozambique, inclusive self-care and self-help projects set up by Lepira, united people with leprosy and lymphatic filariasis (LF) with people with other disabilities, such as blindness and paraplegia, and those considered vulnerable by their communities, such as widows and people who are ultra-poor.⁽¹¹⁹⁾ Group members helped individuals overcome self-stigma, and as community interaction with group members who faced the least stigma (such as widows) forced interactions with those facing the most (people with leprosy), so the various stigmas were slowly chipped away.

In Uganda, an ADD project turned to organisations of people with disabilities to foster solidarity with people with albinism, who face stigmatising myths and are subject to the same discrimination and exclusion as other people with disabilities.⁽¹¹⁹⁾ The ADD project engaged key stakeholders, including OPDs, before a widespread campaign of activities on raising awareness of disability and disability rights. Following the project, people with albinism reported being more confident and receiving more “respect”, schools took action to give inclusive support to students with albinism, and more children with albinism enrolled in schools.

Also, disability awareness campaigns organised by Plan in Togo led to changes in perceptions and knowledge about disabilities.⁽¹¹⁹⁾ These included communication and educational tools, such as training manuals, posters, documentary films and T-shirts. Parents who had previously denied having a child with disabilities started acknowledging their child publicly and cases of abuse and discrimination against children with disabilities became less common.

Measuring stigma

Measuring and monitoring stigma changes is essential at programme level to inform interventions in a given context. As shown above, the reviewed studies used different tools and approaches to measure stigma, including both bespoke questionnaires developed for the purpose of a specific study and standardised validated scales applied across multiple settings. In addition, we identified three studies which solely focused on describing and/or comparing tools for measuring stigma. Two of these were disease specific tools, and one was a generic tool for 'health-related stigma'.

One study piloted several instruments in a community-based rehabilitation (CBR) setting, including the Participation Scale, Internalised Scale of Mental Illness (ISMI) adapted for people with **leprosy**, Explanatory Model Interview Catalogue (EMIC) for persons with and without leprosy, and the General Self-Efficacy (GSE) Scale.⁽¹²⁰⁾

The Participation Scale provides a quantitative measure of the severity of participation restrictions and has been validated for use with people with leprosy and other conditions in a number of LMICs, including India. The ISMI scale was designed to measure internalised stigma (such as devaluation, shame, social exclusion). The EMIC scale comprises a flexible list of items to probe stigma experience or perception on the side of the person with disability or their family or their community. Lastly, the General Self-Efficacy Scale measures positive self-beliefs of being able to cope with a variety of difficult demands in life.

In their study, the authors evaluated construct validity, internal consistency, test-retest reproducibility, and reliability of the instruments. This was assessed by comparing levels of stigma in two groups who were expected to be different, leprosy-affected people living in the community rehabilitation project areas, and those similarly affected in adjacent non-CBR areas. In the CBR project areas, different stigma interventions were implemented, including different types and combinations of health education, counselling, financial support, general education, and social contact.

Overall, authors found that the Participation Scale, the EMIC and the ISMI could be included in the stigma assessment toolkit. The ISMI needed another evaluation of the test-retest reproducibility. The GSE Scale needed adaptations for people in developing contexts and would have to be evaluated again before inclusion in a toolkit for stigma measurement.

The **second study** aimed to develop and test a range of scales measuring different aspects of internal and external stigma related to tuberculosis and **HIV/AIDS** in a South African health care setting.⁽¹²¹⁾ The instrument was developed based on a literature review and covered all health care workers. Questions were adapted from other tools and pre-piloted in a meeting with key stakeholders. The six scales were then piloted:

1. Colleagues' external HIV stigma (healthcare workers other than the respondent).
 2. Colleagues' external tuberculosis stigma.
 3. Respondent's external HIV stigma.
 4. Respondent's external tuberculosis stigma.
 5. Respondent's internal HIV stigma.
-

6. Respondent's internal tuberculosis stigma.

Tool analysis assessed internal construct validity, reliability and external construct validity. Analysis then produced seven scales, displaying internal construct validity:

(1) colleagues' external HIV stigma; (2) colleagues' actions against external HIV stigma; (3) respondent's external HIV stigma; (4) respondent's internal HIV stigma; (5) colleagues' external tuberculosis stigma; (6) respondent's external tuberculosis stigma; and (7) respondent's internal tuberculosis stigma. Subsequent analyses (reliability analysis, structural equation modelling) demonstrated that the scales displayed good psychometric properties in terms of reliability and external construct validity. However, it should be noted that the toolkit did not consider stigma by association (for example, beyond the health care setting), the sample size was relatively small, and the results may not be applicable to other settings. In addition, the tool incorporated all elements of the health care profession, but did not look at inter-group differences.

The **third study** focused on '**health-related**' stigma measurement broadly.⁽¹¹⁾ The authors reviewed a range of various scales measuring stigma related to a range of diseases, including leprosy, HIV, tuberculosis, mental health conditions, inflammatory bowel disease, disability, obesity, and cancer. Scales examined included:

Social Distances Scale – designed initially in the US to measure people's willingness to participate in social contacts of varying degrees of closeness with members of diverse social groups, such as racial and ethnic groups. The modified version of the tool has been widely used in mental health. The tool includes seven questions with four answer categories (degree of willingness to engage) to measure social distance.

Explanatory Model Interview Catalogue (EMIC) – it has different versions developed for leprosy patients in India. It includes qualitative and quantitative variables, but now mainly quantitative measures are used. The tool has 8-25 items. It has been adopted to measure views of non-patients, for example, health care workers.

Berger Stigma Scale – designed to measure stigma on four underlying factors (personalised stigma, disclosure concerns, negative self-image, concern with public attitudes). It has been developed in HIV context; and the tool is quite lengthy. It uses Likert scale.

EMIC affected persons scale – developed in relation to leprosy and mental health. It has been used to assess experienced and perceived stigma among those with health conditions.

Internalized Stigma of Mental Illness Scale – developed to measure subjective experiences, including internalisation. Subscales measure Alienation, Stereotype Endorsement, Perceived Discrimination, Social Withdrawal and Stigma Resistance. The tool has been developed together with people with mental illness. It includes 29 Likert items.

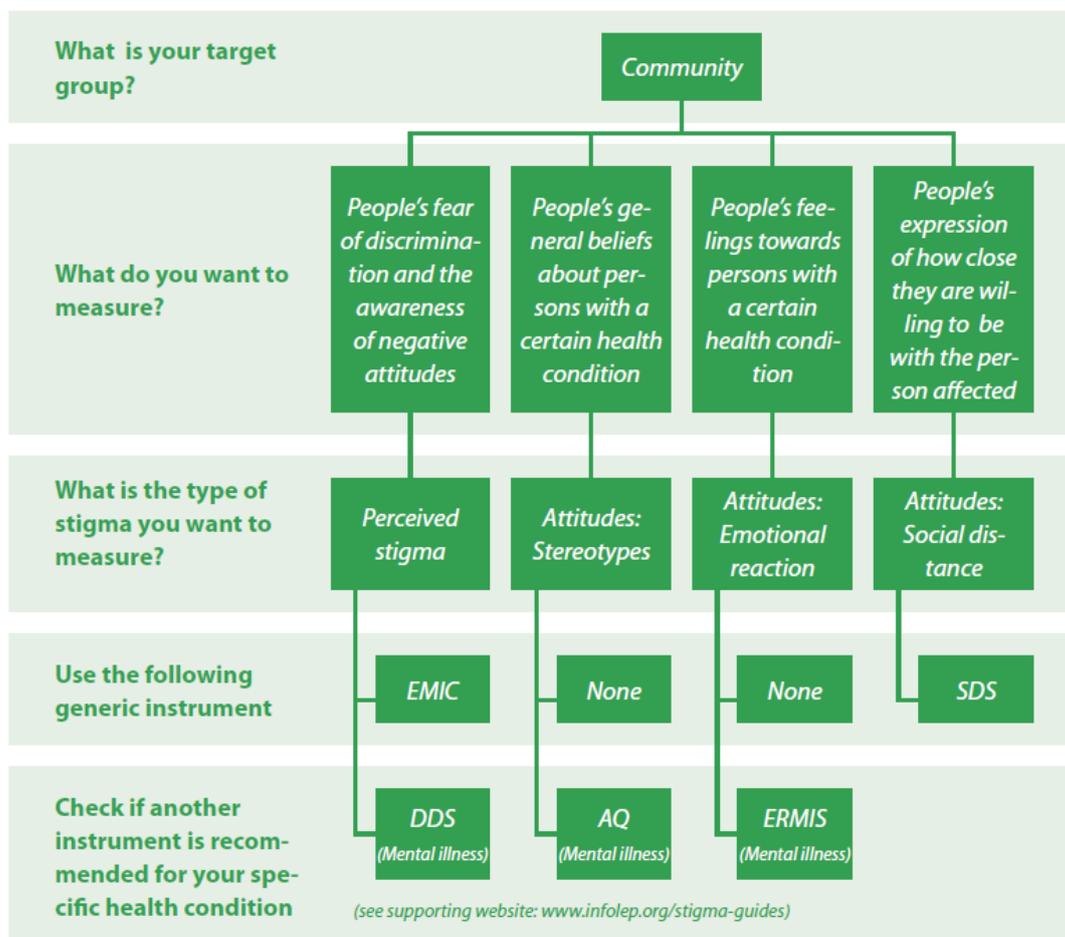
The results of this study demonstrated that 'health-related stigma' is a viable concept, with clearly identifiable characteristics that are similar across a variety of stigmatised health conditions in very diverse cultures. On the basis of this finding, the authors concluded that, "a more generic approach to the study of health-related stigma opens up important practical opportunities – cross-cutting measurement and intervention tools are resource saving and easier to use for personnel working with multiple conditions; allow for comparison between

conditions, and recognise the intersectionality of many types of stigma. Further research is needed to build additional evidence demonstrating the advantages and effectiveness of cross-condition approaches to stigma measurement and interventions”.

According to the Guidance on ‘How to assess stigma’, the purpose of assessing stigma may differ in different situations.⁽¹¹⁸⁾ Before one chooses an adequate method and instrument, one should answer the following questions: a) why do I want assess stigma?, b) what is the target group?, c) which health condition do I want to address?, d) what type/aspect of stigma do I want to assess?, and e) what would I like to do with the results?.

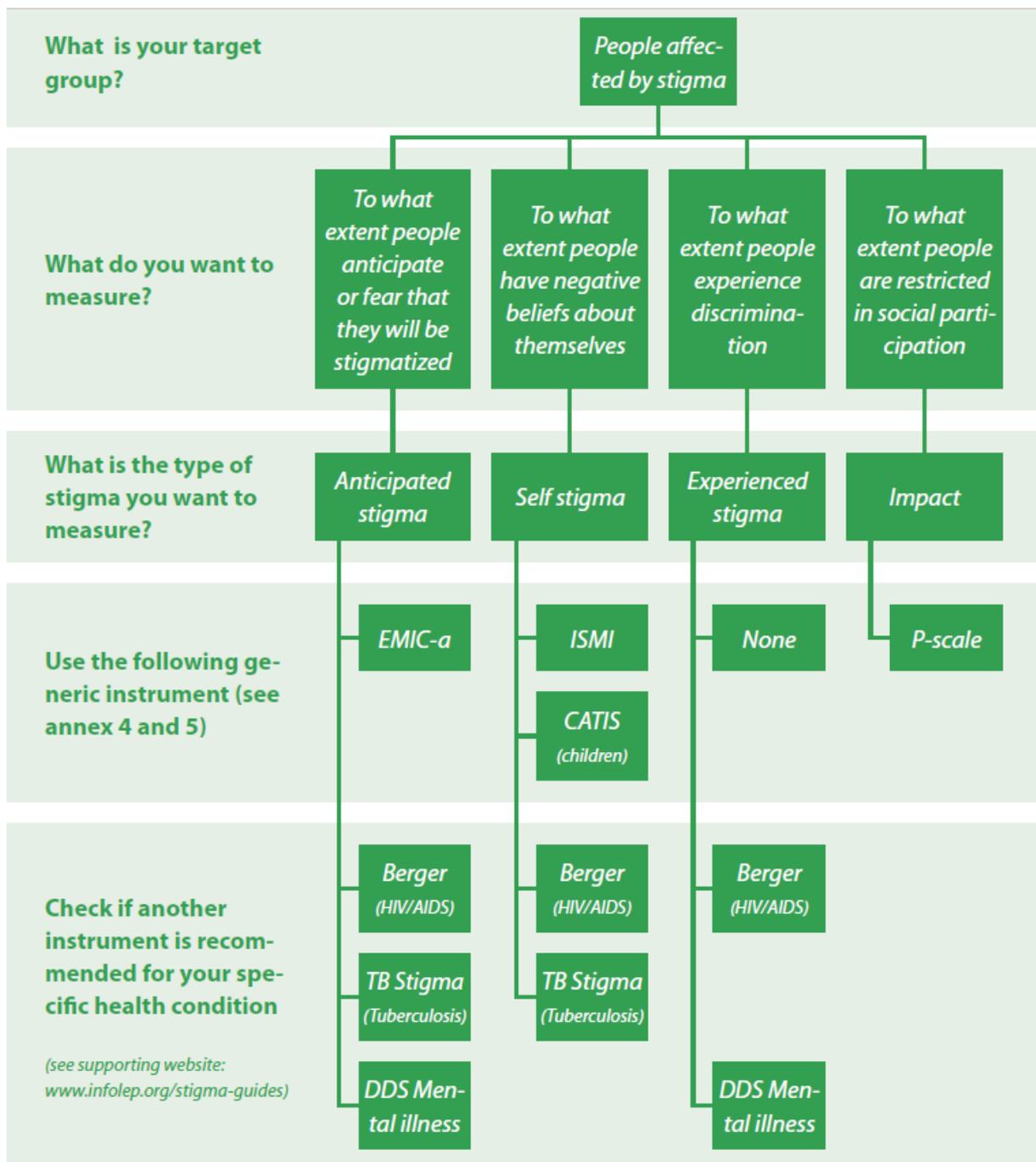
When choosing an instrument, it is important to consider the burden on the respondents (their educational level, level of the questionnaire, and so on), and ensure adequate privacy for the assessment interview. Informed consent should be asked of each interviewee, questionnaires and other tools should always be translated into local language and trialed, and interviewers should be appropriately trained. Methods to assess nature or changes in stigma may include qualitative or quantitative methods, or a combination of both. For the most in-depth and accurate picture, it is recommended to combine both approaches on the target group, and the stigma measuring process may use different pathways, as represented in Figures 6 and 7.

Figure 6: Instruments for measuring stigma in the community (Image reproduced under the Creative Commons License <https://creativecommons.org/licenses/by-sa/3.0/>.)



Source: “Guidelines to reduce stigma – Guide 2”, International Federation of Anti-Leprosy Associations (ILEP).

Figure 7: Instruments for measuring stigma with affected persons (Image reproduced under the Creative Commons License <https://creativecommons.org/licenses/by-sa/3.0/>.)



Source: "Guidelines to reduce stigma – Guide 2", International Federation of Anti-Leprosy Associations (ILEP).

Discussion and conclusion

To the best of our knowledge, this is the first systematic review that synthesised evidence on stigma and discrimination related to different types of impairments and for different population groups in sub-Saharan Africa and south Asia. We found that overall, across the diverse contexts in Africa and Asia, people with disabilities experience a range of stigmatising and/or discriminatory attitudes and behaviours, but there are variations by context, type of impairment, and population sub-group, reflecting the complexity surrounding both the concepts of disability and stigma.

The reviewed studies reported on different sources of disability-related stigma and discrimination, including people with disabilities themselves, their immediate family and community circles, different professional groups, social and political institutions, and the general public. The majority of papers examined stigma from the perspective of more than one group, but not necessarily building linkages between the different types of stigma enacted or experienced by them. Although a number of analytical frameworks examining health-related stigma has been reported in the literature, the studies reviewed rarely articulated the type of stigma and/or discrimination they addressed, or presented a theory of change which they applied to tackle stigma and/or discrimination.

Reviewed studies reported different factors leading to stigma and discrimination. Some studies distinguished between drivers and facilitators; in other studies, the distinction was more settled and the boundaries between the two concepts were blurred. In many studies there was a significant degree of overlap between drivers and facilitators, as well as drivers and manifestations of stigma, which may make it difficult to understand and influence the drivers and facilitators effectively.

Evidence on intersectionality of disability-related stigma with other characteristics was limited and inconclusive, but there are suggestions that internalised stigma may be associated with younger age and severity of impairment and poverty; while enacted stigma may be associated with rural residence, type and severity of impairment, and lower socio-economic status.

The number of studies that tested and measured the impact of interventions on disability-related stigma and/or discrimination was limited, and the majority of these studies were at high risk of bias. Many studies were of small size, had participants selected by purposive or convenience sampling and did not have a comparator group to control for counterfactual.

There was a diversity in the approaches and combinations of interventions used to reduce stigma and discrimination, including education and training, social contact, persuasion and modelling, alternative models of care and economic empowerment. 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 (theory of change). Although a number of studies showed positive effect of the intervention tested, methodological limitations and potential publication bias prevented us from being confident that the described interventions were indeed effective and could be transferred to other settings.

Despite the methodological limitations of the studies included, this systematic review has a number of implications for Sightsavers' programme design and global disability research community.

First, the review provides an overview of what is currently known about stigma related interventions and where the significant knowledge gaps are, highlighting the scope and focus for future research. Studies which measure stigma and discrimination cross different settings in a standardised way, and those that test the effectiveness of stigma interventions will be of particular importance.

Second, the review presents frameworks for understanding the drivers, facilitators and manifestations of stigma and discrimination that can be used when identifying and developing projects to reduce stigma and discrimination.

Third, the review identifies a range of tools and approaches for measuring different aspects of stigma and its outcomes, providing a useful basis for monitoring and evaluation studies.

Finally, the review confirms the complexity that surrounds stigma and discrimination and its impact on diverse populations experiencing them, which calls for more evidence around linkages between different types of stigma (including discrimination), as well as the complex relationships between the stigmatisers and those who are stigmatised.

Implications for programmes

It is important that future programmes which aim to tackle disability-related stigma and discrimination are designed taking into account the findings of this review, 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.
- Embed approaches aimed at mitigating and measuring disability-related stigma and discrimination within development programmes.
- Articulate the type of stigma and/or discrimination the intervention aims to address, and the population groups it aims to target.
- Do not make assumptions about the magnitude of stigma and discrimination and who it affects but collect baseline data using inclusive and participatory approaches 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 (SBC) frameworks, for example, the Behaviour Change Wheel, to more systematically analyse and influence negative behaviours and social norms which drive stigma and discrimination.

- Clearly articulate intervention types and enabling categories and their aims or intentions to influence a diversity of drivers, contextual factors and manifestations of stigma.
- Develop a theory of change underpinning the proposed intervention(s), and clearly articulate the intervention logic, such as 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); integrate rigorous methods within different stages of the project cycle, including formative research, baseline measurement, monitoring and evaluation.
- 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 setting in which Sightsavers works;
- Share findings widely and encourage others to use standardised tools to measure stigma and discrimination (which may be discrete or complementary), and to share results on the effectiveness of interventions across different settings.

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Appendices

Appendix 1. Search strategy

Appendix 2. Drivers and facilitators of stigma

Appendix 3. Manifestations of stigma

Appendix 4. Interventions to tackle stigma