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Systematic Review

Systematic review of interventions for reducing stigma experienced by children with disabilities and their families in low- and middle-income countries: state of the evidence

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Abstract

OBJECTIVES To identify and assess the evidence for interventions to reduce stigma experienced by children with disabilities and their families in low- and middle-income settings.
METHODS Systematic review of seven databases (MEDLINE, EMBASE, Global Health, PsycINFO, Social Policy and Practice, CINAHL, IBSS) for studies of interventions that aimed to reduce stigma for children with disabilities published from January 2000 to April 2018. Data were extracted on study population, study design, intervention level(s) and target group, and type(s) of stigma addressed. A narrative approach was used to synthesise the results.
RESULTS Twenty studies were included. The majority (65%) of interventions targeted enacted stigma (negative attitudes) and the most common intervention approach was education/training (63%). Over half (54%) of interventions were delivered at the organisational/institutional level, and only four studies targeted more than one social level. The most common disability targeted was epilepsy (50%) followed by intellectual impairment (20%). The majority of studies (n = 18/20, 90%) found a reduction in a component of stigma; however, most (90%) studies had a high risk of bias.
CONCLUSIONS This review highlights the lack of quality evidence on effective stigma-reduction strategies for children with disabilities. Validation and consistent use of contextually relevant scales to measure stigma may advance this field of research. Studies that involve people with disabilities in the design and implementation of these strategies are needed.

keywords stigma, disability, child, discrimination, low- and middle-income countries

Introduction

It is estimated that 150 million children globally live with a disability [1], of whom the majority (80%) live in low- and middle-income countries (LMIC). Fifty million children aged under five years are estimated to have developmental disabilities [2] and are likely to experience complex intellectual, physical and sensory impairments over their lifetime. There is evidence that experiences of stigma and discrimination are common for children with disabilities and their families [3-6] and this experience may vary by type and severity of disability [7-9]. However, information on approaches to, and impact of, interventions that address stigma in the context of children with disability and their families in LMIC is generally lacking.

Stigma is a complex psychosocial concept that lacks a universally agreed theoretical approach or definition. Conceptualisations of stigma have increasingly drawn on human rights frameworks and recognise stigma as a form of social oppression. Link and Phelan [10] define stigma as the recognition and labelling of differences between people that connect to negative stereotypes, and therefore result in separation, status loss or discrimination. Health-related stigma has been defined by Weiss (2008) as 'a social process, experienced or anticipated, characterised by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a particular group' [11]. For this paper, we will draw on Van Brackel's recent conceptual model [12], which builds on definitions by Weiss [11] and Scambler [13], and differentiates between the internal perspective of 'people who are stigmatised' and the 'sources of stigma'. Considering people who are stigmatised, stigma is further categorised into

'anticipated stigma' (the expectation of encountering stigma), 'internalised (or self) stigma' (a sense of shame, guilt and fear) and 'experienced stigma' (discrimination). Sources of stigma can include the community, health staff, teachers, laws and policies, and this includes 'enacted stigma' (which refers to discrimination) and 'negative attitudes and prejudice' perpetuated by others, social processes or structures.

Stigma, prejudice and negative attitudes lead to discrimination and the social and economic exclusion [9,14] of children with disabilities and their families, increasing their vulnerability. There is evidence from LMIC that stigma is associated with poor physical and mental health outcomes, social isolation [3,4], limited access to health and education services [5-6,15] and increased financial and emotional strain [16-20]. Stigma may also be a contributor to children with disabilities being at increased risk of abuse, premature death and infanticide, compared with children without disabilities [21,22]. The widespread detrimental consequences of stigma related to child disability highlight the need for interventions aimed at reducing this stigma. Although stigma related to disability is not restricted to lower resourced settings, Kemp *et al.* (2019) suggest stigma may be a greater impediment to accessing services in these settings and that the same cultural and structural factors that influence stigmatising attitudes may also limit the acceptability and uptake of the interventions themselves [23].

There is growing evidence related to some health conditions (e.g. HIV, mental disorders and leprosy) that stigma-reduction interventions can be effective. For example, contact interventions (involving interactions between the public and affected persons with the aim of improving attitudes and reducing discrimination and exclusion) have been found to improve community attitudes about mental health [24] and leprosy [25]. Rights-based peer counselling was found to be effective at reducing internalised stigma and promoting social inclusion among adults with leprosy [26]. The use of 'change agents' or popular opinion leaders to display positive attitudes has shown promising results in the spread of non-stigmatising messages through the modelling of a new behaviour related to HIV and sexually transmitted infection interventions [27,28]. A systematic review of interventions aimed at addressing stigma for children with epilepsy identified different education and counselling programmes, which had variable benefit for the well-being of children with epilepsy [29].

This systematic review aimed to identify and assess the effectiveness of interventions to address stigma experienced by children with disabilities and their families in LMICs.

Method

Search strategy

The systematic review was undertaken in accordance with PRISMA guidelines [30]. The protocol was registered with PROSPERO International Prospective Register of systematic reviews CRD42018102811. The following seven databases were searched in May 2018 to identify interventions published from January 2000 to April 2018: MEDLINE, EMBASE, Global Health, PsycINFO, Social Policy and Practice, CINAHL, International Bibliography of the Social Sciences. A search was carried out using terms for both 'child with disability' and 'stigma and discrimination', with LMIC keywords (according to the World Bank definition July 2017). Boolean, truncation and proximity operators were used to construct and combine searches for the key concepts as required for individual databases, and an example is available as Appendix S1.

Frameworks

For this paper, we drew on the review by Heijinders and Meij [31], which differentiates between the following five intervention/strategy implementation levels: intrapersonal, interpersonal, organisational/institutional, community and governmental/structural level. Recognising that stigma is a complex social process, we also aimed to identify the 'type' of stigma targeted by the interventions. We included four broad types of stigma characterised by Weiss [11], adapted by Van Brackel [12] and extended here to include caregivers/family as well as the affected child:

1 Negative attitudes and prejudice towards the child/family perpetrated by others, social processes or structures;
2 Discrimination or social exclusion 'enacted' by the community, health staff, structures, laws or policies (the 'sources of stigma') towards the child/family or by family members towards the child;
3 Internalised (or self) stigma including internalised negative stereotypes or negative attitudes, feelings of shame or guilt, low self-esteem, withdrawal from social participation by the child and/or by family members; and
4 Anticipated stigma: the perception or fear by the individual that stigmatisation is likely to occur.

Inclusion and exclusion criteria

We used deliberately broad inclusion criteria as we expected limited research in the area and wanted to capture different types of interventions that have been

evaluated. There were therefore no restrictions on study design or language. We included studies of stigma-reduction interventions, for example quantitative studies including RCTs, controlled and uncontrolled pre–post studies, cross-over studies and longitudinal panel studies. Qualitative or mixed-method studies were also included. Participant inclusion criteria were as follows: (i) child with impairment or disability and (ii) family of a child with impairment or disability. We broadly included children with disabilities, as well as specific impairment types, such as physical and sensory impairment, mental illness, cognitive impairment, epilepsy, fits and seizures. We excluded studies that focussed on participants with (i) conditions that constituted a very specific field of research and intervention, such as chronic illnesses and diseases (cancer, heart disease, diabetes, etc.), communicable diseases including HIV/AIDS, drug and alcohol-related issues and short-term disabling conditions and (ii) participants with disabilities or impairments over the age of 18.

Search strategy

Article citations were uploaded and organised for title and abstract review using the reference manager programme Endnote X5. Titles were screened by two reviewers (TS and SP) to determine whether they included relevant information. If the article was deemed relevant by at least one reviewer, the abstract was retrieved. Two reviewers (TS and JA) screened the abstracts for relevant information. If at least one reviewer deemed the abstract relevant, or if the full text had to be obtained to determine if the abstract was relevant, the full text was reviewed. Discrepancies were discussed with a third reviewer (SP) and consensus was reached as to whether or not to include the article.

We undertook double data extraction using a standardised form. The data extraction form was piloted with four studies and included information about the WHO region in which the study was undertaken, study design and participants, intervention type and outcomes related to stigma. We also recorded results on 'knowledge/understanding' about the condition/disability under study if this was assessed alongside another stigma related outcome (e.g. attitudes) because improved knowledge may challenge myths, beliefs and/or stereotypes and therefore contribute to improved attitudes or self-perception [32]. In classifying the intervention, effectiveness results from quantitative studies were summarised as being 'positive' (evidence of statistically significant improvement in the stigma related outcome measure), negative (evidence of statistically significant decrease), 'null' (no statistically significant change) or mixed (findings were a mix of 'positive' and 'negative'/'null').

Quality assessment

The full texts of all eligible studies were assessed against quality assessment criteria adapted from Lund *et al.* [33] and independently assessed by two reviewers (TS and SP; Table 1 shows quality assessment criteria). Differences between the reviewers were discussed, and consensus was reached on all papers.

Results

The database search generated 2860 records, from which 907 duplicates were removed. When screened by abstract, 397 records did not fulfil the necessary criteria. The full texts of 72 papers were then assessed, of which 20 were eligible for inclusion. Data were provided from 16

Table 1 Quality assessment criteria and ratings

Assessment criteria by study design	
All study designs	
Study design, sampling method is appropriate to the study question	
Adequate sample size, for example sample size calculations undertaken*	
Response rate reported and acceptable (>70%)*	
Method of assessment to measure impact on stigma clearly defined and reliable	
Potential confounders taken into account in analysis*	
Confidence intervals are presented*	
Case control (additional criteria)	
Cases and controls are comparable	
Cases and controls are clearly defined	
Cohort (additional criteria)	
Groups being studied are comparable at baseline	
Losses to follow-up are presented and acceptable	
Qualitative (additional criteria)	
Data represented fits the views of the participants studied (credibility)	
Analysis is grounded in the data (confirmability)	
Risk of bias	
Low	All or almost of the above criteria were fulfilled and those that were not fulfilled were thought unlikely to alter the conclusions of the study
Medium	Some of the above criteria were fulfilled, and those not fulfilled were thought unlikely to alter the conclusions of the study
High	Few or no criteria were fulfilled, and the conclusions of the study were thought likely or very likely to alter with their inclusion.

*Not required for qualitative studies.

countries. Reasons for excluding the full text articles can be found in Figure 1.

Study characteristics

Table 2 summarises the characteristics of the studies eligible for inclusion. The 20 included studies provided data from 26 different study settings. The most common WHO study region was Europe (n = 8, 31%), followed by the Americas (n = 7, 27%) and the Africa Region (n = 6, 23%). The majority (n = 24, 92%) of interventions targeted sources of stigma: negative attitudes (n = 19, 73%) and exclusion (n = 5, 19%), while only two (8%) studies targeted people who are stigmatised (internalised stigma) and no studies explicitly assessed anticipated or experienced stigma. Most interventions targeted a single social level, most commonly organisational/institutional (n = 13, 54%) followed by community (n = 6, 25%) and intrapersonal (n = 3, 13%). No interventions were delivered at government/structural level. Twenty-four stigma-reduction strategies were included in the 20 studies, and the majority used education (n = 15, 63%), followed by four studies of contact (n = 4, 17%) interventions. The interventions targeted children with a limited range of impairments types; the most common was epilepsy (n = 10, 50%) followed by intellectual impairment (n = 4, 20%).

Table 3 summarises the designs of the included studies. The majority of studies were quantitative in nature (n = 15), two were qualitative, and three used mixed methods (both qualitative and quantitative). Fourteen studies had before–after study design; however, the majority had no control group (n = 10), only one study used random assignment to intervention or control, and only five described a follow-up period, which varied from 4 weeks to 2 years. The remaining studies only collected data post-intervention. There were two multi-country studies, both of which used phenomenological qualitative methods. Study participants (the group targeted in the intervention) were most commonly primary school teachers (n = 5; 25%), followed by parents (n = 4; 20%). In terms of method of outcome assessment of the quantitative studies, one used a previously validated questionnaire [34] the 'Opinions Relative to Mainstreaming' [35],

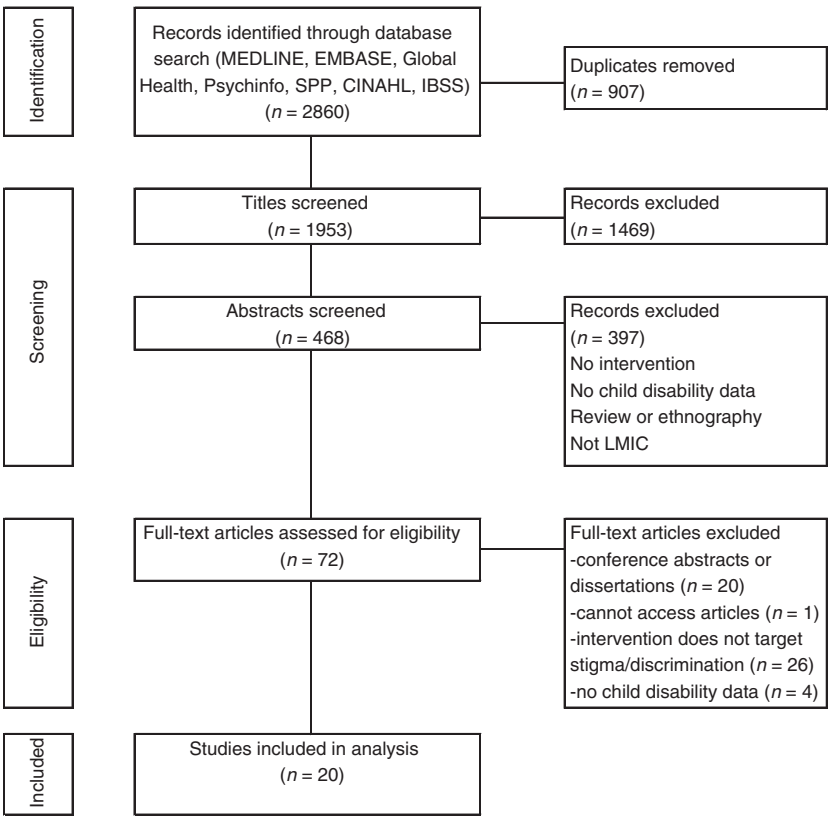

Fig. 1 Study selection PRISMA flow diagram

Table 2 Characteristics of included studies

Characteristic		*N* (%)
Study design (*n* = 20)	Controlled before–after study	4 (20)
	One group before–after study, no control	10 (50)
	One group, post-intervention test	2 (10)
	Longitudinal mixed methods	1 (5)
	Programme evaluation	1 (5)
	Qualitative phenomenological	2 (20)
Decade of publication (*n* = 20)	2000	6 (30)
	2010	14 (70)
WHO Region (*n* = 26)	African Region	6 (23)
	European Region	8 (31)
	Mediterranean Region	0 (0)
	Region of the Americas	7 (27)
	South Asia Region	4 (15)
	Western Pacific Region	1 (4)
Component of stigma targeted (*n* = 26)*	Negative attitudes and prejudice	19 (73)
	Discrimination and social exclusion	5 (19)
	Internalised stigma	2 (8)
Intervention level delivered at (*n* = 24)*	Intrapersonal	3 (13)
	Interpersonal	2 (8)
	Community	6 (25)
	Organisational/Institutional	13 (54)
	Government/Structural	0 (0)
Intervention strategy (*n* = 24)*	Education/training	15 (63)
	Contact	4 (17)
	Community-based rehabilitation	1 (4)
	Support groups	3 (13)
	Home care teams	1 (4)
Target group (*n* = 20)	Child with disability	1 (5)
	Parent of child with disability	3 (15)
	Children	4 (20)
	Teachers	7 (35)
	Health workers	2 (10)
	Health and education students and professionals	1 (5)
	Local community	2 (9)
Target impairment (*n* = 20)	Epilepsy	10 (50)
	Children with disabilities	2 (10)
	Intellectual impairment	4 (20)
	Cerebral Palsy	1 (5)
	Autistic Spectrum Disorder	2(10)
	Deafness	1 (5)
Risk of bias (*n* = 20)	High	18 (90)
	Medium	2 (10)
	Low	0 (0)

*Some studies target more than one intervention.

which assessed teachers' opinions and attitudes related to mainstreaming special needs students in regular education environments. Three studies used questionnaires from previous studies [36-38]: Elafros *et al.* [36] used a three-item assessment to assess felt stigma in Zambia [39], Eze *et al.* [37] used a questionnaire adapted from a previous study of teachers' perception of epilepsy in Nigeria [40] to assess the trainee teachers' knowledge, attitudes and first aid management of epilepsy, and Tilahun *et al.* [38] used a questionnaire assessing beliefs and social distance towards children with autism, adapted from the World Psychiatric Association's programme to reduce stigma and discrimination because of schizophrenia [41]. Eleven studies developed bespoke self-reported tools [42-52]. Three studies that used qualitative methods undertook interviews with a topic guide [53-55], and the data collection approach in the remaining two studies was unclear [56,57].

Risk of bias in included studies

The quality of the studies was generally relatively poor; two (10%) were assessed to have a medium risk of bias, and 18 (90%) had high risk of bias. No studies were deemed to have a low risk of bias. Common methodological limitations included lack of control groups (*n* = 15), clearly defined, valid stigma assessment measures and non-representative samples that result in limited generalisability. Studies predominantly measured aspects of stigma (e.g. negative attitudes) through self-report questionnaires but evidence was lacking on the validity or reliability of the questionnaires used in the study setting. Few studies included control groups (*n* = 4), and lack of adequate adjustment for confounding was also a concern; whilst some distributions of principle confounders were partially described (*n* = 9), few studies accounted for confounding in the study design or analysis. Loss to follow-up was reported in fewer than half of the studies (*n* = 8), and characteristics of losses of participant follow-up were inconsistently taken into account and reported in eight (40%) studies. No studies demonstrated a comprehensive attempt to measure adverse effects. Power calculations were only provided in two studies and although some studies assessed for significant difference through before/after designs, no studies calculated effect sizes.

Type of interventions

We present the results of the 20 included studies according to level at which the intervention was delivered: organisational/institutional, community, intrapersonal and interpersonal, and multiple levels (Tables 4-7).

Table 3 Designs of included studies[‡]

First author, Year, (Ref)	Country	Study design	Length of follow-up after intervention	Sample size (*n*)	Intervention target group	Target impairment	Method of assessment
Quantitative							
Bekiroglu, 2004 [42]	Turkey	One group before–after study, no control	Not described	346	Primary school teachers	Epilepsy	Self-report tool assessing knowledge and attitudes*
Bozkaya, 2010 [43]	Turkey	One group before–after study, no control	4 weeks	851	Primary school students	Epilepsy	Self-report tool assessing knowledge and attitudes*
Elafros, 2013 [36]	Zambia	One group before–after study, no control	Not described	103	Adults and youth with epilepsy	Epilepsy	Questionnaire assessing disclosure and felt stigma†
Eze, 2015 [37]	Nigeria	One group before–after study, no control	12 weeks	226	Trainee teachers	Epilepsy	Questionnaire assessing knowledge, attitudes†
Fernandes, 2007 [45]	Brazil	One group before–after study, no control	2 years	100	Primary school teachers	Epilepsy	Self-report tool assessing knowledge, attitudes and perceptions*
Fernandes, 2001b [44]	Brazil	One group before–after study, no control	6 months	26	Parent	Epilepsy	Self-report tool assessing beliefs, impact on family, and relationships of child and family*
Goel, 2014 [46]	India	One group before–after study, no control	3 months	85	Teachers	Epilepsy	Self-report tool assessing knowledge and attitudes*
Guilhoto, 2010 [47]	Brazil	Controlled before–after study	Not described	Case: 1153 Control: 66	Primary school teachers	Epilepsy	Self-report tool assessing knowledge and attitudes*
Magnusson, 2017 [48]	Belize	One group before–after study, no control	Not described	247	Children	All disability	Self-report tool assessing attitudes*
Palit, 2006 [49]	India	One group post-test, no control	Not described	50	Parents	Cerebral palsy (child)	Self-report tool assessing attitudes*
Sari, 2007 [34]	Turkey	Controlled before–after study	Not described	Case: 61 Control: 61	Primary school teachers	Deafness	Questionnaire assessing* attitudes, and competency†
Somoza, 2013 [50]	Argentina	One group before–after study, no control	Not described	Not	described	Local community (Teachers, parents, children at schools) paediatric staff (hospitals)	Epilepsy

Table 3 (*Continued*)

First author, Year, (Ref)	Country	Study design	Length of follow-up after intervention	Sample size (*n*)	Intervention target group	Target impairment	Method of assessment
Self-report tool assessing knowledge and attitudes*							
Srivastava, 2015 [51]	India	Controlled before–after study	Not described	79	Primary school teachers	ADHD, intellectual disability, ASD, dyslexia	Self-report tool assessing knowledge about teaching methods*
Tekle-Haimanot, 2016 [52]	Ethiopia	One group before–after study, no control	Not described	226	Children	Epilepsy	Self-report tool assessing knowledge and attitudes†
Tilahun (A), 2017 [38]	Ethiopia	Controlled before–after study	Not described	Basic training: 104 Extended training: 97 Control: 108	Community health workers	Autism spectrum disorder	Questionnaire assessing attitudes and social distance preference†
Qualitative							
Cavalcante, 2016 [57]	Brazil, Colombia, Japan	Post-intervention assessment, no control group	Not described	Unclear	Health and education students and professionals	Child disability	Recorded debates held following film viewing analysed using phenomenological method
McConkey, 2013 [53]	Germany, Hungary, Poland, Serbia, Ukraine	Post-intervention assessment, no control group	Not described	Teams: 55 Athletes: 156 Partners: 106 Coaches: 65	Children	Intellectual disability	In-depth interviews using topic guide analysed using interpretive phenomenological approach
Other/Mixed methods							
Dalal, 2006 [56] Programme evaluation	India	Programme evaluation	Not described	Not	described	Local community	General disability

Table 3 (*Continued*)

First author, Year, (Ref)	Country	Study design	Length of follow-up after intervention	Sample size (*n*)	Intervention target group	Target impairment	Method of assessment
Kelly, 2012 [54]	Malawi	One group, post-intervention assessment, no control	Not described	17	Parent	Intellectual disability	Semi-structured interview*
Tilahun (B), 2017 [55]	Ethiopia	Post-intervention cross sectional survey and qualitative study, no control	Not described	104	Community health workers	Mental health	In-depth interviews and questionnaire through face-to-face interview*

*Questionnaire was developed for the study.
†Questionnaire adapted from previous study.
‡Alphabetical order by first author.

Interventions at organisational/institutional level

The majority of interventions were delivered at organisational/institutional level (n = 9) and aimed to reduce negative attitudes towards children with disability, most commonly epilepsy (enacted stigma). Training programmes were the most commonly delivered interventions (n = 8), and different approaches were used including didactic and interactive teaching sessions, videos, theatre and small group discussions. The programmes targeted teachers (n = 7) and school pupils (n = 2) (Table 4). Seven studies reported positive results, with significant improvement in knowledge and reduction in negative attitudes. The remaining two studies reported mixed results, with improvement in knowledge but limited change in attitudes towards children with epilepsy post-intervention [42,45]. However, the majority (n = 7) of studies were assessed to have a high risk of bias, with two [43,48] assessed to have a medium risk of bias.

Interventions at community level

At community level, three contact-based interventions aimed to address negative attitudes and exclusion. Two of these involved direct contact: (i) a film screening in Brazil, Colombia and Japan about lives of children with disabilities and their caregivers followed by community debates [57] and (ii) an inclusive sports programme in Germany, Hungary, Poland, Serbia, Ukraine, including people with and without intellectual disabilities in sports teams [53]. One study in Ethiopia used indirect contact through an educational comic entitled 'We'll make it', which included traditional views of epilepsy and introduced the concept of inclusion and football [52] (Table 5). All studies demonstrated a positive effect; qualitative evidence from the film screening and the sports programme suggested a change in enacted stigma including a decrease in negative attitudes and social exclusion by community members and sports participants. Knowledge and attitude scores significantly improved among children who participated in/received the educational comic book intervention; however, all studies were assessed to have a high risk of bias.

Interventions at the intrapersonal and interpersonal level

Three studies targeted the intrapersonal level [36,44,49], and one study was conducted at the interpersonal level [54]. The strategies to address stigma at the intrapersonal level included support groups. In one study, peer support groups, where content was chosen by the participants who had epilepsy, aimed to target internalised stigma and

Table 4 Description of stigma measures and study findings that target Organisational/Institutional level (n = 9)

First author, Year	Target group	Target impairment	Strategy and Intervention	Type of stigma targeted	Results	Effectiveness*	Risk of bias
Bekiroglu, 2004 [42]	Pre-school	teachers	Epilepsy	Training	programme – didactic (4 lectures with videos about epilepsy)	Negative attitudes	Mixed:
significant ($P < 0.05$)			improvement in response to some, but not all questions about knowledge attitudes towards people with epilepsy	Mixed	High		
Bozkaya, 2010 [43]	Primary school	students	Epilepsy	Training	programme – mixed mode (lectures, case-based discussions, videos, practise with simulated patient with epilepsy)	Negative attitudes	
Significant			improvement in knowledge and attitude scores ($P = 0.001$)	Positive	Medium		
Eze, 2015 [37]	Trainee	teachers	Epilepsy	Training	programme – mixed mode (lecture, AV material and discussion on epilepsy; 1.5 h)	Negative attitudes	
Significant increase in proportion of			respondents with 'good' knowledge and positive attitudes ($P < 0.001$)	Positive	High		
Fernandes, 2007 [45]	Primary school	teachers	Epilepsy	Training	programme – 20 h on epilepsy and health	Negative attitudes	
Significant			improvement in answer to some, but not all, questions asked about attitudes towards epilepsy	Mixed	High		
Goel, 2014 [46]	Teachers	Epilepsy	Training workshops – mixed mode (interactive presentations, videos about epilepsy)	Negative	attitudes	Significant	
			improvement in teacher attitudes towards epilepsy measured across three domains (epilepsy and education, marriage and employment) ($P < 0.05$)	Positive	High		
Guilhoto, 2010 [47]	Primary school	teachers	Epilepsy	Training	programme- didactic: (one lecture delivered in class Or by video conference about epilepsy, including myths)	Negative attitudes	
Significant reduction in correct answers to true/false statements about			stigmatising misconceptions related to epilepsy (e.g. Epilepsy is a spiritual problem)	Positive	High		

Table 4 (*Continued*)

First author, Year	Target group	Target impairment	Strategy and Intervention	Type of stigma targeted	Results	Effectiveness*	Risk of bias
Magnusson, 2017 [48]	School pupils	All disability	Education/awareness programme delivered at schools – mixed mode (puppet show, tortilla making, dance, book reading, video, football, practical activities, discussion (90 min)	Negative	attitudes	Significant	
			improvement in attitude scores ($P < 0.001$)	Positive	Medium		
Sari, 2007 [34]	Primary school	teachers	Deafness	Training	programme – lecture based (eight sessions in 8 days)	Negative attitudes and exclusion	
Significant			improvement in knowledge ($P < 0.001$) and inclusive attitudes ($P = 0.0001$)	Positive	High		
Srivastava, 2015 [51]	Primary school	teachers	ADHD, intellectual disability, ASD, dyslexia	Training	programme – mixed mode (lectures, videos, small group discussions), including on disability and human rights	Negative attitudes and exclusion	
Significant			improvement in attitude (towards inclusive education) scores ($P < 0.001$)	Positive	High		

*Results from quantitative studies (only) categorised as 'positive' (evidence of statistically significant improvement in the stigma related outcome measure), negative (evidence of statistically significant decrease), 'null' (no statistically significant change) or mixed (findings were a mix of 'positive' and 'negative'/'null').

Table 5 Description of stigma measures and study findings that target community level ($n = 3$)

First author, Year	Target group	Disability type	Strategy and Intervention	Type of stigma targeted	Results	Effectiveness*	Risk of bias
Cavalcante, 2016 [57]	Health and education students and professionals	Child disability	Contact-based education: Film screening (documentary about lives of mothers with disabled children) and debate	Negative attitudes	Qualitative evidence of change in professionals' views in relation to their practice	Qualitative evidence of positive change	High
McConkey, 2013 [53]	Sports team members and coaches	Intellectual impairment	Contact: Sports programme which included athletes with and without intellectual disability on same teams	Negative attitudes and social exclusion	Qualitative evidence of improved acceptance, positive attitudes, social bonds and community and social inclusion		
Qualitative evidence of positive change	High						
Tekle-Haimanot, 2016 [52]	School pupils	Epilepsy	Contact (indirect) based education: Educational comic book ('We'll make it') distributed to children at schools	Negative attitudes	Significant improvement in knowledge and attitude scores ($P < 0.001$)	Positive	High

*Results from quantitative studies (only) categorised as 'positive' (evidence of statistically significant improvement in the stigma related outcome measure), negative (evidence of statistically significant decrease), 'null' (no statistically significant change) or mixed (findings were a mix of 'positive' and 'negative'/'null').

Table 6 Description of stigma measures and study findings that target intrapersonal (n = 3) and interpersonal (n = 1) levels

Level	First author, Year	Target group	Disability type	Strategy and intervention	Type of stigma targeted	Results	Effectiveness*	Risk of bias
Intrapersonal	Elafros, 2013 [36]	Adults and youth with	epilepsy	Epilepsy	Support groups – Peer support group (monthly for 1 year), facilitated by clinicians and research assistant, content decided by participants	Internalised stigma, non-disclosure	Significant decrease in internalised stigma (P = 0.02) among youth with epilepsy	
Positive Intrapersonal	High Fernandes, 2001b [44]	Parents	Epilepsy	Support groups and education – Parent support groups, facilitated by psychologist and educational video	Internalised stigma, and Enacted stigma: Negative attitudes (parent and family)	Majority (>80%) of patients reported increasing positive behaviour towards their child and reported improved relationship (no tests of significance)	Unclear	High
Intrapersonal	Palit, 2006 [49]	Parents	Children with cerebral palsy	Support groups – Parent-parent counselling: interaction between groups of i) experienced, trained and ii) new parents of children with cerebral palsy	Internalised stigma: shame/ guilt (parents); Enacted stigma: negative attitudes (parent)	Majority (70%) felt intervention increased attachment, helped them understand their child better, and understand they are 'not responsible' for birth of child with disability and that child should mix with community like other children	Unclear, no pre-test	High
Interpersonal	Kelly, 2012 [54]	Parents	Intellectual disability	Home care teams – Home visits by Community Health Volunteer to support and provide information to families (in between portage team home visits by nurse, psychologist and rehab workers)	Enacted stigma: negative attitudes and exclusion (family and community)	Overall satisfaction by community health volunteers and parents, some increased participation/ involvement with child by father or sibling; CHW perceived to play role in promoting community inclusion	Mixed	High

*Results from quantitative studies (only) categorised as 'positive' (evidence of statistically significant improvement in the stigma related outcome measure), negative (evidence of statistically significant decrease), 'null' (no statistically significant change) or mixed (findings were a mix of 'positive' and 'negative'/'null').

Table 7 Description of stigma measures and study findings that target multiple levels ($n = 4$)

Level	First author, Year	Target group	Disability type	Strategy and Intervention	Type of stigma targeted	Results	Effectiveness*	Risk of bias
Organisational/ institutional and Community	Tilahun (A), 2017 [55]	Community health workers	Autism spectrum disorder	Training programme (including indirect contact) – Health Education and Training (HEAT) Mental Health Training based on classroom teaching over 10 sessions versus HEAT+ (included training on intellectual disability and autism using DVD and pocket guide; including training on community awareness	Negative attitudes and exclusion	Compared to untrained health extension workers (HEW), trained HEW showed significantly fewer negative beliefs ($P < 0.001$) and reduced preferred social distance ($P < 0.001$). HEAT + showed significantly fewer negative beliefs and lower social distance compared to HEAT	Positive	High
Organisational/ institutional and community	Tilahun (B), 2017 [38]	Community health workers	Mental health	Training programme – Health Education and Training (HEAT) Mental Health Training based on classroom teaching over 10 sessions	Negative attitudes	More than 1/3rd had organised awareness-raising meetings in the community; Qualitative evidence of improved attitudes, and using training to address awareness in the community, negative attitudes remained a barrier to doing this for some HEW	Qualitative evidence – mixed	High
Organisational/ institutional and Community	Somoza, 2013 [50]	Community (Teachers, parents, children at schools) Paediatric staff (hospitals)	Epilepsy	Education and training – Theatre in primary schools for school children, parents and teachers; Seminars in hospital for paediatric staff (60min)	Negative attitudes	Improvement in knowledge and attitude scores	Positive	High
Interpersonal, community, organisational/ institutional	Dalal, 2006 [56]	Community	General disability	CBR, education, contact: Medical checks to enable access to disability certificate; children with disabilities collected donations for flood victims; community discussions; established integrated school	Negative attitudes	Qualitative evidence of change in positive attitudes, community and social inclusion	Qualitative evidence of positive change	High

*Results from quantitative studies (only) categorised as 'positive' (evidence of statistically significant improvement in the stigma related outcome measure), negative (evidence of statistically significant decrease), 'null' (no statistically significant change) or mixed (findings were a mix of 'positive' and 'negative'/'null').

non-disclosure [36]. Two studies investigated the effect of parent support groups. One study investigated parent to parent counselling for caregivers of children with cerebral palsy, which took place for 90 min in weekly sessions, and aimed to facilitate exchange of knowledge and experience [49], and the other study combined parent support groups for caregivers of children with epilepsy with an educational component [44]. The interpersonal level intervention [54] consisted of home visits and community-based rehabilitation by community health workers to assist trained professionals in supporting parents in their home environment. The study aimed to reduce negative attitudes and exclusion.

Two of the four studies targeted internalised stigma (e.g. shame and guilt) of the child [36] and parent [49] and two addressed negative attitudes (among caregivers/family members about the child with a disability [44,54]. While one study of support groups found reduction in internalised stigma [36], the effect was either mixed or unclear for the remaining studies [44,49,54] (Table 6).

Interventions targeting multiple levels

The most commonly combined intervention levels were organisational/institutional and community. The studies included schools and healthcare settings and tended to combine individual-level information provision and/or skills building through training, with community-level activities, such as theatre. All studies targeted enacted negative attitudes. One study by Dalal *et al.* [56] intervened at the interpersonal level with organisational/institutional and community, combining community-based rehabilitation, education and contact. Activities included medical checks to enable access to disability certificates, children with disabilities collecting donations for flood victims (door to door and procession), community discussions around abilities of youth with disability and establishing an integrated school. This study demonstrated qualitative evidence of change in positive attitudes, community and social inclusion (Table 6). Three studies included a training programme intervention; Tilahun *et al.* [55] assessed the effect Health Education and Training (HEAT) Mental Health Training on exclusion of children with autistic spectrum disorder as well as negative attitudes of community health workers; Tilahun *et al.* [38] assessed the effect of delivering 10 sessions of classroom-style training to community health workers on awareness-raising efforts in community; and Somoza 2013 [50] used theatre in primary schools for school children, parents and teachers and seminars in hospital for paediatric staff, to address negative attitudes of epilepsy. Results were predominantly positive; however, negative attitudes remained a barrier to training for some health extension workers (HEW) [38] (Table 7).

Discussion

This systematic review identified 20 studies of interventions aimed at reducing aspects of stigma experienced by children with disabilities and their families in LMIC. In terms of type of intervention, the majority of interventions targeted a single social level only (most commonly organisation/institutional) and there was limited evidence for multi-level interventions. Most interventions targeted a single domain of stigma; predominantly, negative attitudes with few studies focussing on other aspects of the stigma process, including internalised stigma. The most common disability type targeted was epilepsy, followed by intellectual disability while physical and sensory impairments were relatively neglected, limiting any comparison of intervention impact by disability type. The most common stigma-reduction strategy utilised was education (n = 15, 63%), followed by 'contact' interventions (n = 4, 17%). The majority of the studies found either a positive or a 'mixed' impact of the intervention on an aspect of stigma. However, caution in the interpretation of findings is warranted because the studies were characterised by a high risk of bias.

There are no previous reviews of stigma-reduction interventions focussed specifically on children with disabilities with which to compare this review. However, our review has some findings in common with previous reviews (which included all-ages) on health-related stigma reduction. Our finding that 'sources of stigma' (negative attitudes and discrimination/exclusion) were most commonly addressed and that education/training was the most common intervention approach aligns with reviews of health-related stigma-reduction interventions in LMIC [23] and multi-level interventions globally [58]. Although the quality of evidence was relatively poor, this review suggested some encouraging trends for education and contact-based interventions in terms of improving attitudes. This aligns with findings of Heijnders and Van Der Meij [31] who suggested that education and contact interventions show promising results in the field of HIV/AIDS, mental illness, leprosy, TB and epilepsy, and Mehta *et al.* [59] who reported that social contact reduced mental-health-related stigma.

Our review also highlighted concerns about the quality of existing studies assessing effectiveness of stigma-reduction interventions related to disability. These concerns align with findings from previous reviews of Heijnders and Van Der Meij [31] and Mehta *et al.* [59], underscoring a need for well-designed research in this area. This

included identifying a need for more rigorous assessment of intervention effect, a concern that was also raised in a review by Kemp *et al*. [23]. In particular, studies lacked control groups, validated measures of stigma [23] and reported statistical significance but not effect sizes [58].

A critical assessment of the studies included in this systematic review suggests key gaps in the literature. The majority of studies evaluated short-term outcomes but lacked evidence of long-term impact, and no studies included measures of change in behaviour. Stigma-reduction interventions focussed on a narrow range of impairments, primarily on children with epilepsy or intellectual impairment and typically focussed on single levels. Considering the qualitative evidence that experiences of stigma vary by type and severity of disability [8,9], this deserves further attention. Few studies appeared to involve people with disabilities in the design and implementation of stigma-reduction strategies. Active involvement of people with disabilities is important for maximising the feasibility, acceptability, sustainability and impact of interventions. Heijnders & van der Meij (2006) argue the need for multi-level interventions that aim to change negative attitudes and discrimination alongside empowerment of affected individuals by ensuring that they take an active role as in the design and implementation of stigma-reduction strategies [31].

Given the poor quality of studies assessed in this review, it is important that results are interpreted with caution. Future research directions should include multilevel interventions that address and/or assess internalised stigma as well as negative attitudes and discrimination/exclusion perpetrated by the 'sources of stigma'. Comprehensive intervention descriptions are necessary to replicate interventions in different contexts and to evaluate the conditions under which stigma may be optimally reduced. In addition, a wider range of disabilities evaluated with these interventions should be included in design and implementation of future studies. A lack of available validated tools for assessing stigma experienced by children and their families is an important area that warrants attention.

The purpose of this review was to describe the evidence on interventions to reduce stigma experienced by children with disabilities and their families in LMIC and inform potential future research studies. We used a comprehensive search strategy that followed PRISMA guidelines, and robust methods that included double data extraction and review to produce an accurate, comprehensive state of the evidence composition. This review has several limitations. Our study did not limit inclusion of articles through methodological appraisal. While we include information on intervention effectiveness, the lack of rigour in these studies may have led to non-generalisable conclusions. Studies undertaken in high-income countries were excluded to focus on the unique challenge of addressing stigma in LMIC in contexts with limited financial and logistic resources and unmet need. Inclusion of studies from high-income settings in future reviews may inform additional learning. The assessment of outcomes that lacked uniformity and validity made both interpretation and comparison of study results difficult.

Conclusions

This systematic review highlights key gaps in the evidence around effective stigma-reduction strategies for children with disabilities and their families in LMIC. There are some promising findings around education and contact interventions to reduce negative attitudes. However, given the methodological limitations we found, these findings have to be interpreted with caution. The validation and consistent use of contextually relevant quantitative measures of stigma may advance this field of research.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Search terms.
Appendix S2. Quality review of included studies.

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