

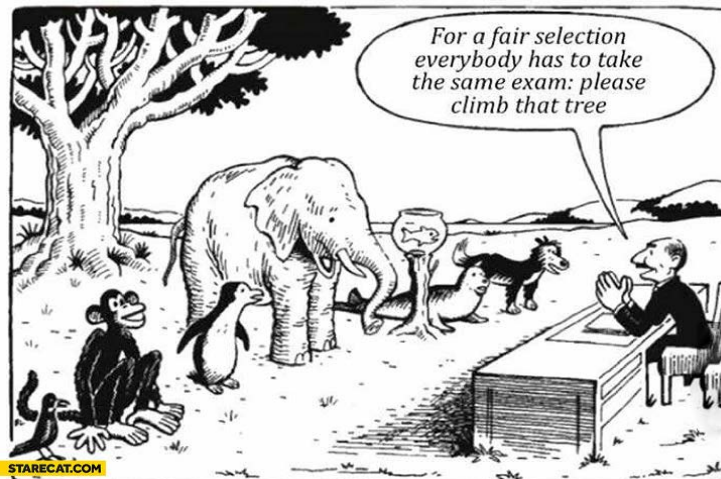
# Report

## The role of stigma in accessing education for people with disabilities in low and middle-income countries: a review of the evidence

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## Our Education System

*"Everybody is a genius. But if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid."* - *Albert Einstein*



# Report

## The role of stigma in accessing education for people with disabilities in low and middle-income countries: a review of the evidence

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**ABSTRACT**

People with disabilities are often subjected to stigma, which can keep them from realising their full potential and their human rights, including the right to education. The UN agenda for Sustainable Development Goals, underscores the urgent need to eliminate and ensure equal access in education to vulnerable groups, including people with disabilities. Thus, it is important to understand the different barriers and facilitators, which are preventing or enabling people with disabilities in their access to inclusive quality education. This report presents findings from a scoping review conducted to give an overview of the evidence-base on the role of stigma in accessing education for people with disabilities in low and middle-income countries (LMICs). Twenty-three articles from LMICs met the predetermined inclusion criteria. These articles described some of the ways stigma is affecting access to and equity in education, especially attitudes coming from teachers, school staff and structures, peers, parents and children's own felt stigma. In turn, these attitudes reflect societal stigma which is due to lack of knowledge and a societal view of disability, based on the medical model of impairment and limitation. There is a need for capacity building of teachers and of changing the medical view of disabilities in society. Evidence-based awareness campaigns and research on the implementation of inclusive education in low and middle-income countries is needed.

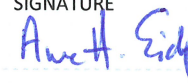
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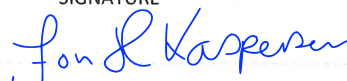
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# Table of contents

<b>1</b>	<b>Introduction .....</b>	<b>4</b>
<b>2</b>	<b>Central Concepts .....</b>	<b>4</b>
<b>3</b>	<b>Methodology.....</b>	<b>7</b>
<b>4</b>	<b>Results .....</b>	<b>7</b>
<b>5</b>	<b>Summarizing and reporting the results.....</b>	<b>14</b>
	5.1 Stigma and teachers.....	14
	5.2 Stigma and peers.....	15
	5.3 Own stigma .....	17
	5.4 Institutional stigma .....	18
	5.5 Societal stigma .....	18
<b>6</b>	<b>Limitations .....</b>	<b>19</b>
<b>7</b>	<b>Conclusion and recommendations .....</b>	<b>20</b>
	7.1 Society and communities.....	20
	7.2 School environments .....	21
	7.3 Gaps in research.....	22
<b>8</b>	<b>References .....</b>	<b>23</b>

## 1 Introduction

This project was commissioned by the Atlas Alliance and carried out by SINTEF Technology and Society, Department of Health Research. The report presents the results from a literature review on *the role of stigma in accessing education for people with disabilities in low and middle-income countries (LMICs)*.

The overall objective of the literature review is to use a scoping review methodology to give an overview of research on the role of stigma in accessing education for people with disabilities in LMICs. Specifically, the review includes research on:

- positive and negative aspects of disability stigma
- the LMIC context
- people with disabilities
- special and mainstream education at primary, secondary, tertiary levels, as well as life-long learning
- year 2000 to April 2017

The review provides an overview of available empirical evidence and gaps in the literature.

This report entails a description of the topic and key concepts for the review, objectives, methodology, results and discussion. The empirical evidence presented in this report may inform the Atlas Alliance's advocacy work for disability inclusion in education programs in partner countries as well as among Norwegian stakeholders involved in development and education.

## 2 Central concepts

There are three central concepts to this review, namely *disability*, *stigma* and *education*, which will be clarified below.

**Disability** has always been part of the human condition (Kleinman, 1980; Kleinman & Benson, 2006; WHO, The World Bank, WHO, & Bank, 2011). Throughout history, people with disabilities have been subject to hatred, curiosity, fascination and sympathy. They have been made exotic, pitied, patronised, ignored and admired (Goodley, 2010). Thus, disability is a complex and contested concept which is in constant flux (Shakespeare, 2015; WHO & The World Bank, 2011), and with no unified definition (Iriarte, 2016). Historically numerous attempts have been made at defining and understanding disability, such as supernatural, spiritual and religious understandings (Goodley, 2010). In more recent history, two major approaches to disability have dominated the field, namely the medical model and the social model of disability (Shakespeare, 2013). The medical model focuses on the impairment, and offers an individualistic understanding of disability which refers to individual characteristics of the body, something missing in the individual: a limb, an organ or a mechanism in the body (Finkelstein & French, 1993; Shakespeare, 2013). The social model for disability, on the other hand, refers to disability as a social construct leading to lack of or loss of opportunities preventing disabled people from taking part in normal life on an equal level with others due to physical and social barriers in society (Finkelstein & French, 1993). The most current understanding of disability integrates components of the medical and the social model, and can be found in the World Report on Disability (WHO & The World Bank, 2011), and based on the International

Classification of Functioning, Disability and Health (ICF) (WHO, 2001), disability is described in the following way:

Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (WHO & The World Bank, 2011).

The strength of the ICF concept is in offering a common language to study the dynamic interaction between health condition, environmental factors and personal factors and therefore enabling to define what can improve the life situation of disabled people (Hollenweger, 2014). It looks beyond the medical condition and includes the social dimension of a person (Eide et al., 2011).

The concept of **stigma** is central to social science in general, and to the field of disability in particular. Stigma is often used as a broad term to include issues of attitudes and perceptions, ignorance, discrimination, prejudice, labelling and stereotyping (Phelan, Link, & Dovidio, 2008; Thornicroft, 2006; Wahl, 2012). While stigma is generally taken to be a negative concept, there are also accounts of attitudes, perceptions and behaviour towards people with disabilities of a more positive character, which may result in more positive than negative consequences for an individual or a group. Positive or negative, stigma is a big part of the overall experience for people living with disabilities (Egbe, 2015; Engebretson, 2013), and the experience of stigma is often described as being worse than the main condition (Thornicroft, 2006). Adding to this, stigma represents a major barrier for accessing health and social services for many people with disabilities (Egbe et al., 2014). Perceptions of disability have a crucial impact on limiting or ensuring the realisation of human rights for people with disabilities (Bricher, 2000; Braathen, Munthali, & Grut, 2015; Harpur, 2012; Siminski, 2003). They provide a starting point for disability related practice, theory and everyday living (Chappell, Goodley, & Lawthom, 2001). All societies have complex belief systems and cultural interpretations related to disability, which are as important in shaping the disability experience as the specific health condition or impairment related to the disability (Groce, 1999; Gronvik, 2007). Beliefs and interpretations lead to assumptions about how individuals with disabilities should be treated and what rights and responsibilities they have (Groce, 1999). In some instances, this leads to people treating disabled individuals in a positive, mythical and elevated manner, or on the other hand in a fearful, disrespectful and excluding manner (Barnes, 2016; Braathen & Ingstad, 2006; Groce, 1999; Whyte & Ingstad, 1998). In the negative meaning, stigma occurs when power is wielded and the stigmatized group is disempowered and subjected to social processes that continue the subjugation (Scior & Werner, 2016). The treatment is largely dependent on whether the attribute of disability is a valued or a devalued attribute in that particular setting, context and culture (Barnes, 2016; Groce, 1999).

The right to **education** is a human right, described in article 26 of the Universal Declaration of Human Rights (United Nations, 1948):

*Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional*

*education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.*

It is also covered in Article 28 of the Convention on the Rights of the Child (United Nations General Assembly, 1989). The right to education for persons with disabilities is further recognised in Article 24 of the Convention on the Rights of Persons with Disabilities (United Nations, 2006). The priority for education is also highlighted in the Sustainable Development Goals, through Goal number 4, 'Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all'. Target 4.5 specifically aims to 'ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous people and children in vulnerable situations'. Furthermore, target 4.a specifies the need to 'build and upgrade education facilities that are child, disability and gender sensitive ' (United Nations, 2015).

Inclusive education is key to achieving high quality education for all, including people with disabilities. It depends on differentiated learning, it is flexible and allows individuals to develop according to their own abilities. A whole systems approach is necessary to ensure that education is available, accessible, acceptable and adaptable to all individuals, regardless of vulnerability. Availability ensures both quantity and quality of provision. Accessibility ensures that there are no physical, resource, pedagogical or other barriers. Acceptability ensures equity and adaptability ensures that learning environments are adapted to the individual. Inclusive education adapts the educational system to the differences in the individual and their capacity to learn (United Nations Committee on the Rights of Persons with Disabilities, 2016).

Despite these rights and priorities, studies from across the African continent consistently show that people with disabilities have lower levels of education compared to people without disabilities. A substantially higher proportion of children with disabilities compared to children without disabilities never attend school and drop out of school. However, given the opportunity to attend school and provided with necessary support mechanisms, people with disabilities have matched achievements to those without disabilities. People with disabilities report that their disability is the primary reason for not attending school (See for instance: Eide et al., 2011; Eide & Jele, 2011; Eide & Kamaleri, 2009; Eide & Loeb, 2006; Eide, Nhwatiwa, Muderedzi, & Loeb, 2003; Eide, van Rooy, & Loeb, 2003; Kamaleri & Eide, 2010; Loeb & Eide, 2004). A few recent studies exploring access to education, for children with disabilities in southern Africa have been carried out. The studies highlight physical, economic and attitudinal challenges as barriers to education (Azalde & Braathen, n.d.; Banks & Zuurmond, 2015; Braathen & Munthali, 2016).

The extent to which and in what way stigma may influence access to education, for people with disabilities, in LMICs has been unclear. Thus, this report reviews the available evidence on the role of stigma in accessing education for people with disabilities in LMICs. It includes all forms of education, formal school education, as well as life-long learning and skill development opportunities, thus it includes all ages. Access in this report will be defined as addressed in the Incheon declaration of the Education 2030 Agenda (World Bank, 2015), and in the SDG goal number 4 (United Nations, 2015). Here, access to education goes beyond mere physical availability of schools, but it calls upon promoting education not only in terms of facilitating equity in provision, but also in facilitating participation, retention and completion through policies, resource investment and increased inclusive pedagogical methods and environments, i.e. enabling equity in education.



### 3 Methodology

The goal of a literature review is to collect, analyse and present available research evidence in a given field of interest. There are several methodologies for literature reviews, some more systematic and organised than others (Arksey & O'Malley, 2005). Both systematic reviews and scoping reviews use strict, transparent methods to identify, organise and analyse all relevant literature in connection to a research question. However, scoping reviews are well suited to give an overview of a potentially large field of research and to identify gaps in knowledge (Arksey & O'Malley, 2005; Armstrong, Hall, Doyle, & Waters, 2011).

The scoping review was carried out according to a five-stage framework described by Arksey and O'Malley (2005):

1. Identifying the research questions
2. Identifying relevant studies
3. Study selection
4. Charting the data
5. Collating, summarising and reporting the results

The first three stages are described in more detail in Appendix A.

### 4 Results

#### Characteristics of selected articles

The combined search strategies (described in detail in Appendix A) produced a total of 3777 citations. Following a screening of titles and abstracts, 69 articles with available full text were identified. Of these, 23 empirical works met the inclusion criteria for this review. Table 1 below contains general information about the 23 included works, consisting of 17 peer-reviewed articles, 5 reports and 1 PhD thesis. Ten of the works come from studies in Africa (Nigeria, Zambia, Malawi, Zimbabwe, Uganda, South Africa and Africa generally), six from South America (Brazil and Colombia), two from Asia (India and Vietnam), two from the Middle East (Jordan and Arab countries in general), two from Europe (Romania) and one report from a global perspective. The included works can be divided according to type of research as follows: Six used quantitative methods (surveys, cross-sectional studies, case-control), three were mixed-methods studies, two were literature reviews and the rest were qualitative in nature (in-depth and semi-structured interviews, focus groups, case studies, analysis of texts).

Since there were no limitation in the search strategies on type of education or age, the included studies covered a range of ages in different educational contexts: 15 of the articles dealt with children within mainstream education, including studies with focus on implementation of inclusive education; Two dealt with students with disabilities studying in universities; five articles dealt with all types of education generally (mainstream, vocational, special education); and one dealt with experience from an adult's point of view learning about microcredit (life-long learning).

Table 1: Description of the included works

Author	Date	Aim of study/article	Type of study	Main findings	Geographical location
Adewuya	2006	To assess school performance of Nigerian adolescents with epilepsy compared to their peers	Case-control study	Poor school performance is multivariate, with psychosocial factors being most important.	Nigeria
Akinsulore	2010	Review undertaken to provide information on prevalence, seizure types, treatment issues and psychosocial impact of epilepsy	Literature review	Point prevalence varies from 5.3 to 37 per 1000. There is a predominance of generalized tonic-clonic seizures. People with epilepsy suffer social deprivation and discrimination in education, employment, housing, marital life as well as associated psychiatric morbidity.	Nigeria
Alkhateeb	2015	To review and analyze research conducted on Inclusive Education (IE) in Arab countries.	Literature review	Little IE research has been conducted in Arab countries. There are no common strategies for dealing with children with disabilities in these countries, and each country has adopted a spectrum of responses from segregation to varying levels of inclusion. Most studies published about IE in Arab countries focused on surveying attitudes. There is little qualitative research and research demonstrating strategies for effective implementation of IE (e.g., awareness creation, teacher development, enhancing parent involvement, and facilitating professional collaboration among teachers). There are also few systematic efforts to promote positive attitude toward effective implementation of IE.	Arab countries
Alvarez	2015	To identify and to analyze the beliefs and attitudes of secondary-school teachers in	Semi-structured interviews of teachers	The belief of deaf people as challenging, sick and impaired is still prevalent in the attitudes of the teachers and inclusion is just perceived as a word in the educational process.	Colombia

		Colombia, in relation to the process of including Deaf students into mainstream classrooms.			
Alves	2012	To observe the reality of inclusion of children with Down's syndrome (DS) in a physical education class	One case-study observation lasting one school year.	The student with DS did not show difficulties in understanding and performing activities in class. However, he did not easily establish social relationships with his peers.	Brazil
Alves	2013	To explore the factors related to the exclusion of children with physical and sensory disabilities in a physical education class	Semi-structured interviews with disabled children and class observations	Exclusion was linked to a lack of adaptation of classes, social isolation and feelings of inferiority. These three factors arose in association with each other and jointly.	Brazil
Alves	2014	To investigate the inclusion of children with disabilities in physical education classes from their own subjective perspective	Semi-structured interviews with girls between 12 and 21 years	Inclusion was linked to adaptation, social participation and demonstration of abilities. These factors act independently and complement each other to construct a sense of belonging, acceptance and value within a group.	Brazil
Al-Zyoud	2012	PhD thesis investigating the current service provision for students with special educational needs (SEN) in Jordanian schools.	Semi-structured interviews with SEN teachers	SEN teachers faced several difficulties responding to needs of children including parent denial, lack of cooperation among teachers, little training of pre-service teachers, bullying by peers, little understanding by administrators of needs of children and negative attitudes rooted in culture and overlapping with religious values. Attitudes also varied according to parents' socio-economic standing, and if the child attended a private or public school.	Jordan
Azalde	*	Report exploring factors relevant for inclusion and exclusion of people with disabilities in life-long learning and skills development.	Focus group discussions and in depth interviews in 2 urban and 2 rural sites	Medical perspective of disabilities still prevails. Limited knowledge of disability policies, little cooperation between ministries, little resources to schools, lack of teacher training, lack of awareness and empowerment of parents and children, lack of physical access, poverty, stigma and	Zambia

				discrimination in hiring practices are barriers for life-long learning.	
Banks	2015	Report identifying the barriers and enablers to inclusion in education for children with disabilities, using Ntcheu district in Malawi as case study.	In-depth interviews with families and teachers of children with disabilities	Attitudes towards education for children with disabilities was an important factor for inclusion as well as poverty and health issues. Schools lacking teacher competence, resources, support and physical access were also barriers. Finally, children with disabilities faced numerous forms of discrimination, violence and social exclusion inside and outside of school	Malawi
Braathen	2016	Report exploring barriers and facilitators for access to education and scholastic achievements for children and young people with disabilities in a rural Malawian context.	In-depth case studies focusing on five children and young people in school-going age in one rural location	There are lack of funding, resources and equipment in special schools. In mainstream schools, lack of physical accessibility, equipment, size of classes and attitudes of teachers are barriers. Lack of adapted exams is also a barrier. Awareness and attitudes of parents can also be barriers to education.	Malawi
Gliga	2010	To evaluate parental attitudes regarding inclusive education of children with disabilities in transition from kindergarten to school.	Questionnaire to parents of children with and without disabilities	Parents of children with disabilities were more in favor of inclusive education and have a deeper understanding and wider knowledge of terminology and specific legislation. Half of the parents of children without disabilities were reluctant to have children with disabilities in the same class as their own child.	Romania
Joshi	2012	To study behavior, attitudes knowledge and myths of epilepsy among urban schoolchildren in Bareilly district.	A cross-sectional survey was conducted among students of 10 randomly selected urban secondary schools in Bareilly district	Although the majority of the students had reasonable knowledge of epilepsy, myths and superstitions about the condition still prevail in a significant proportion of urban schoolchildren.	India

Jung	2013	To map the daily physical activity habits of youth with disabilities in municipal schools in the city of Pelotas, from the perspective of their parents and teachers.	Two questionnaires to a purposive sample of parents and teachers.	According to teachers, most students participate in Physical Education Classes. The results demonstrate that the inclusive process starts the moment that disabled students are included in society and, consequently, achieve opportunities to develop themselves.	Brazil
Koszela	2013	Report exploring stigma towards people with disabilities and the adverse developmental effects it has on education and employment.	Interviews of experts in field of disability	The main cause of stigmatization in Africa is lack of education about disabilities, and the needs and potential of persons and children with disabilities. The unknown creates fear in society and exclusion of persons with disabilities, barring them from obtaining education and later from having access to jobs.	Africa
Majoko	2015	To study the social barriers and enablers of inclusion of children with Autism Spectrum Disorders (ASD) in mainstream primary school classrooms.	Semi-structured interviews of mainstream teachers	Social rejection, communication impairments and behavioral challenges of children with ASD interfered with inclusion in mainstream classrooms. Regular teachers' training, stakeholder collaboration and institutionalization of social support services and programs would facilitate the inclusion of children with ASD in mainstream classrooms.	Zimbabwe
Ndlovu	2016	To identify both the opportunities and obstacles that students with disabilities face in higher educational institutions (HEIs).	Analysis of texts from South African and international literature	Students with disabilities are given the opportunity to attend HEIs due to current inclusion and disability policies, support structures and funding. However, access to education itself is difficult due to lack of physical accessibility, lacking policy implementation, limited fields of study open to disabled students, funding, and lack of support in fieldwork. Negative attitudes are also a problem and the assumptions that the limitation lies with the disabled individual rather than the exclusionary practices.	South Africa
Nuwagaba	2016	To illuminate the barriers that a person with a visual impairment encountered while learning	Case study	Persons with disabilities face multiple barriers regarding learning about microfinance, including social, psychological	Uganda

		about and engaging with microfinance and the strategies he developed to overcome them.		and educational. However, own-agency and attitudes are important in influencing learning.	
Palma	2012	To describe the participation of a student with physical disability in second grade in a mainstream physical education class.	Observations of 7 classes of physical education. Followed by semi-structured interview with the student	The proposed activities in the class promoted the inclusion of the student. There was also interaction between the child and his peers. Inclusion seems to be occurring in these classes.	Brazil
Scior	2015	Report providing an overview of attitudes to intellectual disability around the world, of the range of initiatives implemented in different parts of the world, and identifying priorities for moving forward.	Survey of informants who are active in the field of (intellectual) disability around the globe and review of States Parties reports to the UN CRPD Committee,	Despite the CRPD, children and adults with intellectual disabilities are mostly still an invisible minority. They are accorded low visibility in government actions and are often overlooked or hidden within the disability discourse. Though inclusion of intellectual disabilities is accepted, it is viewed as impractical and concerns for non-disabled make it unpopular. There is a desire for segregation rather than inclusion in large parts of the world, which is rooted in prejudice. This is also reflected in the language being used to describe individuals with intellectual disabilities. In some countries, people with intellectual disabilities have little legal protections. The work aimed at raising awareness is often poorly articulated and not rigorously evaluated. More attention should be given to initiatives that not only raise awareness but also actively combat stigma and change behavior. Adoption of an evidence-based approach would also allow learning from others' efforts and avoid replication.	Global
Selesho	2012	To establish the knowledge and attitude of the student teachers	Questionnaire to third year B-Ed	Student teachers have positive attitudes towards inclusive education. They agree that it enhances social interaction and	South Africa

		in facilitating inclusive classroom.	students at one university.	thus minimizes negative attitudes towards learners with special needs. The study also found that collaboration between mainstream and the special education teachers is important as well as clear guidelines of implementation of inclusive education. These students need more practice in managing inclusive classrooms.	
Tran	2014	To examine difficulties faced by children with disabilities (CWD), and how they deal with these difficulties and to make suggestions for promoting social inclusion of CWD in schools in Vietnam.	Survey and in-depth interviews to children with disabilities and their parents, children without disabilities, and teachers	Understanding of disability is still based on the medical/individual model. The most important difficulties that CWD experience at school are those of learning facilities, the lack of empathy from their student peers and barriers in the physical environment. Children with disabilities deal with their difficulties mostly alone.	Vietnam
Vrasmas	2014	To explore how the universities are responding – at the institutional level - to the rights and needs of the adult with disabilities. -To investigate the main barriers and facilitators for access and participation of individuals with disabilities, at university.	Literature review and semi-structured interviews	Main barriers: Lack of accessible information (in alternative formats); Lack of physical accessibility; Communication with peers; Negative attitude of some teachers and managers; Misc. technical aspects; Emotional adjustment to new challenges; Lack of guidance and orientation inside university; Accessibility of lecture halls, social interactions and oral exams for hearing disabled; and not enough vocal description for blind students. Main facilitators: Friends, families, desire to succeed and support from teachers.	Romania

\*Forthcoming

## 5 Summarizing and reporting the results

The review was restricted to looking specifically at empirical work, which touched on three concepts: disability, stigma and education in low and middle-income countries. The included evidence dealt primarily with barriers towards children or people with disabilities either within inclusive education or as barriers to education in general. Few dealt solely with how stigma directly affects accessing quality education, or equity in education. The evidence from the included works is summarized below according to the sources of stigma in society (teachers, peers, oneself, teaching institutions and society at large). These sources play a role in whether the child or adult with disabilities has access to, participates in and completes education, which is what equity in education should enable. Stigma, which is affecting equity in education, is being perpetuated by attitudes coming from teachers and school staff and structures, peers, parents, family and the individual's own felt stigma, as described below (Figure 1). Societal stigma in turn is due to lack of knowledge and a societal view of disability that is based on the medical model of impairment and limitation.



Figure 1: How stigma affects self-worth

### 5.1 Stigma and teachers

The included literature discusses how teachers' attitudes are a reflection of the beliefs and attitudes of the society they come from. For example, one study in Nigeria among teachers in primary, secondary and tertiary institutions, found that 30.5% believed that epilepsy could be contracted through the saliva of an epileptic patient, 27.7% thought it was synonymous with possession by evil spirits, while 10% misunderstood epilepsy for insanity (this was the term used in that research project). In this study, it was noted that teachers' attitudes were, on the most part, still based on myths, misconceptions and prejudice (Akinsulore & Adewuya, 2010). These negative attitudes are firmly entrenched and often result in negative actions towards disabled children, or complete neglect. These attitudes often go unchecked by other school staff members, including head teachers, and thus becomes the norm for the schools. As a result, the needs of disabled children often remain largely unmet (Al-Zyoud, 2011). The beliefs and values that teachers have about their students are important because these mediate the pedagogical interactions that happen daily in the



classroom (Álvarez, 2015). Teachers' lack of knowledge and their attitudes towards disability are centred on the medical model of limitations. This is made evident in teacher's actions and pedagogical practices. If they consider children with disabilities (CWD) as impaired, limited or unable, the most probable attitude will be overprotection, rejection, neglect or unwillingness to teach, as well as negative expectations regarding academic achievement and future prospects (Álvarez, 2015; Palma & Lehnhard, 2012). In inclusive education schools, this can mean that children are automatically passed onto the next grade without ever learning anything. There is no expectation of children with disabilities' ability to learn and an assumption that they would not be able to pass exams anyway (Azalde & Braathen, n.d.; Koszela, 2013).

This attitude also affects the willingness of teachers to accept and practice inclusive education (IE). Teachers' attitudes affect learning and is one of the most important predictors of successful integration of students with disabilities. IE is largely dependent on teachers' positive attitudes. However, teachers and school administrators are often more reluctant than policymakers to IE (Selesho, 2012). In mainstream schools where children with disabilities are allowed to enrol, some teachers hinder learning by either not prioritizing the child with disability or denying access to the limited school resources like textbooks. Some teachers with no special education training can be impatient with children with disabilities and can blame them for their inability to learn even though the fault lies within the learning environment (Azalde & Braathen, n.d.).

Nevertheless, increased knowledge and training of teachers have been found to predict positive attitudes to CWD and IE (Alkhateeb, Hadidi, & Alkhateeb, 2016). In turn, teachers' positive perceptions of and attitudes toward inclusion of children were made contingent upon specific factors such as: 1) adequate preparation of teachers, 2) reasonable teaching loads, 3) sufficient funding to support inclusion, 3) school accessibility and teacher support, and 4) specific sets of prerequisite skills by children with disabilities (Alkhateeb et al., 2016). Conversely, lack of these factors are also some of the existing barriers to enabling IE in schools and enabling people with disabilities to access education in general, along with lack of parental involvement, unclear school inclusion policies, previous work experience with CWD, and pedagogical skills (Alkhateeb et al., 2016; Azalde & Braathen, n.d.; Banks & Zuurmond, 2015; Braathen & Munthali, 2016; Selesho, 2012).

Teachers need specific competency in individualized instruction and skills, to promote social acceptance of CWD, specialist training, and facilitation of consultation and partnerships with school personnel. This will help achieve social changes. Collaboration between regular and specialized teacher enhances inclusion. Professional preparation of teachers for inclusive education should include applied experience in child diversity, differentiation of instruction, classroom and behaviour management and collaboration. Increased teacher competency will foster pre-service and in-service positive attitudes, skills, knowledge, and understandings of inclusion (Majoko, 2016).

## 5.2 Stigma and peers

Studies have found that children with disabilities tend to have limited interactions with their peers. Often, interactions that do occur do so only during planned activities. Few children actively seek interaction with CWD of their own accord. Though there seems to be acceptance, this non-involvement and indifference is also a form of isolation and exclusion (Alves & Duarte, 2012, 2013, 2014; Banks & Zuurmond, 2015; Palma

& Lehnhard, 2012). Quality of social interaction in class influences sense of belonging, importance and value within a group and consequently perception of inclusion. CWD need to be able to demonstrate their legitimacy within a group and teachers need to give CWD opportunities to show their abilities by facilitating participation. Having their abilities questioned by peers acts as a trigger to prejudice and against inclusiveness. Participation enables CWD to feel as important members within a group, with their own values and own contributions to common goals (Alves & Duarte, 2014).

Children with all types of disabilities face bullying, discrimination and violence. Though CWD like going to school and to participate in classes, the constant bullying they experience is not conducive to their retention in school (Banks & Zuurmond, 2015; Palma & Lehnhard, 2012; Tran, 2014). Children with communication disabilities appear to be particularly vulnerable (Banks & Zuurmond, 2015). In Zimbabwe, Majoko (2016) found that social exclusion was a barrier to inclusion of children with autism spectrum disorder (ASD) into mainstream education. Children with ASD were not accepted by their peers due to misunderstood ASD behaviour; societal stigma, based on superstitions or fear of ASD being communicable; and bullying or fear of bullying by association. Children with ASD were found to be socially rejected because they lack social skills and have static expectations which their peers cannot understand (Majoko, 2016). Stigma by association or the fear of playing or associating with CWD was a concern in many of the included articles.

A survey in India uncovered not only vast gaps of knowledge about epilepsy's aetiology among secondary school students, but also stigmatic beliefs which affect how epileptic peers are viewed. The majority believed that epilepsy was an inherited disorder and if witnessing someone having a seizure, about 40% of them would help that person by either throwing water on them or making them smell something strong, like an onion or a shoe. In addition, about 40% believed that a person with epilepsy is dangerous and that their IQ is lower than average, and the majority of students felt pity (Joshi, Mahmood, Bamel, Agarwal, & Shaifali, 2012).

Teachers' knowledge of disability is relevant in order to be able to adapt their pedagogical practice. Physical changes are not enough, changes of attitudes and showing respect to individuals are important (Palma & Lehnhard, 2012). Teachers should prepare peers to receive CWD and adapt class to allow its practice (Alves & Duarte, 2013). Children without disabilities need to be taught and sensitized to disability issues. A disability studies "infusion" in primary school curriculum, where they learn to appreciate human diversity and acceptance would promote knowledge, awareness and increased understanding of disabled peers and reduce stigmatization and patronizing attitudes (Majoko, 2016).

Teachers need to teach cooperation and make peers aware that everyone is different and has potential. Planning activities that are easier to execute would increase participation and make CWD feel included and not rejected or sidelined. It also transforms opinions, which children without disabilities have about children with disabilities. In this manner, they learn to interact and learn of similarities and differences (Palma & Lehnhard, 2012).

Even in institutions of higher learning, communication with peers was found to be a barrier, which students with disabilities needed to tackle. One of the main facilitators of being able to succeed in school was the

support they received from other students and the lasting social links and friendships that they developed (Vrășmaș, 2014).

The most difficult barrier, which children and adults with disabilities experience at school, besides the physical barriers and limited learning facilities, are the attitudes from their peers, which though often empathetic, do not express respect or regard for their abilities and do not promote close friendships (Tran, 2014).

### 5.3 Own stigma

Adewuya and colleagues' (2006) study on school performance of Nigerian adolescents with epilepsy found that though the factors of poor performance were many, psychosocial factors were the most important, i.e. poor family functioning, their attitude to their own chronic disorder, and their own felt stigma (Adewuya, Oseni, & Okeniyi, 2006). Social barriers can have psychological consequences, including loss of confidence and withdrawal from activities and social interactions. When people with disabilities are regarded as less important or different, they feel inferior, and thus fear socialization. (Nuwagaba, Rule, Education, Africa, & Rule, 2016). Feelings of inferiority are a result of being treated with indifference, negligence, rejection, and bullying (Alves & Duarte, 2013). Internalising negative attitudes of oppression of non-disabled, increases people with disabilities' sense of inferiority and prevents participation in learning. In addition, unfavourable learning contexts, including physical barriers, make people with disabilities feel vulnerable, creating fear and constraining learning. Physical barriers can therefore also become a psychological barrier to learning (Nuwagaba et al., 2016).

Therefore, promoting positive social interactions are important for inclusion of CWD. Not only can exclusion lead to depression, but social isolation has also been associated with school dropout (Alves & Duarte, 2013). However, inserting a child into a class environment is not enough. It will not guarantee the construction of social interactions (Alves & Duarte, 2012). Alves and Duarte (2013) found that though there was acceptance among peers, there were no real interactions. Lack of adaptation, both physical and pedagogical, leads to non-participation and isolation of CWD. The inability to participate make non-disabled children judge and question the abilities of their disabled peers. This constructs a barrier to CWD's sense of belonging and inclusion (Alves & Duarte, 2013; Tran, 2014). Another isolating factor is the uncomfortable feeling children with disabilities face due to large age gaps between them and their peers which can arise with delayed school entry (Azalde & Braathen, n.d.).

This felt stigma and exclusion is a result of the lack of adaptation in terms of curriculum, use of technical aides or methods of teaching. This results in further isolation from educational settings as children find their own way to cope, which is removed from the inclusive school setting. In Vietnam, Tran found that instead of asking for help from their peers in school, CWD opted to form their own self-help groups with other CWD in the neighbourhoods where they lived (Tran, 2014). School settings and particularly teachers are important in promoting the social inclusion process and enabling social interactions between children, especially in Vietnam where the traditional value of the teacher for the children in school is so powerful (Alves & Duarte, 2012, 2013; Tran, 2014). Reasons for not achieving inclusion has been found to be due to lack of

professional training and school infrastructure. Inclusion should achieve both educational goals and promote social interactions with peers (Alves & Duarte, 2012, 2013).

#### 5.4 Institutional stigma

As countries implement inclusive education, societal views of CWD are also changing. In Brazil, for example, enrolment of CWD in mainstream schools is increasing each year, thus increasing interaction and acceptance between children with and without disabilities. Increased types of disabilities in schools reflects the increasing abilities of teachers to teach in inclusive environments as well as awareness in schools, and among families and communities (Jung & Xavier, 2013). In addition, in South Africa, current curricula in student teachers programme show that inclusive education is being integrated into learning modules (Selesho, 2012). As a consequence participation in non-segregated environments is increasing and contributing to the change in perception of people with disabilities (Jung & Xavier, 2013).

In South Africa, one finds that institutions of higher education are still engaging in residual discriminatory and exclusionary discourses, attitudes and practices. This can also explain why people with disabilities are underrepresented in the workplace. Persistent inaccessibility of schools suggests that society still believes that people with disabilities must adapt to the physical environment and is unable to see that the lack of access is a social problem and an infringement on the rights of people with disabilities (Ndlovu, 2016). Rather than receiving institutional support, students are left to cope on their own and to find their own solutions to the barriers they encounter (Vrășmaș, 2014). A shift in understanding in society to the social model is thus important (Ndlovu, 2016).

Studies from Romania have found that parents of non-disabled children accept the idea of inclusive education (IE) but are not quite ready to embrace it fully. They feel that IE will slow the academic progression of their non-disabled children. Schools, preoccupied with academic excellence, are also reluctant in implementing IE. Awareness in institutions and in society in general, as well as participation by children and adults with disabilities in their own inclusion is important (Tran, 2014; Vrășmaș, 2014). School settings are important for social awareness and for promoting sustainable inclusion processes (Tran, 2014). Inclusive education has increased acceptance of diversity, and repeated contact could help children without disabilities discover strengths and skills of children with disabilities. Inclusion requires cooperation from family, community, and NGOs (Gliga & Popa, 2010). Other necessary changes include changes in legislation (parent partners), and earlier inclusion and support for children with disabilities (Gliga & Popa, 2010).

#### 5.5 Societal stigma

Successful implementation of inclusive education leads to increased inclusion of people with disabilities in society at large, which in turn has a positive effect on societal views of children and adults with disabilities. However, in many countries and contexts stigmatic barriers in society remain, leading to reduced chances for education for children and adults with disabilities. In Nigeria, for example, societal branding of epilepsy is very strong, and it is difficult for people with epilepsy to escape its prejudice. Even among people in society who saw no reason for people with epilepsy not to attend school, people with epilepsy's contribution to society was seen as different or inferior (Akinsulore & Adewuya, 2010). Another example is intellectual

disabilities. Findings from a global survey about people with intellectual disabilities, affirm that they are still heavily stigmatised in most parts of the world. They are undervalued and ostracised and there is a belief that they should be segregated and kept far away from their community, not only because of fear, but also because of the stigma they bring to their families. In these societies, people with intellectual disabilities are seen as responsibilities of their families, so society can just ignore their existence, and they can be excluded from education altogether (Scior et al., 2015). A study from Zambia found that also communities sometimes dissuade parents from enrolling CWD in schools. This stigma can even extend to teachers, whose qualification can come into question by the community if they choose to teach CWD (Azalde & Braathen, n.d.). A study from Malawi found cases where parents themselves did not see the capabilities of their children with disabilities and therefore did not understand why they should be sent to school (Braathen & Munthali, 2016).

This report presents the findings from a survey of informants who are active in the field of (intellectual) disability around the globe.

The medical model understanding of disabilities still persists and there are still barriers to active participation like overprotection by teachers, prejudice and physical barriers (Jung & Xavier, 2013; Tran, 2014; Vråşmaş, 2014). However, the opinion among people have positively changed due to increased opportunity of CWD in education, recreation and work. (Jung & Xavier, 2013)

## 6 Limitations

The purpose of this scoping review has been to provide a narrative of the research findings as well as identify gaps in the evidence base on how stigma affects access to education for people with disabilities in LMICs. It has not been to include and thus synthesise findings only in studies which have shown to follow rigorous research standards, as is the requirement in systematic reviews, but as the name suggests, to scope a field of interest and get an overview of available research. This has shown to be the correct method for this review, since very little research dealt with this topic, and applying quality appraisal on inclusion would have reduced the possibility to summarise and disseminate any findings at all. In general, the evidence base on stigma's role in accessing education for people with disabilities in LMICs is weak.

It is important to note that the methodology used in the various studies referred to above differs greatly and thus comparability and definite conclusions should be drawn with caution. Adding to this, the definitions for stigma and for disability are different across studies, and the nature of impairment and type of stigma studied differs. The evidence often discuss barriers and enablers to education in general, or exploring the experiences of inclusive education or inclusion of people with a range of disabilities in mainstream education. There is not enough evidence to give us a complete picture of the impact of stigma itself or in relation to other barriers for people with disabilities in accessing education. Despite this, when several studies points towards similar conclusions, it is safe to assume that there is some truth to these conclusions.

## 7 Conclusion and recommendations

The cumulative stigma in society serves as a wall against equity and access to quality education for people with disabilities. People with disabilities are being confronted by stigma from society in general, and from teachers, staff and peers in educational environments, which are affecting their own self-worth and appreciation of their own abilities. Though there was limited empirical evidence available on the topic of how stigma affects access to education for people with disabilities, the existing evidence presents some viable solutions to counter this problem at societal level and in schools.

### 7.1 Society and communities

The empirical evidence suggests that a factor reinforcing stigma and affecting physical inaccessibility is the pervasive medical model view of disability in society. This perspective focuses on the limitations of the individual, and the necessity to adapt the individual to society. The problem therefore lies with the individual and directly affects how society handles inclusion of people with disabilities. However, the ICF perspective of disability recognises that though an individual might have a functional limitation, it is systemic barriers, negative attitudes and exclusionary practices and environments, which disables individuals. This perspective shifts the responsibility of disability over to society, and is necessary for people with disabilities to be included in society. The research evidence suggest that awareness of this outlook is low in schools and in communities and societies at large, and there is thus a need for awareness raising. Ideally, governments could implement national policies, which already exist in many countries, and established in connection with the ratification of CRPD, which takes on an ICF understanding of disability. However, lack of resources often results in governments not prioritising this type of implementation. Nevertheless, integrating ICF thinking into teaching and health personnel curricula, need not be costly. Countries could start by integrating this perspective into learning modules, not unlike how South Africa is including inclusive education into learning modules in teacher colleges. Integrating ICF thinking into curricula should promote awareness and changes in attitudes among these professional groups, which is a first step towards counteracting stigma in society. Quality of education could be further improved if inclusive education were integrated into learning modules for teachers. Learning how to individualise teaching is something all children could benefit from, especially since there are children currently attending schools with varying degrees of disabilities as well as hidden disabilities. Increasing the quality and equity of education among teachers, and thus among children, should be a priority for a ministry of education.

NGOs fighting for the rights of people with disabilities can also play a role because they can work closely with communities to increase knowledge within these communities and to ensure inclusive environments, both physically and socially. In this work, NGOs can ensure that children with disabilities utilise their right to education, so that enrolment in school increases. One study showed that the inclusion process improved when people with disabilities started to participate in society, and increasingly got opportunities to develop. This inclusion process was largely responsible for bringing knowledge not only to professionals but also to families and the community, and in the process reducing stigma. NGOs can also work with the community to ensure physical accessibility to schools and in schools, either by lobbying those responsible for school infrastructure or by leading the community in necessary school improvements. Finally, disabled people's

organisations using campaigns which have proven to be effective, could work together with the media to try to be more proactive in reaching communities with information.

## 7.2 School environments

For children with disabilities to develop to the best of their abilities, enabling school environments need to be created. Policies need to be established at school level to ensure and sustain these types of environments. Policies should also describe how schools will work together with parents to achieve common goals. Schools could then work within this established framework, and within their resources to gradually advance inclusive education, benefitting not only children with disabilities, but all children. The literature showed that disabled children's retention and success in school depends as much on psychosocial adaptation as on the physical environment. If teachers already have the necessary pedagogical tools to individualise education, then an established school policy would support a teacher's efforts in this direction. If teachers lack this type of training, enrolling in further education courses could be a solution. This is something an education ministry should prioritise with the view to improve the quality of education of teachers in general.

In addition, besides physical inaccessibility, lack of structures and resources, and lack of policies, teacher's attitudes and aptitudes seem to be the most important enabler of inclusive education. As suggested by most of the articles, teachers need capacity-building, resources and support if they are to be able to provide inclusive education for all.

As studies in Brazil suggested, mainstream teachers felt that besides school infrastructure, lack of professional training was a major barrier to promote inclusion in schools. For children with disabilities, lack of adaptation, social isolation and feelings of inferiority, made them feel excluded. Simply inserting a child with disabilities in a classroom did not guarantee the development of social relationships nor make them feel less isolated. Inclusion goes beyond educational goals, and teachers have an important role to play. Teachers have a role in preparing their classroom to receive children with disabilities, providing them with knowledge in order to dissipate fear of the unknown and accept diversity. Teachers are also vital in promoting opportunities for children with disabilities to demonstrate their abilities, and to ensure the quality of social interactions in the classroom. However, this requires skills, and training.

In addition to capacity-building, schools need to ensure reasonable teaching loads and necessary help and resources in order to maximize the pedagogical effects of teachers, and thus provide quality education. Mainstream teachers need help in the classroom, and cooperation from service and administrative school personnel, as well as help from special education teachers. In turn, these specialised teachers need to be provided with an acknowledged high-quality education, which would be recognised by their peers and by society. Classroom teachers should not be expected to work without any resources or help. Improving the quality of teaching in low and middle-income countries will require extra financing and resources, and countries with limited resources will feel hesitant in making this kind of investment. Nevertheless, just like investing in a population's health, investing in quality education will have a positive return in productivity, and ultimately on countries' wealth. Implementing inclusive education ensures that education be available,

accessible, acceptable and adaptable to all children. This requires quality in the education at system level, so that all children despite their vulnerability achieve their potential.

### 7.3 Gaps in research

There is much research regarding people with disabilities and access to health services and attitudes of health personnel, but very little empirical evidence regarding people with disabilities and education in low and middle-income countries, in general, and the role of stigma in affecting equity in education, in particular. More research on barriers and facilitators for inclusive education in low-income countries is needed in order to ensure education strategies are appropriate and inclusive.

In addition, besides physical inaccessibility, lack of structures and resources, and lack of policies, teacher's attitudes and aptitudes seem to be the most important enabler for inclusive education. As suggested by most of the articles, teachers need capacity-building, resources and support if they are to be able to provide inclusive education for all. Therefore, more research in development of tools for capacity building of teachers, and how they can contribute to achieve equity in education is necessary.

As mentioned in several articles, lack of awareness in society was one of the many barriers people with disabilities face in accessing education. There are many initiatives globally dealing with raising awareness of disabilities and combating stigma, but they are largely campaigns not based on evidence of effectiveness or scientifically evaluated (Scior et al., 2015). Organisations or governments have to work together with research environments to guarantee that the adoption of awareness campaigns are based on evidence of effectiveness and that its implementation will be evaluated in terms of effectiveness, cost-effectiveness, quality and equity. There is also a need to explore the frameworks currently used in awareness campaigns to ensure that the ICF approach to disability is included in these frameworks.

Finally, as suggested by Majoko, school curricula should also be developed, implemented and evaluated, which integrated knowledge on disability and equity (Majoko, 2016). Schools are good arenas for changing future individual, community and societal perspectives.

As stigma literature suggests, stigma is a consequence of social comparison, and it is therefore highly embedded in cultural beliefs, and inextricably tied to social context. As such, it is not easily quantifiable, nor easily discernible from other beliefs and actions within a society. Therefore, to work with stigma it is often necessary to work at system level, and the culture at large.



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## Identifying the research questions

The first stage of a literature review is to identify research questions, which form the basis for the next methodological steps (Arksey & O'Malley, 2005). Several different frameworks are useful to assist in the development of research questions and inclusion criteria for literature reviews. The PCC (Population, Concept, Context) framework is the most suitable method in scoping reviews, since it allows for broad research questions and less restrictive inclusion criteria (O'Connor, Green, & Higgins, 2008). Based on the objectives for this scoping review, the PCC can help define the research question of the 'the role of stigma in accessing education for people with disabilities in LMICs' in the following manner:

**Population:** The population studied was *people with disabilities*.

**Concept:** The concept or theme for the review was *stigma*.

**Context:** The context for the review was *educational environments in lower and middle-income countries*.

This scoping review is also interested in literature after the year 2000 because the right of education for persons with disabilities was first officially established with Article 24 of the Convention on the Rights of Persons with Disabilities in 2006.

In addition, the concept of disability used in this scoping review is as broad as possible and includes the following medical categorisations of disability: physical, sensory, developmental and psychosocial impairments, as well as people with epilepsy and albinism.

Based on the PCC framework applied here, the research question can be defined accordingly: "What is the role of stigma in accessing education for people with disabilities in LMICs?"

Where the concept of access is broad and includes not only physical availability of schools, but also quality of education in terms of facilitating equity in provision, and participation and retention through resource investment and increased pedagogical inclusive methods (UNESCO, 2016).

The following sub questions can also be formulated "How does the role of stigma affect access for people with disabilities in accessing education in LMICs" and "What available research and gaps exist after the year 2000?"

## Identifying relevant studies

Once research questions and search terms were selected, relevant search engines and databases were identified. In a scoping review, the aim is to identify a variety of publications and studies, and it is thus important to search in multiple broad search engines and databases (Arksey & O'Malley, 2005). The literature review search included all types of empirical research, both qualitative and quantitative studies, in addition to policy analysis and literature reviews. In order to identify literature on disability stigma and education in LMICs, the following databases and search engines were utilised:

- Oria (only for Scandinavian research)
- Web of Science

- Scopus
- Google search
- Open Grey

Relevant citations were downloaded, and reviewed to see if they fit the pre-defined inclusion and exclusion criteria. In addition some citation searches were also performed, i.e. finding relevant grey literature or articles in the list of references of relevant articles (Aveyard, 2014).

## Study selection

### Inclusion and exclusion criteria

Inclusion and exclusion criteria were developed and applied to empirical work that represented a 'best fit' with the central research question: 'What is the role of stigma in accessing education for people with disabilities in lower and middle-income countries?' The following inclusion and exclusion criteria were applied:

Inclusion criteria:

- Research published after the year 2000
- Primarily in English but could also include Scandinavian languages, Portuguese or Spanish
- Empirical work
- Dealing with the three themes of the study: people with disabilities, education and stigma
- Accessible through SINTEFs library sources

Exclusion criteria:

- Older than year 2000
- Studies from high-income economies as defined by the World Bank<sup>1</sup>
- Reports, fictional books, brochures, textbooks and so on that are not based on empirical research

All empirical work regardless of the quality, type of intervention or research methods used, were included in the scoping study in order to provide as full a picture as possible.

The following search terms, with truncations and synonyms were used:

Disability:

- Disability
- Sensory disability/impairment
  - Visual disability/impairment
  - Blind
  - Hearing disability/impairment
  - Deaf
- Developmental disability/impairment
  - Intellectual disability/impairment

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<sup>1</sup> [https://datahelpdesk.worldbank.org/knowledgebase/articles/906519#High\\_income](https://datahelpdesk.worldbank.org/knowledgebase/articles/906519#High_income)

- Psychosocial disability/impairment
  - Mental disorder/illness
- Epilepsy
- Albinism

Stigma:

- Stigma
- Discrimination
- Beliefs
- Myths
- Attitudes
- Perceptions

Education:

- Public education/ school
- Private education/ school
- Special needs education/ school
- Mainstream (general) education/ school
- Inclusive education

LMIC: Excluding high-income countries

### Results of the literature search

The combined search strategies produced 3777 citations. Following a screening of titles and abstracts, 69 articles were deemed relevant for the review and retrieved for full text reading. If relevant, they were entered into Mendeley<sup>2</sup>. Some works were not available through library sources and were not included in this review. Full text reading facilitated the examination of the remaining articles against the main inclusion criteria, which required studies to address in some manner how stigma affected access to and equity of education for people with disabilities. After full text reading, 23 empirical works met the inclusion criteria for this review. The inclusion process is described in Figure 1.

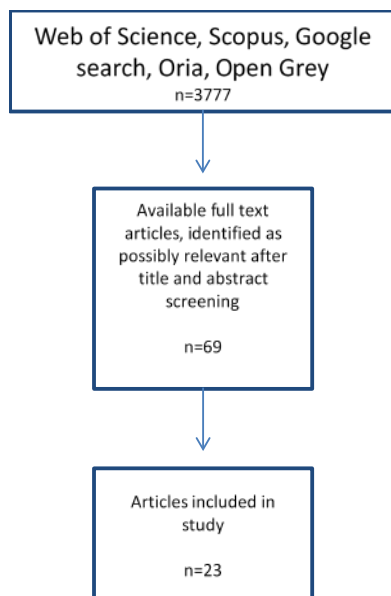


Figure 1 Flow chart showing inclusion process

<sup>2</sup> Mendeley is a reference database that stores, manages and searches for bibliographic references



An initial search using the broad search terms ("disability" AND "education" AND "stigma" AND "LMICs") resulted in few relevant articles, thus the search terms were broadened to include synonyms and truncations (see 3.1 for search terms used). This resulted in many more identified citations, with the majority not relevant for this review. The following citations were excluded based on their title: clinical research (neurobiology, metabolic, pharmacology, clinical aspects of mental health, animal trials, and cognitive studies) behavioural and attitude studies (OCD, eating disorder, treatment attitudes, drug and alcohol use, partner violence, health seeking behaviour, help seeking behaviour, reproduction and sexuality, parental coping, depression ), epidemiological studies, availability of services studies, law and policy studies, education related studies (learning technologies, assessment tools, online learning, sexual education, perception of sound, assistive reading), and employment related studies. Studies dealing with disabilities and attitudes, stigma, resilience, coping or knowledge, but not related to education were excluded by reading the abstracts. Full text reading excluded the remaining articles that though they seemed to be about stigma, education and disability did not assess or mention how stigma affected education access and equity for people with disabilities. No articles or empirical works were excluded based on quality.