



Regional Workshop on the Measurement of Child Disability

Final Report

(Geneva – Switzerland, 6 to 10 July, 2015)

Article 31 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) mandates that ratifying States Parties “collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention”¹.

Valid, reliable, and relevant data on children with disabilities are essential to **understand** the situation of children with disabilities, and to **assist** in tracking results against national, regional, and international conventions and goals. Data are also important to **investigate** the role of environmental factors (including societal attitudes and physical barriers) in the experience of disability. Further, data are essential to **inform** policies and programs, **facilitate** the planning of services, and **improve** participation and quality of life for children with disabilities and their families as well as to **advocate** for the rights of children with disabilities.

For countries to fulfill their commitments under the CRPD as well as to inform and support the monitoring of sustainable development goals that leave no one behind, there is an urgent need for countries to strengthen their capacity to collect, analyze, understand, use and disseminate data on children with disabilities in a manner that is accurate and comparable across different settings, countries, and populations.

¹ Retrieved from <http://www.un.org/disabilities/default.asp/default.asp?id=291>

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1. Why a workshop in Europe and Central Asia?

Despite the overwhelming need for and interest in disability data in Europe and Central Asia (ECA), particularly as it relates to children, children with disabilities remain “invisible”. The Washington Group on Disability Statistics (WG) has been working with UNICEF since 2011 on a survey module specifically designed to capture child functioning and disability.

Following an initial introduction to the concept of disability measurement at the TransMonEE meeting in Luxembourg in November 2015, the Regional Workshop on the Measurement of Child Disability organized by UNICEF and the WG was intended to help strengthen local capacities on issues related to measurement of child disability and ensure a broad and common understanding of the statistical concepts, models, and measures related to child disability. It was intended that, at the end of one week, participants in the workshop would have an increased knowledge of the main issues related to the collection, analysis, interpretation, and use of data on child disability, and be able to develop a comprehensive data collection plan, with clear objectives, indicators, and appropriate data collection methods and tools. Further, it was expected that participants would have a deepened knowledge of how to read and interpret data on children with disabilities and understand how to disseminate and use data effectively to promote the rights of children with disabilities. Ultimately, the intent of the workshop was to **ensure that the progressive realization of the rights of all children is made evident, through the use of statistical data, in Eastern Europe and Central Asia.**

2. What is disability?

What is Disability? According to the UN Convention on the Rights of Persons with Disabilities (CRPD), 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. The diverse group of participants in the workshop and their varied knowledge provided an excellent setting in which to experience the difficulties inherent to trying to make sense of, and reach an agreement about, the complex concept of understanding and measuring disability. Country delegations were composed of stakeholders representing both producers and users of data on children. Among the 112 participants, 26 countries and 6 organization were represented; 21 National Statistic Offices were in attendance, as well as representatives from various line Ministries, UNICEF staff and civil society. The workshop enabled participants, who often have little opportunity for collaborative work, to discuss concepts and practical applications – discussions that were key to advancing the development of a common understanding of disability.

Until recently, the medical view of disability prevailed in the ECA region. Traditionally, this reductionist view has been responsible for all work related to disability, and children with disabilities have been viewed as “defective” and in need of protection from States. This is likely the only region in the world where nearly all professionals working in areas related to children with disabilities were trained under the theoretical foundations of “defectology”², a theoretical tradition with almost 100 years of legacy.

Existing data available to UNICEF indicate that children with disabilities in the region face important barriers in terms of access to basic services and are frequently subject to stigmatization and exclusion. A disproportionate number of children who are deprived of parental care or in living in formal or residential care today are children with disabilities³. Children with disabilities and their families are usually left out due to harmful social norms and cultural beliefs, attitudes and practices. This limits their development and puts them at risk of neglect, abuse, exploitation and exclusion.

The overwhelming signature and ratification of the CRPD in the region⁴ is relatively recent and the paradigm shift – from a medical to a social model - that will be required will take time and a collaborative effort. The change will also not occur evenly throughout the region. At this time, while some countries have made great strides in changing their conceptual frameworks and their work modes, many are still grappling with how to effectively implement a Convention that does not comfortably align with their traditional modus-operandi.

The absence of a common understanding of disability has been a major cause of the lack of agreement on disability data globally. On the one hand, different terms are used

² Collected Works of L S Vygotsky. Volume 2, The Fundamentals of Defectology, Plenum Press 1993;

³ TransMonEE Data on rate of children with disabilities deprived of parental care and in residential care

⁴ Data Collection on Children with Disabilities in Eastern Europe and Central Asia - Summary report of TransMonEE Country Analytical Reports on Disability Measurement, 2013. It can be found at www.transmonee.org

with the same meaning, while on the other hand the same term is also used with different meanings.

Nevertheless, in general disability is no longer understood in a reductionist way. It is no longer viewed as an individual attribute with a clinical diagnosis that can be subjected to treatment or prevention (medical model). A person with a disability is no longer viewed as a victim of circumstance and needing the charity of others in order to survive (charity model). Disability is multi-dimensional; it is a “set of characteristics everyone shares to varying degrees and in varying forms and combinations”, and has biological, environmental and socially constructed components.

3. Why measure disability?

In the workshop, participants had an opportunity to learn about the important relationship between research questions and the choice of data needed to properly answer them. The workshop participants were asked to, throughout the 5 days, engage in a daily exercise (case study analysis⁵) during which they had a chance to discuss and understand data collection challenges through the lens of specific examples.

In ECA, as well as in other regions, collecting data is the main function of many stakeholders. In some cases, data on adults with disabilities are largely available, while data on children with disabilities, specifically, are scarce. Although most countries in the region are signatories to both the Convention on the Rights of the Child (CRC) and CRPD, and although both Conventions place the obligation of data collection on signatories, collecting data related to children is still in its early days.

Throughout the 5 days of the workshop, the focus on data collection was on household surveys and census, as opposed to administrative data. Tracking prevalence of disability through the use of a survey is an important first step in generating estimates at the level of the population, and in monitoring trends and identifying the needs and characteristics of subgroups within persons with disabilities. Data gathered in this manner can be used for many purposes, among which to raise awareness about the number and overall situation of children with disabilities. Administrative data are also important both because they are collected more frequently and because such data can capture information on children who are not in households (i.e. in formal care). A number of participants expressed their need for further clarification regarding administrative data, as well as further exploration of the ways in which household survey and administrative data complement each other.

Workshop facilitators focused on providing examples of ways in which data availability has benefited research agendas, policies, programmes, and evidence-based interventions. Finally, the facilitators also highlighted the use of household data in monitoring and evaluating the impact of activities and policy changes, while contributing to the general knowledge about childhood disability. Participants engaged

⁵ The case studies analyzed throughout the five days were: Education for Children with Disabilities; Cash Transfer Programme; Autism; National Action Plan on Disability; Deinstitutionalization.

in discussions related to collecting data via large population-based surveys, small sample surveys, the uses and benefits of each, as well as the many challenges associated with each option.

4. How to measure disability?

While data on disability are inadequate and much needed for the all of the population, children represent a special group that deserves particular consideration, but that also poses special challenges for measurement. While many countries have collected data on disability as part of employment-related surveys on their active population, children have been less visible in the data collection agenda. General household surveys and censuses that include general questions about people with disabilities have also been found to inadequately identify children with disabilities.

Children are constantly developing and in transition first from infancy to childhood, then childhood to adolescence and finally from adolescence to adulthood. The speed and variability of trajectories of these changes makes it challenging to identify functional difficulties. The distribution of types of disability is also different for children compared with adults. In adults the major problems are mobility, seeing and hearing, personal care - especially so with advancing years, while in children the main disabilities are related to intellectual functioning and behavior.

The workshop focused on discussing validated questions and methods that can be used to identify children with disabilities. However, in order to serve purposes that go beyond generating reliable prevalence estimates (i.e. that can track UNCRPD/CRC commitments to equal access to services), the discussed disability questions will need to be added to broader survey instruments that also collect data on children's access to education, health care, social protection and other entitlements.

4.1. Purpose and Objectives

The various possible purposes for data collection were presented and discussed during the workshop. An important first step in data collection is determining its purpose. The purpose will determine what tools and methods are most appropriate. Service provision, determining prevalence of disability in a population, as well as the equalization of opportunities for those with and without disability were presented among the main "purposes" for the collection of data on disability.

In terms of prevalence, estimating the level of disability in a population (through the operationalization of the WG/UNICEF Module on Child Functioning and Disability) is important for several reasons. It allows policymakers, analysts, and researchers to identify potential need for accommodation. Quantifying disability using this tool also helps design interventions in order to prevent disability and to improve the participation of children who already experience disabilities. For strategic planning, it is important not only to measure the level of disability but also to monitor and understand trends in disability prevalence.

The WG/UNICEF Module on Child Functioning and Disability can also be used to determine whether children with disabilities are participating in age appropriate activities to the same extent as are children without disabilities. This is done by using the WG/UNICEF questions to disaggregate indicators of participation by disability status. For example, if the questions are asked in the same data collection tool as are questions on school attendance, it possible to see whether the percent of children attending school is the same for children with and without disability.

Another purpose for data collection related to child disability is the assessment of environmental barriers and facilitators. Society may hinder a child's participation because it either creates barriers (e.g., inaccessible play areas) or fails to provide facilitators (e.g., unavailability of trained inclusive education teachers). Assessing the impact of the environment involves an examination of the physical environment (e.g., natural environment and human-made changes to environment), social environment (e.g., support and relationships of family, peers, and community members), cultural environment (e.g., how disability is perceived in the community), and institutional environment (e.g., availability of assistive devices).

The findings in relation to an environmental assessment provide a rich source of information for policy and service planning. When information on the environment is analyzed in conjunction with information on age, sex, geographical location, and type of functional limitation, a nuanced picture across a range of policy fields emerges. For example, collecting information on the availability of communication assistive devices for children living in rural areas can be used to monitor the participation of children with such limitations in school. Data that are disaggregated on a number of dimensions are important as disability intersects with other determinants of inequality, such as gender and ethnicity, and can therefore assist in demonstrating transparency and accountability in the distribution of resources to services, groups, and individuals.

A forth purpose for data collection is the design, monitoring and evaluation of services and policies. The provision of services at the population level includes, among others, addressing needs for housing, transportation, assistive devices and technology, and education. Services directed to the general population may be made more inclusive or there may be specific services targeted to children with disabilities or even a particular sub-set of this group. At the policy development stage, data on child disability can help identify the background characteristics of groups of children, either excluded or at risk of exclusion, and thereby inform the planning and implementation of appropriately targeted policies. If policies are initiated to enhance the participation of children with disabilities, the effect on participation can be determined by comparing baseline data to data collected after the policy changes have been implemented.

Beyond determining the purpose, it is also important to define clear and realistic objectives. A detailed review of existing data should be carried out prior to conducting any new data collection effort. This is essential to exposing the gaps in what is known, and identifying what new information is needed to address the purpose identified. Existing data might be used to develop a profile of disability among children in the target population, or may offer insight into the process of planning new data collection

efforts. It should, however, be borne in mind that no country in the region has yet collected disability data using the new WG/UNICEF module.

Defining objectives requires consultation with key partners, data users, and other stakeholders to ensure that any unique challenges are addressed early during the design phase when modifications are easiest. Early involvement of the disability community is imperative because they are often best informed about the needs, priorities, and goals of persons with disabilities.

4.2. Methodologies and Tools

The workshop also focused on methodologies and tools to consider when planning activities related to measuring childhood disability. When collecting data on child disability five main methods are used: population censuses, population-based surveys, administrative registries, direct assessments and qualitative studies. While a brief description of all 5 methods was provided, including purpose, strengths and limitations of each, and implications of use, the great majority of the workshop was dedicated to population-based surveys.

Methods of collecting data on child disability produce different types of information. The aim of the data collection will help to determine the most appropriate method. While population-based surveys can provide breadth of information on multiple domains, administrative registries can be used to determine service use; direct assessments can provide greater depth of information on a single domain, while qualitative studies provide insights into contexts and processes.

Population-based surveys are designed to be representative of the target population and often cover many different topics such as health, education, labor force, agriculture, etc. Data on disability can be collected by adding a module (refer to: UNICEF/WG Module on Child Functioning and Disability) to an existing survey. These data can then be analyzed according to household and child characteristics. For example, depending on the survey, the percentages of school-age children attending school can be compared by disability status, urban-rural residence, household wealth, sex, and other characteristics critical for decision-making.

Generally, when measuring disability through population-based surveys, data are gathered on children with and without disabilities, their families and the environment. The questions must be specifically design for particular age ranges. As with all instruments designed to capture information related to/about children, ethical questions are of eminent concern. While a session on ethical issues was held, this was an issue discussed at length during the presentations on methodology and tools particularly issues related to children as respondents, and proxy respondents (generally parents and caregivers). While it is acknowledged that some parents may not have complete knowledge of children's impairments or functional difficulties especially in areas that are less visible and internalized such as emotions, the best practice at this point is to use parental proxies.

In population-based surveys, all interviewers must receive training concerning the disability questions. While population-based surveys are quite flexible in depth/range of topics they cover, there can be somewhat limited. For instance, population-based surveys do not cover populations of vulnerable children such as institutionalized, homeless and refugees. At this time, population-based surveys are particularly important for UNICEF and government counterparts due to the general lack of reliable data available of childhood disability.

When adopting an existing tool written in a language other than the original language of the survey, the main issues to take into consideration are related to translation and cultural appropriateness. Tools must always be checked for cultural and developmental appropriateness to increase both reliability and validity. Care should be taken if any changes are made to the existing tool to ensure that the concepts and construct that are meant to be captured in the original language are maintained in the translated version. Even small changes in wording can introduce unanticipated error during data collection.

New tools should be designed when a tool does not exist to respond to the data collection needs or available tools do not meet the information needs of different child disability data collection plans. However, developing a new tool can be a lengthy process of creating, evaluating, modifying, testing and retesting the tool, and the costs associated with each of these steps should not be overlooked. The international community is invested in developing tools that can be adopted in many data collection programs as they were designed to be culturally neutral and developmentally appropriate. New tools should take into account cultural norms, the interaction between functional limitations and contextual factors, and consider wording and tone: questions should be clear, concise, and inoffensive. Extensive cognitive testing of each tool should be undertaken and, again, the workshop covered this issue, including the presentation and discussions of various examples. Cognitive testing results can provide useful information by documenting patterns of interpretation of questions, potential sources of response error as well as providing a richer understanding of the type of data that has been collected.

a. UNICEF/WG Module on Child Functioning and Disability

Workshop participants also had an opportunity to learn about the new UNICEF/WG Module on Child Functioning and Disability under development since 2011. The purpose of the Module is to identify the sub-population of children (aged 2-17 years) with functional difficulties that may place them at risk of experiencing limited participation in a non-accommodating environment. The aim of the Module is to provide cross-nationally comparable data that can be obtained by adding the questions to national multipurpose population surveys or to topic specific surveys (e.g., health, education, etc.). This new tool was developed to avoid a medical approach to disability (commonly found in existing tools) and uses the International Classification of Functioning, Disability and Health (ICF) bio-psycho-social model of disability.

Response options reflect the disability continuum and ask about difficulties a child may have in doing certain activities in several domains of functioning: Seeing, Hearing, Mobility, Self-Care, Upper Body Functioning, Communication, Learning, Emotions, Behavior, Attention, Coping with Change, Relationships and Playing. The tool has undergone cognitive testing in Belize, Montenegro, Oman, India and USA (3 rounds), and field-testing of versions of the Module has been completed in 5 countries (Haiti, India, Cameroon, Italy, El Salvador and Samoa). One last test is scheduled to take place in Serbia. Finalization of the Module and release is planned for March 2016.

b. UNICEF/WG Module on Inclusive Education

In addition to the Module on Child Functioning, UNICEF and the WG are also developing a Module on Inclusive Education that focuses on environmental influences on school participation. This tool relies on parental perceptions/assessments and captures information on children with and without disabilities in formal education settings. An extensive review of existing tools to measure school environment and participation found that existing measures were primarily used in smaller scale research studies, and many of the surveys used outdated definitions of disability, focusing on disability as a primary cause of lack of participation.

The Module under development covers four domains related to environment and disability within the context of school participation:

- Attitudes: parental perceptions, and their perceptions of other's attitudes including other children and school staff;
- Getting to school: transportation including the need for assistance and aspects of environmental and social safety;
- Accessibility: physical accessibility including entryway, corridors, bathrooms, lunch room, classroom, common areas etc., information accessibility, communication accessibility, and programmatic accessibility/adaptability); and
- Affordability: fees, costs, and competition for resources associated with attendance, the availability of types of assistance including financial, assistive devices, rehabilitation, and non-educational benefits for example, meals.

The Module also contains a section for children not currently attending school that gathers information on reasons for not attending school. The tool is scheduled to undergo cognitive and field-testing and is planned to be finalized by the end of 2016.

4.3. Implementation

Finally, workshop participants also discussed data collection implementation. Issues related to training of the data collection team were discussed, to ensure high-quality data collection in communities and countries that have few professional resources.

Workshop participants also discussed issues related to data analysis. In order to correctly and effectively analyze the data, it is important to be familiar with the design of the study used to generate them. It is also essential to have a thorough

understanding of the disability measurement tools used. The focus of the disability assessments (whether a relatively brief screen or an in-depth clinical evaluation) and the questions that are of interest to stakeholders should guide the analytic approach. Data analysis can be as simple as converting the number of children with disabilities into a percentage of the overall population and disaggregating it, or as complex as employing sophisticated modeling techniques to interpret the data.

Finally, and more importantly, data must be translated into action. Knowledge generated through data collection should be used to promote change in the life of children, highlight barriers to inclusion and point towards solutions geared towards better access to services. When translating knowledge into action it is important to consider: the approach to be taken, who are the intended knowledge users, what are the priorities to be set, what are the key messages to be derived from the data analysis, how impact will be measured, and what are the facilitators and barriers. Synthesis, dissemination, exchange and application of knowledge all serve as processes to use evidence to make an impact.

It is important to remember that where disability is a stigma, people may be reluctant to talk about or report on it. This can be addressed through strategic communication and awareness-raising activities. Consulting with people with disability and organizations representing them can further enhance strategies for ensuring accessibility, help prioritize which accessibility formats are most relevant and inspire creative and unique solutions to specific groups. Just as important as having knowledge to share, is the strategic dissemination and sharing of that knowledge. Developing a simple communication strategy that outlines what information will be shared, when, with whom and how, is needed to convert knowledge into awareness that can generate action.

5. Regional challenges

There are many challenges to gathering accurate data on disability among children: definition of disability; purpose of measurement; operational measures; domains of functioning; data collection methods; reporting sources; response categories/severity threshold/cut-off; different age-group bands. All are globally recognized and important, although in this regional workshop three challenges were identified as highly relevant to the ECA region: 1) definition of disability and the appropriate use of comparable language; 2) domains of functioning (within the framework of the ICF-CY); 3) how to reconcile survey and administrative data sources.

5.1. Definition of disability and appropriate use of comparable language

Issues related to language were raised almost immediately upon the start of the workshop. Throughout the five days, many discussions related to definition of disability, acceptable terminology, comparable terms, ethical use of some terms, etc., took place and an understanding was reached, even if not universally agreed upon.

There was an overwhelming agreement, on the part of the participants, that the lack of a common definition of disability in ECA is directly impacting the lack of comparable data on children with disabilities. Thus, there is a lack of accountability towards ensuring that children with disabilities in the region enjoy the same opportunities as all other children. While most countries/territories in ECA have signed and/or ratified the CRPD, and acknowledge the obligation to ensure the use of a definition of disability that is in compliance with the CRPD, in most cases, data are still being collected in ways that reflect a mostly-medical approach to disability.

More broadly, participants also discussed States' responsibilities in ensuring that negotiations during and upon the signature of the CRPD involve a large representation of each States' DPO constituency to ensure the language of the CRPD (translation) reflects the spirit of the original document (written in English). Many of the workshop participants expressed concern with some of the terms used in the Russian version of the CRPD (used in many ECA Russian-speaking countries), namely the use of the word "инвалидность" meaning "impairment" and "disability". In this case, the essential difference between "impairment" and "disability" that lies at the heart of the Convention is, essentially, lost in translation.

Throughout the five days, attention was paid to making clear the distinctions between some of the most commonly used terms related to children with disabilities, such as: disability, impairment, functional limitation, functional difficulty, environmental factor, special need, special educational need, inclusive school. Although no solutions were found in how to ensure all language related to children with disabilities is standardized in ECA, workshop participants are now better equipped to make the argument that, indeed, attention should be paid to ethical and language issues when speaking of/on behalf of children with disabilities.

5.2. Domains of functioning as a framework for questionnaire design

The overwhelming move towards signature and ratification of the CRPD in ECA has brought about the realization that a paradigm shift in the way in which disability is conceptualized, implies a shift in the way implementation of practices and policies related to children with disabilities is conceptualized. Within this context, the workshop provided much anticipated introductory discussions regarding models of disability and the use of the ICF as a broad theoretical framework for classifying health-related human functioning, with an extended view that encompasses issues specific to children and youth (ICF-CY). Both represent a shift from the medical model to the bio-psycho-social model that offers a holistic approach to human functioning and disability very much in line with that of the CRPD. In redefining the *model* of disability, the questions used to assess disability in a population have also shifted:

- from an impairment/medical based approach (Do you have a disability? If Yes: Are you blind, deaf, crippled, mentally retard... etc.), often using language that is considered inappropriate and stigmatizing
- to questions that focus on functional difficulties (Do you have difficulty walking or climbing stairs?) that, together with information collected on environmental

barriers that may hinder full and effective participation in society on an equal basis with others, describe more fully the *process* of disability.

The ICF-CY was developed to ensure that domains relevant to toddlers, children and youth were taken into consideration, such as acquiring language and engagement in play. These domains of functioning informed the content of the UNICEF/WG Module.

Using the ICF-CY provided a common language and framework for the design of the data collection module. In disability statistics, the importance of adopting a universal perspective of disability has been recognized. Data collection tools based on ICF's universal model will make it possible to gather more accurate and more relevant data about the full extent of disability that are comparable across contexts. A common definition of disability is crucial to understanding and improving outcomes for children with disabilities as well as for increasing the power of information through the ability to relate data from different sources, such as in service settings and at the population level. When consistent language and concepts are used, they facilitate comparisons, provide complementary information and help knowledge building. Synergy is enabled between different information systems such as surveys, research and administrative records.

Finally, and crucial for the shift in conceptualizing disability in ECA, from a statistical point of view, collecting data on severe impairments alone provides a low prevalence of disability in a population and does not provide a complete picture of disability, either in an individual or in a population. For example, using a list of impairments such as blindness and deafness will identify a small sub-population with more severe sensory impairments and subsequent participation restrictions, but not the broader range of people who have functional limitations and need accommodation. Furthermore, knowing that a child is blind, deaf, has cognitive or mobility impairments does not tell us anything about how these impairments affect the child's participation in his or her community. Impairments are not proxies for disability; they cover only one particular aspect of disability. Throughout the workshop, the discussions related to the definition, models and ICF-CY application were very well received and very lively, pointing to the need of in-depth and inter-disciplinary technical development of capacities.

5.3. How to optimize the use of survey and administrative data sources

Due to the fact that UNICEF and the Washington Group have focused a great deal of their work on modules/sets of questions that can be easily added to existing population-based household surveys, workshop participants recommended that future workshops on measuring childhood disability include tools and methodologies for data collection and analysis using administrative sources.

6. Workshop assessment

The workshop was overwhelmingly well received. Because it was the first regional workshop of its kind, extensive feedback was requested on each session, on the overall content and delivery, at the end of each day. Further, a final overall evaluation was

also requested. Workshop participants were asked to rate the sessions as “excellent”, “very good”, “good”, “fair” or “poor”, and provide comments as needed.

Day 1 was rated as “excellent” by 31 of respondents, and “very good” by 36 respondents. Fourteen (14) respondents rated the workshop as “good”, and 3 as “fair”. With an extensive opening ceremony, and an introduction to the theme that many participants were already familiar with, evaluation comments focused on time management and housekeeping items.

Day 2 was rated as “excellent” by 33 of respondents, and “very good” by 32 respondents. Eighteen (18) respondents rated the workshop as “good”, 3 as “fair” and 1 respondent as “poor”. While some participants considered the content of the sessions to be “too basic”, the overall interest was high, particularly on the sessions related to choosing the right methodology for measuring childhood disability, although participants would have liked more emphasis on data analysis (Day 4 content).

Day 3 was rated as: “excellent” by 35 participants, “very good” by 30 participants, and “good” by 17 participants. Only 1 participant gave a “fair” rating, and 1 other participant a “poor” rating for Day 3 sessions. Overall, the participants were very satisfied with the presentation of UNICEF/WG Module on Child Functioning and Disability, and to learn about the process of development, design, testing and possible applications. Participants were also very happy with the opportunities to engage with other participants, and mentioned that exchange among them, beyond presentations, was very rich and productive.

Day 4 ratings were also similar to the previous 3 days: 31 participants rated the sessions as “excellent”, 30 rated the sessions as “very good”, 15 as “good” and 1 as “fair”. Overall, the session focused on the ICF-CY was very well received, as well as the sessions on data analysis and interpretation. As in previous days, participants’ comments referred to the need to further contextualize the content and provided examples to the region/countries where the workshop takes place.

Day 5 was dedicated to closing remarks and workshop certificates. The evaluation of the overall workshop were as follows: 43 participants rated the workshop as “very good”, 18 participants as “excellent”, and 16 participants as “good”. There were no ratings as “fair” or “poor”. The length of the workshop was considered “adequate” by 62 participants, “tool long” by 17 participants, and “too short” by 2 participants. Fifty-two participants rated the workshop as having “just enough” participants, while 18 rated it as having “too many participants”, while 2 participants rated the workshop as having “too few” participants. With regards to the effectiveness of the facilitators team, 39 participants rated the team as “effective”, 30 participants rated the team as “very effective”, 4 as “adequate” and 2 as “somewhat adequate”.

7. Ways Forward

As expected, the workshop created momentum in the region, great interest in the application of the content, and also clarified/consolidated existing plans. To better respond to country delegations' expectations and needs (specifically related to capacity development) a few recommendations have been proposed.

First, it has been proposed that a specific workshop be conducted on how to integrate the UNICEF/WG Child Functioning and Disability Module in population-based surveys (such as MICS and/or DHS) that are currently being planned; it is important to ensure not only measuring the prevalence of childhood disability but also the monitoring of child rights (i.e. the access of CwD to services), an analysis that can only be done when data on disability are looked at in conjunction with data on access to health care, schools, and protection outcomes.

Second, it has also been recommended that discussions related to integrating the UNICEF/WG Child Functioning and Disability Module in population-based surveys be expanded to include discussions of specific actions leading to analysis of administrative data and qualitative research, in ways that contribute to a broader picture of the lives of children with disabilities, available services and barriers.

Third, it has been recommended that UNICEF determine how it might be able to respond (at country, regional and global levels) to the various requests for capacity development. The workshop identified good-practices in the region with regards to inter-disciplinary working groups and has generated a great deal of interest on the application of the ICF-CY in tool design and monitoring of the CRPD implementation. Therefore, it has been requested that UNICEF consider providing capacity development opportunities related to the use of the ICF-CY within the context of data collection.

With regards to ongoing actions in ECA, UNICEF (at the Country Office level) will continue to support the national surveys in applying the new concepts and tools/methods through the work of National Statistics Offices as well as line Ministries and civil society. A key follow up action, for UNICEF at all levels, is the important first step of changing the paradigm and working definitions used in the countries.

Finally, the Serbia UNICEF Country Office, in collaboration with the Serbia NSO, UNICEF CEE/CIS RO, UNICEF HQ and the Washington Group are planning the field-testing of the UNICEF/WG Child Functioning and Disability Module. This additional field test to be done in the ECA Region is greatly anticipated.

Annex 1. Agenda of the workshop

Regional Workshop on the Measurement of Child Disability for Europe and Central Asia

6-10 July 2015, Geneva

Venue: Hotel Crowne Plaza Geneva,

DAY 1, Jul-6 - Chair: Lori Bell, Regional Advisor, Monitoring and Evaluation		
Time	Session	Facilitator/Presenter
08.30 - 09.00	Registration of workshop participants	
09.00 - 09.10	Welcome	Marie-Pierre Poirier, Regional Director, UNICEF Regional Office for CEE/CIS Catalina Devandas Aguilar, UN Special Rapporteur on the Rights of Persons with Disabilities Jennifer Madans, Associate Director for Science, National Center for Health Statistics; Chair, Washington Group on Disability Statistics
09.10 - 09.20	Introduction of facilitators and participants	Lori Bell, Regional Advisor, Monitoring and Evaluation, Planning, Monitoring and Evaluation Section, UNICEF RO for CEE/CIS
09.20 - 09.30	Overview and workshop norms <i>Presentation 101</i>	Claudia Cappa, Statistics Specialist (Child Protection, Child Disability, ECD), Data and Analytics Section, Division of Data, Research and Policy, UNICEF HQ; Member of Washington Group on Disability Statistics
09.30 - 10.15	The need for quality disability data in the region <i>Presentation 102</i>	Siraj Mahmudlu, Monitoring & Evaluation Specialist/ Regional MICS Coordinator, Planning, Monitoring and Evaluation Section, UNICEF RO for CEE/CIS Paula Frederica Hunt, Senior Expert, Inclusive Education, Disability, Education and Development Lda. Nevena Peneva, Research Support Officer, Equality and Citizens' Rights Department, European Union Agency for Fundamental Rights (FRA) Simona Giarratano, Social Policy Officer, European Disability Forum (EDF)
10.15 - 11.00	Defining disability <i>Presentation 103</i>	Daniel Mont, Principal Research Associate at University College London; Associate Expert, Washington Group on Disability Statistics
11.00-11.15	<i>Break</i>	
11.15 - 12.30	The importance of measuring child disability <i>Presentation 104</i>	Claudia Cappa

12.30 - 13.30	<i>Lunch</i>	
13.30 - 14.45	Models of disability <i>Presentation 105</i>	Mitchell Loeb, Health Scientist in the Office of Analysis and Epidemiology at the National Center for Health Statistics; Chair, Technical Working Group on Children, Washington Group on Disability Statistics
14.45 - 15.00	Introduction to case studies <i>Presentation 106</i>	Marguerite Schneider, Researcher in disability studies, University of Cape Town; Associate Expert, Washington Group on Disability Statistics
15.00 - 15.15	<i>Break</i>	
15.15 - 17.00	Group discussion and case studies	Claudia Cappa Mitchell Loeb Jennifer Madans Daniel Mont Marguerite Schneider
17.00- 18.30	Welcome reception	
DAY 2, Jul-7 – Chair: Philippe Testot-Ferry, Regional Advisor, Education		
08.45 – 09.15	Registration Day 2	
09.00 - 09.15	Recap of previous day and objectives of day 2	Mitchell Loeb
09.15 - 10.15	Importance of child development to the measurement of child disability <i>Presentation 201</i>	Claudia Cappa
10.15 - 11.00	Environment and participation <i>Presentation 202</i>	Marguerite Schneider
11.00 - 11.15	<i>Break</i>	
11.15 - 12.30	Planning data collection on child disability <i>Presentation 203</i>	Jennifer Madans
12.30 - 13.30	<i>Lunch</i>	
13.30 - 15.00	Selecting a method for collecting child disability data <i>Presentation 204</i>	Mitchell Loeb
15.00 - 15.15	<i>Break</i>	
15.15 - 17.00	Group discussion and case studies	Claudia Cappa Mitchell Loeb Jennifer Madans Daniel Mont Marguerite Schneider
DAY 3, July-8 - Chair: Jean-Claude Legrand, Regional Advisor, Child Protection		
08.45 – 09.15	Registration Day 3	
09.00 - 09.15	Recap of day 2 and objectives of day 3	Claudia Cappa
9.15 – 10.00	Selecting an instrument to collect child disability data <i>Presentation 301</i>	Daniel Mont
10.00 – 11.00	WG Modules on Disability for Adults <i>Presentation 302</i>	Jennifer Madans
11.00 - 11.15	<i>Break</i>	
11.15 - 12.30	UNICEF/WG Module on Child Functioning and Disability <i>Presentation 303</i>	Mitchell Loeb

12.30 - 13.30	<i>Lunch</i>	
13.30 - 14.15	UNICEF/WG Module on Inclusive Education <i>Presentation 304</i>	Claudia Cappa
14.15 - 15.00	Exercise – Practicing interviews	Claudia Cappa Mitchell Loeb Jennifer Madans Daniel Mont Marguerite Schneider
15.00 - 15.15	<i>Break</i>	
15.15 - 17.00	Group discussion and case studies	Claudia Cappa Mitchell Loeb Jennifer Madans Daniel Mont Marguerite Schneider
DAY 4, Jul-9 – Chair: Octavian Bivol, Regional Advisor, Health		
08.45 – 09.15	Registration Day 4	
09.00 - 09.15	Recap of day 3 and objectives of day 4	Mitchell Loeb
09.15 - 10.00	Implementing data collection <i>Presentation 401</i>	Jennifer Madans
10.00 - 11.00	Ethical considerations for measurement <i>Presentation 402</i>	Marguerite Schneider
11.00 - 11.15	<i>Break</i>	
11.15 - 12.30	Data analysis and interpretation <i>Presentation 403</i>	Daniel Mont
12.30 - 13.30	<i>Lunch</i>	
13.30 – 15.00	Translating knowledge into action <i>Presentation 404</i>	Claudia Cappa
15.00 - 15.15	<i>Break</i>	
15.15 - 17.00	Group discussion and case studies	Claudia Cappa Mitchell Loeb Jennifer Madans Daniel Mont Marguerite Schneider
DAY 5, Jul-10 – Chair: Lori Bell, Regional Advisor, Monitoring and Evaluation		
08.45 – 09.15	Registration Day 5	
09:00 - 09:15	Recap of day 4 and objectives of day 5	Claudia Cappa
09.15 - 10.45	Presentations of case studies 1-3	Marguerite Schneider
10.45 - 11.00	<i>Break</i>	
11.00-12.30	Presentations of case studies 4-5 and discussion	Daniel Mont
12.30 - 13.30	<i>Lunch</i>	
13.30 - 14.30	Workshop feedback from participants	Lori Bell
14.30 - 15.30	Closing ceremony - Certificate distribution	Fabio Sabatini, Regional Chief of Planning, Planning, Monitoring and Evaluation Section, UNICEF RO for CEE/CIS Jennifer Madans

Annex 2. Participant list

COUNTRY	PARTICIPANT NAME	AFFILIATION
Facilitators	Mitchell Loeb	Health Scientist in the Office of Analysis and Epidemiology at the National Center for Health Statistics; Chair, Technical Working Group on Children, Washington Group on Disability Statistics
	Jennifer Madans	Associate Director for Science, National Center for Health Statistics; Chair, Washington Group on Disability Statistics
	Paula Frederica Hunt	Senior Expert, Inclusive Education, Disability, Education and Development Lda.
	Claudia Cappa	Statistics Specialist (Child Protection, Child Disability, ECD), Data and Analytics Section, Division of Data, Research and Policy, UNICEF HQ; Member of Washington Group on Disability Statistics
	Marguerite Schneider	Researcher in disability studies, University of Cape Town; Associate Expert, Washington Group on Disability Statistics
	Daniel Mont	Principal Research Associate at University College London; Associate Expert, Washington Group on Disability Statistics
Albania	Emira Galanxhi	Director of Social Statistics, Albanian Institute of Statistics (INSTAT)
	Narbis Ballhysa	Program Director, Albanian Disability Rights Foundation
	Irena Mitro	Specialist of the Social Inclusion Directorate, Ministry of Social Welfare and Youth (MoSWY)
	Shqiponja Lamçe	Specialist of the Pre-University Education Directorate, Ministry of Education and Sports (MoES)
	Elda Hallkaj	Statistics and Monitoring Officer, UNICEF
Armenia	Anna Hakobyan	Head of disability issues division of disability and elderly issues department of the Ministry of Labor and Social Affairs of RA.
	Gagik Gevorgyan	Member, State Council on Statistics, National Statistical Service of Republic of Armenia
	Nune Pashayan	Head of children health protection department, Ministry of Health
	Narine Hovhannisyan	Head of General Education Department of the Ministry of Education and Science
	Armen Soghoyan	Director of the Agency of Medical and Social Analysis, Ministry of Labor and Social Affairs
	Lusine Yeremyan	Monitoring & Evaluation, Child Rights Systems Monitoring Specialist, UNICEF
Azerbaijan	Yashar Pasha	Head of Department Population Living Conditions and HBS statistics, State Statistical Committee
	Habib Kerimov	D-I and Child Protection Department, Head of Child State Institutions and Alternative services division, Ministry of Education
	Fatima Jafarova	Programme Assistant, UNICEF
Belarus	Elena Kukharevich	Deputy Chairperson of the National Statistical Committee
	Inna Konoshonok	Head, Department of Living standards statistics and household surveys, National Statistical Committee
	Valentina Dogonova	Monitoring and Evaluation Officer, UNICEF
Bosnia and Herzegovina	Gorana Knežević	Advisor, BIH Agency of Statistics
	Elvira Bešlija	Head of Council, BIH Council on Persons with Disability
	Haris Bešlija	Assistant, BIH Council on Persons with Disability
	Anna Riatti	Deputy Representative, UNICEF
Bulgaria	Miryana Malamin-Siriyski	Programme Director, "Maria's World Foundation" NGO
	Krasimira Kostadinova-Trifonova	Assistant Professor PhD, National Center of Public Health and Analyses
	Nadezhda Harizanova	State expert, Department of Integration of people with disabilities, Ministry of Labour and Social Policy
	Elena Atanassova	Child Rights Monitoring Specialist, UNICEF
CIS Statistical Office	Olga Remenets	Head of Population and Labour Statistics Division
Croatia	Dubravka Rogić-Hadžalić	Head of Directorate for Social Statistics Central Bureau of Statistics
	Dušica Zurovac	Expert on disability measurement in the Institute for expertise, professional rehabilitation and employment of persons with disability in Zagreb
	Marijana Šalinović	M&E Focal Point, Social Policy Officer, UNICEF
Georgia	Ketevan Melikadze	Social Welfare Officer, UNICEF

Hungary	Barbara Panyik	Population and Social Protection Statistics Department, Central Statistical Office of Hungary
Italy	Elena De Palma	Researcher, Service of Health and Assistance, Disability and Social Integration, National Statistic Office
Kazakhstan	Zhanyl Zhontayeva	Director of Department of Primary and Secondary Education, Ministry of Education and Science
	Aigul Khaldenova	Chief Expert of the Department of Social Services, Ministry of Health and Social Development
	Gulmira Karaulova	Head of Department of Social and Demographic Statistics, Statistics Committee of the Ministry of National Economy
	Bolat Turmaganbet	Chief Expert of Department of social and Demographic Statistics, Statistics Committee of the Ministry of National Economy
	Zhanar Sagimbayeva	Monitoring & Evaluation Officer, UNICEF
Kosovo (UNSCR1244)	Arijeta Sojeva	High Senior of Vital Statistics, Pristina
	Afrim Maliqi	Director, HandiKOS Association of Paraplegics and Paralysed children, Pristina
	Enver Mekolli	Head of Education, Science and Technology Department (EMIS)
	Afrim Ibrahim	Child Protection Officer, UNICEF
	Cairan O'Toole	Child Rights Monitoring Specialist, UNICEF
Kyrgyzstan	Galina Samohleb	Head of Household Statistics Department, National Statistical Committee
	Kuban Beishenov	Senior Specialist of Social Statistics Department, National Statistical Committee
	Aktan Balbakov	Head of Social Services Department, Ministry of Social Development
	Gulnaz Kochorbaeva	Specialist of Health Department, Ministry of Health
	Venera Urbaeva	Child Protection Officer, UNICEF
Latvia	Dace Krievkalne	Senior officer of Culture, Education, Science and Health Statistics Section, Central Statistics Bureau of Latvia
The former Yugoslav Republic of Macedonia	Robert Velichkovski	Advisor in the Department for EU Integration, Ministry of Health
	Dusan Tomsic	Associate in the Unit for Social Inclusion, and Acting Head of the Unit for People with Disabilities and the Elderly, Ministry of Labor and Social Policy
	Elena Kocovska	Program Manager for Education and Employment of People with Disabilities, NGO Polio Plus;
	Nadica Kostoska	Deputy Head, Department for EU, Ministry of Education and Science
	Aleksandar Lazovski	Social Protection Specialist, UNICEF
Moldova	Vasile Cușca	Head of the Department on social protection policies for persons with disabilities, Ministry of Labor, Social Protection and Family of Republic of Moldova
	Galina Morari	Deputy Head, Department of Hospital Care, Ministry of Health of Republic of Moldova
	Viorica Marț	Senior Consultant, Department of Pre-university Education, Ministry of Education of Republic of Moldova
	Nadejda Cojocari	Consultant, National Bureau of Statistics of Republic of Moldova
	Elena Laur	Monitoring & Evaluation Officer UNICEF
Montenegro	Jelena Konatar	Senior Advisor, Ministry of Education Department of Information and Communications Technologies
	Katarina Bigović	Advisor, International Cooperation and European Integration Section, National Statistical Office - MONSTAT
	Tamara Milić	Advisor for Education of Children with Special Education Needs, Ministry of Education
	Sabra Decević	President of NGO Children of Montenegro
	Ana Zec	Programme Specialist, UNICEF
Poland	Małgorzata Piekarzewska	Methodologist and Expert on Health Interview Surveys, Central Statistical Office of Poland
Romania	Steluța Aura Rădoi	Head of Office – Demography, Health, Culture and Justice Statistics, Department of Studies, Demographic Projections and Population Census, National Institute of Statistics
	Izabella Gabriela Popa	Superior Counsellor, National Authority for Child Rights Protection and Adoptions
	Mihaela Ungureanu	President, National Authority for Disabled Persons
	Viorica Ștefănescu	Child Rights Systems Monitoring Specialist, UNICEF

Serbia	Snežana Plavšić	Epidemiologist, Unit for control and prevention of non-communicable diseases, Institute of Public Health of Serbia
	Snežana Lakčević	Head of Unit for Census, Statistical Office of the Republic of Serbia
	Mirjana Ognjanović	Advisor, Unit for Research and Development, Institute of Social Protection
	Gordana Cvetković	Head of Unit for Inclusive Education, Ministry of Education
	Aleksandra Jović	Monitoring & Evaluation Focal Point - Child Rights Monitoring Specialist, UNICEF
Spain	Maria Del Rosario Gonzalez Garcia	Head of Health Department, Spanish National Statistical Institute
Tajikistan	Elena Budnikova	Deputy head of the department for demography, employment and social statistics, Agency of Statistics
	Zarinamoh Davlatova	Head of the main department of statistics in Khatlon region, Agency of Statistics
	Sanavbar Rakhmatullaeva	Main specialist of the Department of medical services for mothers and children, Ministry of Health and Social Protection of the Population
	Farkhod Saydullaev	Child Rights Monitoring Specialist, UNICEF
Turkey	Elçin Er	Head of Department for the Disability and Elderly Services, Ministry of Family and Social Policy
	Mehmet Fatih Köse	Head of Projects, Research and Development Department Ministry of National Education
	Banu Ekinci	Head of Department of Chronic Disease of Elderly People and Disability, Ministry of Health, Public Health Institute
	Mehmet Günal	Head of Health and Social Protection Statistics Group Turkish Statistics Office
	Silvia Mestroni	Monitoring and Evaluation Specialist, UNICEF
Turkmenistan	Jennet Atayeva	Deputy Head of the Social Statistics Department of the State Statistics Committee
	Ogulgerek Guyjeva	Director of the Information Centre of the Ministry of Health and Medical Industry of Turkmenistan
	Gulalek Garyagdyeva	Head of the Pension and Welfare Payments Division under the Pension Fund of the Ministry of Labour and Social Protection of Population
	Hekim Altayev	Chair of the Central Medical-Social Expertise of the Ministry of Health and Medical Industry of Turkmenistan
	Dilara Ayazova	Programme Assistant, UNICEF
Ukraine	Andrii Gerasymenko	Deputy Head of the Department of Social Services Statistics, State Statistics Committee
	Gabrielle Akimova	Child Protection Specialist, Disability focal point, UNICEF
Uzbekistan	Jamshid Sharipov	Head of Department of Statistics of Living Standards and Social Sphere, State Committee on Statistics of Republic of Uzbekistan
	Barno Abdusamatova	Chief Specialist, Pediatrics Section, Main Department for Motherhood and Childhood Protection, Ministry of Health
	Khikmatilla Daminov	Head of Department of Enlightenment and Spirituality of the Ministry of Public Education of Republic of Uzbekistan
	Abduaziz Eshmuratov	Director of the Orphanage #1 of Tashkent city Ministry of Labor and Social Protection
	Zokir Nazarov	Monitoring & Evaluation Officer, UNICEF
Handicap International	Aude Brus	Research coordinator, Handicap International, Technical Resources Division
European Disability Forum	Simona Giarratano	Social Policy Officer
Fundamental Rights Agency	Nevena Peneva	Research Support Officer Equality and Citizens' Rights Department
UNICEF CEE/CIS RO, Geneva	Lori Bell	Regional Advisor, Monitoring and Evaluation
	Siraj Mahmudlu	Monitoring and Evaluation Specialist/Regional MICS Coordinator
	Guzal Kamalova	Child Protection Consultant
	Natia Partskhaladze	Child Protection Specialist
	Bettina Schwethelm	Young Child Health and Development Specialist
	Teuta Halimi	Monitoring Officer
	RO Advisors	As per the Workshop Agenda