



**Report of**

## **The 10th Meeting of European and Central Asian Statisticians**

**Child Rights Monitoring**

**Data on Equity: potential and challenges**



**Parc Hotel Alvisse, Luxembourg, 10-11 November 2014**

## Introduction

The Transformative Monitoring for Enhanced Equity (TransMonEE) Database, established in 1992 by the UNICEF Innocenti Research Centre, captures a vast range of data relevant to social and economic issues relevant to the situation and wellbeing of children, young people and women in countries of Eastern Europe and Central Asia. The database is updated every year thanks to the collaboration of National Statistical Offices (NSOs).

NSOs that are part of the TransMonEE regularly come together in network meetings with the aim of strengthening collaboration and enhancing quality of national data on key indicators of child wellbeing.

The 2014 TransMonEE network meeting was held in Luxembourg City, Grand Duchy of Luxembourg, from 10 to 11 November 2014. The expected outcomes of the meeting were:

- Increased awareness of good practices and ongoing methodological work in terms of improved disability prevalence measurement;
- Increased awareness of the importance of dissemination and use of child focused data made available through the TransMonEE.
- Contributions made to plans for the future direction and continuous improvement of the TransMonEE
- Increased coherence and synergy between organizations working on statistics related to children operating at a regional level.

The National Statistical Offices of the following countries were represented at the meeting:

Albania, Armenia, Azerbaijan, Belarus, Bosnia and Herzegovina, Bulgaria, Croatia, Czech Republic, Estonia, Georgia, Hungary, Kazakhstan, Kyrgyzstan, Latvia, Montenegro, Romania, Republic of Moldova, Russian Federation, Serbia, Slovakia, Tajikistan, the former Yugoslav Republic of Macedonia, Turkey, Turkmenistan, Ukraine and Uzbekistan. Representatives of Eurostat, Interstate Stat Committee of Commonwealth of Independent States, European Disability Forum, the European Agency for Special Needs and Inclusive Education, Open Society Foundation and Washington Group on Disability Statistics also attended the meeting.

**Ms. Kirsi Madi**, Deputy Regional Director of UNICEF Regional Office (RO) for Central and Eastern Europe and Commonwealth of Independent States (CEE/CIS), opened the meeting, welcomed participants and emphasised the importance of quality and reliable data in identifying the most disadvantaged children, including children with disabilities, the bottlenecks in their access to services and full realisation of their rights. UNICEF's research and analysis of existing data clearly indicate that children with disabilities remain a group still often excluded and stigmatized in our region.

Ending the era of the MDGs - 2015 will be an important year for a) taking stock on what has been achieved for children so far and b) the unfinished agenda in our region, to reduce inequities related to service provision for systematically excluded groups such as children with disabilities, children from ethnic minority groups and children in rural areas. Measuring the positive change in social norms and the reduction in discrimination will be key.

She cited the even more important role that work on data will play in shaping and monitoring the post-2015 sustainable development goals. Sustainable development means moving past national averages and examining the inequities that persist in both developing and developed countries. Unlike for the MDGs, how to measure progress is being considered from the onset – and data and statistics will be essential components of global, regional and national governance mechanisms.

**Ms. Lori Bell**, Monitoring and Evaluation Advisor at the UNICEF RO for CEE/CIS, recalled the history of TransMonEE and thanked participating countries, many of whom have been contributing to regional data gathering for decades. She presented the objectives and agenda, drawing attention to the changed format of the two-day meeting. The 2014 meeting was to adopt a thematic approach, dedicating one day to the examination of a particular data gathering challenge: the identification of children with disabilities. While economic growth in the region has meant that the majority of children have access to basic services necessary for their development and well-being, specific groups such as children with disabilities are often left behind. In order to monitor this disadvantaged group, reliable statistics and analysis on children with disabilities is essential. She expressed her

aspirations for the TransMonEE 2014 meeting – that by the end of the meeting, partners share a common understanding of the most useful tools for identifying children and persons with disability. Ms. Bell urged the NSOs to join hands in their efforts to improve the working definitions of people and children with disabilities, to benefit from the growing global momentum around disability measurement, towards designing better, more targeted policies and programmes throughout the region.

All presentations are available on the TransMonEE website: [www.transmonee.org](http://www.transmonee.org).

### **Session 1: Overview of the TransMonEE data and trends over time**

**Mr. Siraj Mahmudlu**, Monitoring and Evaluation Specialist at the UNICEF RO for CEE/CIS, provided an overview of the recent TransMonEE data on selected indicators, including on children with disabilities. Children with disabilities were usually over-represented in residential care and disadvantaged in terms of their access to education. Globally, the prevalence of children with disabilities is estimated at approximately 10%. Data from the region shows considerable variability between countries (due to differences in the definitions and sources of data used), but in general low prevalence rates indicate a gross under-estimation of population and children with disabilities. The needs of this invisible population are therefore not well understood.

### **Session 2: UN Convention on the Rights of Persons with Disabilities (UNCRPD), disability statistics and approaches to its measurement**

**Mr. Andras Lenart** from the European Agency for Special Needs and Inclusive Education talked about the UNCRPD and the paradigm shift in understanding and defining disability. He provided information about the mission, structure and the organization of the work of his Agency. He also alluded to difficulties in keeping countries within a common joint approach in approaching disabilities and to the importance of use of complementary approaches by different entities in collection of data on persons with disability.

**Mr. Lucian Agafitei** from Eurostat, the European Commission, provided information about the approaches to disability measurement and sources and dissemination of data collected by Eurostat. Current sources of data on disability include European Health and Social Integration Survey, European Health Interview Survey (EHIS), Statistics on Income and Living Conditions (SILC) and Labour Force Survey ad hoc module on employment of people with disabilities. SILC currently collects data on limitations in usual activities caused by a health problem using the Global Activity Limitation Indicator (GALI). GALI data is collected only on people aged 15 and above. Future plans to improve measurement of disability include administering the health module (including functional limitations variables) in SILC every three years, improving comparability of GALI and allowing for the breakdown of all key (Europe 2020) indicators by two core health variables, including by activity limitation (GALI). There will also be discussions in 2015 on the possibility of including a child module in the future EHIS wave.

**Mr. Mitchel Loeb** from the Washington Group (WG) on Disability Statistics gave information about the WG, provided detailed information about different measurements tools concerning disability, including the new module on child functioning and disability. The WG was established as a City Group under the aegis of the UN Statistical Commission to address the need for population-based measures of disability, foster international cooperation in the area of health and disability statistics, produce internationally tested measures to monitor status of persons with disability and incorporate disability into national statistical systems. The measures of disability that the WG has been working on include short set of questions for censuses, extended questions set on functioning for national surveys, a module on child functioning and disability (being tested) and a module on measuring environmental factors and school participation (under development).

There is no single operational definition of disability, as the purpose will determine which definition to use. For the methodological work, the ICF (International Classification of Functioning) model of WHO has been used as a conceptual framework serving as a bio-psycho-social model. The global trend is to move away from data that is based on diagnosis of medical conditions and to apply a social approach.

Modules developed for adults are not sensitive enough or adequate to measure disability of children. That is why a new module on Child functioning and Disability has been developed by the WG and UNICEF. The aim is to

identify children aged 2-17 years who are at greater risk of experiencing limited social participation compared with all children of the same age.

Some resources are being developed to provide guidance to those considering collection of data on children with disabilities. Both the Guidelines for Producing Statistics on Children with Disabilities and the Manual/User's Guide for the UNICEF/WG module on child functioning and disability will be ready by early 2015. There will also be five-day regional workshops on measuring disability in 2015-16.

### Questions raised during the discussion

- Child disability module may be used independently or integrated in some other surveys. When it is integrated into other surveys, there are more opportunities to cross-analyse data.
- The survey module questions may be used as part of administrative data systems, but need to be modified in consultation with the WG.
- When using administrative statistics which includes data on children with disability it is important to understand why they are collected and for what use – so as to be able to appropriately interpret and use the data. Data that is collected through surveys can be used to provide additional complementary dimensions to administrative data.
- The WG should do better in terms of supporting countries to understand how data can be analysed and interpreted by policymakers, especially when six questions on disability are included into censuses.
- The WG is open to all countries that would like to participate as members. Moreover, WG is willing to help any country that would like to understand more about or move forward on any issue related to the disability statistics.

### Session 3: Country Experiences with disability measurement tools

**Ms. Lori Bell** presented the summary report of TransMonEE country analytical reports (CARs) developed by 19 participating countries in 2013 on the topic of disability measurement. The reports were reviewed to assess the conformity of the currently used definitions with the one specified in the UNCRPD. While most countries have signed the UNCRPD, the synthesis clearly identified challenges related to non-alignment of the definition and terminology with UNCRPD which is also often not harmonised within the country, confusion with respect to the difference between impairment and disability, lack of adequate legislation to strengthen the regulation of measurement and lack of modernisation. However, CARs also provided examples of emerging good practices, such as increasing disaggregation of data, moving towards social approach to disability measurement, rolling out real-time disability data monitoring systems and inter-sectoral collaboration on disability measurement.

Kazakhstan, Kyrgyzstan, Croatia and the Republic of Moldova shared their experience and practices in terms of disability measurement. **Kazakhstan** provided information about the survey on the quality of life of children with disability as well as the plans to integrate the new WG/UNICEF module on child functioning and disability into their Multiple Indicator Cluster Survey (MICS). **Kyrgyzstan** described the current disability measurement system in the country highlighting the need for better stakeholder cooperation in the country towards harmonising definitions and methods of measurement. **Croatia** informed the participants about the Registry of Persons with Disabilities as well as the very recent Act on the Unified Body of Experts for Determination of Disability that envisages establishment of an independent body of experts. The body will provide expertise to all sectors by using a uniform set of criteria based on the principles of the social/medical model of disability determination. **The Republic of Moldova** focused on the recent reform of disability identification in the country. The new definitions go beyond the medical factors and considers psycho-pedagogical, personal, professional and other social factors that help realise human potential, guarantee realisation of their rights and ensure equal opportunities and participation in society.

### Session 4: Discussion on good practices and next steps

Working groups that focused on discussions throughout the day, new information received and next steps to be undertaken by countries cited the need for:

- ratification and careful implementation of the UNCRPD

- defining criteria for disability based on medical and social models while understanding the difference between the two paradigms and developing compatible methodologies for collecting data on measuring disability.
- application of mixed methodologies (quantitative and qualitative) for collecting data
- establishment of inter-sectoral coordination mechanism including civil society
- sharing the information with all the stakeholders in the country

### **Session 5: Enhancing the availability, quality and comparability of TransMonEE data**

**Ms. Virginija Crujisen**, TransMonEE Database Management Consultant, provided updates on availability of data in TransMonEE for indicators on disability, children without parental care, and justice for children. She also brought examples of inconsistencies among selected indicators emphasizing the need to pay particular attention to quality of data and definitions.

### **Session 6: 2014 Country Analytical Reports**

**Mr. Siraj Mahmudlu** presented the objectives and structure of the TransMonEE CARs in 2014. The topic in 2014 is country systems for alternative care provision for children deprived of care of their biological parents. Key recommendations for the next steps were also outlined. As it is important to use the development of the CAR as an opportunity to bring together all the concerned stakeholders together, discuss definitions and data sources and foster inter-sectoral collaboration in collection and analysis of quality data on children deprived of parental care, the countries were encouraged to pursue a participatory process, even if this requires extending the deadlines.

### **Session 7: TransMonEE process as a means to bridge inter-agency data discrepancies – experience of Serbia**

**Ms. Mirjana Ognjanovic** from the National Institute for Social Protection of Serbia described the process her country has been following to avoid data discrepancies among different government entities. This involved revising indicators and meta-data for them, revising data collection instruments, reviewing reliability of each data source in order to define the most optimal source for key indicators and further developing the analytical and monitoring capacity within Centres for Social Welfare. This exercise has contributed to reliability, consistency, comparability and eventually increased use of data. Next steps include standardizing meta-data, improving coordination within the national statistical system and raising awareness and capacity of policy-makers for more systematic use of data in policy-making.

### **Session 8: Discussion on improvement of coverage, quality and disaggregated data**

The subsequent group work focused on identification of a good example of data availability and/or disaggregation among the participating countries and suggestions for improvement of inter-sectoral cooperation. Suggestions from the groups included establishing inter-sectoral working group to review data gaps and to work on producing the missing data, cooperating with universities and research institutions on supporting the responsible institutions in providing data to NSOs and working on harmonized definitions.

### **Session 9: Strengthening TransMonEE – Recent improvements**

**Mr. Flavio Bianconi**, TransMonEE Database Development Consultant, updated the participants about the TransMonEE database system and linkages among files, changes in the guidelines and template and the new data validation module that is under development. The validation module, which is expected to be put in action in 2015, will be used first by the participating country and will contain formulas that are directly linked to the TransMonEE templates.

### **Session 10: Dissemination and use of children-related data at the regional and country levels**

**Mr. Siraj Mahmudlu** provided brief information about dissemination of TransMonEE data at the regional level and beyond and mentioned the planned work to improve the TransMonEE website. Two countries, Belarus and the former Yugoslav Republic of Macedonia, shared their experience with dissemination of child-related data

and in particular data contained in the TransMonEE database. **Belarus** talked about the access to and use of data collected for or contained in TransMonEE within the country and shared their plan to cooperate with the Ministry of Education in further the use of education-related data of TransMonEE. **The former Yugoslav Republic of Macedonia** provided information about their regional and inter-sectoral workshops to raise statistical literacy on data, including on indicators included in TransMonEE and fill in some of the data gaps. Workshops at municipality level were helpful to generate interest both in production and in use of data.

The working groups that focussed on identification of innovation/good practices in dissemination and/or communication of social statistics suggested, inter alia, increased interactivity of data, dissemination of data, including of TransMonEE data, using infographics and social media and enabling users to provide feedback on data.

### Wrap up and next steps

**Ms. Claudia Junker** from Eurostat talked about how Eurostat can help NSOs, particularly from the EU, Enlargement and ENP countries, to strengthen their statistical systems including the implementation of some of the recommendations that have been discussed at the TransMonEE meeting. She also mentioned the importance of getting more feedback from NSOs about how duplications in data collection can be further reduced.

**Ms. Olga Remenets** from the Interstate Statistical Committee of the CIS highlighted the complementarity of different sources and types of data talking about the equal importance of qualitative data as well as of measuring process indicators alongside impact level indicators. She also emphasised the need for promoting accessibility and use of data. For this purpose, proper data analysis is key for making sure that policy-makers use the available data.

**Mr. Fabio Sabatini** from the UNICEF RO for CEE/CIS noted the commitment of governments and in particular of NSOs to TransMonEE, use of data for comparative and trend analyses and the ability of TransMonEE to bring up issues related to unfulfilled agenda for the realisation of child rights in Europe and Central Asia. This was demonstrated by representation of all the countries at this two-day meeting to discuss the definition and measurement of disability and to agree on actions to further improve the national data collection systems for monitoring child rights.

### Suggested follow-up actions to the meeting

#### Disability measurement

- Hold in-country consultations to inform the concerned stakeholders about the discussions at the TransMonEE meeting and elaborate next steps to be undertaken to conform to the definition of the UNCRPD for persons with disability.
- Determine the need for and suggested composition of the country teams to participate at the regional workshop on disability measurement that UNICEF is planning to organise in 2015 (or 2016).
- Contact UNICEF or WG directly for additional support in terms of data collection or capacity-development for measurement of disability

#### Data dissemination

- Provide suggestions for improvement of the TransMonEE website
- Share good practices and lessons learned on dissemination of child-related statistics with the wider network

#### 2014 data collection and beyond

- As part of the development of CAR on child care systems, organise additional in-country consultations about the definitions and data collection methodologies and as relevant, establish inter-sectoral working groups for harmonised work on data on child rights monitoring.

*The presentations made at the meeting are available at [www.transmonee.org](http://www.transmonee.org).*