
Desk Review for Developing Measures on Discriminatory Attitudes and Social Norms towards Children with Disabilities in Europe and Central Asia region

July 31, 2018

The desk review was conducted by Drexel University and the UNICEF Europe and Central Asia Regional Office. It is 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).

This package of materials would not be possible without the overall guidance and technical contributions of UNICEF Regional Office for Europe and Central Asia staff and UNICEF North Macedonia staff including:

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Thanks to Drexel Research Assistants Priyanka Padidam, Astha Ramaiya, Jenny Samuel, Snigdha Velugu, and Farren Rodrigues for their assistance with background research and data analysis.

Additionally, thanks to disability experts Dr. Paula Frederica Hunt, Dr. Judith Hollenweger Haskell, and Ms. Sheena Bell for providing inputs to improve the appropriateness and relevance of the tools from the disability perspective.

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Introduction

UNICEF's commitment to addressing the rights of children with disabilities has evolved significantly over recent decades. While children with disabilities have the same rights as all other children, they are often subject to severe discrimination, prejudice, segregation, and exclusion from all aspects of social life. Article 8 of the UN Convention on the Rights of Persons with Disabilities (CRPD), adopted in 2006 and ratified by more than 150 countries, requires States Parties to adopt immediate, effective, and appropriate measures to raise awareness throughout society and to combat stereotypes, prejudices, and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life. In Europe & Central Asia (ECA), there could be as many as 5.1 million children living with disabilities, of which 3.6 million are not counted in social registers. As a result, they are often invisible, kept out of school and out of the public eye. This region also has one of the highest rates in the world of institutionalization or placement of children with disabilities in alternative care without appropriate support.

In 2015, Drexel University undertook a Systematic Review and Assessment of Approaches to Research and Data Gathering on Knowledge, Attitudes, and Practices (KAP) related to children with disabilities in ECA with a focus on social norms. The findings of that study drew attention to the need for more rigorous research protocols and a set of data collection tools to robustly measure attitudes and norms around children with disabilities.

With this consultancy, Drexel University aims to fill the existing research gap by developing an M&E framework to track and assess the results of interventions aiming to change discriminatory attitudes and social norms towards children with disabilities in the ECA region.

The M&E framework will be based on a conceptual model developed by the Drexel team in collaboration with UNICEF ECA colleagues and will inform the design of data collection tools. A pilot study will serve to test and validate these three components (See *Figure 1* for a definition of pilot studies). The UNICEF ECA Regional Office (ECARO) has identified **the Republic of North Macedonia as a validation site** for this pilot study. The Drexel team will focus on examining how attitudes and social norms lead to social exclusion, manifested as exclusion at home, exclusion at school, and institutionalization. Since stigma can be conceptualized as an intermediate variable that leads to differential treatment of children with disabilities, stigma needs to be treated as an attitude and measured. Data from the pilot study will feed back into the conceptual model and M&E framework.

Pilot studies

“are preparatory studies designed to test the performance characteristics and capabilities of study designs, measures, procedures, recruitment criteria, and operational strategies that are under consideration for use in a subsequent, often larger, study”
(Moore, Carter, Nietert, & Stewart, 2011).

Figure 1: Defining a Pilot Study

The first step of this project involves conducting a **guided and strategic desk review** of key documents, with an emphasis on UNICEF-sponsored disability research and communication programming in the pilot country.

Desk Review Methodology

This desk review is divided into two parts. **Section 1 is a summary of key findings and recommendations from the systematic review Drexel undertook in 2015**, as it applies to this current work. There were three reports for that systematic review: a review of 44 global, peer-reviewed, public studies evaluating norms attitudes related to children with disabilities; a review of 18 reports on UNICEF-sponsored research in ECARO countries; and recommendations for theorizing and future research based on the first two reviews. Drexel reviewed these reports to extract findings relevant to the development of this pilot study.

Section 2 aims to understand the Macedonian context where this pilot study will take place. For this, Drexel reviewed a total of 25 resources shared by UNICEF ECARO and the UNICEF country office or available on the country office website (www.unicef.mk).

Section 1: Systematic Review and Assessment of Approaches to Research and Data Gathering on KAP Related to Children with Disabilities with a Focus on Social Norms

ECARO has identified many deprivations that children with disabilities face and has taken action to address negative attitudes, harmful beliefs, and social norms that uphold these deprivations through more strategic and evidence-based policies, community empowerment, coalition building, partnerships and the application of communication for behaviour and social change approaches. To support this initiative, in September 2015, ECARO engaged Drexel University to perform a secondary analysis of existing research in order 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 ECARO region) and how can the tools be improved to better evaluate individual attitudes and social norm change?”** This section provides key insights gained from a review of the three deliverables of that systematic review.

Systematic Review of Research on Attitudes and Norms Towards Children with Disabilities

To develop rigorous tools that evaluate attitudes and social norms related to children with disabilities, it is first necessary to understand how such concepts are being defined and measured in existing research. Drexel reviewed a total of 44 peer-reviewed, public studies, most of which originated in industrialized countries. When these studies were assessed for quality, almost half were deemed to be of low quality. The studies identified through the systematic review were lacking in several regards: clear definitions of key concepts, such as attitudes and disabilities; the involvement of children with disabilities and key beneficiaries; the use of participatory approaches or mixed methods; and measurement of the key components of social norms. Key recommendations from the review include encouragement to ground research in theoretical frameworks, define research concepts and standardize

definitions for disability, measure social norms, validate existing scales in the field, and ensure ethical standards. The report also called for more robust and rigorous research globally. Additionally, the review identified three validated tools described in APPENDIX A: that individual tools and the questions in each of them as well as highlights the specific stakeholders with whom the tools have been validated. The proposed pilot will use these validated tools to:

1. **Examine the extent to which the validated tools fit within the ECA context:** Macedonia will serve as a test site for these tools
2. **Ensure reliability and validity:** To the extent possible, any changes made to the tools will be kept to a minimum. Any proposed changes to the questions or response categories will be accompanied with justifications.
3. **Assess the use of the individual questions for other stakeholders:** A review of these validated tools indicates that while these tools are for specific audiences, individual questions within each scale can be utilized or adapted to examine attitudes of other stakeholders. Therefore, the Drexel team proposes to review each individual question to assess its use, in its exact or in an adapted form, for different types of stakeholders¹ included in the pilot study.

UNICEF-sponsored Studies in ECA Countries

Drexel also examined 18 reports from UNICEF-sponsored research on discriminatory attitudes and norms towards children with disabilities conducted in the ECA region over the period of 2010 to 2016. This included an **in-depth analysis of 164 attitudinal measures** across the reports to assess the quality of the research and to generate recommendations for future research.

The UNICEF research, similar to the peer-reviewed literature, was lacking in methodological rigor. None of the reports provided study protocols with methodological details and the research largely failed to examine social norms. Attitudes towards children with disabilities were measured in each study, but there was not a common aspect of discrimination that they all addressed. Degree, direction, and valence in the measurement of attitudes were not consistent and the scales did not include cognitive, affective, and behavioural components. Furthermore, information on validity and reliability testing of the instruments used was noticeably absent.

Despite these limitations, **a few of the tools from this research can potentially be adapted for this pilot study.** Some elements can be borrowed from the KAP study tool used by both UNICEF Bosnia and Herzegovina and UNICEF Montenegro. Additionally, UNICEF Georgia

¹ This process will be undertaken once UNICEF and Drexel have reached agreement on the final list of stakeholders to be included in the pilot

inserted a stigma scale in both their 2013 VAC Study and their 2014 National Youth Survey that offer a starting point for such measures. However, stigma and discrimination can also be considered to be outcome variables of interest, therefore it becomes important to study stigmatizing attitudes and norms. Questions from these two tools can be found in APPENDIX B:

The Drexel team has carefully examined and summarized the specific recommendations from the systematic review of peer-reviewed public research and the review of UNICEF-led research in APPENDIX C: *Recommendations from the Systematic and UNICEF-sponsored Research Reviews and their Application to this Pilot Study* with notes on the ways in which this future work does and does not allow us to apply the recommendations. Some of these are described more fully in subsequent sections of the desk review. **The Drexel team anticipates reviewing these notes in collaboration with UNICEF to reach consensus on the specific details for this current work.**

Applying Overarching Recommendations on Attitudes and Norms towards Children with Disabilities

The findings from the reviews of peer-reviewed and UNICEF-sponsored research allowed the Drexel team to write a third report describing recommendations for future theorizing and research on discriminatory attitudes and social norms among children with disabilities. These recommendations were organized to follow the three stages of the research process: planning for research, implementing research, and disseminating research (Figure 2). This entire report is relevant for the purposes of this current study, given that this study is essentially the next step i.e. **it operationalizes the earlier recommendations through the development of a conceptual**

framework, tools, and monitoring and evaluation plan. The Drexel team intends to use this report as a guiding document throughout the entire process. For the purposes of this desk review and in the context of designing the pilot study, the **most relevant recommendations requiring discussion and agreement between the Drexel team and UNICEF** are summarized below.



Figure 2: Phases of the Research Process

Use the ICF-CY framework to standardize definitions and typologies of disabilities

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).

The International Classification of Functioning, Disability and Health (ICF) and the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) are classification systems for disability adopted by WHO member states in 2001 and 2007, respectively. The ICF and ICF-CY provide standard language and a conceptual basis for the definition of health and disability but go one step further than the CRPD. It provides a robust and detailed classification system through which to measure disability (Figure 3). Moreover, it conceptualizes disability and functioning along a continuum and acknowledges the effects of contextual factors on disability and functioning (Simeonsson, Leonardi, Lollar Bjorck-Akesson, Hollenweger, & Martinuzzi, 2003). As a “derived classification” based on the ICF, the ICF-CY presents the same foundation as the ICF but provides additional detailed information on the application of the framework to children and youth (Lollar & Simeonsson, 2005). Therefore, the ICF-CY contains codes and descriptions of codes that define characteristics and activities important to these stages of development. Additionally, it captures the more frequent environmental transitions that children undergo, as compared to adults, such as from nursery to primary to secondary school.

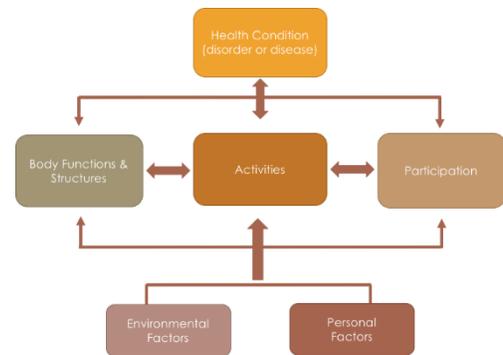


Figure 3: ICF-CY Framework

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 4). The medical model understands disability as a problem, pathology or defect of a person, whereas the social model believes 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).

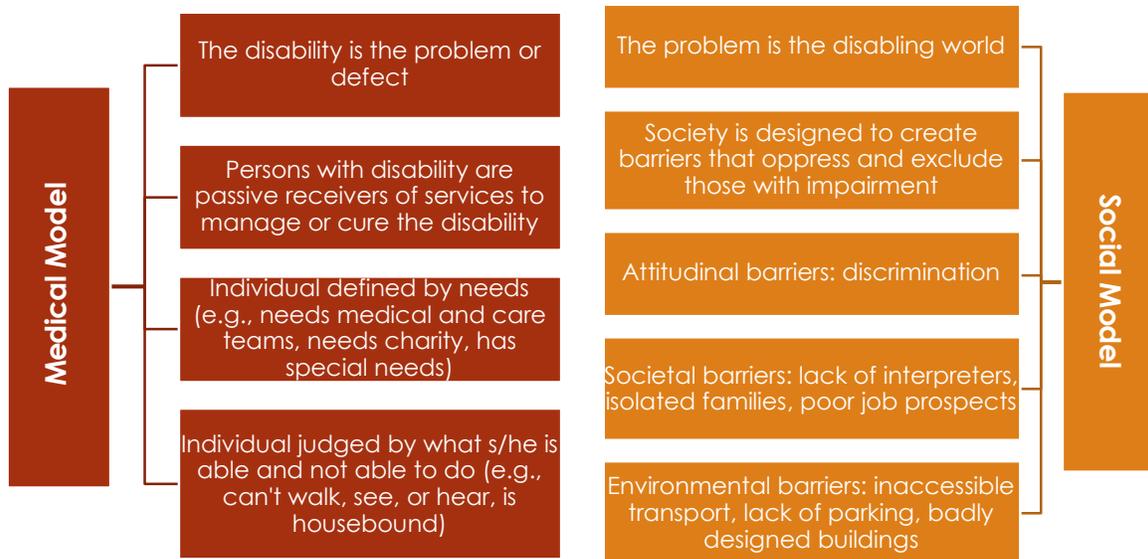


Figure 4: Overview of the Medical and Social Models of Disability

UNICEF has adopted the social model for the implementation of its research and interventions. According to the ICF-CY, disability is multidimensional, interactive, and relates to four aspects: 1) body functions and structure; 2) activities; 3) participation; and 4) environmental factors. (Figure 5).



Figure 5: ICF framework aspects

While individual disability (from the medical model perspective) is determined by body functions and structures, disability is more than that and includes limitations in activities and participation due to specific environmental factors which lead to negative and discriminatory practices such as stigmatizing, stereotyping, marginalizing, or neglect. **While it is important to use the ICF-CY as an overarching framework for a full-scale study, it is not feasible to include all the framework's elements in the pilot study. The Drexel team proposes focusing the pilot study on the middle two circles of Figure 5 and to consider the role of intangible environmental factors, specifically discriminatory attitudes and norms, in limiting or restricting activities and participation.** This pilot study will not include

questions on the structural environment to promote accessibility or the policy environment including laws, policies, and their implementation. However, there is a link to be made between social norms and accessibility and policy formulation and implementation in the sense that decisions about the structural environment is made by individuals whose own attitudes likely impact their decisions. This is a research question better asked in a separate study altogether. This said, the pilot will consider the extent to which perceptions of the structural environmental factors (circle 4 of Figure 5) influence discriminatory attitudes and norms.

The reviewed research also underscored the need to explore a wider range of disabilities. However, this pilot will not include considerations of body functions and structures, which while important, go beyond the capacity of this pilot study. **The Drexel team and UNICEF need to discuss and finalize the operational definition of disability that will be covered within this pilot.** Since this study is based on the premise that “disability” is why this marginalized group of children are discriminated against, we have to have a mental counterbalance or comparison point. There are several ways of classification: One can take a granular approach and focus on specific types such as Down Syndrome or Autism Spectrum Disorders. Or, one can take a broader perspective looking at children with disabilities and children without disabilities. Previous research has documented variation in discriminatory attitudes towards children with disabilities of different types of disability (Barr & Bracchitta, 2015; Brown et al., 2011; Nowicki, 2006; Pruett et al, 2008). Therefore, another approach includes classifying disabilities by type, including physical, learning, hearing, visual disabilities, or focusing on visible versus invisible disabilities. Any classification used is important from a specialization and tailored programming standpoint. Our purpose here is to design a robust tool that can be used across contexts (and, if feasible, be adapted for specific situations), hence the need for clarity on how “disability” should be classified.

At the same time, the study will attempt to uncover the participant’s definitions of disability by asking participants to define their understanding of disability. These will be assessed against UN adopted definitions to determine level of understanding. Subsequently, participants will be given a common definition of disability, pertinent to this pilot study, before proceeding to the social norms questions.

Expand the scope of disability research

The effects of discrimination and negative attitudes impact individuals with disabilities throughout their entire life, yet the Drexel University undertook a Systematic Review and Assessment of Approaches to Research and Data Gathering on Knowledge, Attitudes, and Practices (KAP) related to children with disabilities in ECA with a focus on social norms undertaken by Drexel University in 2015 indicated that research has primarily focused on the experiences of secondary school age children.

There are different ways to define “children.” Biologically, a child is birth through puberty. According to the CRC, a child is a minor below 18 or below the age of majority. Using a life-course approach could uncover different barriers that children with disabilities encounter at

various points in time and provide a clearer picture of the social systems, structures, and norms that contribute to or manifest themselves as disabling barriers (Priestley, 2003). This has ramifications for the entire research process, for instance as respondent groups are selected, questions are written, and research methods and techniques are chosen. **A study that adopts a life-course approach will, however, require a large sample size, as parents and children from each age group must be selected. Such a design may be beyond the available time and resources designated for a pilot study.** The Drexel team and UNICEF need to come to a consensus on the definition of children. One feasible suggestion is **to focus on children age 6 – 9**, to gain insight into the experiences of children with disabilities as they first transition from home into a formal school system.

Utilize social norms frameworks to measure the four constructs of social norms.

Both global and UNICEF-sponsored research in the ECA region did not include robust measures of social norms, and some did not measure norms at all. ECARO recognizes the importance of addressing social norms to tackle the deprivations that children with disabilities face. Before discussing actual indicators and questions, it is important to keep the following points on norms theorizing in mind:

- Utilize multiple measurements.** Norms exist at the intersection of beliefs, expectations and behaviours and hence are inherently complex. As such it is impossible to develop a single simple quantitative indicator to examine them. A nuanced understanding of norms therefore requires measurement of descriptive and injunctive norms as well as rewards and punishments. Additionally, since perceptions of self and others define and drive norms both qualitative and quantitative measures are needed to gain a comprehensive understanding of normative drivers.
- Include a social norms approach within C4D interventions.** First and foremost, to understand if a practice or individual behaviours associated with a practice are normative, it is important to measure if a behaviour indeed is governed by normative drivers (Figure 6).

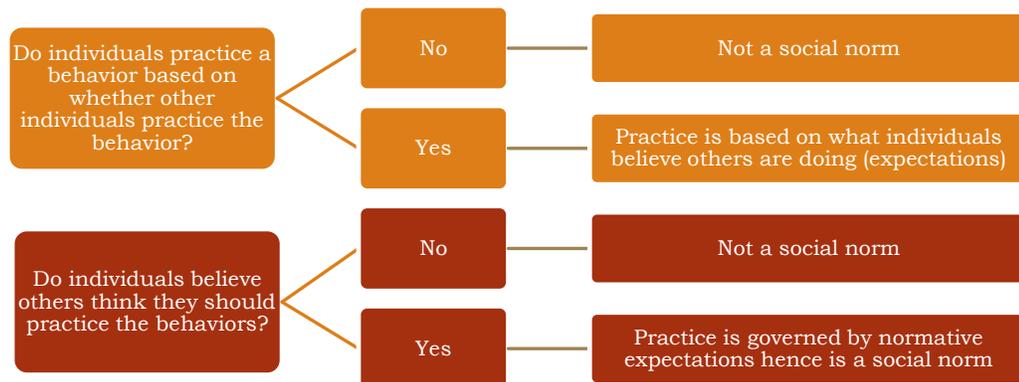


Figure 6: Determining what behaviours are driven by social norms

A norms-based approach can use many different strategies, channels, and activities available to C4D practitioners as a whole. They can target audiences across different levels in the social ecological model. A distinguishing feature of these approaches is their focus on addressing perceptions, rewards, and sanctions. Social norms do not change in the absence of a catalyst (internal or external) that allows individuals to understand (mis)perceptions and ways to mitigate or enhance rewards and sanctions associated with normative behaviours.

3. **Identify a clear “call to action” in addressing norms.** In order to measure changes in social norms it is important to have clarity on what specific behaviour change is expected. Social norm change, can be achieved in one of two ways (Figure 7):
 - a. **The abandonment of a negative norm** where social norms programming and monitoring and evaluation focus on the prevention of re-emergence and maintaining absence.
 - b. **Introducing an innovation associated with a separate set of behaviours for a given practice** i.e., replacing a negative norm with a new practice, which over time becomes the “new norm.” This approach then requires monitoring of the uptake of the new practices. This concept of norm replacement is grounded in the idea that every innovation begins as a deviation from existing social norms.

Information on what types of norm change can be expected from a C4D programme is critical to ensuring appropriate measurements are used to examine effectiveness.

Apart from these critical programming and monitoring and evaluation issues, robust research must include all the key constructs from social norms theorizing. In their simplest form, social norms are the unwritten rules that guide human behaviour and can be broken down into four measurement constructs (UNICEF & Mackie, 2015):

- **Descriptive Norms:** Beliefs about what other do
- **Injunctive Norms:** Beliefs about what others approve of or think one should do
- **Social Sanctions:** Beliefs about the perceived sanctions or punishments from performing or not performing a behaviour
- **Benefits/Rewards:** Beliefs about the perceived benefits or rewards to oneself or others associated with complying or not complying with a norm

From a purely measurement perspective, monitoring and evaluation of social norms must include questions to measure all four of these components. *Table 1* provides some hypothetical examples of how the four social norms constructs can be operationalized to measure specific dimensions relating to discrimination within the education, health, and social sectors. These

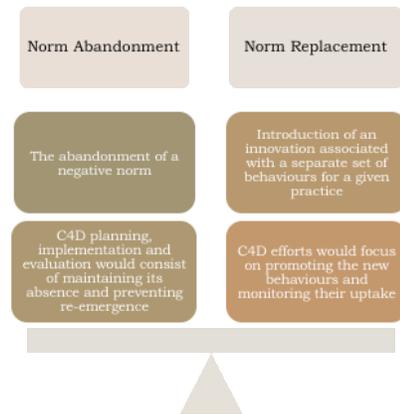


Figure 7: Two ways of achieving social norms change

types of questions can be incorporated into ongoing KAP studies aiming to study norms change.

Table 1: Application of Social Norms to Access to Education and Institutionalization of Children with Disabilities: Illustrative Examples of Questions to Ask

Social Norms Construct & Definition	Access to Education	Institutionalization
	Children with disabilities sharing a classroom with children without disabilities	Sending children with disabilities away to live in an institution
<p>Descriptive Norms (Empirical Expectations)</p> <p>Beliefs about what others do</p>	<p>Q: How many children with disabilities in your community go to an inclusive school?</p> <p>[Response options: None, few, some, all]</p>	<p>Q: How many children with disabilities in your community are sent away to an institution?</p> <p>[Response options: None, few, some, all]</p>
<p>Injunctive Norms (Normative Expectations)</p> <p>Beliefs about what others approve of or think people should do</p>	<p>1) Do you approve or disapprove of children with disabilities sharing a classroom with children without disabilities?</p> <p>2) Do others like you approve or disapprove of children with disabilities sharing a classroom without disabilities?</p>	<p>1) Do you approve or disapprove of sending children with disabilities away to live in an institution?</p> <p>2) Do others like you approve or disapprove of sending children with disabilities away to live in an institution?</p>
<p>Social Sanctions (Outcome Expectancies)</p> <p>Beliefs about the perceived sanctions or punishments from performing or not performing a behaviour</p>	<p>What are the punishments or sanctions of letting children with disabilities share a classroom with children without disabilities?</p>	<p>What are the punishments or sanctions of sending children with disabilities away to live in an institution?</p>
<p>Benefits (Outcome Expectancies)</p> <p>Beliefs about the perceived benefits or rewards to oneself or others as a result of complying with norms</p>	<p>What are the benefits or rewards of letting children with disabilities share a classroom with children without disabilities?</p>	<p>What are the benefits or rewards of sending children with disabilities away to live in an institution?</p>

Examine attitudes robustly

While much current discussion is around evaluating the role of social norms in discriminatory practices toward children with disabilities, attitudes still play an important role. For one, attitudinal change can be measured in a much shorter timeframe than social norms change. Also, specific questions for attitudinal measures would help provide a richer understanding of the socio-cultural factors contributing to discrimination of children with disabilities. For instance, individuals may have positive attitudes towards children with disabilities, but still engage in discriminatory practices towards them. Such a discrepancy between approval and actual practice would suggest that social norms are at play.

It is important to devise robust measures consisting of individual items and scales to measure attitudes. The attitudinal questions (scales) that Drexel will use in the pilot study will incorporate best practices in attitude measurement from the literature such as specifying degree and direction, avoiding the use of neutral language, alternating between positively and negatively worded statements, and including items covering the three components of attitudes (Figure 8). The Drexel team will also take into account other relevant recommendations relating to attitudinal measures culled from the systematic reviews described earlier.



Figure 8 Key Elements of Attitude Measurements (Antonak & Livneh, 2000; Sommer, 2006; Wittenbrink & Schwarz, 2007).

In its most basic form, attitudinal measures can have respondents chose between one of two categories. This type of measure only provides **direction**; it only tells us when a person is for or against something.

- Example: Do you think children with disabilities should be institutionalized? A) Yes; B) No

In order to gain a measure of **degree**, it is important to use category scales which are more sensitive and provide respondents more options.

- Example: To what extent is it acceptable or unacceptable for you that your child shares a classroom with a child with disabilities? A) Very acceptable; B) Acceptable; C) Neither acceptable nor unacceptable; D) Unacceptable; E) Very unacceptable

Self-reports of attitudes are strongly influenced by the context, format, and wording of items. Therefore, **the wording and the directionality** of the statements can and will be varied in the pilot tools. By definition, attitudes are comprised of three elements depicted in Figure 9 with examples of each component.



Figure 10 provides some examples of attitudinal scale statements relating to children with disabilities incorporating best practices associated with attitudinal measurements:

Figure 9: Attitude Components

Now I will read to you several statements. Please evaluate to what extent you agree or disagree with each of the statements using a scale from 1 to 5 where 1= I don't agree at all and 5 = I completely agree

- A)** *For children with special needs, it is better to stay in special institutions than to live in their families, because these institutions have experts who are specially trained to work with them*
- B)** *Other children who are growing up in families with children with special needs, learn to be more attentive and more tolerant*
- C)** *Parents who are raising children with special needs, usually have to dedicate their life to them completely*
- D)** *If a child with special needs is left without parental care, it is better to put it in a foster family than in a large-scale institution*
- E)** *I feel sorry for families with a child with special needs, because they are victims of unfortunate coincidence.*
- F)** *Families of children with special needs cannot be expected to overcome all the challenges alone, they must be supported by the wider society*
- G)** *In families where a child with special needs is growing up, other children are usually neglected*

Figure 10: Examples of Robust Attitudinal Statements Associated with Children with Disabilities

Finally, the literature indicates that the **usefulness of attitudinal scales can be improved by asking open-ended questions**, which ask the respondent to justify or explain their responses. The pilot study will therefore include open-ended questions to understand reasons for specific answers.

Attitudinal scales must consider a wide range of attitudinal barriers the people and children with disabilities face. At the same time, to avoid having overly-generalized data, attitudinal measures should focus on specific disabilities, topics, and issues to ensure that the data generated can inform programming. However, while such disaggregation is important, the pilot study may need to focus on disabilities as a whole, given time and resource constraints.

Additional Considerations

In addition to these recommendations, there are a few other points that were highlighted in the earlier recommendations that are worth mentioning for consideration when undertaking the validation in the pilot country.

1. There is a great need to **involve children with disabilities in the research** about, with, and for them. Participatory research methods shift the focus from research on to research with children with disabilities, thus giving children with disabilities the power

to shape how their experiences are understood and communicated (Chappell, 2000). Further considerations for participatory methods will be provided in the Inception Report and as pilot tools are designed.

2. **All research involving human subjects needs to undergo ethical review**, including research as part of a pilot study. Research involving vulnerable populations, such as children and persons with disabilities, requires extra measures and safeguards to ensure their rights are protected. More details on obtaining IRB approval for this pilot study will be provided in the Inception Report.
3. **Pretesting data collection instruments and tools** directly with intended audiences presents an opportunity to evaluate the cultural appropriateness of tools, revise questions and statements for comprehension and relevance, elicit specific local terminology or response options to make certain questions close-ended, and ensures questions are generating the data they are intended to collect. The importance of validating the data collection scales, measures, and instruments designed specifically for this pilot study cannot be overstated. Since the overall purpose of this exercise is to validate attitudinal and social norms measures, a two-stage process is suggested. First, draft tools in English will be translated and pretested in a small group. This will be followed by pilot testing with a relatively representative group of different types of research participants. Suggestions for effective pretesting will be provided in the Inception Report.

SECTION 2: The Macedonia Context

While this pilot study is designed to be adapted to other contexts in the ECA region, it is important to gain insight about the situation of children with disabilities within the Republic of North Macedonia, where the pilot study will take place. To do so, Drexel reviewed a total of 27 resources shared by UNICEF ECARO and the UNICEF CO or available on the UNICEF country office website, listed in *Table 2* below. However, while it is clear that the Republic of North Macedonia is serving as a validation site to test the tools that measure discriminatory social norms against children with disabilities, this pilot is not designed to serve as a small-scale study to plan for a future scaled-up project within the country.

Table 2: List of Macedonian Resources

Document Title ²	Date
MICS report	2006
Child-friendly schools: A situation analysis for the Republic of North Macedonia	2007
It's About Ability	2008
Child friendly schools case study: North Macedonia.	2009
Inclusive education as part of a child-friendly schools' framework	2010
MICS report	2011
Building equity for children: A situation analysis of girls and boys in the Republic of North Macedonia	2013
Building equity for children: Findings of a situation analysis of girls and boys.	2013
Case studies from schools involved in UNICEF's inclusive education training-of-trainers programme (2012-2014).	2014
KAP survey towards inclusion of children with disabilities	2014
KAP towards children with disabilities	2014
Mainstreaming respect for diversity and multiculturalism in early childhood development	2014
Mapping of disability person organisations	2014
#FightUnfair campaign	2015
Assessment of alternative forms of care and family support services for children with disabilities.	2015
Assessment of capacity of services provided by health, education, and social sectors for inclusion of children with disabilities.	2015
Communication strategy to support inclusion of children with disabilities (2015-2020)	2015
Inclusive education report from the baseline study	2015
Towards a cross-sectoral approach to inclusion of children with disabilities.	2015
Inclusive education report from the progress study	2016
Towards Inclusive Education	2016

² Citations for the documents in this table can be found in Appendix D.

Be fair campaign	2017
Creating Together campaign	2017
Every child needs a family campaign	2017
See the child, not the disability campaign	2017
The Republic of North Macedonia UNICEF 2017 Annual Report	2017
Applying Behavioural Insights to Social Workers' Motivation	2018

These documents detail the work that UNICEF the Republic of North Macedonia is doing to support the Government as it introduces policies and practices to ensure that the rights of children with disabilities are protected across health, early childhood education and education, and social and child protection sectors. Information in this section is structured around the disability work that is currently being done in the country.

Disability C4D Strategy & M&E Framework

The CO has developed a Communication for Development (C4D) strategy and M&E framework to help support the overall goal of the Programme of Cooperation between UNICEF and the Government (2016-2020), which states: "By 2020, more children with disabilities and their families are empowered to realise their rights and enjoy a better quality of life and equitable access to basic services."

The C4D strategy is guided by principles in the CRC and the CRPD and grounded in the ICF's bio-psycho-social model of disability. In addition, the strategy is holistic in its application of a socio-ecological perspective and use of multiple communication approaches to reach a range of audiences. The strategy also places great emphasis on using participatory approaches so that children with disabilities can be meaningfully involved and their experiences can shape the work being done on the ground.

The scope and direction of the strategy was driven by evidence generated from a KAP study towards children with disabilities, a mapping exercise of disability organizations, and assessment of key systems. It assumes that the survey findings of the general public are consistent with the views and mindset of the majority of the population, and that for change to take root, communication efforts must tackle knowledge, attitudes and beliefs, self-efficacy,

Communication Goals:

- 1) Mobilize broad support and increase the number of citizens supporting equal rights and inclusion of Children with disabilities.
- 2) Build the capacity of rights holders so that they can be agents of change

Objective 1 Create a broad coalition to drive social change

Objective 2: Increase awareness among the general public and key decision makers of the rights of Children with disabilities and social-rights based model

Objective 3: Build the capacity of rights holders -- Children with disabilities and their families-- so that they become agents of change

Objective 4: Increase the number of citizens who have higher expectations of Children with disabilities and see them as having the same potential as children without disabilities

and norms. The communication goals and objectives are outlined in *Figure 11*.

Figure 11: C4D Strategy Goals and Objectives

The Drexel teams see multiple opportunities to build upon and strengthen the objectives of the C4D strategy and the objectives of this consultancy. However, it is important to get feedback from ECARO on the extent to which these objectives align with the current and planned efforts in other ECARO country offices, as the Republic of North Macedonia is serving as a test site for deliverables that will be used across the region.

Health

As mentioned previously, there are three main models through which to view disability: medical, charity, and social, with the social model widely considered as the ideal perspective for reducing stigma and discrimination. In the Republic of North Macedonia, a 2014 KAP survey found that 44% of people believe that the medical model is the best approach to dealing with disabilities (UNICEF, 2014b). This perspective puts undue burden on the health sector, as people think children with disabilities mainly need medical care and access to rehabilitation services, and it prevents people from seeing their own role in removing barriers, discrimination, and stigma around children with disabilities.

Even though the UNICEF CO and the Government of the Republic of North Macedonia want to shift the public away from the medical model, the health sector still has a role to play in the more holistic social and rights-based model. However, access to high quality health services is low. All home visiting nurses have been trained in early detection of developmental difficulties and 42% in early intervention. In addition, a small number (7%) of general practitioners and family medicine specialists at primary health care level are trained in early detection and intervention and in the basic ICF framework (UNICEF, 2017). Furthermore, healthcare providers may be technically capable of providing services to children with disabilities but may not have been trained in the “softer skills” of patient care, such as bedside manner, which could affect their attitudes toward providing the services. Since this study is focusing on attitudinal and normative issues, it will focus on these intangible aspects of quality of healthcare.

Inclusive Education

The importance of mainstreaming children with disabilities in inclusive education is widely supported in the social and human rights-based model of disability. In the Republic of North Macedonia, UNICEF and the Government have already given much attention to inclusive education (IE). Still, barriers such as a lack of common understanding of definitions in IE,

limiting attitudes of the public, and attitudes and low preparedness in schools continue to present challenges.

Definitions in IE

The CRC, CRPD, and the Salamanca statement all provide guidelines for inclusive education. The Republic of North Macedonia is a signatory to these statements; however, the Towards Inclusive Education study found that existing legislation isn't aligned with the standards laid out by these conventions (UNICEF, 2016b). In laws specifically on Primary Education and the other laws and bylaws relating to education, disability is not mentioned as grounds of discrimination. In reality there is no legal barrier in enrolling a child with disabilities in mainstream schools. For example, Article 6 of the law on primary education notes: For students with special educational needs appropriate conditions for acquiring primary education and education in regular and special primary schools are also provided and they are entitled to individual assistance for acquiring elementary education and upbringing. The UNICEF study points out that inclusion involves modifications to content, approach, structure, and strategy, not just placing children with disabilities into regular classrooms. Contrary to this, it found that current education programs are not creative or flexible, so teachers are unable to make adaptations for all students to reach their full potential. Defining inclusion in a more holistic way could set the path for teachers to make the necessary adjustments to their classrooms.

When discussing IE, it is important to note that IE is about addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures, and communities, and reducing exclusion within and from education. It therefore addresses the exclusion of many marginalized groups, not just children with disabilities. In UNICEF's Inclusive Education Baseline Study, children with disabilities are included as part of a larger category of children with special educational needs³ (UNICEF, 2015b). This study found that there is an inconsistent understanding of what constitutes special education needs and children with disabilities. Many teachers and principals think that they are catering to and meeting the requirements of children with special education needs, while support staff at schools think the opposite and students with special education needs are scoring lower than expected in both math and language tests. The Inclusive Education progress study also found such discrepancies on progress because of unclearly defined indicators and concepts (UNICEF, 2016a). Similarly, an unpublished 2017 study on inclusive practice in mainstream secondary schools draws a general conclusion that, at this stage, inclusion is reduced to improvised

³ Special educational needs are "needs that are a result of the differences in the psycho-physical abilities, ethnicity, culture, mother tongue, religion, social and economic status" (UNICEF, 2015b, p. 24).

implementation as a direct consequence of the superficial understanding and interpretation of inclusion. Very often, schools set in place only partial measures and the implementation of such measures is done only “pro forma,” yielding no actual positive effects in practice. The lack of clearly defined inclusion standards results in low expectations and unrealistic picture of the process of inclusion (UNICEF, 2017).

Attitudes of the Public

In 2007, a situation analysis of child-friendly schools found barriers to implementing IE include: the socially acceptable exclusion of certain populations, inter- (intra-) ethnic conflict, and a general lack of understanding for students with disabilities (UNICEF, 2007). Several teachers interviewed thought special schools were better for children with disabilities. Despite the increase in attention paid to IE, these barriers persist.

Since only 30% of the population subscribes to the social model of disability, it is not surprising that many people hold limiting attitudes towards children with disabilities. A 2014 KAP survey found that almost half (48%) of respondents said that children with disabilities should go to special schools and not be integrated into “regular” schools (UNICEF, 2014b). A staggering 96% of respondents do not believe that children with disabilities should attend the same classes in the same schools as children without disabilities (UNICEF, 2015a). This preference of segregating children with disabilities is largely due to the view that institutions are better for, as the institutions have experts trained to care for. Over three-fourths of people believe inclusion is the responsibility of government and organizations and that they do not play a role in improving the situation of. Furthermore, 60% of respondents hold the view that have less chances of getting a job compared to other with the same education level, yet do not recognize this view as problematic to.

On the other hand, through focus groups, the Mainstreaming Respect for Diversity Study found that pre-school aged children age 4-6 do not openly express negative attitudes toward, but rather they are unaware of them because are underrepresented in kindergartens (UNICEF, 2014d). Yet despite having neutral attitudes toward, these young children interviewed believe that are unable to participate in their games. This indicates that ignorance and prejudices about issues surrounding are learned and with early exposure, the development of such negative attitudes could be prevented.

School Attitudes and Preparedness

Studies and programs on IE in schools have demonstrated conflicting perspectives on the state of IE in the Republic of North Macedonia.

Between 2014 and 2017, 30 schools in the country participated in a series of UNICEF supported workshops and training on IE. Five case studies from schools involved in those

workshops demonstrate that the response to training from participants has been largely positive (UNICEF, 2014a). Participants were able to take the lessons learned back to their respective schools and begin implementing new approaches to IE. However, challenges remained, including pressure from parents of children without disabilities, teachers who refuse to work with children with special education needs and low parental involvement. One case study specifically mentioned the importance of training teachers on the human rights approach and social model of disability to improve attitudes. The 2016 IE progress study also stressed the importance of assessing teachers' mind-sets, their understanding of intelligence as fixed or flexible and their willingness to use an individualized approach to educating children (UNICEF, 2016a).

Multiple studies indicate that teachers' perceptions of the state of IE in their school and classroom may not be representative of the actual situation. In the IE progress study, teachers believed that they possessed the requisite skills to teach marginalized groups of children (UNICEF, 2016a). However, the scores on a reading and mathematics assessment were below expectations for children in these marginalized groups. And in the Mainstreaming Respect for Diversity study, while both parents and educators have high aspirations for all children to learn the skills and develop the desire to assist and engage with children with disabilities, parents assess the current ability of children to do so at lower levels than teachers do (UNICEF, 2014d). The mismatch between teachers' perceptions of and the reality of the state of IE suggest further information about teachers' KAP around children with disabilities is needed, and they should be a key population in the pilot study.

In 2018, UNICEF commissioned the UK Behavioural Insights Team (BIT) to deliver an initial assessment and recommendations on how to improve the performance of the teaching and social work professions in the country using behavioural insights. While not specific to inclusive education, among other things their unpublished assessment noted teachers are overburdened by paperwork; teachers didn't feel respected and that they felt the state of schools and classrooms and lack of teaching aids did not allow them to do their jobs properly. These should be considered in further exploring how such situations shape their attitudes towards children with disabilities.

Finally, there is an emphasis within the education sector on test outcomes and the national examination system that creates a barrier to inclusion for children with disabilities. Teachers are not encouraged nor given the tools and guidelines to support working IE and have been taught to see helping children with disabilities as the work of specialists. The education sector funding mechanisms favour placing children with disabilities in special schools rather than mainstreaming them, which further reinforces this viewpoint (UNICEF, 2015c). The pilot study could include attitudinal questions about funding and training for children with disabilities. Additionally, aspects such as funding and training should be considered as overarching factors in the conceptual model that will come from the results of the pilot study.

Social and Child Protection

In the Republic of North Macedonia, it is the social sector that is tasked with formally identifying children with disabilities and providing the follow up and support they need to receive required services. The Centres for Social Work serves as the primary entry points to care for families, but due to insufficient resources and staff, the centres often find themselves unable to fulfil this role. Competing priorities and obligations, such as the pay-out of cash benefits, exacerbate the situation. As a result, identification of disabilities in children is delegated to the health sector and does not come with the comprehensive package of services. Or the social workers at these centres may make identifications without referrals, working in silos and not communicating with providers in the education and health sectors. Parents tend to avoid both the Centres for Social Work and the medicalized service provision because of the lack of holistic support (UNICEF, 2015c). Additionally, it seems that many professionals are “guided by laws and rulebooks rather than standards for good practice” which affects the quality of care and support that children with disabilities and their families receive (UNICEF, 2015a). This unwillingness to go beyond their mandate may arise from the KAP relating to children with disabilities of the providers. However, it is also important to consider, as noted in the recent assessment based on behavioural insights (UNICEF, 2018), that social workers are less likely to comply with legislative requirements of conducting outreach because rules are almost impossible to follow. In other words, because of overly strict legislation they delegitimise the whole rule-based system, resulting in a non-compliance environment where important rules are less likely to be followed.

Attitudes toward children with disabilities also affect their access to social support and protection. The 2014 KAP Study found that most people (55%) believe that children with disabilities cannot be fully integrated into society and approval for relationships with those with disabilities decreases as the relationship becomes closer (UNICEF, 2014c). For example, 76% of people believe it’s acceptable to be neighbours with a child an intellectual disability but only 3% would find it acceptable for their son or daughter to marry a Child with an intellectual disability at an older age. These beliefs may in part come from lack of contact with persons with disabilities. More than half of the respondents (52%) said they know very little or nothing at all about children with disabilities and only 45% said they know in any capacity children with disabilities. Such stigma can prevent parents from utilizing existing services, which prevents children with disabilities from receiving the care and treatment they need (UNICEF, 2013). Additionally, social exclusion and stigma related to ethnicity and economic status can compound the discrimination experienced by children with disabilities and their families, highlighting the importance of looking at issues around disability from a holistic perspective.

C4D EFFORTS

Norms change does not happen in the absence of communication. Therefore, any M&E of programmatic efforts on social norms relating to children with disabilities needs to include a

robust monitoring system, paying special attention to the extent to which activities are designed and implemented to change norms. To provide evidence of effectiveness, it is necessary to understand the approaches and activities of the programs. While understanding C4D efforts to change norms around children with disabilities is not part of the pilot study, it is an important consideration for the M&E plan which will be finalized based on the results of the pilot.

The UNICEF CO has a long list of C4D efforts including a book, conferences, pledges, workshops, inclusive community events, efforts to mainstream inclusion in children’s television programmes, and media campaigns that have been started to reduce stigma and improve support for children with disabilities. Future countries that will adopt the study and framework will need to document communication approaches and activities to ascertain contribution and attribution of norms change. Selected examples of the C4D efforts in the Republic of North Macedonia can be found in APPENDIX E: .

Multiple Indicator Cluster Survey 2006 and 2011

The Multiple Indicator Cluster Survey (MICS) on children’s and women’s situation was conducted most recently in the Republic of North Macedonia in 2005-2006 and 2011. The variables assessed in the MICS are progress markers for child-related targets and goals set globally (the Sustainable Development Goals) and include some questions related to children with disabilities. The questionnaire was administered to mothers and caregivers of children ages 2-9 and assesses the number of disabilities or impairment, such as sight, deafness, and speech. Figure 12 shows the ten types of disabilities considered in the dataset, categorized by the authors of this desk review as physical or learning/developmental.

In 2006, the survey found that 10% of children in the Republic of North Macedonia aged 2-9 have at least one disability⁴. In both 2006 and



Figure 12: Ten disabilities assessed in MICS

⁴ No prevalence of Children with disabilities or other relevant statistics were provided in the 2011 MICS report. Therefore, the Authors performed secondary data analysis on both the 2006 and 2011 reports. Further statistics in this section are from that data analysis.

2011 the prevalence of physical disability varies significantly with several sociodemographic characteristics, including region, mother's education level, wealth index, ethnicity, and the age of the child. For example, in 2006 the percent of children age 2-9 years that have at least one reported disability was 24.1% in the poorest quintile and 12.9% in the richest quintile. In 2011, although these numbers decreased to 13.3% and 7.6%, respectively, they still show the trend of disparity between the poor and wealthy. Additionally, Roma children are more likely than other children to have at least one reported disability: in 2006, 19.9% of Roma respondents had a child aged 2-9 with at least one physical disability, whereas for the general population, the prevalence was only 16.4%. No data on Roma children was available in the 2011 dataset. Comparing the 2006 and 2011, showed shifts in where disability is concentrated. In 2006, the regions with the highest prevalence of children with at least one physical disability were East (37.2%), Polog (20.3%), and North-East (20.3%). By contrast, in 2001, the regions with the highest prevalence were South-East (12%), North-East (11.8%), and Pelagonia (9.9%).

Similar trends can be seen for learning and developmental disabilities. In both 2006 and 2011, more mothers in the poorest quintile had children age 2-9 with at least one learning/developmental disability, as compared to mothers in the wealthiest quintile (2006: 18.5% vs 11.4%; 2011: 15.0% vs 8.7%). Additionally, Roma mothers are more likely to have children age 2-9 with a learning or developmental disability compared to Macedonian mothers (19.5% vs 13.9%, respectively.) The 2011 data compared to the 2006 data also shows regional shifts and decreases in the highest prevalence of mothers with children age 2-9 with at least one learning or developmental disability, from East (24.7%), Pelagonia (21.0%), and Skopje (17.1%) in 2006 to South-West (11.6%), Polog (9.1%), and Pelagonia (9.1%) in 2011. For more details, see *APPENDIX F: Secondary Analysis of 2006 and 2011 MICS Data*.

KAP Survey 2014

In 2014, UNICEF Macedonia undertook a KAP study to examine various kinds of social barriers to the inclusion of children with disabilities in Macedonia's society. The survey aimed to assess the public's knowledge, attitudes, and practices toward children with disabilities and was administered to a total of 1000 respondents aged 15 and older. Among several other measures, to determine attitudes toward children with disabilities, respondents were asked which of the following three statements were closer to their views:

1. I feel sorry for children with disabilities, they need help and financial assistance in order to fit in society;
2. Children with disabilities need medical care, rehabilitation services and other special services to fit in society;
3. Environmental barriers, such as physical and those that people create through attitudes and stereotypes need to be removed for children with disabilities to fit in society;

Only 30% of respondents saw disability through the Social and Rights-based Model (Statements 3), while 44% saw it through the Medical Model (Statement 2) and 25% through the Charity Model (Statement 1).

Respondents were also asked, “How possible is it for a child with disabilities to lead an independent and productive life as an adult, if given support from professionals, institutions, and society?” Response options included “fully possible,” “somewhat possible,” and “not possible.” Overall, only 16% believe it is fully possible for children with disabilities to lead an independent life if given support. The majority of respondents (66%) believe it is “somewhat possible,” while 18% believe it is not possible.

See *APPENDIX G: Secondary Analysis of KAP Data* for additional information.

Limitations

In addition to the pilot study, this consultancy also includes the development of a conceptual model and a M&E framework that will be finalized based on the result of the study. This desk review primarily focusses on the immediate next step i.e. the pilot study. However, it is important to also consider additional recommendations from the previous reviews as they provide some insight into those deliverables as well. For example, the 2015 Systematic Review and the documents from the UNICEF CO indicate that the conceptual model should be broad, incorporating all levels of the Socio-Ecological Model, even if the pilot study must be narrow.

Mapping of disability services are an important part of the development of the M&E framework. The Republic of North Macedonia has already completed this step, which will feed into the framework as a planned step. In 2014, UNICEF conducted a mapping of all the civic organisations and informal groups related to disability in the Republic of North Macedonia. The exercise identified a total of 136 organizations and initiatives that serve and support children with disabilities, acknowledging that some organisations in the country may have been missed. The mapping gathered basic information through phone and internet research and then performed 32 in-depth interviews with select organisations throughout the country. The mapping provided information on the geographical distribution, the activities performed, and some perspectives and attitudes. The mapping revealed that CSOs actively include persons with disabilities on their governance boards or as volunteers and use participatory approaches to planning and assessing needs of the community. Some (26%) also carry out research for planning and advocacy purposes, including people with disabilities in that research. As such, this already exists in the country as a good practice for monitoring and evaluation and will be leveraged directly in the pilot study. Any field-based research however will need to start with mapping of the landscape to define audiences and also measure changes against. The Drexel team will keep these aspects in mind when writing the monitoring and evaluation plan.

Monitoring and evaluation is essentially useful to answer critical questions regarding implementation and outcomes. Any monitoring and evaluation plan therefore must gain a

thorough understanding of the local programming context and content, i.e. be based on a robust communication strategy. The Republic of North Macedonia has been involved in a variety of C4D efforts dealing with children with disabilities, much of this information is documented on the website. Since the purpose of this pilot study is to develop tools for measuring discriminatory attitudes and norms towards children with disabilities and not to monitor and examine the effectiveness of country initiatives, the pilot will not include critical questions on exposure, dose, and recall, i.e. those independent variables that assess the effectiveness of communication efforts' in changing attitudes and norms. The Drexel team will attempt to provide some of this information in the overall monitoring and evaluation plan.

Next Steps and Clarification Points

Throughout the desk review, there are several issues that require discussion and agreement between the Drexel team and UNICEF. To the extent possible, we have described the issues and also provided some proposed solutions. Final decisions on these points is one of the first next steps.

- 1. Agree on the common measures.** In terms of specific measures, the Drexel team is proposing the inclusion of the following:
 - Three validated scales identified by the systematic review
 - Measures from existing UNICEF research in the ECA region
 - Innovative social norms measures that reflect new advances in social norms theorizing and measurement
 - Adaptation of attitudinal scales that follow best practices including degree and direction, components, and valence.
 - Generating individual understandings of “disability” from participants’ perspective
 - Incorporating tools and techniques specifically designed for children with disabilities

Additional literature searches have revealed specific tools dealing with stigma, social distance, and social exclusion. The Drexel team consider these when designing the pilot study. Feedback from UNICEF on these proposed components of the tool would help in drafting tools.

- 2. Reconsider a life cycle approach.** While the value of a life cycle approach is obvious to uncover changes in experiences with and types of discrimination based on the age of a child, time and resources constraints dictate that the tools be specific to disabilities among a specific group of children. The Drexel team and UNICEF have come to the consensus to focus on three age groups of children: 0 to 3 years, pre-school age 3-5 years, and early primary school age 6 to 11 years. For the children in age group 0 to 3 years, the focus will be on their experience with the social work and healthcare sector, since this is largely when children are being identified and initiated into care. In the Republic of North Macedonia pre-school age children are 3- to 5-year-olds, in which we can focus on continued contact with social work and health professional and additionally include initial

contact with the early childhood education sector as they transition from home into a formal school system. The 6- to 11-year-old group will be able to provide rich information on the experience of children during primary education.

- 3. Determine which impairment/condition will be included in the pilot.** While the recommendations from the systematic review call for examination of discrete types of disability, keeping in mind that these categorizations can take several forms, it is important to establish a clear agreed upon definition of what is meant by children with disabilities as a counter point to a child without disabilities. We propose using the UN CRPD definition as follows: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (2006, pg 3). Given time and resource constraints, Drexel proposed using this common definition of disability as a whole. Therefore, a child without impairments is a child without disabilities. However, attitudes may vary towards different types of impairments, so ECARO and Drexel have agreed that it will be useful to choose one physical and one intellectual impairment on which to focus. Decision about which impairment is most suitable for the context will need to be made in conjunction with the UNICEF HQ, RO, and CO.
- 4. Focus on intangible attitudinal and normative discrimination.** Discrimination manifests itself in many ways. Structural discrimination comes from the lack of accommodations resulting in physical inaccessibility of children with disabilities to all aspects of life, such as schools, markets, public buildings, places of worship, and transport. Institutional discrimination can refer to the laws and statutes and ways in which children with disabilities are excluded from certain rights. This study may consider the attitudes of key players in promoting structural and institutional discrimination but is not designed to examine the physical environmental and institutional barriers faced by children with disabilities. Regardless of the types of stakeholders the line of questioning will focus on the attitudinal and normative dimensions of discrimination (intrapersonal, interpersonal and social), ranging therefore from children with disabilities internalization of discrimination, environmental discrimination as manifested in the home and the school environment and social discrimination which culminates in a preference for institutionalization.
- 5. Select Stakeholders.** It is clear that there are numerous stakeholders involved in this situation. Based on the existing studies and campaigns, the following have all been identified as important stakeholders:
 - Children with disabilities themselves
 - Parents of children with disabilities
 - Peers of children with disabilities
 - Education sector, including the administration and teachers

- NGOs working with and for children with disabilities
- Healthcare sector, including a range of medical professionals
- Social sector, including social workers
- General public without personal experiences of children with disabilities, such as parents of children without disabilities
- Local government and municipalities
- Government officials in the education, labour, social policy, health sectors

While it is not possible to include all stakeholders in the pilot study, efforts should be made to incorporate as many diverse perspectives as is feasible given financial and other resource constraints. The Drexel team and UNICEF need to discuss and finalize the key stakeholders to be included in the research so specific tools can be created for each group.

6. Determine process for tool development and finalization. The Drexel team plans to develop ONE core questionnaire for “primary audience groups,” pretest this core tool across the primary stakeholder groups, and subsequently adapt the core tool for other stakeholders that belong in the secondary and tertiary groups. Adaptations for the various stakeholder groups may involve removing irrelevant questions or adding additional questions. This will be followed by the pilot study, which will serve as the basis for an overall conceptual model and M&E plan. Feedback from UNICEF on this proposal is needed before drafting tools.

7. Calculate sample sizes based on level of disaggregation. The review recognizes the importance of selecting research sites that are representative of the main stakeholder groups whose social norms and attitudes are critical to decisions on the inclusion of children with disabilities. This current work will keep this in mind when writing the M&E plan. For the pilot study, however, it is essential to use some level of convenience sampling. Drexel will provide information from previous work and the literature on appropriate sampling frames and units and sizes in the inception report. Since pilot studies are not designed to be representative their sampling does not have to be based on population demographics. Instead once the number of stakeholders and the extent to which disaggregation is important to design individual tools for specific categories of stakeholders is determined it is easy to calculate sample sizes. It is critical to keep in mind that higher levels of disaggregation are not additive but results in multiplicative increases in sample sizes. For example, looking at respondents as rural or urban would be two groups per respondent type. If the data also needs to be disaggregated by economic status with three levels (poor, middle class, and wealthy), then it would be necessary to have six groups of each respondent type.

These seven items will be discussed by Drexel, UNICEF ECARO, and the Republic of North Macedonia UNICEF CO. All decisions made regarding the above points will be reflected in the Inception Report and the subsequent documents.

References

- Antonak, R., & Larrivee, B. (1995). Psychometric analysis and revision of the opinions relative. *Exceptional Children*, 62(2), 139-149.
- Barr, J. J., & Bracchitta, K. (2015). Attitudes toward individuals with disabilities: The effects of contact with different disability types. *Current Psychology*, 34(2), 223-238.
- Brown, M., Duff, H., Karatzias, T., & Horsburgh, D. (2011). A review of the literature relating to psychological interventions and people with intellectual disabilities: Issues for research, policy, education and clinical practice. *Journal of Intellectual Disabilities*, 15(1), 31-45.
- Chappell, A. L. (2000). Emergence of participatory methodology in learning difficulty research: Understanding the context. *British Journal of Learning Disabilities*, 28: 38-43.
- Convention on the Rights of Persons with Disabilities (CRPD) (2006).
<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- Lollar, D., & Simeonsson, J. (2005). Diagnosis to Function: Classification for Children and Youths. *Journal of Developmental & Behavioral Pediatrics*, 26(4): 323-330.
- Moore, C. G., Carter, R. E., Nietert, P. J., & Stewart, P. W. (2011). Recommendations for planning pilot studies in clinical and translational research. *Clinical and Translational Science*, 4(5): 332-337.
- Nowicki, E. A. (2006). A cross-sectional multivariate analysis of children's attitudes towards disabilities. *Journal of Intellectual Disability Research*, 50(Pt 5), 335-348.
- Priestley, M. (2003). Symposium on disability and the life course: Introduction to the symposium. *Disability Studies Quarterly*, 23(2), 1-5.
- Pruett, S. R., Lee, E. J., Chan, F., Wang, M. H., & Lane, F. J. (2008). Dimensionality of the Contact with Disabled Persons Scale: Results from exploratory and confirmatory factor analyses. *Rehabilitation Counseling Bulletin*, 51(4), 210-220.
- Simeonsson, R.J., Leonardi, M., Lollar, D., Bjorck-Akesson, E., Hollenweger, J., & Martinuzzi, A. (2009). Applying the International Classification of Functioning, Disability and Health (ICF) to measure childhood disability. *Disability and Rehabilitation*, 25(11-12) 602-610. <http://doi.org/10.1080/0963828031000137117>
- UNICEF. (2007). *Child-friendly schools: A situation analysis for FYR Macedonia*. Retrieved from [https://www.unicef.org/tfyr-macedonia/CFS_BASELINE_STUDY_FINAL_ENG\(1\).pdf](https://www.unicef.org/tfyr-macedonia/CFS_BASELINE_STUDY_FINAL_ENG(1).pdf)
- UNICEF. (2013). *Building equity for children: Findings of a situation analysis of girls and boys*. Retrieved from https://www.unicef.org/tfyr-macedonia/SitAn_Macedonia_5May2014.pdf

- UNICEF. (2014a). *Case studies from schools involved in UNICEF's inclusive education training-of-trainers programme (2012-2014)*. Retrieved from [https://www.unicef.org/tfymacedonia/Inclusive Education - ang%281%29.pdf](https://www.unicef.org/tfymacedonia/Inclusive_Education_-_ang%281%29.pdf)
- UNICEF. (2014b). *Knowledge, attitudes, and practices (KAP) survey towards inclusion of children with disabilities: presentation*. Retrieved from [https://www.unicef.org/tfymacedonia/GfK Skopje KAP Survey 2014 Report 261220 14 Publish ENG \(4\).pdf](https://www.unicef.org/tfymacedonia/GfK_Skopje_KAP_Survey_2014_Report_261220_14_Publish_ENG_(4).pdf)
- UNICEF. (2014c). *Knowledge, attitudes, and practices (KAP) towards children with disabilities: key findings of a household study*. Retrieved from [https://www.unicef.org/tfymacedonia/Unicef - Disabilities Infografici EN final.pdf](https://www.unicef.org/tfymacedonia/Unicef_-_Disabilities_Infografici_EN_final.pdf)
- UNICEF. (2014d). *Mainstreaming respect for diversity and multiculturalism in early childhood development*. Retrieved from [https://www.unicef.org/tfymacedonia/MultikulturnoObrazovanie forWeb final EN.pdf](https://www.unicef.org/tfymacedonia/MultikulturnoObrazovanie_forWeb_final_EN.pdf)
- UNICEF. (2015a). *Assessment of capacity of services provided by health, education, and social sectors for inclusion of children with disabilities*. Retrieved from [https://www.unicef.org/tfymacedonia/Children with disability report ENG.pdfn](https://www.unicef.org/tfymacedonia/Children_with_disability_report_ENG.pdfn)
- UNICEF. (2015b). *Inclusive education report from the baseline study*. Retrieved from [https://www.unicef.org/tfymacedonia/Unicef - izvestaj za merenje sostojba vo uciliste ANG - ZA WEB.pdf](https://www.unicef.org/tfymacedonia/Unicef_-_izvestaj_za_merenje_sostojba_vo_uciliste_ANG_-_ZA_WEB.pdf)
- UNICEF. (2015c). *Towards a cross-sectoral approach to inclusion of children with disabilities*. Retrieved from [https://www.unicef.org/tfymacedonia/Policy Brief AssessmentOfCapacityOfDisability Services v6 EN FINAL-SENTTOPRINT.pdf](https://www.unicef.org/tfymacedonia/Policy_Brief_AssessmentOfCapacityOfDisability_Services_v6_EN_FINAL-SENTTOPRINT.pdf)
- UNICEF. (2016a). *Inclusive education report from the progress study*. Retrieved from [https://www.unicef.org/tfymacedonia/Inclusive Education Progress study 2016 EN.pdf](https://www.unicef.org/tfymacedonia/Inclusive_Education_Progress_study_2016_EN.pdf)
- UNICEF. (2016b). *Towards inclusive education: report of the conducted research regarding inclusion of children with disabilities in regular primary education*. Retrieved from [https://www.unicef.org/tfymacedonia/Towards inclusive education ENG final.pdf](https://www.unicef.org/tfymacedonia/Towards_inclusive_education_ENG_final.pdf)
- UNICEF. (2017). *UNICEF Annual Report 2017: Macedonia (The former Yugoslav Republic of)*. [https://www.unicef.org/about/annualreport/files/Macedonia \(The former Yugoslav Republic of\) 2017 COAR.pdf](https://www.unicef.org/about/annualreport/files/Macedonia_(The_former_Yugoslav_Republic_of)_2017_COAR.pdf)
- UNICEF. (2018). *Applying Behavioural Insights to Teachers' and Social Workers' Motivation*. Unpublished report (received from UNICEF Macedonia).
- UNICEF & Mackie, G. (2015). *What are social norms? How are they measured?* Retrieved from [https://www.unicef.org/protection/files/4_09_30_Whole What are Social Norms.pdf](https://www.unicef.org/protection/files/4_09_30_Whole_What_are_Social_Norms.pdf)

Yuker, H. E., Block, J. R., & Young, J. H. (1970). *The Measurement of Attitudes Toward Disabled Persons*. Washington DC.

APPENDIX A: Scales from Systematic Review of the Literature

The tables below list individual questions in the three validated tools identified in the systematic review and identify (in orange) the specific stakeholders with whom the tool has already been validated. The Drexel team will see if it is possible to adapt some of these questions for other stakeholder groups. It is important to note, however, that these scales were created many years ago, before the CRPD. Therefore, adaptations of these questions will be sure to consider their limitations and adjust them to reflect current thinking on disability.

Chedoke-McMaster Attitudes towards Children with Handicaps Scale (CATCH). The CATCH scale consists of 36 items and uses a 5-point Likert scale (0 denoting strongly disagrees, and 4 denoting strongly agree). The scale is divided into three sets of 12 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 alternating positively and negatively worded items. Higher scores on CATCH indicate more positive attitudes towards peers with disabilities. The CATCH scale can be used to assess attitudes of peers of children with disabilities (Rosembaum, Armstrong & King, 1986).

- This scale was designed for children aged 9-13 and the questions are aimed to assess their experiences and attitudes of children towards their peers with disabilities.
- 36- item scale
- Uses a 5-point Likert scale (0-strongly disagree and 4-strongly agree)
- Higher scores indicate more positive attitudes towards peers with disabilities

No.	Questions	Children with disabilities	Parents of children with disabilities	Peers of children with disabilities	Teachers	School Admin	Health Workers	NGO's, Social Workers	Parent's w/o children with disabilities	Govt. Officials
1	I wouldn't mind if a handicapped child sits next to me									
2	I wouldn't introduce a handicapped child to my friend									
3	Handicapped children can do lots of things for themselves									
4	I wouldn't know what to say to a handicapped child									
5	Handicapped children like to play									
6	I feel sorry for handicapped children									
7	I would stick up for a handicapped child who was being teased									
8	Handicapped children want lots of attention from adults									
9	I would invite a handicapped child to my birthday party									
10	I would be afraid of a handicapped child									
11	I would talk to a handicapped child I didn't know									
12	Handicapped children don't like to make friends.									
13	I would like a handicapped child to live next-door to me									
14	Handicapped children feel sorry for themselves									
15	I would be happy to have a handicapped child for a special friend									
16	I would try to stay away from a handicapped child									
17	Handicapped children are as happy as I am									

18	I wouldn't like a handicapped friend as much as my other friends								
19	Handicapped children know how to behave properly								
20	In class I wouldn't sit next to a handicapped child								
21	I would be pleased if a handicapped child invited me to his house.								
22	I try not to look at someone who is handicapped								
23	I would feel good doing a school project with a handicapped child								
24	Handicapped children don't have much fun								
25	I would invite a handicapped child to sleep over at my house								
26	Being near someone who is handicapped scares me								
27	Handicapped children are interested in lots of things.								
28	I would be embarrassed if a handicapped child invited me to his birthday								
29	I would tell my secret to a handicapped child								
30	Handicapped children are often sad								
31	I would enjoy being with a handicapped child								
32	I would not go to a handicapped child's house to play								
33	Handicapped children can make new friends								
34	I feel upset when I see a handicapped child								
35	I would miss recess to keep a handicapped child company								
36	Handicapped children need lots of help to do things								

Opinions Relative to Integration scale (ORI). 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 (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. The ORI scale can be particularly beneficial when assessing attitudes toward Inclusive Education (IE). IE is an approach to designing an education system that meets the needs of all students, based on the tenets of the CRC, the CRPD, and the Salamanca Statement (UNICEF, 2016b). While IE definitions encourage adaptations to eliminate discrimination against many marginalized groups of children, this pilot study will focus on IE as it relates to children with disabilities.

- This attitudinal scale was developed to assess the 'effects of the selected institutional variables on the attitude of the regular-classroom teachers toward the mainstreaming process" (Larrivee & Cook, 2001)
- Assesses inclusion
- 25 item-scale
- 6-point Likert scale (+3: agree very much to -3: disagree very much)
- Higher scores indicate more favourable attitudes

N o.	Questions	Children with disabilities	Parents of children with disabilities	Peers of children with disabilities	Teachers	School Admin	Health Workers	NGO's, Social Workers	Parent's w/o children with disabilities	Govt. Officials
1	Most students with disabilities will make an adequate attempt to complete their assignments.									
2	Integration of students with disabilities will necessitate extensive retraining of general classroom teachers.									
3	Integration offers mixed group interaction that will foster understanding and acceptance of differences among students.									
4	It is likely that the student with a disability will exhibit behaviour problems in a general classroom.									
5	Students with disabilities can be best served in general classrooms.									
6	The extra attention students with disabilities require will be to the detriment of the other students.									
7	The challenge of being in a general classroom will promote the academic growth of the student with a disability.									
8	Integration of students with disabilities will require significant changes in general classroom procedures.									
9	Increased freedom in the general classroom creates too much confusion for the student with a disability.									
10	General-classroom teachers have the ability necessary to work with students with disabilities									
11	The presence of students with disabilities will not promote acceptance of differences on the part of students without disabilities.									
12	The behaviour of students with disabilities will set a bad example for students without disabilities.									
13	The student with a disability will									

	probably develop academic skills more rapidly in a classroom than in a special classroom.								
14	Integration of the student with a disability will not promote his or her social independence.								
15	It is not more difficult to maintain order in a general classroom that contains a student with a disability than in one that does not contain a student with a disability								
16	Students with disabilities will not monopolize the general-classroom teacher's time								
17	The integration of students with disabilities can be beneficial for students without disabilities.								
18	Students with disabilities are likely to create confusion in the general classroom.								
19	General-classroom teachers have sufficient training to teach students with disabilities								
20	Integration will likely have a negative effect on the emotional development of the student with a disability.								
21	Students with disabilities should be given every opportunity to function in the general classroom where possible.								
22	The classroom behaviour of the student with a disability generally does not require more patience from the teacher than does the classroom behaviour of the student without a disability								
23	Teaching students with disabilities is better done by special rather than general classroom teachers.								
24	Isolation in a special classroom has beneficial effect on the social and emotional development of the student with a disability.								
25	The student with a disability will not be socially isolated in the general classroom.								

Attitude Toward Disabled Person Scale (ATDP). 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 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-disabled persons (Yuker, Block, & Youngg, 1970). Items from this scale can be used to assess attitudes of the general public.

- 20-item scale
- 6-point Likert scale (+3: I agree very much to -3: I disagree very much)
 - No neutral point is included
 - Composite score of 0 to 180 is calculated
- High scores indicate that the respondent perceives disabled persons as being not very different from non-disabled persons

No.	Questions	Children with disabilities	Parents of children with disabilities	Peers of children with disabilities	Teachers	School Admin	Health Workers	NGO's, Social Workers	Parent's w/o children with disabilities	Govt. Officials
1	Parents of children with disabilities should be less strict than other parents.									
2	Persons with physical disabilities are just as intelligent as nondisabled ones.									
3	People with disabilities are usually easier to get along with than other people.									
4	Most people with disabilities feel sorry for themselves.									
5	People with disabilities are often the same as anyone else.									
6	There should not be special schools for children with disabilities.									
7	It would be best for persons with disabilities to live and work in special communities.									
8	It is up to the government to take care of persons with disabilities.									
9	Most people with disabilities worry a great deal.									
10	People with disabilities should not be expected to meet the same standards as people without disabilities.									
11	People with disabilities are as happy as people without disabilities.									
12	People with severe disabilities are no harder to get along with than those with minor disabilities.									
13	It is almost impossible for a person with a disability to lead a normal life.									
14	You should not expect too much from people with disabilities.									
15	People with disabilities tend to keep to themselves much of the time.									
16	People with disabilities are more easily upset than people without disabilities.									
17	People with disabilities cannot have a normal social life.									
18	Most people with disabilities feel that they are not as good as other people.									
19	You have to be careful what you say when you are with people with disabilities.									
20	People with disabilities are often									

APPENDIX B: Scales from UNICEF Country Offices

Elements from several tools from the review of UNICEF-sponsored research can be borrowed and tested during the pilot study. The Drexel team will pull out questions that are most relevant to the pilot study and assess whether they can be used as is or require some adaption. Justifications for any changes made will be provided.

UNICEF Bosnia & Herzegovina and UNICEF Montenegro

Since these two countries essentially used the same questionnaire (there are some differences), one table has been created summarizing the questions.

Table 6: Knowledge, Attitudes, and Practices Survey on Children Disability	
Attitudinal Questions	Response Categories
B2: In your opinion, to what extent does each of the following groups of children belong to category of children with disabilities? [Asked for the 14 categories of children with disabilities]	<ul style="list-style-type: none"> • Doesn't belong at all • Somewhat belongs • Both yes and no • Mainly belongs • Fully belongs • Don't know / refuse to answer
C2: Now I will read you several statements. Please evaluate to what extent you agree with each of the statements using a scale from 1 to 5, where 1=don't agree at all and 5 = I completely agree <ul style="list-style-type: none"> • The state and society should do everything in their power to ensure equal opportunities and chances for children with special needs, regardless of the costs • Regardless of the pain and the effort that they and their families make, children with special needs cannot be fully fit in society, the way in which other children do • Child with special needs are equally valuable members of society, as well as all other citizens • The state and society are not able to significantly help children with special needs, no matter how much they try and how much money they invest 	I don't agree at all I don't agree at all [this must be a typo] Indecisive I agree I completely agree
E1: Now I will read to you several statements. Please evaluate to what extent you agree with each of the statements using a scale from 1 to 5 where 1= I don't agree at all and 5 = I completely agree <ul style="list-style-type: none"> • For children with special needs, it is better to stay in special institutions than to live in their families, because these institutions have experts who are specially trained to work with them • Other children who are growing up in families with children with 	I don't agree at all I don't agree Indecisive I agree I completely agree

<ul style="list-style-type: none"> special needs, learn to be more attentive and more tolerant • Parents who are raising children with special needs, usually have to dedicate their life to them completely • If a child with special needs is left without parental care, it is better to put it in a foster family than in a home • I feel sorry for families with a child with special needs, because they are victims of unfortunate coincidence. • Families of children with special needs cannot be expected to overcome all the challenges alone, they must be supported by the wider society • In families where a child with special needs is growing up, other children are usually neglected • Parents of children with special needs often take too patronizing attitude towards their child, which leads to isolation of that child from other children 	
<p>F5: In your opinion, do children with disabilities have the same opportunities and chances for development of personal potential as other children in BiH/Montenegro do?</p>	<p>Yes, No, don't know/refuse to answer</p>
<p>F9: In your opinion, what is the best way to help children with special needs and make their life in our society easier?</p>	<p>All children with special needs should be put in special institutions, with specially trained staff and activities adjusted to their abilities Only a minority of more difficult cases of children with special needs should be put in special institutions and the majority of children with special needs should be included in all regular activities along with other citizens All the children with special needs should live together with other people (not in specialized institutions) and be, as much as they can, adapted to living in society. The wider society should, above all, become adapted to children with special needs, in order for them to get included into everyday life in the easiest possible way. Do not know</p>

UNICEF CO of the Republic of North Macedonia

<p>I will now read to you some of the existing groups of children. For each, please tell me which of the following situations are acceptable for you personally. <i>Rotate order of statements. Multiple responses. Show card with situations</i></p>	
<p>1. Children who have persistent difficulties learning and understanding (A)</p>	<p>Doesn't belong at all Somewhat belongs Both yes and no Mainly belongs Fully belongs Don't know/Refuse to answer</p>
<p>2. Children with intellectual disability (H)</p>	
<p>3. Children who have persistent difficulties interacting with peers and behaviour (A)</p>	
<p>4. Blind children (I)</p>	
<p>5. Children with autism (H)</p>	
<p>6. Children with Down Syndrome (H)</p>	
<p>7. Children with vision impairment (diopetre greater than + - 10) or hearing impairment (I)</p>	
<p>8. Deaf children (I)</p>	
<p>9. Children who do not understand the spoken language (A)</p>	
<p>10. Children who stutter (I)</p>	
<p>11. Children with asthma (H -H)</p>	
<p>12. Children with epilepsy (H-H)</p>	
<p>13. Children who have difficulties in moving and using body parts (A)</p>	
<p>14. Children with a lack a part of the body (I)</p>	
<p>Now I am going to read some statements. Please state how much you agree with them using the scale 1 to 5 where 1 means ABSOLUTELY DO NOT AGGREE and 5 means FULLY AGREE <i>Single answer per statement. Show card with statements and scale 1 to 5</i></p>	
<p>1. The state and society should do everything possible to ensure equal opportunities and chances for children with disabilities, regardless of the costs.</p>	<p>Absolutely do not agree Do not agree Neither agree or disagree Agree Fully agree</p>
<p>1. Regardless of the effort that they and their families make, children with disabilities cannot be fully integrate in society, the way in which other children do.</p>	
<p>2. Children with disabilities can equally contribute to society, as other citizens.</p>	
<p>3. No matter how much the state and society tries and how much money they invest, there is not much that can be done to help children with disabilities</p>	
<p>Which of the following 3 statements is closer to your views? <i>Single answer. Show card.</i></p>	<p>1. I feel sorry for children with disabilities, they need help and financial assistance in order to fit in society 2. Children with disabilities need medical care, rehabilitation services and other special services to fit in society. 3. Environmental barriers, such as physical and those that people create through attitudes and stereotypes need to be removed for children with disabilities to fit in society.</p>
<p>Which of the following 2 statements is closer to your views? <i>Single answer. Show card.</i></p>	<p>1. With the help of family and the environment, child with disabilities should adapted to life in society, 2. Society and the environment should be adapted the child with disabilities, taking into consideration their needs</p>
<p>How possible is it for a child with disabilities to lead an independent and productive life as an adult, if given support from professionals, institutions and society? <i>Single answer.</i></p>	<p>1. FULLY possible 2. SOMEWHAT possible 3. NOT possible 4. Don't know/Refuses to answer</p>
<p>MAKE SURE TO READ OUT: Now I am going to ask questions to compare children WITH disabilities to children WITHOUT disabilities. <i>Show card</i></p>	

Using the following pairs of attributes, try to describe the AVERAGE CHILD in Macedonia (child without disabilities)?									
1.	Insecure	1	2	3	4	5	6	7	Self-confident
2.	Independent	1	2	3	4	5	6	7	Depend on others
3.	Accepted by other children	1	2	3	4	5	6	7	Estranged from other children
4.	Equal opportunities as other children	1	2	3	4	5	6	7	Do not have equal opportunities as other children
5.	Sad	1	2	3	4	5	6	7	Cheerful
7.	Uncertain future	1	2	3	4	5	6	7	Safe future
8.	Optimistic	1	2	3	4	5	6	7	Pessimistic
9.	Brave	1	2	3	4	5	6	7	Fearful
Based on what you know or assume, using the same pairs of attributes, try to describe A CHILD WITH DISABILITIES in Macedonia?									
<i>Show card</i>									
1.	Insecure	1	2	3	4	5	6	7	Self-confident
2.	Independent	1	2	3	4	5	6	7	Depend on others
3.	Accepted by other children	1	2	3	4	5	6	7	Estranged from other children
4.	Equal opportunities as other children	1	2	3	4	5	6	7	Do not have equal opportunities as other children
5.	Sad	1	2	3	4	5	6	7	Cheerful
7.	Uncertain future	1	2	3	4	5	6	7	Safe future
8.	Optimistic	1	2	3	4	5	6	7	Pessimistic
9.	Brave	1	2	3	4	5	6	7	Fearful

UNICEF Georgia

Georgia developed a stigma scale which originally contained 16 items and was later scaled down to 5 items. The stigma scale was inserted into the VAC Survey and the National Youth Survey.

Table 7: Georgia VAC Survey

Scale Items	Response Categories
H4: What do you think, is it hard for people with disabilities to find a job?	Yes, Maybe, No, Don't know
H5: What do you think, is it hard for people with disabilities to get married?	
H6: If you have or had a child with disabilities, would your family members have negative attitude towards you because of this child?	
H7: In your opinion, do other family members have negative attitude towards the child with disabilities?	
H8: What do you think, does a child with disabilities cause problems to his/her family not only in terms of financial aspect?	
H9: What do you think, is it a problem for a family to declare about having a child with disabilities?	
H10: What do you think will people who have a family member with disabilities have problems to get married?	
H11: What do you think, if it was possible, would the parent try to hide the fact, that he/she has a child with disabilities?	
H12: What do you think, would/does society have negative attitude towards the family who has a child with disabilities?	
H13: What do you think, does society thinks that the family, where disabled child is born should leave/pass such child to the respective institution/organization?	
H14: In your society, does having a child with disabilities cause feeling of shame or awkwardness?	
H15: Do you think that people do not like to buy food from person with disabilities?	
H16: Do you think that people around you avoid having contact with child with disabilities?	
H17: Do you think that people try to avoid visiting the families which have children with disabilities?	

Table 8: National Youth Survey

Attitudinal Questions	Response Categories
78.1: In your opinion, is it a problem for a family to disclose the fact that there is a disabled child in the family?	Yes, Partially, No, Difficult to answer
78.3: In your opinion, if it were possible, would the parent hide from others that s/he has a disabled child?	
78.4: In your opinion, does the society believe that the family with a disabled child must leave/give away the child to a relevant institution/establishment?	

78.5: Do you think that the people around you restrain from relations with a disabled child?	
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APPENDIX C: Recommendations from the Systematic and UNICEF-sponsored Research Reviews and their Application to this Pilot Study

Table 9: Consolidated List of Recommendations from the Systematic and UNICEF-sponsored Research Reviews

Recommendation	Notes on Application to this Consultancy
Conduct research in low-income countries	While the ECA region does not include any low-income countries, the conceptual model, M&E framework, and data collection tools have the potential to be adapted for use around the globe.
Develop clear strategies for selecting research sites	The first part of this current work is designed as a pilot study to help develop a robust tool to measure attitudes and norms towards children with disabilities. Pilot studies do not have the same stringent methodological requirements as full-fledged field-based research, for example the research site selection for the pilot is likely to involve some level of convenience sampling. After the pilot study, the finalized M&E plan will provide clear strategies on research site selection for field-based monitoring and evaluation.
Plan ahead for disaggregation of results by background and variables	Pilot studies are designed to be demographically and economically similar to the larger representative population, however the data is not generalizable. Mistakenly, some think of pilots as “mini-baselines” This is incorrect. In the interests of time and resources, the level of disaggregation needed in the pilot needs to be determined. The overall M&E plan will provide information to ensure disaggregation so as to get an accurate representation of the intended audiences in future full-scale initiatives.
Ground research within theory-based conceptual frameworks*	A draft conceptual model examining discriminatory attitudes and norms towards children with disabilities will draw upon the Children and Youth Version of the International Classification of Functioning, Disability, and Health (ICF-CY) and will be finalized using findings from the pilot study so that future research can be grounded in theory.
Adopt a life cycle approach	Does discrimination towards children with disabilities vary depending on their age and where they are in a life course perspective? This is a critical research question. This pilot study will not adopt a life-course approach due to time and resource constraints, but it will keep this perspective in mind and include recommendations to address this in the overall M&E plan.
Standardize definitions and typologies of disabilities being studied*	The pilot study will use the ICF-CY Framework’s categorization of disabilities from both the traditional medical and socio-cultural perspective to define disabilities. The inputs of ECARO

	colleagues will be used to decide how to define disability and what disabilities to focus on.
Define measurable constructs to measure attitudes	The pilot study will define attitudes as having three components: cognitive, affective, and behavioural dimensions. It will also ensure directionality and valence.
Create attitudinal measures that differentiate among types of disability	While attitudinal measures should focus on specific disabilities to avoid eliciting overly-generalized data, the pilot study may need to focus on disabilities as a whole given time and resource constraints.
Ensure attitudinal measures specify direction and degree	The attitudinal measures used in the pilot study will follow best practices by specifying direction and degree, avoiding neutral language, alternating between positive and negatively worded statements, and covering all three components of attitudes.
Take advantage of existing scales, but validate them in the field	The pilot study will test and adapt the three validated scales identified during the systematic review.
Focus on understanding and measuring social norms*	This desk review provides a detailed explanation of social norms and how to measure them, as well as example questions that could be used in the pilot study.
Ensure ethical standards for human subjects' research are in place	The pilot study will seek ethical approval from international and local ethical review committees. More details will be provided in the inception report.
Involve all key stakeholders*	A list of important stakeholders and potential participants for the pilot study can be found in the summary and clarification points section. Not all groups can be included in the pilot study, but efforts will be made to incorporate the widest possible range of experiences.
Include the perspectives of Children with disabilities*	The pilot study will involve children with disabilities so as to ensure that this research is done with them instead of about them.
Draw upon participatory approaches and use mixed methods*	The pilot study will consider the feasibility of using participatory research methods so that children with disabilities can be actively involved in the research. The pilot study will also utilize both qualitative and quantitative methods. Additional details will be provided in the inception report.
Standardize data collection, reporting, and dissemination of UNICEF-sponsored research	The M&E framework that will be developed will promote the use of UNICEF's quality review checklist and external review facilities for research and studies on social norms and attitudes towards children with disabilities. The developed protocol and all tools will be externally reviewed by UNICEF's review facility.
*denotes recommendation that came out of both the systematic review and review of UNICEF-sponsored research	

APPENDIX D: Citations for Macedonia Document Review

Government of Republic of Macedonia. (2006). *Multiple indicator cluster survey*. Retrieved from <http://mics.unicef.org/surveys>

Government of Republic of Macedonia. (2011). *Multiple indicator cluster survey*. Retrieved from <http://mics.unicef.org/surveys>

UNICEF. (2007). *Child-friendly schools: A situation analysis for FYR Macedonia*. Retrieved from [https://www.unicef.org/tfyrmacedonia/CFS_BASELINE_STUDY_FINAL_ENG\(1\).pdf](https://www.unicef.org/tfyrmacedonia/CFS_BASELINE_STUDY_FINAL_ENG(1).pdf)

UNICEF. (2008). *It's about ability: An explanation of the Convention on the Rights of Persons with Disabilities*. Retrieved from [https://www.unicef.org/tfyrmacedonia/About_Ability_final_English\(2\).pdf](https://www.unicef.org/tfyrmacedonia/About_Ability_final_English(2).pdf)

UNICEF. (2009). *Child friendly schools case study: Macedonia*. Retrieved from https://www.unicef.org/education/files/CFS_MacedoniaCaseStudy_April2009.pdf

UNICEF. (2010). *Inclusive education as part of a child-friendly schools' framework: Results and recommendations from a study in Macedonia*. Retrieved from https://www.unicef.org/tfyrmacedonia/INCLUSIVE_REPORT_ENG.pdf

UNICEF. (2013a). *Building equity for children: A situation analysis of girls and boys in the former Yugoslav Republic of Macedonia*. Retrieved from https://www.unicef.org/tfyrmacedonia/SitAn_Macedonia_5May2014.pdf

UNICEF. (2013b). *Building equity for children: Findings of a situation analysis of girls and boys*. Retrieved from https://www.unicef.org/tfyrmacedonia/SitAn_Macedonia_5May2014.pdf

UNICEF. (2014a). *Case studies from schools involved in UNICEF's inclusive education training-of-trainers programme (2012-2014)*. Retrieved from https://www.unicef.org/tfyrmacedonia/Inclusive_Education_-_ang%281%29.pdf

UNICEF. (2014b). *Knowledge, attitudes, and practices (KAP) survey towards inclusion of children with disabilities: presentation*. Retrieved from [https://www.unicef.org/tfyrmacedonia/GfK_Skopje_KAP_Survey_2014_Report_261220_14_Publish_ENG_\(4\).pdf](https://www.unicef.org/tfyrmacedonia/GfK_Skopje_KAP_Survey_2014_Report_261220_14_Publish_ENG_(4).pdf)

UNICEF. (2014c). *Knowledge, attitudes, and practices (KAP) towards children with disabilities: key findings of a household study*. Retrieved from https://www.unicef.org/tfyrmacedonia/Unicef_-_Disabilities_Infografici_EN_final.pdf

UNICEF. (2014d). *Mainstreaming respect for diversity and multiculturalism in early childhood development*. Retrieved from https://www.unicef.org/tfyrmacedonia/MultikulturnoObrazovanie_forWeb_final_EN.pdf

- UNICEF. (2014e). *Mapping of disability persons' organisations*. Retrieved from [https://www.unicef.org/tfymacedonia/Mapping_Report-for_UNICEF_Publish_\(EN\).pdf](https://www.unicef.org/tfymacedonia/Mapping_Report-for_UNICEF_Publish_(EN).pdf)
- UNICEF. (2015a). *Assessment of alternative forms of care and family support services for children with disabilities*. Retrieved from https://www.unicef.org/tfymacedonia/UNICEF-Alternative_Care_Assessment-A4-ANG_for_web.pdf
- UNICEF. (2015b). *Assessment of capacity of services provided by health, education, and social sectors for inclusion of children with disabilities*. Retrieved from https://www.unicef.org/tfymacedonia/Children_with_disability_report_ENG.pdfn
- UNICEF. (2015c). *Communication strategy to support inclusion of children with disabilities (2015-2020)*. Retrieved from the UNICEF Macedonia office, unpublished.
- UNICEF. (2015d). *Inclusive education report from the baseline study*. Retrieved from https://www.unicef.org/tfymacedonia/Unicef_-_izvestaj_za_merenje_sostojba_vo_uciliste_ANG_-_ZA_WEB.pdf
- UNICEF. (2015e). *Towards a cross-sectoral approach to inclusion of children with disabilities*. Retrieved from https://www.unicef.org/tfymacedonia/Policy_Brief_AssessmentOfCapacityOfDisability_Services_v6_EN_FINAL-SENTTOPRINT.pdf
- UNICEF. (2016a). *Inclusive education report from the progress study*. Retrieved from https://www.unicef.org/tfymacedonia/Inclusive_Education_Progress_study_2016_EN.pdf
- UNICEF. (2016b). *Towards inclusive education: report of the conducted research regarding inclusion of children with disabilities in regular primary education*. Retrieved from https://www.unicef.org/tfymacedonia/Towards_inclusive_education_ENG_final.pdf
- UNICEF. (2017a). *#FightUnfair campaign*. Retrieved from https://www.unicef.org/tfymacedonia/campaigns_29051.html
- UNICEF. (2017b). *Be fair: for a childhood without barriers campaign*. Retrieved from https://www.unicef.org/tfymacedonia/campaigns_30476.html
- UNICEF. (2017c). *Every child needs a family campaign*. Retrieved from https://www.unicef.org/tfymacedonia/campaigns_29268.html
- UNICEF. (2017d). *Inclusive children's festival "Creating Together" at the Skopje Film Festival*. Retrieved from https://www.unicef.org/tfymacedonia/media_30776.html
- UNICEF. (2017e). *See the child, not the disability campaign*. Retrieved from https://www.unicef.org/tfymacedonia/campaigns_31425.html

APPENDIX E: Examples of C4D Efforts in the Republic of North Macedonia

Below is a list of selected C4D efforts in the Republic of North Macedonia. It is important to note that this list does not include a complete overview and several recent media and community C4D interventions as well as details from existing and current campaigns is not included here, but available upon request from the UNICEF CO.

Conferences and Public Declarations

At the 2017, Every Child Needs a Family conference, the government pledged to end placement of children under 3 years of age in large scale institutions by 2020. The pledge includes commitments to 1) ensure every child grows up in a safe and caring family environment by investing in prevention of abandonment and support to biological families; 2) develop new forms of foster care and expand the network of foster families; 3) invest in improving the quality of alternative care through standardization; 4) invest in early detection and intervention of developmental difficulties; and 5) invest in children themselves through preschool and ECD efforts. The conference included a panel discussion on establishing sustainable community-based alternatives that showcased successful practices and lessons learned from Slovenia, Montenegro, Serbia, and Georgia.

Workshops

In 2017, the Creating Together Initiative held a workshop for 86 children with and without disabilities. The school-based workshop included videos that address barriers, taboos, and stereotypes about people with disabilities. There was also a photography and poster exhibition with entries submitted by children of all abilities. Finally, students were able to debate on the topic "Creativity: A window to the World of Diversity."

Campaigns

Several media campaigns have been created to address stigma and discrimination. The 2017 Be Fair campaign aims to increase public awareness and support for the rights and inclusion of Children with disabilities by promoting the social model of disability, change individual's attitudes towards Children with disabilities so they see the child first and their abilities instead of disabilities, and stimulate the public to identify with the barriers Children with disabilities face on a daily basis. The campaign uses a wide range of communication approaches and platforms to disseminate messages including social experiments (e.g. hidden camera to capture individuals' attitudes towards a woman with Down Syndrome working at a pharmacy), videos, public service announcements, social media, the "Without Barriers" app, "Ability Talk" workshops led by individuals with disabilities, and media outlets (e.g. radio and newspapers). In 9 months, the campaign has reached an estimated 5 million people, has engaged more than

200,000 people and has contributed to a government commitment to accelerate reforms for inclusion. There are plans to formally evaluate the campaign in 2018.

A companion campaign to Be Fair is “See the Child, Not the Disability,” which hopes to “unleash the potential in every child and address the attitudinal barriers to inclusion.” It includes a series of billboards (erected in over 100 locations) showcasing Children with disabilities as friends, students, learners, musicians, sports champions, and more. A children's film festival "Caravan for a Childhood without Barriers" is travelling around the country and hopes to stimulate dialogue about disability issues.

Additionally, since 2015, the #FightUnfair social media campaign has aimed to engage advocates to speak out about the unfair situation of Children with disabilities. People are able to sign a pledge stating that they will change the way they see Children with disabilities. This is part of the multi-year strategy to mobilize broad support for Children with disabilities and increase the number of citizens who support equal rights and inclusion of Children with disabilities.

APPENDIX F: Secondary Analysis of 2006 and 2011 MICS Data

The MICS survey conducted in Macedonia collects data on several different indicators such as, education, child malnutrition, immunization, water and sanitation, and birth registration, that contribute to the overall well-being of both women and children. Therefore, along with evaluating the progress of different interventions and improving the internal data and monitoring systems in Macedonia, the different variables assessed in the MICS survey are progress markers for global child-related targets and goals (Multiple Indicator Cluster Survey, 2006).

The MICS survey was conducted by UNICEF at a national level, in both rural and urban areas in 8 regions (Multiple Indicator Cluster Survey, 2006). Women aged 15-49 were interviewed from a sample of 5250 households. The survey consisted of 3 questionnaires. The first one was used to collect information about household members such as, household listing forms, education, water and sanitation, household characteristics, child labor, child discipline and child disability. The second questionnaire was specifically for the women in the household to collect information about child mortality, maternal and newborn health, marriage/union, contraception, attitudes towards domestic violence, sexual behavior and HIV/AIDs. The last part of the survey was a questionnaire about children under 5 which was administered to their mothers or caretakers and looked at birth registration and early learning, child development, breastfeeding, care of illness, immunization and anthropometry.

Our analysis looked at data from the first questionnaire that includes questions on child disability. These screening questions are aimed to determine disability status. This questionnaire was administered to mothers or caregivers of children 2-9 years old. Mothers and caretakers reported knowing different disabilities in their children. This questionnaire assesses

the number of disabilities or impairment such as, sight, deafness and speech (Multiple Indicator Cluster Survey, 2006). Using pub

The analysis of the MICS 2005-2006 and 2011 data was done using the data analysis program STATA. Frequency and significance, using chi square, for the 2005-2006 and the 2011 MICS data sets was calculated for physical and learning/developmental disabilities for the following variables: region, area, wealth index, and ethnicity. Results are found in Table 10 below.

The ten types of disabilities from the datasets were: delay in sitting, standing, or walking; difficulty seeing either in the daytime or at night; appears to have difficulty hearing; no understanding of instructions; difficulty in walking, moving arms, weakness or stiffness; have fits become rigid, lose consciousness; not learning to do things like other children his/her age; no speaking/cannot be understood in words; appears mentally backward, dull or slow; and cannot name at least one object. These ten disabilities were grouped into two categories, physical impairments and learning/developmental impairments (see Figure 12: *Ten disabilities assessed in MICS* Those designated as physical disabilities were all abnormalities of a physiological or an anatomical structure (Emory, 2018). The disabilities labelled as learning/developmental disabilities all result in a difficulty with academic skills like reading and writing. They have a direct impact on the ability of a child to learn and progress in terms of skills.

<i>Table 10: Physical and Learning/Developmental Disabilities by Sociodemographic Characteristics of the Mother.</i>	Has a child aged 2-9 years with at least one physical disability		Has a child aged 2-9 years with at least one learning or developmental disability	
	2006	2011	2006	2011
REGION				
Skopje	16.7	9.4	17.1	6.0
Pelagonia	11.6*	9.9	21.0*	9.1
Vardar	16.8	8.8	7.3	5.7
North-East	20.3	11.8	8.3*	6.2
South-West	17.4	5.0	10.6	20.8*
South-East	11.9*	12.0	7.5	5.4
Polog	20.3	8.5	8.3*	11.6
East	37.2*	8.4	24.7*	0.0
AREA				
Urban	20.1*	9.1	15.0	7.0
Rural	15.6*	9.3	13.9	8.8
WEALTH INDEX				
Poorest	24.1*	13.3*	18.5*	15.0*
Second	16.9	10.4	15.8	9.1
Middle	13.9*	7.3	10.9	0.0*
Fourth	13.2*	6.9	9.6	6.2
Richest	12.9*	7.6	11.4	8.7
ETHNICITY				

Macedonian	16.4*	8.5	13.9	6.3
Albanian	18.2	8.9	11.9	11.5
Roma	19.9	-	19.5*	-
Other	21.8*	14.7*	17.9	7.4
<i>*Significant values of p value ≤ 0.05</i>				

APPENDIX G: Secondary Analysis of KAP Data

In 2014, UNICEF Macedonia undertook a Knowledge, Attitudes and Practices (KAP) study to examine various kinds of social barriers to the inclusion of Children with disabilities into Macedonia's society. The survey aimed to assess the public's knowledge, attitudes and practices towards children with disabilities (UNICEF, 2014). The survey was administered to a total of 1000 respondent aged 15 or older, through face to face interviews in respondents' homes or through computer assisted personal interview technique (CAPI). The KAP survey was a quantitative data collection method that uses both close and open-ended questions, aimed at capturing the interviewee's opinions. The results of the KAP study can be used as a baseline to determine the existing gaps and significance of certain demographic and cultural factors that can be potential barriers to changing attitudes, behaviours, and misunderstandings respondents may have toward Children with disabilities.

The following two tables look at respondents' attitudes toward Children with disabilities disaggregated by variables such as gender, age, ethnicity, area, education level completed and level of contact with Children with disabilities. The analysis of people's views on Children with disabilities based on their level of contact with Children with disabilities comes from an idea proposed by the Intergroup Contact Theory. The Intergroup Contract Theory says that those who have personal contact with marginalized or negatively stereotyped groups in society, such as individuals with disabilities, generally have more positive attitudes towards that group (Allport, 1954).

The analysis of the KAP study data was done using the data analysis program STATA. The data will be analysed using specific survey questions to assess the level of contact people have with Children with disabilities and their attitudes towards Children with disabilities by gender, age, ethnicity, are and education level. Results are shared in Table 11 below.

<i>Table 11: Disability Models and Views of Disability by Sociodemographic Characteristic of the Respondent.</i>	Disability Models			Views of Disability	
	Feel sorry, need help (%)	Need medical care (%)	Environmental barriers need to be removed (%)	Need to adapt to life in society (%)	Society and environment should be adapted to their needs (%)
GENDER					
Male	24.0	46.2	29.8	39.5	60.5

Female	26.8	42.6	30.6	41.9	58.1
AGE					
15-19	20.7	45.6	33.7	41.1	58.9
20-29	26.7	39.3	34.0	36.2	63.8
30-39	25.0	40.0	35.0	45.5	54.5
40-49	21.8	48.3	29.9	35.8	64.2
50-59	27.1	46.4	26.4	46.1	53.9
60+	26.0	47.0	27.0	40.7	59.3
ETHNICITY					
Macedonian	24.6	43.9	31.5	33.9	66.1
Albanian	25.7	48.2	26.1	60.3*	39.7*
Other	30.6	36.5	32.9	34.1	65.8
AREA					
Urban	24.4	44.6	30.9	37.2*	62.8*
Rural	26.7	44.0	29.3	45.3*	54.7*
EDUCATION					
Primary	32.7*	45.4	21.9*	45.2	54.8
Secondary	24.8	44.7	30.5	40.0	60.0
College+	23.5*	44.1	32.4*	39.6	60.4
LEVEL OF CONTACT WITH Children with disabilities					
Do not know a Children with disabilities	26.3	44.9	28.8	44.9*	55.1*
Less frequent	23.7	45.1	31.2	34.1*	65.9*
More frequent	24.9*	42.5	32.6	37.1	62.9
<i>*Significant values of p value ≤ 0.05</i>					

Table 12: Possibility of Children with disabilities to lead an independent and productive life as an adult by sociodemographic characteristic of the respondent.

N=1000	Fully Possible (%)	Somewhat possible (%)	Not possible (%)
GENDER			
Male	14.9	67.0	18.1
Female	17.8	66.4	15.8
AGE			
15-19	14.1	65.2	20.6
20-29	18.0	66.7	15.3
30-39	20.3	64.4	15.2
40-49	13.3	71.7	15.0
50-59	17.6	64.0	18.3
60+	14.0	66.5	19.4
ETHNICITY			
Macedonian	15.9	68.4	15.6

Albanian	17.3	63.3	19.3
Other	16.7	63.1	20.2
<i>AREA</i>			
Urban	16.7	68.3	15.7
Rural	15.9	64.1	19.5
<i>EDUCATION</i>			
Primary	15.1	59.6*	25.2*
Secondary	15.1	68.4	16.5
College+	16.6	68.5*	14.9*
<i>LEVEL OF CONTACT WITH Children with disabilities</i>			
Do not know a Children with disabilities	13.8*	68.0	18.2
Less frequent	17.3	68.2	14.5
More frequent	21.5*	62.3	16.2
<i>*Significant values of p value ≤ 0.05</i>			