Systematic Review and Assessment of Approaches to Research and Data Gathering on Knowledge, Attitudes and Practices (KAP) related to Children with Disabilities in the CEE/CIS Region

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The systematic review and assessment were conducted by Drexel University and the UNICEF Europe and Central Asia Regional Office. They are part of a package of materials developed between 2015-2019, including a systematic review, and operational research protocol and a monitoring and evaluation (M&E) framework developed to measure changes in discriminatory attitudes and social norms regarding children with disabilities in Europe and Central Asia (ECA).

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## Background

In September 2015, the UNICEF CEE/CIS<sup>1</sup> Regional Office in Geneva signed a PCA with Drexel University for secondary analysis of data to answer one overarching research question: "What is the quality of tools being used to generate evidence on measuring discriminatory attitudes and social norms towards children with disabilities (specifically in the CEE/CIS region) and how can the tools be improved to better evaluate individual and social change?"

The PCA includes three interrelated objectives:

- **Objective 1**: Desk Review of existing literature on attitudes and norms towards children with disabilities
- **Objective 2**: Critical review of UNICEF tools in CEE/CIS countries
- **Objective 3**: Recommendations for future theorizing and research in this area

This report summarizes findings for Objective 1, which seeks to understand how discriminatory attitudes and social norms related to children with disabilities are being conceptualized and measured by conducting a systematic review of instruments being used in the literature for measuring attitudes and social norms, their psychometric properties and making recommendations on tools that would be suitable for future studies. In so doing, this study attempts to identify current practices which can then be used as a benchmark for assessing UNICEF's own research in this subject area within the CEE/CIS region.

This report is divided into 7 major sections (Figure 1). The Introduction outlines the rationale for undertaking this study, an overview of the seminal conventions protecting the rights of children with disabilities, key definitions, and dominant disability models. The Methods section presents the search strategy used to conduct the systematic review, as well as information on the quality assessment tool. The Results section presents the findings. The Discussion section offers an interpretation of the findings with respect to the guiding research question, and acknowledges some of the limitations of this work. The Conclusion attempts to synthesize the findings from the review by providing actionable steps. Finally, the References and Appendices provide additional information for those interested in more details.

Report Structure						
Introduction	Methods	Results	Discussion	Conclusion	References	Appendices

## Figure 1: Structure of the Report

<sup>&</sup>lt;sup>1</sup>The CEE/CIS region is now the ECA (Europe and Central Asia) region. Some countries differ, so the name is kept here as it was at the time of publication.

## Introduction

Global estimates indicate that roughly 15% of the population (one billion people) live with some form of a disability (World Health Organization [WHO] & World Bank, 2011) (Figure 2). The prevalence of disabilities is much higher in developing countries as compared to developed countries, with 80% of individuals with disabilities residing in low-income countries (World Health Organization [WHO] & World Bank, 2011). Moreover, data from the *World Health Survey* indicate that disabilities are more prevalent among poor, female, and elderly populations and that low income, low educational attainment, and unemployment status are correlated with disabilities (WHO & World Bank, 2011).

According to UNICEF (2013), "the exclusion and invisibility [of children with disabilities] serves to render them uniquely vulnerable, denying them respect for dignity, their individuality, even their right to life itself" (p. 4). Worldwide there are an estimated 93 million children with disabilities, although this number could actually be much higher (WHO & World Bank, 2011). In Central and Eastern Europe and the Commonwealth of Independent States (CEE/CIS), there are approximately 5.1 million children with disabilities and an estimated 3.6 million of these children are considered "invisible," meaning they are not included in official registers and are likely to be subjected to segregation and exclusion from social aspects of life (UNICEF, 2015).



Figure 2: Disability Statistics

The discrimination of children with disabilities is not necessarily

rooted in the "intrinsic nature" of the disability, but rather, arises as a result of the confluence of multiple determinants and compounding factors (UNICEF, 2013, p. 4). Examples of these include but are not limited to:

- Lack of understanding and knowledge of the causes and implications of disability
- Negative attitudes
- Fear of difference
- Fear of contagion or contamination
- Negative religious or cultural views of disability
- Poverty
- Social isolation
- Humanitarian emergencies
- Lack of services and support
- Hostile and inaccessible environment
- Inadequate funding
- Inadequate policies and standards
- Lack of data and evidence

In the CEE/CIS region, a child with a disability has a 17 times higher likelihood of being institutionalized in comparison to a child without disability (UNICEF, 2012). In fact, an estimated 626,000 children with disabilities in the CEE/CIS region do not live at home, making it the region with the highest rate of institutionalization in the world (UNICEF, 2012).

## **Disability Models and Approaches**

Global understanding of disability and response strategies have evolved steadily over the last thirty years (Buntinx & Schalock, 2010; WHO, 2011), with a gradual shift in the conceptualization of disability from a medically focussed model to a more social ecological model (**Figure 3**). The medical model understands disability as a problem, pathology or

defect of a person, whereas the social model views disability as a consequence of environmental, societal, and attitudinal barriers that impede individuals with disabilities from participating in community life to the same extent as others (Buntinx & Schalock, 2010). At the heart of the social model is the idea that society is responsible for "disabling" individuals without adequate consideration of how environments that suit the needs of the majority (the abled) create barriers that exclude the minority (those with disability).



Figure 3: Overview of the Medical and Social Models of Disability

The International Classification of Functioning, Disability, and Health (ICF), endorsed by 191 WHO member states, defines disability as difficulties encountered in the form of: alteration in body structure and function, limitations in activity and/or restriction of participation or involvement in any area of life (World Health Organization, 2001). This definition combines the medical and social models by acknowledging the "multidimensional and interactive nature of disability," while also supporting the idea that disability works along a spectrum with some individuals being more restricted in their ability to participate in society than others (Cappa, Petrowski, & Njelesani, 2015, p. 319; Bickenbach, Chatterji, Badley, & Ustun, 1999).

Growing global acceptance of the social model of disability has drawn attention to ways of improving the quality of life for individuals with disabilities. UNICEF and other organizations advocate for the application of a human rights and equity framework to disability issues. Understanding disability as a human rights issue is grounded in international conventions, specifically the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD), that establish universal protections for individuals with disabilities, especially children, and guide the policies of State Parties (Buntinx & Schalock, 2010). The CRC articulates the civil, political, economic, social, health and cultural rights of all children including children with disabilities (The United Nations, 1990).

Countries that have ratified the CRC affirm their roles and responsibilities as duty bearers. Among those responsibilities are two that focus specifically on children with disabilities:

- Article 2: "states Parities shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of...disability" (The United Nations, 1990, 2)
- Article 23, Preamble 1: "States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community" (The United Nations, 1990, 23)

The CRPD outlines and advocates for the rights of all persons with disabilities. While children's rights are mentioned throughout the document, Article 7 is dedicated specifically to children with disabilities. In addition, the CRPD provides definitions for disability and discrimination on the basis of disability:

- **Disability:** "long-term physical, mental, intellectual, or sensory impairment which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (CRPD, Article 1, 2006)
- **Discrimination on the basis of disability**: "any distinction, exclusion, restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil, or any other field" (CRPD, Article 2, 2006).

In addition to macro-level efforts to improve quality of life, there is growing interest in examining and unpacking the role of social norms in the persistence of generalized discrimination towards children with disabilities. Social norms exist at the intersection of beliefs and expectations about how one should behave based on what others are doing. Social norms persist based on the assumption that adhering to the norms provides tangible or intangible rewards while breaking with tradition will result in sanctions (Bicchieri, 2006; Mackie, Moneti, Shakya and Denny, 2015). The mechanisms by which social norms operate and persist vary from context to context. Regardless, social norms change can be achieved in one of two ways: norm abandonment or norm replacement. Norm abandonment focuses on ending or eliminating a norm, whereas norm replacement consists of introducing a new innovation (in the form of a separate set of practices) that over time replaces traditions and becomes the "new norm".

There is considerable overlap in the many terms used to describe social norms components. Empirical expectations (what most individuals in a community do) are analogous to descriptive norms which describe the perceived prevalence of a given behaviour. Normative expectations refer to beliefs that one ought to conform to a behaviour which overlaps with definitions of injunctive and subjective norms that are conceptualized as the approval and disapproval of individuals in one's relevant networks. Text Box A below describes and provides a hypothetical example of the four key elements of social norms (descriptive norms, injunctive norms, and outcome expectancies in the form of sanctions and benefits) as they relate to discrimination towards children with disabilities.

#### Text Box A: Hypothetical Example of the 4 Key Elements of Social Norms

There are four key elements to consider when measuring social norms: descriptive norms, injunctive norms, and outcome expectancies in the form of sanctions and benefits. These are described below using hypothetical examples of how social norms drive discrimination towards children with disabilities.

- Descriptive norms (empirical expectations) are the beliefs about what others are doing. In other
  words, if a person does something because she believes that others in her community also do it, then
  it is called a descriptive norm. For example: In my community, most parents who have children with
  disabilities send them away to an institution.
- 2. Injunctive norms (normative expectations) are beliefs about what others approve of or think people should do. An example of an injunctive norm would be If a teacher says, "I don't want to have children with disabilities in my classroom because parents of children without disabilities will complain that I don't pay enough attention to their children's needs."
- 3. Sanctions are the beliefs about the perceived sanctions or punishments resulting from performing or not performing a behavior. Sanctions can be tangible or intangible. For example: Parents of children with disabilities do not let their disabled child attend social gatherings or functions for fear of bringing shame to their family.
- 4. Benefits are the beliefs about the perceived benefits or rewards to oneself or others as a result of complying with norms. If an individual believes that it is important to behave in a certain way because it will lead to desired benefits, then they will be more likely to perform a behavior. Benefits can be tangible or intangible. For example: Children without disabilities tease their peers with disabilities in order to gain social status and credibility.

These four elements of social norms can and should be measured using both quantitative and qualitative methods.

Given the interest in deriving a better understanding of why and how discriminatory attitudes and norms towards children with disabilities exist, this review seeks to identify and assess how researchers, globally and in the CEE/CIS region, measure discriminatory attitudes and social norms towards children with disabilities. Being able to accurately measure discriminatory attitudes and social norms towards children with disabilities are population is important for several reasons. First, it provides a means of accurately capturing a population's attitudes and norms towards children with disabilities as a group. Second, quality tools are needed to be able to measure the effects of interventions working to bring about attitudinal shifts and social change. Third, these tools serve as a mechanism for holding countries accountable to the CRC and CRPD, and for gauging progress in protecting children with disabilities from discrimination.

## Methods

This section of the report details the search strategy utilized for the systematic review and describes the quality assessment tool used to categorize studies as being of high, medium, or low quality.

## Search Strategy Procedures

The key constructs guiding this systematic review and their definitions are provided in **Appendix 1**. The systematic review searched for peer-reviewed and grey literature published between 2005 and 2016 across three databases: PubMed, Academic OneFile, and Google Scholar. PubMed is a digital archive that houses biomedical and life science literature from the U.S. National Institutes of Health's National Library of Medicine. Academic OneFile is one of the largest scholarly databases covering topics in the area of social science, medicine, education, the humanities, and more. Google Scholar is a repository of peer-reviewed and grey literature that consolidates scholarship from various disciplines and regions. Together these three databases enabled the authors to cast a wide net when searching for relevant scholarship<sup>2</sup>.

**Table 1** outlines the specific inclusion and exclusion criteria used to select publications. It is important to reiterate that this review focussed specifically on research measuring discriminatory attitudes and norms towards children with disabilities. This body of literature is considerably smaller than that involving adults or people with disabilities (i.e. research pertaining to both adults and children with disabilities). Further, given the long history of theorizing and research on both attitudes and social norms, this review focused on the most recent developments and applications by selecting scholarship published in the last ten years.

## Table 1: Systematic Review Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
<ul> <li>Peer-reviewed or grey literature publications measuring attitudes or social norms towards children with disabilities</li> <li>English language publications</li> <li>Published between 2005-2016</li> </ul>	<ul> <li>Publications not measuring attitudes or social norms towards children with disabilities</li> <li>Editorials, commentaries, conference proceedings, and book chapters</li> <li>Non-English publications</li> <li>Published prior to 2005</li> </ul>

The authors followed standard procedures for conducting systematic reviews, including searching under various but equivalent keywords across different databases. Initially, the systematic review searches used five categories of key terms: Discrimination, Measurable Outcomes, Children, Disabilities, and Location (**Appendix 2**). Measurable Outcomes refer to

<sup>&</sup>lt;sup>2</sup> A previous global systematic review of peer reviewed literature on social and behavior change interventions addressing violence against children carried out by the authors revealed that these three databases yielded the widest range of results.

key research constructs when assessing discriminatory attitudes and stigma; these include terms such as attitudes, beliefs, opinion, norms, rules, patterns, behaviours, knowledge. Combinations of the key terms involving at least one word from each category were used to carry out the searches across databases. However, this yielded few if any relevant publications and so the Location key terms were dropped.<sup>3</sup>

### **Selection of Studies**

A PRISMA diagram developed by Moher, Liberati, & Tetzlaff (2009), describes the review process, including how many records were identified through database searching, number of abstracts reviewed, full text articles assessed for eligibility and studies included in the review (**Figure 4**). The search yielded over 8 million results. Due to the high volume of hits on Google Scholar, titles were reviewed until 20 consecutive titles were deemed irrelevant to the research question guiding the review. A total of 306 publications were set aside for abstract review. Of those, 79 publications were read fully. Twenty-two publications were deemed to not meet the inclusion criteria, eight could not be obtained, and five were not pertinent to attitudes towards children. In the end, 44 publications made the final cut, of which 37 (84.1%) were peer-review articles and 7 (15.9%) were dissertations. The final database of publications did not yield any studies, commissioned or undertaken by UNICEF.



Figure 4: PRISMA Diagram for the systematic review search strategy

<sup>&</sup>lt;sup>3</sup> With five key terms, the search yielded a total of 26, 624 results from PubMed, none of which were relevant to the study objectives.

In addition to the 44 articles included in the review, the search also yielded 11 publications which were categorized as systematic reviews and narratives/annotated bibliographies. These were excluded from the quality assessment process described below, since they did not fit the analysis categories devised for primary research articles. Of the 11 scientific publications, one (9.1%) was a meta-analysis, eight (72.7%) were systematic reviews and two (18.2%) were narratives/annotated bibliographies. Six (54.5%) of the 11, one metaanalysis and five systematic reviews outlined measures within their articles (Beelmann & Heinemann, 2014; Cervasio, 2010; De Boer et al., 2012; Macmillan et al., 2014; Scior, 2011; Vignes et al., 2008). Key characteristics from these studies including objectives, total number of studies included, types of measures analysed and conclusions made by the authors on the measures are described in Appendix 3. It is worth mentioning that the articles included in the systematic reviews and meta-analysis were cross-checked with those included in this review. Only one article that met all the inclusion criteria had not been captured based on the search strategy described above. Many of the articles in the systematic reviews and the meta-analysis were published prior to 2005 or did not focus specifically on children with disabilities.

### **Quality Assessment**

The next step involved assessing the quality of the publications. A coding matrix and quality assessment tool by Sirriyeh et al. (2011) was adapted for this purpose (Appendix 4). Publications were assessed on 17-20 items depending on the type of study (i.e., quantitative, qualitative, or mixed methods) and assigned point values from 0-2 depending on how well they met the coding category descriptions. To compare the studies, all scores were converted into percentages with 85-100% signifying high quality; scores between 84-70% were considered to be of medium quality; and publications scoring 69% or below were categorized as low quality. **Table 2** summarizes the studies by methodological approach and quality assessment.

Type of article	Total Number	Quality Assessment		
		High	Medium	Low
Quantitative	36	2	15	19
Qualitative	5	1	4	0
Mixed Methods	3	0	2	1
Total	44	3	21	20

#### Table 2: Quality Assessment Results by Methodological Approach and Quality Rating

## Results

This section presents the results of the systematic review, by first describing some of the general characteristics of the sample and key takeaways from the quality assessment exercise. An analysis of the conceptualization of constructs and definitions of key terms across the 44 studies comes next. Then, findings relating to the analysis of tools for measuring attitudes are presented. The section concludes with the presentation of findings relating to the use of participatory research methods and adherence to ethical standards.

Before delving into the results, it is important to state up front that articles within the CEE/CIS region were scant (n=5). Making generalizations specifically for this region difficult. Furthermore, the studies reviewed focused on attitudes with little to no conceptualization and measurement of the social norm constructs, i.e. empirical and normative expectations and outcomes expectancies.

## **General Characteristics**

This sample of studies is geographically diverse (**Table 3**). Out of the 44 studies, a total of 28 (63.6%) were based in industrialized countries. Five studies originated in the CEE/CIS region (11.3%) (See **Appendix 5** for a summary of these five studies). Three studies each came from the Latin America and Caribbean region (6.8%) and West and Central African region (6.8%). Two studies were conducted in Eastern Asia and the Pacific region (4.5%). One study each were conducted in Eastern and Southern Africa region (2.3%) and Middle East and North African region (2.3%). The location of one study was not provided (2.3%).

UNICEF Regions	# of Studies	Countries
Industrialized countries	28	USA (9), United Kingdom (4), Greece (3), Canada (2), France (2), Israel (2), Australia (1), Belgium (1), Czech Republic (1), Netherlands (1), Republic of Korea (1), Spain (1)
CEE/CIS	5	Turkey (3), Georgia (1), Serbia (1)
Latin American and Caribbean	3	Haiti (2), Brazil (1)
West and Central Africa	3	Nigeria (2), Ghana (1)
Eastern Asia and the Pacific	2	Taiwan/China (2)
Eastern and Southern Africa	1	Kenya
Middle East and North Africa	1	Egypt
Unknown	1	Unknown

## Table 3: Geographic Distribution of Systematic Review Studies

Studies were also assessed with regards to the disability focus of the research being conducted (**Figure 5**; See **Appendix 6** for a list of citations by disability focus). Only three studies (6.8%) examined disability in its broadest interpretation. Some 16 studies (36.3%) focused on intellectual disability. Six of those studies (37.5%) examined intellectual disability, physical disability, and a combination of intellectual and physical disability. The other ten studies (62.5%) dealt exclusively with intellectual disabilities, with four studies focusing on autism spectrum disorders. Twelve studies (27.3%) focused on physical disabilities. Five of these articles dealt solely with physical disabilities, while the other seven examined physical disabilities and another type of disability (often intellectual). Mental health issues were covered by eight studies (18.2%). One study each dealt with visual impairment, hearing and speech impairment, and hearing impairment alone. Some nine articles (20.5%) neither specified the type(s) of disability nor provided definitions of disability.



Figure 5: Disability Focus of Studies

The population focus of the research articles was examined in three ways. First, the studies were assessed on the basis of whether research participants were adults or children. With regard to the inclusion of children/adolescents in the research, in the sample, 29 studies (66.0%) involved children or adolescents as participants. Some 14 studies (31.8%) involved adults who interact or will interact regularly with children (e.g., teachers, health professionals, parents, nursing or teaching students). One study examined university students' attitudes towards children with cerebral palsy (Nabor & Lahmkuhl, 2005).

Second, the age group that this body of disability research focuses on was examined (**Table 4**)<sup>4</sup>, with additional categories made for studies that combined age groups (e.g., primary and secondary school age children). For studies involving adults, we looked to see if those adults work with specific age groups, for instance, secondary school teachers. The findings indicate that disability research focuses on secondary school age children (16 manuscripts; 36.4%) or a combination of primary and secondary school age children (12 manuscripts; 27.2%). Seven studies (15.9%) did not specify an age groups with parents of children with disabilities worked across all age groups with parents of children less than one year to 18 years of age (Helfinger et al., 2014). A few studies worked with preschool age children (2 manuscripts only worked with pre-schoolers and 3 worked with preschool and primary age students), but no studies explored attitudes towards children with disabilities under two years of age.

## Table 4: Age Focus of Disability Research

Age Group	# of Articles
Children less than two years of age	0
Preschool children (3-5 years)	2
Primary school age (6-12 years)	3
Secondary school age (13-18)	16
Primary and secondary school age children (6-18 years)	12
Preschool and primary school age children (3-12 years)	3
All ages (0-18 years)	1
Not specified	7

<sup>&</sup>lt;sup>4</sup> Citations for these studies are also provided in Appendix 5

The third dimension of this analysis sought to bring to the fore whether studies had applied an equity or human rights focus to their analysis. Studies were assessed on the basis of whether background characteristics (e.g., age, gender, ethnicity, etc.) had been examined in the context of understanding attitudes and social norms towards children with disabilities. Of the 44 studies, 34 (77.2%) controlled for some background characteristics. A majority of studies controlled for gender (28 studies; 82.4%), about a third (11 studies; 32.45) controlled for age, only three studies (8.8%) controlled for ethnicity, and two studies (5.9%) controlled for socio-economic status.

## **Quality Assessment**

Out of the 44 articles, 36 (81.8%) used quantitative methods, 5 (11.4%) used qualitative methods and 3 (6.8%) applied a mixed methods approach. Overall, 3 (6.8%) articles were assessed as being of high quality (**Appendix 7** summarizes these three 'high quality' studies); 21 (47.7%) were deemed to be of medium quality; and 20 (45.5%) articles were identified as being of low quality. Of the five studies undertaken in the CEE/CIS region, two studies each qualified as being of low and medium quality and one was of high quality.

A closer examination of the quality assessment reveals general areas of strength and weakness across the 44 studies. The majority of studies received full points for: statement of aims/objectives (95.5%), fit between stated research and method of data collection (89.7%), description of outcome measures (88.6%), and description of the research setting (79.5%). What sets the three "high quality" studies apart from the rest is that they provided definitions and were based on a theoretical/conceptual framework. The two quantitative "high quality" studies also distinguished themselves from other quantitative studies by using appropriate statistical analyses to make inferences and by using validated tools.

In terms of areas of weakness, about half of the studies in the sample did not receive any points for the following criteria: sample size considerations in the analysis (52.8%), definitions of key terms (52.3%), statistical assessment of the validity of measurement tools (52.8%), and detailed recruitment information (40.9%). Among the 20 "low quality" studies, these areas of weakness are even more salient. An overwhelming majority (90%) did not provide any information on sample size considerations, 70% did not define key terms, 65% did not provide a statistical assessment of validly for the measurement tool or adequately justify the analytical method used and 60% did not provide recruitment data.

## **Conceptual/Theoretical Frameworks**

Twenty-five (56.8%) articles noted an explicit conceptual/theoretical framework. **Figure 6** summarizes the key theories utilized in the studies.



Figure 6: Theories Referenced in the Systematic Review Manuscripts

The three most commonly used theories were: the theory of planned behaviour (48%), contact theory (40%) and Goffman's theory of social stigma (24%). Within the CEE/CIS region, three of the studies explicitly mentioned the theory of planned behaviour and one study (25%) outlined contact theory. **Table 5** describes these three commonly utilized theories.

Theory	Description of theory
Theory of Planned Behaviour (TPB)	Provides a way to predict intentions and subsequently behaviour from an individual's attitudes, perceived behavioural control and perceived subjective norms, which are in turn governed by their behavioural, normative and control beliefs respectively (Ajzen, 1985)
Contact Theory	States that within a complex social system, one of the most effective ways to reduce prejudice between conflicting group members is positive direct and indirect interpersonal contact. Positive interpersonal contact is governed by key rules including common goals, intergroup cooperation, enabling environment, equal status and sustained formal and informal interactions (Allport, 1954)
Theory of Social Stigma	Indicates that social stigma is a physical attribute, a personal trait which results in rejection. Stigma is considered to spoil "normal identity" with society being composed of the stigmatized group, the normals and the wise (Goffman, 1963).

### Table 5: Overview of Commonly Cited Theories

## **Definition of Key Terms**

To measure a construct, a clear definition of each key term (discrimination, attitudes, children and disability) is required. At the overall level, slightly more than half of the reviewed articles (23 manuscripts; 52%) did not outline any definitions.

Attitudes were defined in 11 (52.4%) of the articles and while varying definitions were used, Triandis' (1971) and Antonak and Livneh's (1988) definitions of attitudes were the most commonly cited (5). Attitudes were defined as "an idea charged with emotions which predisposes a class of actions to a particular class of social situations" (Triandis, 1971, p.2). This definition includes the three components (cognitive, affective and behavioural attributes) typically identified with attitudes towards disability (Antonak & Livneh, 1988).

Stigma was defined in 7 (33.3%) of the articles. Within the literature, stigma and discrimination have been used together. Definitions from Goffman's theory of social stigma (1963) and Link and Phelan's stigmatization model (2001) were used most often (n=5). Goffman (1963) describes stigma in the context of negative and often inaccurate beliefs. Stigma, therefore leads to discriminatory actions and behaviours, which results in discrimination.

Disability as a construct was specifically operationalized in 3 (14.3%) of the articles (Nabors & Lehmkuhl, 2005; World Health Organization, 2001). The definitions drew upon two sources: the International Classification of Functioning, Disability, and Health (ICF) and Goffman's (1963) definition of special needs. In an additional two studies, the term children with disabilities was defined (Özer et al., 2012; Vignes et al., 2009). The definition used by Vignes et al. (2009) is an adaption of the ICF definition. **Figure 6** displays the exact wording of the definitions for both disability and children with disabilities from the reviewed literature.



Figure 6: Definitions of Disability and Children with Disability from the Systematic Review

### **Measurement of Attitudes**

In order to operationalize and assess discriminatory attitudes, it is important to examine scales that have been reported in the literature and determine their psychometric properties, i.e. their validity and reliability. Measurements of attitudes are categorized into three groups: 1) Measuring attitudes using existing tools/scales; 2) Measuring attitudes using unique tools/scales; and 3) Measuring attitudes in the CEE/CIS region.

## Measuring attitudes using existing tools/scales

A majority (79.5%) of the articles included in the review used existing measures. The three most commonly used scales are: 1) Chedoke-McMaster Attitudes towards Children with Handicaps Scale (CATCH); 2) Attitude toward Disabled Person Scale (ATDP); and 3) Opinions Relative to Integration (ORI). **Figure 7** provides a brief overview of these three scales. More detailed information including information on their internal consistency and reliability can be found in **Appendix 8**.

### CATCH Scale

- •Measures attitudes towards peers with disabilites
- •Useful measure if the purpose of research is to identify determinants of children's attitudes or to evaluate programmes designed to improve attitudes (Rosenbaum, Armstrong, & King, 1985)

#### ADTP Scale

- •Developed for research examining attitudes towards disabled persons as a group
- •Versatile scale designed to be used with persons with and without disabilities
- Allows for measure of two types of attitudes: "the prejudice of non-disabled persons and the attitudes of disabled persons towards themselves and being disabled" (Yuker, Block, & Young, 1970, p.18

### ORI Scale

- •Most appropriate if the focus of research is on inclusion
- •Measures teachers' attitudes towards mainstreaming children with disabilities in classrooms

Figure 7: Summary of Top Three Existing Scales Used to Measure Attitudes

## Measuring attitudes using unique tools/scales

Out of the 44 articles, 9 studies (20.5%)<sup>5</sup> created and used their own tools/scales. These tools/scales used a combination of quantitative (3 studies), qualitative (5 studies) and mixed methods (1 study) data collection methods.

**Quantitative methods**: Three studies<sup>6</sup> created quantitative tools/scales specific to their research objectives (Hirfanoglu et al., 2009; Momberg, 2008; Wanjiru, 2014). **Figure 8** briefly describes the study objective and the unique tool developed by the researchers. More information including reliability and validity assessments is available in **Appendix 9**.

## Hirfanoglu et al. (2009)

- Evaluated knowledge, perceptions, and attitudes towards epilepsy and correlations with quality of life and stigma among children with epilepsy and their families
- Measured attitudes and perceptions among children and asked about their own attitudes towards living with epilepsy
- Perceptions were also measured to understand communities' views about epilepsy and children living with epilepsy

## Momberg (2008)

- •Surveyed Egyptian teachers to understand their attitudes towards and acceptance of inclusive education
- Attitudes asked about funding, structural constraints, training, support and teacher efficacy which could prevent a teacher from teaching a student with special needs in an inclusive school

## Wanjiru (2014)

- Tried to establish the relationship between parental background characteristics with attitudes towards their children with hearing impairment
- The scale comprised of parent's beliefs about hearing impairment, feelings and actions or the way they treat children with hearing impairment

## Figure 8: Description of Three Unique Quantitative Measures

**Qualitative methods:** Five studies that created their own measures relied upon qualitative methods to measure discriminatory attitudes and social norms towards children with disabilities. The key findings from these qualitative studies are presented in **Figure 9**. More detailed in information is available in **Appendix 10**.

## **Qualitative Research Method Used**

- All of these studies used individual interviews.
- Lindsay and McPherson (2012) allowed children to decide whether they felt more comfortable discussing bullying and exclusion in an individual or group setting, and conducted focus group discussions to accommodate children who felt uncomfortable discussing these topics on a one-to-one basis.

### **Qualitative Research Participants**

- In four of the studies, the participants of these studies were children under 18 with disabilities (Chen & Shu, 2012; Elkington et al., 2012; Lindsay & McPherson, 2012; Moses, 2010).
- Huang (2006) sought to measure the perceptions of mothers of young adolescents with mild to moderate mental retardation.

### Qualitative Research Constructs

- Questions probed participants about their personal experiences of being a person with disabilities or a parent of a child with disabilities.
- Interviews specifically elicited information on:
- •Stigma (Chen & Shu, 2012; Elkington et al., 2012; Moses, 2010)
- •Bullying and exclusion (Lindsay & McPherson, 2012)
- •Perceptions (Huang, 2006; Moses, 2010).

#### Figure 9: Overview of Qualitative Studies with Unique Measures for Attitudes

<sup>&</sup>lt;sup>5</sup> The 9 articles using their own scales include: Chen & Shu, 2012; Elkington et al., 2012; Hirfanoglu et al., 2009; Huang, 2006; Lindsay & McPherson, 2012; Momberg, 2008; Moses, 2010; Tabakhmelashvili, 2008; Wanjiru, 2014

<sup>&</sup>lt;sup>6</sup> The three articles using their own quantitative scales include: Hirfanoglu et al., 2009; Momberg, 2008; Wanjiru, 2014

**Mixed methods:** Of the 9 studies that created their own measures, Tabakhmelashvili (2008) is the only example that used both quantitative and qualitative data collection methods to measure attitudes. In this research study, a questionnaire containing close- and openended questions was administered to a sample of teachers in Tbilisi, Georgia. The questionnaire asked teachers their opinions about the inclusion of children with special needs. Close-ended questions assessed attitudes using Chaiken's (1993) definition of attitudes as "a psychological tendency that is expressed by evaluating a particular entity with some degree of favour or disfavour" (Tabakhmelashvili, 2008, p. 41). An open-ended question provided participants an opportunity to express opinions not covered by the close-ended items of the questionnaire. Content validity was met by inserting the definition of inclusion in the introductory page of the questionnaire and by basing the questions on existing theory and literature. The attitudinal scale had a Cronbach's alpha of 0.85. The qualitative component of this study involved using structured guides were for in-depth interviews with two inclusive education specialists at the Ministry of Education and Science asking about the general situation with regards to inclusive education in Georgia.

## Measuring attitudes in the CEE/CIS region

A closer examination of the five studies<sup>7</sup> from the CEE/CIS region reveals that researchers are using both validated tools from the literature, as well as developing their own unique tools in this region. Some of the validated tools being used by researchers include:

- Friendship Activity Scale measures a child's behavioural intentions towards interacting across a series of activities with a peer with disabilities. For each activity, a child is asked if they would/probably would/probably would not/would not engage in the activity with a child with disabilities. A high score indicates a positive attitude (Özer et al., 2012)
- Adjective Checklist is designed to assess children's attitudes by asking them to judge various attributes of a child with intellectual disabilities (Özer et al., 2012)
- Teachers Attitudes towards Children with Intellectual Disability Scale (TACIDS) is a survey developed for preschool, classroom, and pre-service teachers to assess their attitudes towards teaching students with intellectual disabilities (Özer et al., 2013).
- **Opinions about Mental Illness** is a multidimensional scale used to measure attitudes towards mental illness. The scale covers five dimensions: authoritarianism; benevolence; mental hygiene ideology; social restrictiveness; and interpersonal aetiology (Pejovic-Milovancevic et al., 2009)

As described in earlier, Tabakhmelashvili (2008) and Hirfanoglu (2009) developed their own tools to examine attitudes of teachers towards inclusive education and to assess attitudes and stigma towards children with epilepsy.

<sup>&</sup>lt;sup>7</sup> Again, a summary of these five studies is located in Appendix 4.

### **Community-based Participatory Research**

As research is moving towards a more participatory model to improve community capacity building and sustainability, all studies were examined to see if the primary audience was involved in the study planning, data collection, analysis or evaluation (Hacker et al., 2012). **Only 3 (6.8%) studies involved participants in the data collection process** (Cameron & Rutland, 2006; Lindsay & McPherson, 2012; Nowicki, 2006).

## Human Subjects Research (HSR)

The involvement of children in research of any kind has been the focus of increasing international attention. While no international standards exist, a number of organizations have been working to develop ethical guidance for research involving children. Researchers have a legal obligation to uphold and protect children's rights as articulated in the CRC throughout the entire research process; these legal obligations align with the three fundamental principles of research: respect for persons, beneficence, and justice (Graham, Powell, Taylor, Anderson & Fitzgerald, 2013). Some critical safeguards for research involving children include gaining ethical approval for research from a Research Ethics Committee; ensuring informed consent and assent are obtained in an appropriate manner; engaging in a reflexive discussion about the harms and benefits of involving children in research; and putting in place mechanisms to ensure privacy and confidentiality of data (Graham et al., 2013). Out of the 44 studies, six studies<sup>8</sup> (13.6%) did not mention receiving ethical clearance from an institutional review board (IRB)or describe the process for obtaining assent from underage participants along with informed consent from a responsible adult. Seventeen (38.6%)<sup>9</sup> studies outlined they obtained consent/permission from school authorities, teachers, students and/or parents. Lastly, a total of 21 (47.7%) studies<sup>10</sup> obtained institutional clearance and collected assent/consent from participants.

<sup>&</sup>lt;sup>8</sup> The six studies were: Agbenyega, 2007; Dupoux et al. 2006, 2005; Hutzler, Fliess-Douer et al., 2007; Hutzler et al. 2005; and Xafopoulou et al., 2009.

<sup>&</sup>lt;sup>9</sup> The seventeen studies were: Chen & Shu, 2012; Laws & Kelly, 2005; Matziou et al., 2009; Barned, 2009; Wanjiru, 2014; De Boer et al., 2014; Sipersteing et al., 2007; Omoniyi, 2014; Pejovic-Milovancevic et al., 2009; Cameron & Rutland, 2006; Han, 2012; Mombera, 2008; Reina et al., 2011; Olaleye et al. 2012; Anastasiadou, 2016; Ranson & Byrne, 2014; and Nowicki, 2006.

<sup>&</sup>lt;sup>10</sup> The twenty-one studies include: Bell et al., 2011; Elkington et al., 2012; Moses, 2010; O'Driscoll et al., 2012; Mavropoulou & Sideridis, 2014; Hirfanoglu et al., 2009; Tabakhmelshvili, 2008; Ozer et al., 2013; Heflinger et al., 2014; Crothers et al., 2007; Santiago et al., 2015; Bossaert & Petry, 2013; Shalev et al., 2016; Huang, 2012; Orta, 2016; and Ozer et al., 2012.

## Discussion

The objective of this review was to understand how discriminatory attitudes and social norms related to children with disabilities are being conceptualized and measured globally, and more specifically within the CEE/CIS context. At the overall level, the quality of studies is too variable to unequivocally answer the research question guiding this study. Nearly half of the studies (45%) were found to be low in quality when assessed on a range of core research criteria. Nevertheless, the review of studies yielded several important points to consider as this area of research moves forward.

Despite the fact that the burden of disability is felt more strongly in developing countries, most of the published literature and research on disability originates from developed countries, especially North American and Western European countries (Kampfe, 2009; WHO, 2011). The sample of studies from this review corroborate this finding with 64% (28) of studies coming from industrialized countries. Research conducted in the CEE/CIS region is scant, making it difficult to draw out a specific region-based synthesis from those studies.

Overall, the scope and focus of research with and about children with disabilities could be broader. Disability research engages primarily with secondary school age children (or their teachers and parents) or mixed groups of primary and secondary school age students. Fewer studies focused on pre-schoolers or worked across the life cycle, and no studies focussing on children under two years of age were found. Moreover, the preponderance of disability research examines intellectual (16) and physical disabilities (12) with limited attention placed on uncovering attitudes and social norms towards children with other types of disabilities such as mental health disorders, hearing, visual, and auditory impairments, or co-occurring disabilities. Further, nine of the 44 studies (20.5%) included in the review neither specified the type(s) of disability being investigated nor provided definitions of disability. Even among studies in this review that focused on specific types of disability such as intellectual or physical disabilities, definitions of what constitutes a specific type of disability were absent. Broadening the scope of disability research and using standardized terminology would go a long way to fulfilling the principles of inclusion that underpin and drive much of this work, and would provide a more comprehensive picture of how discriminatory attitudes and norms towards children with disabilities can be shifted.

In general, there is minimal beneficiary involvement in the planning, data collection, data analysis, and interpretation phases of disability research. With only three studies in this review that actively engaged participants in the data collection process, there is room for research that incorporates principles of participatory research. A bottom-up approach with its emphasis on community members as experts can help foster changes in discriminatory attitudes and norms that are likely to be sustained over the long-term. An examination of the participants involved in the research studies revealed that this too is fairly limited in scope. Parents are often the primary caregivers for children with disabilities, yet only four studies examined parents' attitudes towards their child with disability. Another audience category, notably absent from the current review, was medical professionals, who are a critical point of contact for children with disabilities. Understanding their attitudes towards this group is especially important in the context of the institutionalization of babies and young children with disabilities. Children and adolescents were involved in about two-thirds

of the research studies included in this review. However, this work tends to focus heavily on able-bodied children's attitudes towards those with disabilities.

With regards to ethical procedures for carrying out human subjects' research, it is important to point out that slightly less than half the studies in this review reported having obtained institutional clearance and having collected assent/consent from participants. An additional third of the studies mentioned getting consent/permission from school authorities, teachers, students and/or parents. Safeguarding the rights of research participants, especially children who are considered a vulnerable population, is of paramount importance.

Theories, for their explanatory and predictive capabilities, are being increasingly recognized as essential elements of evidence-based research, programming, and evaluation (Green, 2000). Our review reveals that only slightly more than half of the reviewed studies provided information on the conceptual or theoretical framework guiding the research. The theory of planned behaviour, which focuses primarily on individuals, was the most commonly used theory. The application of Goffman's (1963) theory of social stigma provides some indication of theorizing designed to help stage individuals with a view to move individuals along a continuum of change (i.e., encouraging change from normals, to passive wise, to active wise) (Smith, 2012). Reliance on Allport's (1954) contact theory provides information on optimal program design to improve positive contact with children with disabilities, and therefore fostering both individual and social change.

More than half of the articles in this study did not provide definitions for their key constructs (e.g., attitudes). Given the multiplicity of definitions for attitudes, this lack of definitions makes it difficult for findings to be synthesized across studies. For instance, three validated scales –CATCH, ADTP, and ORI -- emerged as those most commonly used to measure attitudes. Yet, these scales all focus on different aspects of attitudes; And, they also vary with regards to the respondents they should be used with and the type of research these scales are best suited for. The CATCH scale examines attitudes of children towards peers with disabilities; the ADTP scale examines attitudes towards disabled persons as a group; and the third ORI scale is most appropriate if the focus is on inclusion. Similarly, the nine studies in this review that created and used their own tools/scales grounded their measures to fit their individual research needs for instance: attitudes among specific respondents (peers, parents, teachers); type of disability (intellectual disabilities, epilepsy), and individual aspects of attitudes (interaction, inclusion, friendship). In addition, social norms were noticeably absent from the reviewed studies, with none of the studies conceptualizing and operationalizing social norms constructs (e.g., empirical, normative and outcome expectations) to guide their work.

A key weakness in the reviewed studies relates to their failure to provide sufficient details on sampling frameworks and sizes. Over three-quarters of studies in this review controlled for background characteristics in their analyses. Nevertheless, few if any studies specifically conducted research to assess if and how these factors shape attitudes towards children with disabilities. For instance, no studies investigated whether attitudes towards children with disability differed based on the child's gender or ethnicity.

One final point to consider is the fact that the sample of studies for this review did not yield any UNICEF publications. This is despite the fact that UNICEF has commissioned and undertaken multiple studies on this topic, across the globe and more specifically within the CEE/CIS region. When it comes to research on discriminatory attitudes and norms towards children with disability, UNICEF as an organization could prioritize a wider dissemination strategy for making research findings from their studies available for others to draw on.

## **Recommendations**

The review did yield important insights that can be used to guide and bolster future research endeavours. These insights have been collapsed into **12** key recommendations summarized below (**Figure 7**).



#### Figure 7: Recommendations to Guide Future Research

### 1. Conduct research in low-income countries

The ethical principle of distributive justice implies that researchers and research donors have an obligation to distribute the benefits of research in an equitable manner. In the context of disability research and given that the burden of disabilities falls more heavily in developing countries, this would suggest that additional steps need to be taken in order to promote, facilitate, and disseminate research for and about children with disabilities living in lowincome countries.

## 2. Ground research within theory-based conceptual frameworks

An overarching theory-based framework to drive research and programming addressing attitudes and norms towards children with disabilities is missing. The ICF framework, cited in one study, could serve as a starting point to develop an overarching theory of change to

measure changing attitudes and norms relating to children with disabilities across contexts (Olaleye et al., 2012). Apart from the value of having an overarching framework, it is equally important to ground individual programmes in theoretical models. Only slightly more than half of the reviewed studies provided information on the conceptual or theoretical framework guiding the research. This is concerning given that theories explain what will be studied – the key factors, concepts (constructs), and variables -- and also describe the interactions between these components. In so doing, theories provide a roadmap for how change is expected to occur and can be used to guide research and evaluation. Having both an overarching and programme specific theory of change is essential for capturing individual and social change within and across contexts.

## 3. Adopt a life cycle approach

The life course approach acknowledges that human development and aging are lifelong processes and underscores the importance of understanding the social, economic, and historical contexts in which individuals make decisions and take action in their lives (Elder Jr., Johnson, & Crosnoe, 1998). Adopting a life course perspective is relevant to disability studies because it allows researchers to examine individual life experiences, which can help uncover different social meanings attributed to disability by age group by bringing to the fore specific disabling barriers children encounter at various time points in life, especially during developmental transitions (e.g. childhood into adolescence and adolescence into adulthood) (Priestley, 2003). Further, this approach has the potential of ensuring that research is grounded within a broader perspective of social systems, structures, and norms that contribute to or manifest themselves as disabling barriers (Priestley, 2003).

## 4. Standardize definitions and typologies of disabilities being studied

As this body of research grows, the harmonization of definitions and typologies of disabilities is essential. The standardization of definitions and typologies of disability would allow for research findings to be comparable across contexts and diverse populations. This would allow for research to be translated into actionable steps (Proctor, Powell, & McMillen, 2013; Rabin et al., 2012). Once again, using the ICF as an overarching framework for disability research and practice could help standardize definitions and typologies of disabilities.

## 5. Define measurable constructs to measure attitudes

In addition to standardizing the definition and typologies of disabilities, it is fundamentally important to define the key constructs (e.g., attitudes) in any research endeavour. Defining key constructs not only enhances the utility of conceptual frameworks, models, and theories, but also enhances the comparability of findings across studies and facilitates the aggregation of data (e.g., systematic reviews and meta-analyses) and data sharing (Rabin et al., 2012). This is an especially important for constructs such as attitudes which are defined and measured differently across and even within disciplines. While it is possible to retrofit individual items from existing measures to develop overarching measures of attitudes towards children with disabilities, best practices in research would dictate a sequential process of defining the primary audience and overarching constructs of interest, developing a context specific and rigorous monitoring and evaluation plan, reviewing the literature to identify validated tools and designing new tools if and when needed, followed by testing and retesting the tools within the local context, prior to utilization.

## 6. Focus on understanding and measuring social norms

Social norms were noticeably absent from the reviewed studies. Discrimination can be hypothesized to be perpetuated through attitudes at the individual level and by norms at the social level. Discrimination against children with disabilities is normative to the extent that norms guide individual thoughts and behaviours. There is a clear need to define, create, and test tools measuring social norms constructs such as empirical and normative expectations and associated rewards and benefits. Unpacking the interplay between and the impact of attitudes and norms on discrimination against children with disabilities is therefore important and challenging from both theoretical and measurement perspectives. Without understanding and measuring social norms constructs, it will be difficult to fully understand the relationship between attitudes and norms in the context of discrimination against children with disabilities.

## 7. Plan ahead for disaggregation of results by background variables

Research indicates that gender, disability status, and ethnicity are key risk factors for discrimination (World Bank, 2011). In fact, girls with disability are two times as likely to be victims of discrimination on account of their gender and their disability status (UNICEF, 2013). While over three-quarters of studies in this review controlled for background characteristics in their analyses, few if any studies specifically conducted research to assess if and how these factors shape attitudes towards children with disabilities. From a measurement perspective, the planning process for research must involve a thorough discussion of sampling frameworks and sizes to allow for disaggregation of results further down the road. This ensures that disaggregated analyses can be done and forms a critical step in improving measures so that they are culturally and contextually appropriate. Finally, discussing disaggregation at the beginning of the research process helps generate an evidence base to fulfil equity and human rights agendas for vulnerable populations.

### 8. Take advantage of existing scales, but validate them in the field

In terms of measurement, this systematic review contained examples of studies that relied upon existing tools/scales and others where unique tools/and scales were developed. Among the studies making use of pre-existing measures of discriminatory attitudes, two scales were frequently used: CATCH and ATDP. In addition to our review, each one of these scales appeared in three of the systematic reviews and meta-analyses examining measures of attitudes towards children with disabilities.<sup>11</sup> MacMillan et al. (2013) found that the CATCH scale was reported to be the most reliable, valid, and comprehensive instrument. Similarly, Vignes et al. (2008) concluded that the CATCH scale is one of the most complete instruments they reviewed because it measures all three attitude components. A third validated tool includes the ORI scale designed specifically to measure inclusion of children with disabilities. All three scales have consistently displayed high reliability scores of >0.7 across different settings and populations. Depending on the audience, context and proposed objectives and outcomes of specific programmes, these validated scales can be

<sup>&</sup>lt;sup>11</sup> The CATCH scale was used in three studies reviewed by De Boer (2012), in five studies included in MacMillan et al. (2013), and in six studies assessed by Vignes et al. (2008). The ATDP scale was used in both articles reviewed by Cervasio (2010), in four studies assessed by MacMillan (2013), and in two studies included in Scior (2011). The ATDP scale was excluded by Vignes et al. (2008) because their review focused on measuring attitudes of children and the ATDP scale was developed for adults. On the whole, the articles included in these systematic reviews and meta-analyses differed from those included in our review; most of the articles using the CATCH or ATDP scales in these reviews and meta-analyses were published prior to 2005, the start date for our review.

recommended for use. However, it is important to recognize that these scales have been tweaked over time to meet the needs of individual studies included in the review. Therefore, before using them in the CEE/CIS region, the original versions of these tools must be adapted to the CEE/CIS context and then validated in the field before being scaled up.

#### 9. Ensure ethical standards for human subjects' research are in place

Obtaining ethical approval of research is an essential first step in ensuring the protection of children. In addition, researchers can engage children in decision-making processes during the research process in age and developmentally appropriate ways, for example, by obtaining informed assent from a child using clear, simple language, visuals whenever possible, and a teach-back approach to ensure comprehension. Informed consent from a responsible parent or guardian should also be obtained. Similarly, researchers can create opportunities for children to decide on how they would like to participate as Lindsay and McPherson (2012) did by allowing children to decide whether they felt more comfortable talking in an individual or group interview setting. Finally, researchers should consider the inclusiveness of the research methods they select to ensure hard-to-reach and hidden populations are not left out, but rather can meaningfully participate.

## 10. Involve all key stakeholders

Assessing attitudes and social norms among audiences across different levels in the socioecological model may yield interesting insights and ideas for programmatic responses. Examining parental attitudes is critical, but it is also important to remember that in many developing countries caregiving responsibilities fall on siblings, extended family members, and even communities. Best practices in research require taking steps to ensure that the communities that stand to benefit most from research and practice are in fact involved in such research (FHI 360, 2009). It is therefore essential to identity primary, secondary and tertiary audiences and gain insights into the attitudes and norms towards children with disabilities across audiences in order to holistically effect changes in prevailing discriminatory attitudes and norms.

## 11. Include the perspectives of children with disabilities

Inclusiveness should form a core requirement for all research on discriminatory attitudes and norms towards children with disabilities. Graham et al. (2013) suggest that, "the competence, dependence, and vulnerability of children should not determine their inclusion or exclusion" in research, but rather it "should inform how their participation takes place" (Graham et al., 2013, p. 14). And, as the slogan for the disability rights movement says, "Nothing for us without us." Creating and nurturing opportunities for children and adolescents with disabilities to play a more fundamental part of the design, implementation, and evaluation of programmes has to over time become integral to best practices rather than an innovation.

## 12. Draw upon participatory approaches and use mixed methods

This review indicates that only three studies involved participants in the data collection process. Using a participatory approach ensures that research hears and is guided by multiple voices across the design, analysis and dissemination stages. Participatory research methods also play a critical role in uncovering local understanding of and terminology for disability. Techniques such as free-listing and pile sorts can help generate words, phrases,

and expressions that can then be incorporated into quantitative surveys or qualitative interviews to make tools more culturally appropriate. Moreover, using these techniques in conjunction with or to follow more traditional data collection methods, can provide a rich context with which to understand and measure changes in prevailing attitudes and norms towards children with disabilities (Ulin, Robinson, & Tolley, 2005). In fact, the reliance on a mixed methods approach that combined qualitative and quantitative data for the validation of tools and/or to help with the triangulation of findings was minimal. Researchers should explore using mixed methods, whose flexibility can potentially capture a more holistic and accurate understanding of discriminatory attitudes and norms towards children with disabilities, which could generate new opportunities to bring about individual and social change (Ponterotto, Matthew, & Raughley, 2013, p.47).

## Limitations

There are inherent limitations to conducting a systematic review that are worth mentioning. First, the search strategy included only English language publications. It is possible that in circumscribing the search parameters in this way, studies from developing countries were not adequately represented. Second, the quality assessment of the studies is based on information available in the publication. Studies may have received fewer marks for specific criteria for no better reason than page and word count limitations imposed by the peerreview process. This may also explain the lack of conceptual frameworks and definitions of key terms. Third, not all studies provided the exact tool or scale used, thereby limiting our ability to statistically assess the quality of these instruments.

## Conclusion

This report tries to understand how discriminatory attitudes and social norms related to children with disabilities were being conceptualized and measured within the existing global literature and within work conducted in the CEE/CIS region. The findings of this review have been summarized into 12 key insights to guide future research. The overarching take away is perhaps the relevance of the adage "What gets measured, gets done" (Thacker, 2007).

The fulfilment of human rights and equity agendas becomes increasingly difficult, especially in low-income countries where the burden of disability is highest but research investments are lowest. The predominant focus on primary and secondary school age children means that less is understood about the experiences of younger children, adolescents transitioning into adulthood, or how discrimination manifests and affects children over the life course. The absence of standardized definitions and typologies for disabilities, conceptual frameworks grounded in theory and accompanied by clearly defined, measurable constructs, poses clear measurement challenges.

If the selection of research participants is not broadened to include a wider array of audiences and stakeholders, then shifting prevailing attitudes and norms will remain a distant goal. Further, few studies in this review include children with disabilities, meaning their voices are not being expressed or heard as much as they should. Without more experimentation with participatory and mixed methods approaches, researchers lose out on eliciting a rich context with which to understand discriminatory attitudes and norms towards children with disabilities. The review did not cull any examples of studies examining social norms and without such measures, it is difficult to forge a path for social change to occur. And, if disaggregation of data is not thought through before sampling decisions are made, then analyses by background variables cannot be undertaken and opportunities to capture critical differences and key nuances are missed.

While the adage does not directly apply to the recommendation concerning the ethics of human subjects' research, research credibility and the legitimacy of findings can be undermined if ethical safeguards for children are not put in place. In fact, it might be safe to amend the adage to say "What gets measured robustly, gets done." In other words, for evidence to guide future research and practice, it must meet the highest of standards.

As a starting point for conducting additional research in the CEE/CIS context, the authors propose adopting the ICF framework as an overarching model for research aimed at measuring discriminatory attitudes and social norms towards children with disabilities. Once the key research questions and outcomes have been identified, then the most appropriate tool for the research study can be selected. The review yielded three reliable and valid scales that researchers could and should take advantage of, but only if the scales can help answer the research questions and only if they are adapted to account for field realities (skipping over this critical step would compromise the quality of the research). The ORI scale is best suited for research examining teachers' attitudes towards inclusion. The CATCH scale is more appropriate for research examining or identifying determinants of children's attitudes or evaluating programmes designed to improve attitudes. Finally, the ATDP scale is recommended for research measuring attitudes towards individuals with disabilities as a

group from the perspectives of an able-bodied and disabled individual. While the review did come across these validated tools, it is important to recognize that these tools do not address social norms at all. Moreover, no tools or scales were identified that capture the perspectives of children with disabilities who experience discriminatory attitudes, stigma, and exclusion due to entrenched social norms.

These recommendations are tempered with caution for a couple of reasons. Programme planning, implementation and evaluation are closely interlinked processes and measurement should be guided by a fuller understanding of the inputs, outputs, and planned outcomes of programmes. Further, tool adaptation and validation through adequate pretesting, back translations, testing and re-testing of the tool is required before any broad-based tool to examine discriminatory attitudes can be proposed.

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## Appendix 1: Definitions of Key Constructs Guiding the Systematic Review

Key Constructs	Definitions
Children with disabilities	Those below the age of 18 years who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis (UN, 1990c, 2007)
Discrimination on the basis of disability	Any distinction, exclusion, restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil, or any other field" (CRPD, Article 2, 2006).
Attitudes	<ul> <li>Overall affective evaluation of the behaviour (Ajzen, 1985; Montano &amp; Kaspryzyk, 2008)</li> <li>Three types of attitudes:         <ul> <li>Affective: addresses feelings and emotional reactions</li> <li>Behavioural: relates to actual or intended behaviour</li> <li>Cognitive: beliefs and knowledge (Antonak &amp; Livneh, 2000; Vignes, Coley, Grandjean, Godeau, &amp; Arnaud, 2008, 182)</li> </ul> </li> </ul>
Socials norms	<ul> <li>Beliefs, expectations, group knowledge, and common knowledge (Bicchieri &amp; Muldoon, 2014)</li> <li>What people in some groups believe to be normal in the group, that is believe to be a typical action, an appropriate action or both (Mackie, Moneti, Shakya, &amp; Denny, 2015, 7)</li> <li>From social norms theory (Cialdini Reno, &amp; Kallgren, 1990): <ul> <li>Injunctive norms "belief about whether most people approve or disprove of the behaviour" (Montano &amp; Kasprzyk, 2008)</li> <li>Descriptive norms: belief about whether most people perform the behaviour (Montano &amp; Kasprzyk, 2008)</li> </ul> </li> </ul>
Stigma	• Stigma is considered to spoil "normal identity" with society being composed of the stigmatized group, the normals and the wise (Goffman, 1963).

## Appendix 2: Key Terms for the Systematic Review Searches

The search strategy for this systematic review identified five domains of key words: discrimination, outcomes, children, disabilities, and location. A list of equivalent key word terms was generated in order to cull the widest range of potentially relevant literature. Searches were done by combining at least one word from each category listed below. The same combinations of searches were done across the three databases to ensure the search process was systematic. The table below lists the various key words used during the search process for each of the domains.

Discrimination	Measurable Outcomes	Children	Disabilities	Location
Prejudice Stigma Segregation Exclusion Inequity Maltreatment Neglect Stereotype	Attitudes Opinions Beliefs Norms Patterns Rules Behaviours Knowledge	Youth Adolescents Young people Teenagers	Disabled Special Needs Impairment Handicapped	CEE/CIS Individual countries in CEE/CIS region Europe Central Asia Eastern Europe

## Appendix 3: Summary of Meta-Analyses and Systematic Reviews

		Sample		
Citation	Objectives	Size	Measures	Conclusions
Beelmann & Heinemann (2014)	The present meta-analysis aims to integrate existing research on the effectiveness of structured intervention programs designed to promote positive intergroup attitudes and prevent prejudice in children and adolescents— independent of the underlying theoretical concept (e.g., contact- or knowledge/ information-based, promoting individual social-cognitive competencies).	(Studies) 122	Questionnaires (Preschool Racial Attitude Measure II, Multi-racial attitude measure, Liking board, F- Scale, Peers Attitudes Toward the Handicapped Scale, Intended Behavior Measure, Knowledge of Mental Handicap), Tests, Interview and Observations	The type of instrument used for the outcome measure accounted significantly for effect-size variability, Q (df = 4) = 19.55, p <.001, with questionnaires yielding significantly higher effect sizes than test scores.
Cervasio (2010).	The research questions to be answered are: (a) What are the attitudes of senior level graduating nursing students toward children with disabilities?; (b) What are the attitudes of registered nurses toward children with disabilities?; and (c) Is there a significant attitude difference between senior level graduating nursing students and registered nurses toward children with disabilities	2	Attitudes Towards Disabled Persons scale	Few articles in general education measure the attitudes of elementary school teachers toward children with disabilities outside of the United States. It is not clear how the nursing profession evaluates student attitudes outcome as an outcome measurement of education.
De Boer, Pijl, & Minnaert (2012).	Describe students' attitudes towards peers with disabilities, which variables relate to students' attitudes, and the relationship between students' attitudes and the social participation of peers with disabilities	20	Adjective Checklist; Attitudes Toward Augmentative/ Alternative Communication; Acceptance Scale for Kindergarten—Revised; Behavior Intention Scale; Children's Attitudes Towards Integrated Physical Education—Revised; Chedoke McMaster's Attitudes Toward Children with Handicaps; Attitude Questionnaire; Multi-Response Attitude Scale; Nondisabled Peers' Acceptance Scale; Peer Attitudes Toward the Handicapped Scale; Pictorial Scale; Primary Student Survey of Handicapped Persons; Shared Activity Questionnaire-Short Form; Social Problem-Solving Test—Revised	Many studies examined one or two attitude components for which different questionnaires were used. This lack of coherence in the way that questions were presented may affect the way students' responses reflected their attitude. An instrument in which all three components are included is therefore recommended, as findings may vary according to the type of component assessed.

<b>C</b> <sup>1</sup> 11 <sup>1</sup>		Sample	<b>M</b> • <b>m</b> • <b>m</b> • <b>m</b>	Constructions
Citation	Objectives	Size (Studies)	Measures	Conclusions
Macmillan, Tarrant, Abraham, & Morris (2014)	The aim of this review was to systematically review and synthesize observational evidence of associations between children's naturally varying contact with people with disabilities and their attitudes towards disability.	35	Chedoke-McMaster Attitudes Towards Children with Handicaps, Attitudes Towards Disabled Persons scale, written vignette, post-box technique, peer-nomination methods	In total, there were 26 different measures of attitudes towards disability in this review. CATCH, used in five studies, was the most common measure. In a review of children's attitudes towards disability instruments, CATCH was reported to be the most reliable, valid, and comprehensive instrument. The heterogeneity of the studies, and in particular the variety of attitude measures, meant that a quantitative synthesis was not suitable. A common measure of attitudes would enable pooling of data across studies and meta- analysis; this would allow for stronger conclusions regarding whether contact is associated with attitudes.
Scior (2011)	<ol> <li>To what extent does the general public hold adequate knowledge about intellectual disability?</li> <li>What attitudes towards people with intellectual disabilities prevail among the public? What beliefs about the causes of intellectual disability are prevalent among the public? Have there been any changes in attitudes and beliefs over the years?</li> <li>What is the influence of socio- demographic characteristics, such as age, gender, educational attainment and prior contact with someone with intellectual disabilities, on these factors?</li> <li>What are the results of cross-cultural comparisons of attitudes and beliefs towards intellectual disability?</li> <li>Are there any studies evaluating the effects of interventions aimed at improving the public's understanding and attitudes? If so, what are their results?</li> </ol>	75	1) Questionnaires (12 item Semantic differential scale, own scale, social dominance orientation scale, Mental Retardation Attitude Inventory - Revised, Interaction with Disabled Persons scale, Social Desirability Scale, Q.Sort, Attitudes to Sexuality Questionnaire - Intellectual Disability, Attitudes questionnaire, Attitudes towards Disabled Persons Scale, Volunteering Intentions Scale, Community Attitudes towards Mental Illness Scale, Vignettes, Adjective generation technique, Semantic differential scale, Social distance Scale, Intellectual Disability Literacy Scale, Attitude to Mental Illness Questionnaire) ; 2) personal interviews; 3) telephone interviews	The evidence is dominated by attitude surveys using (mostly local) convenience samples. Some 43% of the literature reviewed is based on student samples, rendering the findings unrepresentative. While there is evidence to support the notion that explicit attitudes predict future behaviour, this relationship is strongest with non-student samples, and where self-report measures of behaviour are used, factors that were not addressed in most of the studies reviewed. Furthermore, responses were mostly measured to a hypothetical individual, while responses to individuals with whom the respondent has had naturalistic contact were less frequently assessed. While some studies drew upon contact theory, very little of the research tested any theoretical model. Moreover, few studies considered the complex processes involved in the formation of stigma, prejudices, and discrimination.
Vignes et al. (2008)	This study aimed to identify instruments for measuring children's attitudes towards their peers with disabilities that are suitable for use in epidemiological studies	19	Acceptance scale, Activity Preference List, Adjective Checklist, Attitudes Scale, Attitude Towards Chronically Disabled Patients	Only three instruments, the Adjective Checklist (ACL), Activity Preference List, and Chedoke- McMaster Attitudes Towards Children with Handicaps Scale (CATCH) have been used in

Citation	Objectives	Sample Size (Studies)	Measures	Conclusions
	and to report on their psychometric properties.		Questionnaire, Behavioral Intention Scale, Chedoke-McMaster Attitudes Towards Children with Handicaps Scale, Children's Attitude Toward Handicapped Scale, Children's Knowledge about Handicapped Persons Scale, Children's Social Distance from Handicapped Persons Scale, Emotional Reaction Scale, Semantic Differential Scale, Social Distance Scale, Foley Scale, Friendship Activity Scale, Multi- Response Attitude Scale, Peer Attitudes Towards the Handicapped Scale, Personal Attribute Inventory for Children, Shared Activities Questionnaire	a country with a language other than the one they were developed in. Stages of development and validation were reported only for three instruments (CATCH, Acceptance Scale, Personal Attribute Inventory for Children). Development of other instruments has occasionally been presented in books (PATHS, ACL) or unpublished manuscripts (ACL, Activity Preference List; SAQ) . For the remaining instruments, the validation process was not specifically explained. Of the 19 instruments matching the current study's inclusion criteria, only two (CATCH and Acceptance Scale) measured all three attitude components simultaneously. Measurement instruments need to be acceptable to respondents in terms of cultural considerations. All except one of the instruments (Attitude Towards Chronically Disabled Patients Questionnaire) were developed in English, and nearly all of the research studies using these instruments have been carried out in English-speaking countries. The Acceptance Scale and CATCH are the most complete instruments. This does not mean that all other survey instruments are unsatisfactory, as the choice of the most appropriate instrument depends on specific research objectives.

## Appendix 4: Coding Matrix and Quality Assessment Tool

The coding matrix and assessment of quality was adapted from Sirriyeh, Lawton, and Garner (2011) and is outlined below. This tool was chosen because it allowed quality assessment for quantitative, qualitative and mixed method studies. The tool also had good face validity, inter-rater reliability adequate test-retest reliability.

ltem	Coding Category	Description
1.	Citation	Full citation APA style
2.	Type of manuscript	Peer Review Journal Article, Report
3.	Conceptual/Theoretical Frameworks	Theory of change is outlined and applied to examine the key components
4.	Statement of aims/objectives	Description on why the manuscript was written and its contribution to literature is provided.
5.	Definitions of key terms	Definitions of the key terms corresponding to the four key components in the desk review are defined. The outcome is defined and identified.
6.	Description of the research setting	Where is the research is being conducted and primary audience is identified
7.	Sample size consideration in the analysis	How was the sample size calculated? For quantitative studies, power analysis is provided; for qualitative studies enough individuals to reach saturation.
8.	Representative sample of primary audience	Is the sample representative to make inferences and generalization? i.e. different ages, sex, villages?
9.	Description of procedure for data collection	Detailed description of when, where and how the data was collected is outlined.
10.	Rationale for choice of data collection tools	Description on why data collection tools were selected? Were they created? Were they validated and reliable existing scales?
11.	Detailed recruitment data	Method of recruitment (sampling frame), number of people approached, number of people recruited, number of people dropped out.
12.	Outcome Measures - Description	Details on how the outcome is being measured. The outcome is operationalized based on the definition.
13.	Statistical assessment of reliability of measurement tool (quantitative only)	How is reliability tested: test-retest, internal consistency or inter-rater reliability? Cronbach's alphas for scale measures
14.	Statistical assessment of validity of measurement tool (quantitative only)	How is content, construct (concurrent, convergent and discriminative, criterion), predictive validity established?
15.	Fit between stated research and method of data collection (quantitative only)	Method of data collection (Descriptive (case, observational), Correlational (case-control), Quasi-Experimental (field experiment), Experimental (random assignment), Review) is the most suitable approach to answer research question.
16.	Fit between research question and format and content of data collection tool (qualitative only)	Does the structure and content of data collection allow for the research question to be answered?
17.	Fit between research question and method of analysis	Method of analysis most suitable to answer the research question. Are important confounders and mediators controlled for?
18.	Good justification for analytical method selected	Detailed explanation on why an analytical method was selected.
19.	Assessment of reliability of analytical process	Use of range of methods to assess reliability of results. Is inter-rater reliability established and more than one researcher analysing the transcripts? (qualitative); is the data comparable to other studies in the region? (quantitative)
20.	Strengths, limitations critically assessed	Discussion of strengths and limitations of all aspects of study design, measures, procedure, sample and analysis.
21.	Recommendations	Authors provide specific recommendations for improvement of measures?
22.	Evidence of primary audience involvement	Were participants/community representatives included in the design, data collection or evaluation phase?

Each manuscript will be given a rank of low, medium or high based on specific criteria outlined above

The assessment criteria looked at conceptual/theoretical frame; statement of aims/objectives; definitions of key terms; description of research setting; sample size consideration; representative sample of primary audience; description of procedure for data collection; rationale for choice of data collection tools; detailed recruitment data; outcome measures description; statistical assessment of reliability of measurement tool; statistical assessment of validity of measurement tool; fit between stated research and method of data collection; fit between research question and format and content of data collection tool; fit between research question and method of analysis; good justification for analytical method selected; assessment of reliability of analytical process; strengths, limitations critically assessed; recommendations and lastly as a bonus criteria, evidence of primary audience involvement (items 3-21). A numerical number was assigned for each item. 0 was given if the outlined "coding category" was not mentioned, 1 was given if it was suggested/partially mentioned and 2 if all the elements in the "description" were outlined. If the study design was participatory, bonus points from 0 - 2 were provided for that study. For guantitative studies, there were a total of 18 items, which gave a maximum score of 36. For gualitative studies, there were a total of 16 items, which gave a maximum score of 32. For mixed method studies, there were a total of 19 items, which gave a maximum score of 38. To compare the different types of studies, all scores were converted into percentages. A percentage of 85 – 100% was considered 'high', 70 – 84% was considered 'medium' and 69% and below was considered 'low'.

To ensure reliability of the quality assessment scores, double coding was conducted on a subset of the articles. The lead author coded the entire database. The second author independently coded 20 percent of the databases to ensure inter-rater reliability. Differences in coding were discussed and any challenges with the quality assessment tool itself were also discussed.

## Appendix 5: Summary of Studies from the CEE/CIS Region

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Criteria			Individual Studies from the	CEE/CIS Region	
Citation	Pejovic-Milovancevic, M., Lecic-Tosevski, D., Tenjovic, L., Popovic- Deusic, S., & Draganic- Gajic, S. (2009). Changing Attitudes of High School Students Towards Peers with Mental Health Problem. <i>Psychiatria Danubina</i> , 21(2), 213–219. doi:10.1111/j.1744- 6163.1968.tb01043.x	Tabakhmelashvili, T. (2008). Regular teachers 'attitudes towards inclusion of students with special needs into ordinary schools in Tbilisi. University of Oslo, Norway.	Özer, D., Nalbant, S., Ağlamış, E., Baran, F., Kaya Samut, P., Aktop, A., & Hutzler, Y. (2013). Physical education teachers' attitudes towards children with intellectual disability: the impact of time in service, gender, and previous acquaintance. Journal of Intellectual Disability Research, 57(11), 1001- 1013. doi: 10.1111/j.1365- 2788.2012.01596.x	Hirfanoglu, T., Serdaroglu, A., Cansu, A., Soysal, A. S., Derle, E., & Gucuyener, K. (2009). Do knowledge of, perception of, and attitudes toward epilepsy affect the quality of life of Turkish children with epilepsy and their parents? Epilepsy and Behavior, 14(1), 71–77. doi:10.1016/j.yebeh.2008.08.011	Özer, D., Baran, F., Aktop, A., Nalbant, S., Ağlamış, E., & Hutzler, Y. (2012). Effects of a Special Olympics Unified Sports soccer program on psycho-social attributes of youth with and without intellectual disability. Research in developmental disabilities, 33(1), 229- 239.doi:10.1016/j.ridd.2011.09.011
Туре	Peer Review	Dissertation	Peer Review	Peer Review	Peer Review
Location	Serbia	Georgia	Turkey	Turkey	Turkey
Aims and Objectives	An anti-stigma program was initiated in schools with the aim to address and decrease discrimination of adolescents with mental disorders.	The study aimed to investigate the attitudes of teachers with and without experience in inclusive education, towards the inclusion of students with special needs into regular schools in Tbilisi. In addition, teachers' attitudes in relation to gender, teaching experience, teachers' educational background and school and class size was measured.	The purpose of this study was to investigate attitudes towards teaching students with intellectual disabilities(ID) within a representative sample of secondary school Physical Education (PE) teachers, and to determine the effects of age, gender, teaching experience, and having acquaintance with ID and students with ID on attitudes.	The primary objectives of this study were, first, to evaluate knowledge of, perception of, and attitudes toward epilepsy and, second, to correlate this information with quality of life and stigma among children with epilepsy and their families.	The purpose of this study was to investigate the effects of a Special Olympics (SO) Unified Sports (UNS) soccer program on psycho-social attributes of youth with and without intellectual disabilities (ID).
Theoretical/ Conceptual Framework	Social Stigma Theory of Planned Behaviour	Theory of Planned Behaviour	Theory of Planned Behaviour	None outlined	Theory of Planned Behaviour Contact Theory

Research Design	Quasi experimental one group pre-post design.	Cross-sectional survey of teachers and representatives from Ministry of education and science.	Cross-Sectional survey	Cross-sectional survey	Pre-and post-test with randomization
Type of Study	Quantitative	Mixed Methods	Quantitative	Quantitative	Quantitative
Sample Size and Frame	63 students in 2 schools. No additional information on sampling frame	The study involved teachers in all public schools in Tbilisi, Georgia. Sample included 298 participants. In addition, 2 inclusion specialists were interviewed.	PE teachers across 81 cities in Turkey. Minimum calculated sample size required was 367. The study included 729 respondents, 515 men and 214 women.	220 children with epilepsy (between 8 and 17 years of age) and their parents (n = 313). Patients with epilepsy (having at least two unprovoked seizures) diagnosed by a paediatric neurologist and regularly followed in the hospital's paediatric neurology department were included in the study.	A special education school and a secondary school from a large urban community in Turkey. A total of 76 students were selected (38 had ID and 38 had no ID).
Measures	The Opinion about Mental Illness Questionnaire (OMI) (Struening & Cohen 1963) was administered to the young to fill in prior to the workshops and six months after the program. OMI is composed of 51 Likert- type opinion items "referent to the cause, description, treatment, and prognosis of severe mental illness". The factor scores on the five dimensions of attitude toward the mentally ill can be derived from the responses to the following items: Authoritarianism, Benevolence, Mental Hygiene Ideology,	Questionnaire with two parts: 1) demographic variables of the respondents and the characteristics of the schools in which they teach; 2) Items on teachers' opinions about inclusion of children with special needs. (Chronbach's Alpha was 0.85) Formal or structured interview guides with 10 items were constructed for two inclusive education specialists at the Ministry of Education and Science focusing on the general situation and tendencies regarding	Teachers Attitudes towards Children with Intellectual Disability Scale (TACIDS), developed in Turkey for preschool teachers, classroom teachers, and pre-service teachers (Sucuogulu et al., 1997). The TACIDS consists of two basic parts. The first part has 39 items (22 positive and 17 negative) with a five-point strongly agree to strongly disagree statements. Factor analysis found seven factors accounting for 58.3% of variance. Factor 1 'social effects' eight items (Cronbach's alpha = 0.88). Factor 2 'feelings' three items (Cronbach's alpha = 0.83).	Attitudes: Children were asked if they were concerned over having seizures, if they felt sad after seizures, how did they cope with seizures, did they take their drugs regularly or forget to take medicine, and what were their beliefs on healing. Perception: Children were asked whether they felt others acted compassionately or cruelly toward them, whether they believed epilepsy is a shameful condition, whether they felt bothered by the difficulty they face in their daily activities, and whether they felt restricted from joining social activities. Attitudes and perceptions were only measured in children not parents. Cronbach's alpha coefficient was assessed to estimate internal consistency reliability,	A Friendship Activity Scale (FAS) was developed based on theories of social cognition concerning the development of friendship (Siperstein & Bak, 1985). It has two forms: the original version of the FAS consisted of 17 items and the revised version of 10 items. Items include a four-point scale indicating whether they would (4), probably would (3), probably would not (2), or would not (1) include the child attributed in the listed activity. The Turkish version of the 17-item FAS was developed by Nalbant, Aktop, Ozer, and Hutzler (2011) had an acceptable internal consistency reliability (Cronbach's alpha) of .86 The ACL developed by Siperstein (1980), designed to assess children's attitudes by asking their judgment of the attributes of a new peer (with ID, about

Soc Inte	cial Restriction and erpersonal Etiology.	inclusive education in Georgia	Factor 3 'educational rights' four items (Cronbach's alpha = 0.62). Factor 4 'interaction between children' four items (Cronbach's alpha = 0.65). Factor 5 was labelled 'supporting services' four items (Cronbach's alpha = 0.59). Factor 6 'difficulties' two items (Cronbach's alpha = 0.63). Factor 7 'barriers' two items (Cronbach's alpha = 0.47). Cronbach's alpha for the total scale = 0.84.	which was determined to be 0.92. Test-retest reliability was good as reflected by K values of 0.69 for children. Predictive validity was assessed which demonstrated that feeling stigmatization was statistically associated with increase in negative perception (r=0.20), perceived lack of social support (r=0.27, decreased knowledge (r=- 0.18); negative perception significantly associated with poor school performance (0.35), depression (r=0.3), lower self-esteem (-0.18); negative attitude significantly associated with poor school performance (r=0.39), depression (r=0.45), perceived lack of social support (r=0.32) and lower self-esteem (-0.03).	whom they are given a short description) (Manetti, Schneider, & Siperstein, 2001). This instrument includes 34 items scored on a dichotomic scale as positive (e.g., ''proud'', ''happy'') and negative (e.g., ''careless'', ''ugly'') adjectives that are equally represented in the Checklist. The summary score of the ACL is the total of the positive adjectives minus the total of the negative adjectives, plus a constant of 20 (in order to avoid multiplying negative numbers in some statistical procedures). A summary score above 20 indicates relatively positive impressions, whereas a summary score below 20 indicates negative impressions.
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## Appendix 6: Studies by Disability and Population Focus

The first table groups studies by disability focus and provides citations for each grouping.

Disability Focus		# of Articles	Citation
Α	ll types	3	Dupoux et al. (2006); Santiago et al. (2016); Vignes et al. (2009)
In	tellectual	16	
	Only intellectual disability	10	Barned (2009); Chen & Shu (2012); Mavropoulou & Sideridis (2014); Orta (2016); Ozer et al. (2012); Ozer et al. (2013); Pejovic- Milovancevic et al. (2009); Ranson & Byrne (2014); Shalev et al. (2016); Siperstein et al. (2007)
	Combined: Intellectual and another disability	6	Cameron & Rutland (2006); Crothers et al. (2007); De Boer et al. (2014); Godeau et al. (2010); Laws & Kelly (2005); Nowicki (2006)
Pł	nysical	12	
	Only physical disability	5	Hirfanoglu et al. (2009); Hutzler et al. (2007); Lindsay & McPherson (2012); Nabors & Lehmkuhl (2005); Zanni et al. (2012)
	Combined: Physical and another disability	7	Cameron & Rutland (2006); Crothers et al. (2007); De Boer et al. (2014); Godeau et al. (2010); Laws & Kelly (2005); Matziou et al. (2009); Nowicki (2006)
Mental Health Disorders		8	Anastasiadou (2016); Bell et al. (2011); Elkington et al. (2011); Heflinger et al. (2014); Huang (2006); Matziou et al. (2009); Moses (2010); O'Driscoll et al. (2012)
Auditory/Visual/ Speech Impairments		3	Olaleye et al. (2012); Reina et al. (2011); Wanjiru (2014)
Not specified		9	Agbenyega (2007); Bossaert & Petry (2013); Dupoux et al. (2005); Han et al. (2012); Hutzler et al. (2005); Momberg (2008); Omoniyi (2014); Tabakhmelashvili (2008); Xafopoulos et al. (2009)

The second table separates studies by age group and provides citations for each grouping.

Age Group	# of Articles	Citation
Children less than two years of age	0	
Preschool children (3-5 years)	2	Nabor & Lahmkuhl (2005); Nowicki (2006)
Primary school age (6-12 years)	3	Cameron & Rutland (2006); Laws & Kelly (2005); Mavropoulou & Sideridis (2014)
Secondary school age (13-18)	16	Agbenyega (2007); Chen & Shu (2012); Bossaert & Petry (2013); Elkington et al. (2011); Godeau et al. (2010); Han et al. (2012); Huang (2006); Hutzler et al. (2007) Pejovic- Milovancevic et al. (2009); Olaleye et al. (2012); Orta (2016); Ozer et al. (2012); Ozer et al. (2013); Ranson & Byrne (2014); Shalev et al. (2016); Vignes et al. (2009)
Primary and secondary school age children (6-18 years)	12	Anastasiadou (2016); Crothers et al. (2007); Dupoux et al. (2006); Dupoux et al. (2005); Hirfanoglu et al. (2009); Lindsay & McPherson (2012); Moses (2010); O'Driscoll et al. (2012); Reina et al. (2011) Santiago et al. (2016); Siperstein et al. (2007); Xafopoulos et al. (2009)
Preschool and primary school age children (3-12 years)	3	De Boer et al. (2014); Momberg (2008); Wanjiru (2014)
All ages (0-18 years)	1	Heflinger et al. (2014)
Not specified	7	Barned (2009); Bell et al. (2011); Hutzler et al. (2005); Matziou et al. (2009); Omoniyi (2014); Tabakhmelashvili (2008); Zanni et al. (2012)

## Appendix 7: An Annotated Bibliography of High Quality Studies

Three "high quality" publications came out of the quality assessment. A summary of each study along with its quality assessment score is provided below.

Publication Title	Score
Perceived mental illness stigma among youth in psychiatric outpatient treatment	90.6%
Physical education teachers' attitudes towards children with intellectual disability: The impact of time in service, gender, and previous acquaintance	88.9%
A National Study of Youth Attitudes Toward the Inclusion of Students With Intellectual Disabilities	86.1%

## Perceived mental illness stigma among youth in psychiatric outpatient treatment

This qualitative study explored the experiences of mental illness stigma among 24 youth (75% Latino) in psychiatric outpatient treatment in the US. The authors used Goffman's definition of stigma in conjunction with Link and Phelan's model of stigmatization which describes the implementation of overt (individual level) and institutional (structural level) practices of discrimination, as well as the response of the stigmatized individual as part of the discrimination process (social-psychological processes). This theoretical understanding of stigma guided the development and analysis of the individual interviews. Youth reported experiences of stigma within their families and social networks. Almost all youth mentioned that society perceives and labels individuals with mental illness as different. Individual experiences of stigma were characterized by rejection by others and changes in relationships. Acknowledgement of societal stigma and individual-level experiences appeared to take a toll on youth. Youth explicitly described internalized stigma and shame, underscoring how labelling influences individuals' self-concept and the strategies used to manage a stigmatized identity. The findings support the application of Link and Phelan's theoretical model of stigma, even though no evidence of structural discrimination emerged from this sample. The results also suggest using a multi-level approach to address stigma at the individual, family, and community levels.

**Citation**: Elkington, K. S., Hackler, D., McKinnon, K., Borges, C., Wright, E. R., & Wainberg, M. L. (2011). Perceived mental illness stigma among youth in psychiatric outpatient treatment. *Journal of Adolescent Research*, 27(2), doi: 0743558411409931.

# Physical education teachers' attitudes towards children with intellectual disability: the impact of time in service, gender, and previous acquaintance

This study investigated the attitudes of secondary school physical education (PE) teachers in Turkey towards teaching students with intellectual disability (ID) and sought to determine the effects of age, gender, teaching experiences, and acquaintance with ID and students with ID on their attitudes. This authors used Ajzen and Fishbein's definition of attitudes and argued that positive attitudes are needed for inclusion to be successful. A

total of 729 secondary school PE teachers working in 81 cities in Turkey completed the Teachers Attitudes towards Children with Intellectual Disability Scale by mail. The authors hypothesized that female PE teachers, young PE teachers, PE teachers with less teaching experience, and PE teachers who know of ID and have a student with ID in their present class would have more positive attitude scores. The results revealed that both male and female teachers had similar attitude scores. Both younger PE teachers and those with less teaching experience had more favourable attitudes towards inclusion. This may be due to recent changes to PE training curriculums, which now include an obligatory course on adaptive physical activity. Those who knew someone with ID also had more favourable attitudes towards inclusion than their counterparts. The hypothesis that having a student with ID in the class would lead to higher attitude scores, however, was not supported. The authors advocate for in-service education programmes and practicum experiences to build teachers' skills and self-efficacy to adapt their teaching for inclusion. In terms of measurement, the general reliability of the tool was high, but the internal consistency was low. The authors suggest revising the tool to improve the internal consistency.

**Citation**: Özer, D., Nalbant, S., Ağlamış, E., Baran, F., Kaya Samut, P., Aktop, A., & Hutzler, Y. (2013). Physical education teachers' attitudes towards children with intellectual disability: the impact of time in service, gender, and previous acquaintance. *Journal of Intellectual Disability Research*, *57*(11), 1001-1013. doi: 10.1111/j.1365-2788.2012.01596.x

## A National Study of Youth Attitudes Toward the Inclusion of Students With Intellectual Disabilities

This study described a national survey of 5,837 US middle school students to gauge their attitudes towards the inclusion of peers with ID. The authors conceptualized youths' attitudes in terms of their image of a student with ID, their intentions to interact with a student with ID, their expectations for inclusions, and whether they believed students with ID can take part in academic and non-academic classes. The authors hypothesized that contact with and exposure to individuals with ID would influence how youth view their peers with ID; youths' perceptions of the competence of students with ID would influence their belief about whether students with ID should be in classes with them and their willingness to interact with those students; and youths' expectations about the ways that inclusion could affect them personally would influence their beliefs about inclusion. Findings indicated that youth have limited contact with students with ID; perceive them as moderately impaired rather than mildly impaired; view inclusion as having positive and negative effects; and do not want to interact socially with a peer with ID, particularly outside of school. Structural equation modelling showed youths' perceptions of the competence of ID students is a pivotal factor in their willingness to interact with these students and their support of inclusion. The results suggest that attitudes can change, but effort, creativity, and commitment are necessary to facilitate positive attitudes. Finding ways for youth to witness the competence of people with ID would go a long way toward fostering positive attitudes. It is also important to remember that attitudes are complex and thus future studies should use multiple measure of attitudes.

**Citation**: Siperstein, G. N., Parker, R. C., Bardon, J. N., & Widaman, K. F. (2007). A National Study of Youth Attitudes Toward the Inclusion of Students With Intellectual Disabilities. *Exceptional Children*, 73(4), 435–455. doi:10.1177/0014402907073004

## Appendix 8: Three Most Common Existing Scales to Measure Attitudes

This table provides a summary of the three most common existing scales used to measure attitudes.

Name of Scale (# and % of sample)	Description of the tool	Citations	Location and Sample	Internal Consistency and Reliability
Chedoke- McMaster Attitudes	The CATCH scale consists of 36 items and uses a 5-point Likert scale (0 denoting strongly disagree and 4 denoting strongly agree). The scale is divided into three sets of 12	Bossaert & Petry (2013)	Students 10 – 15 years old in Flanders, Belgium (n = 2522)	Cronbach's alpha of 0.9. In addition, internal consistency of affective, behavioural and cognitive subscales as 0.77, 0.84 and 0.68 respectively
towards Children with Handicaps Scale (CAICH)	items covering the affective, behavioural and cognitive components of attitudes. One half of the items are positively worded and the other half are negatively worded. These items are arranged at random with	Godeau et al. (2010)	All secondary schools with Special Education Units in Haute-Garonne County, Southwest France (n=6).	Translation, pretesting and Factor analysis of CATCH scale
(4 articles	alternating positively and negatively worded items. Higher scores on CATCH indicate more positive attitudes	Olaleye et al. (2012)	Secondary school students in Osun State Nigeria (n = 118)	Cronbach's alpha of 0.83
[9.0%]) towards peers with disabilities.		Vignes et al. (2009)	7 <sup>th</sup> grade students (12-13 years) in Toulouse area of France	
Attitude Toward Disabled	The ATDP scale includes 20 items and uses a 6-point Likert scale. Responses range from +3 (I agree very much) to -3 (I disagree very much and does not include a neutral	Matziou et al. (2009)	Students and paediatric nurse professionals in Greece	Split half reliability and test re-test reliability ranging from 0.75 – 0.85 and 0.66 – 0.89
Person Scale (ATDP) 3 (6.8%)	point. A composite score from 0 to 180 is calculated. A high score indicates that the respondent perceives disabled persons as being not very different from non-	Orta (2016)	High school students (18 year olds) in the United States	Internal consistency of 0.82
	disabled persons (Yuker, Block, & Younng, 1970).	Santiago, Lee, & Roper (2015)	Undergraduate kinesiology students in the United States	Internal consistency ranging from 0.76 – 0.82
Opinions	The ORI scale consists of 25 items with positive and negative statements (Antonak & Larrivee, 1995). The responses are on a 6-point Likert scale ranging from ±3	Dupoux, Wolman, & Estrada (2005)	High school teachers in Port au Prince, Haiti (n = 152) and South East Florida in the US (n = 216)	Cronbach's alpha of 0.90 and 0.67
Relative to Integration (ORI) 3 (6.8%)	(agree very much) to -3 (disagree very much). The scale measures teachers' attitudes towards mainstreaming children with disabilities in classrooms. Higher scores indicate more favourable attitudes.	Dupoux, Hammond, Ingalls, & Wolman (2006)	Elementary and secondary school teachers in Haiti (n = 183)	Split half reliability and showed a Spearman-Brown coefficient of 0.68
		Han (2012)	Pre-service teachers in Korea and United States	Cronbach's alpha of 0.76

## Appendix 9: Unique Quantitative Scales to Measure Attitudes

This table summarizes the three unique quantitative scales created to measure attitudes.

Citation	Research Objectives	Sample and Location	Validity	Description of Tool	Internal Consistency /Reliability
Hirfanoglu et al. (2009)	Evaluate knowledge, perceptions and attitudes toward epilepsy and correlations with quality of life and stigma among children with epilepsy and their families.	8 – 17 year old children with epilepsy and their parents in Turkey (n = 220 children and 330 parents)	Predictive validity: Significant associations of stigma with lack of/negative knowledge, perceptions and social support and relationship with poor school performance	To measure attitudes, children were asked if they were concerned over having seizures, if they felt sad after seizures, how did they cope with seizures, did they take their drugs regularly or forget to take medicine, and what were their beliefs on healing. To measure perception, children were asked whether they felt others acted compassionately or cruelly toward them, whether they believed epilepsy is a shameful condition, whether they felt bothered by the difficulty they face in their daily activities, and whether they felt restricted from joining social activities. Attitudes and perceptions only measured in children not parents	Cronbach's alpha and split half
Momberg (2008)	Identify factors that influence Egyptian teachers' attitudes towards and acceptance of inclusive education.	Teachers in Cairo and Alexandria in Egypt (n = 270)	Principal component analysis using varimax rotation, with 4 factors, with factor loadings of > 0.5	Thirty-one questions dealt with barriers that might prevent a teacher from accommodating a student with special educational needs within a truly inclusive school. Issues such as funding, structural constraints, training, and support and teacher efficacy were discussed. A modified 4- point Likert scale was used as it was felt that it was not in our interest to assign the weight of 3 points to someone who is undecided. Respondents were asked to indicate to what extent they agreed with given statements. Each statement was scored from "strongly disagree" to "strongly agree".	reliability ranged between 0.71 – 0.92 across these populations and settings
Wanjiru (2014)	To establish relationships between parental background characteristics with attitudes towards their children who are hearing impaired.	Parents of deaf children in nursery through third grade in Githunguri district in Kenya (n = 65)	Content validity: By providing supervisors with the instrument to assess if they measured the objectives of the study	A 30 item Likert scale was created which comprised of parent's beliefs about hearing impairment, feelings and actions or the way they treat the children with hearing impairment. The scale covered attitudes about myths, caretaking, feelings and emotions, self-efficacy and behaviours towards their hearing-impaired child.	

## Appendix 10: Qualitative Studies Measuring Attitudes

This table summarizes the five qualitative studies that developed their own tools to measure attitudes.

Citation	Objectives	Location and Sample	Description of Tool
Chen & Shu (2012)	To gain an understanding of the experience and process of stigmatization	Special Education program for grades 10 – 12 at a senior high vocational school in Eastern Taiwan (n = 17)	<ul> <li>Interviews were conducted to assess stigmatization. A grounded theory approach was used to elicit information on stigmatization focusing on three areas:</li> <li>The participants' experiences of stigmatization in school. Examples of the questions asked include: Whom were you teased by in school or out of school? Who laughed at you? Who bullied you in school? Who are your friends in school? How did somebody bully you? When did you feel shamed in school? When did you feel embarrassed? What makes you feel shamed? When did you feel at ease in school?</li> <li>The participants' own views of the stigmatizing treatment they received in school. Example questions include: Why did somebody laugh at you in school? How did you feel when somebody bullied you?</li> <li>The participants' personal responses to the stigmatization they experienced; for example, they were asked: How did you face a shameful situation? What methods did you use when faced with an embarrassing situation? What did you do after somebody bullied you? Who helped you when somebody bullied you? Did you talk to someone after a bad experience? What can make you feel at ease in school? What did you do with your friends?</li> </ul>
Elkington et al. (2012)	To understand the experiences of mental illness-related stigma	Adolescents and emerging adults attending four community mental health clinics providing multidisciplinary psychiatric care and support services for youth or young adults with mental illness in New York City (n = 24)	<ul> <li>Interviews were conducted to assess stigmatization using Link and Phelan's model of stigmatization. Interviews began by building rapport and by asking participants to describe themselves, their families, friends, and schools/communities. Questions included:</li> <li>Description of beginning psychiatric treatment for the first time and their current attitude toward treatment (e.g., "What was it like when you first started receiving treatment in this clinic or a clinic like this one?").</li> <li>Experiences of stigma at the individual level, including experiences of discrimination and rejection by peers, romantic partners, and family members (e.g., "You've just described some of the people in your life. I'm wondering if anyone acted differently toward you, either in a good or bad way, after you began receiving treatment in this clinic?"),</li> <li>Structural level questions such as separation from mainstream groups at school; denial of club or group membership (e.g., "After beginning treatment, some people have said this changed. What about you?").</li> <li>Participants' social-psychological processes related to stigma, such as self-devaluation, poor self-concept, coping mechanisms (e.g., "Sometimes when people go to a clinic like this one it affects how they feel about themselves. What do you think changes and why might they think that? What about you?" "We've talked about experiences where people treated you differently since you began treatment. What do you do to manage these experiences?".</li> </ul>

Citation	Objectives	Location and Sample	Description of Tool
Huang (2006)	To measure perceptions of mothers with children with mild-moderate mental retardation as their children enter into their teenage years	Mothers of young teenagers age 13 - 15 years with mild-moderate mental retardation in Taipei, Taiwan (n = 10)	Interviews consisted of 20 questions, six of which asked for basic information. The rest assessed perceptions of mothers who had children with disabilities. In particular, questions focused on: 1) education; 2) community perception; 3) husband's perceptions and family life; and 4) perceptions before and after having a child with disability.
Lindsay & McPherson, 2012;	To study the experiences of bullying and social exclusion of children and youth with cerebral palsy?	Children and youth diagnosed with cerebral palsy between the of 8– 19 years who currently attend an integrated classroom in a large urban paediatric rehabilitation centre in Ontario, Canada (n = 15 in-depth interviews and 1 FGD with 6 participants).	Questions asked in both focus group and one-on-one interview settings include: 1) Do you feel that you belong with other kids? If so, can you give an example?; 2) Has somebody who you think is your friend bullied and/or excluded you?; 3) Has anyone ever made fun of you or made you feel bad?; 4) What are your experiences of being bullied and/or excluded (e.g., where bullying occurs and under what circumstances)?; and 5) Is there anything else that you would like to add that you did not get a chance to talk about?
Moses, 2010	Study adolescents' perceptions of being treated 'differently' because of mental health problems by family members, peers, and school staff.	Adolescent clients (ages 12–18 years) of a mental health wraparound program in a mid-sized mid-western American city (n = 60)	In individual interviews, participants were asked the following open-ended questions to understand mental illness stigma: "How do you feel other people in your life who know that you are getting treatment for emotional or behaviour issues treat you?" Next, youth were asked to specifically comment on any perception of being treated differently by family, peers and friends, and teachers/ school staff. The following probes were used: 1) Do you feel [family/ peers/school staff] treat you any differently than they used to before you started treatment? and 2) Do you feel that others treat you differently in comparison to (a) your siblings (in the family), (b) other kids?