United Nations Expert Group Meeting on

Disability data and statistics, monitoring and evaluation: the way forward, a disability inclusive development agenda towards 2015 and beyond

UNESCO Headquarters, Paris, France

(8-10 July 2014) – Room V

Aide Memoire

I. INTRODUCTION


The meeting will invite, in their individual capacity, experts from around the world including those with experience in: disability, development economics and statistics. The meeting will also include a sub thematic session to explore open technological solutions for data collection.

The meeting is expected to result in a policy brief analyzing the current status of disability statistics and recommendations for action to strengthen data collection efforts to promote evidence-based policy making. The meeting is also expected to contribute towards the implementation of the outcome document of the General Assembly High Level Meeting on Disability and Development held on 23 September 2013 which stressed the urgent need for accurate data on disability.

The recommendations from the meeting is expected to strengthen work by the international system and national statistics agencies to address data gaps and revise methods of data collection, synthesis and reporting, with a view to improve coverage of topics, timeliness and data comparability taking into account the specific situation of persons with disabilities.
II. BACKGROUND

General Assembly High-level meeting on disability and development (HLMDD)

On 23 September 2013, the General Assembly convened the High-Level Meeting on Disability and Development at the level of Heads of State and Government under the theme: “The Way Forward: a disability inclusive development agenda towards 2015 and beyond”. The Meeting presented a historical opportunity to translate the international commitment to disability-inclusive society and development into concrete action and changes on the ground, and to mainstream disability in the global agenda towards a post-2015 development framework. At this meeting, Member States adopted a concise and action-oriented outcome document\(^1\) reiterate their determination to ensure the realization of the Millennium Development Goals for persons with disabilities and stress the importance of giving due consideration to all persons with disabilities in the emerging post-2015 development agenda.

The need for accurate data is clearly mentioned in the outcome document, in its paragraph (i) calls for improving disability data collection, analysis and monitoring for development policy, planning and implementation taking into account regional contexts. It further underlines the need for internationally comparable data and statistics disaggregated by sex and age, including information on disability.

The emerging post-2015 development framework and disability

The need for accurate data has resulted in a growing call for the collection, analysis and use of data on disability to inform all development efforts. In addition to the outcome document, other high level commitments relating to the post-2015 development agenda, the international community have strongly voiced their concern over growing inequality and exclusion, offering new possibilities to mainstream disability in development.

For example, the Rio +20 outcome document, “The Future We Want”, includes a number of specific references to disability, highlighting, inter alia, that sustainable development requires the meaningful involvement and active participation of persons with disabilities. The need for development policies that support inclusive housing and social services, as well as a safe and healthy living environment for all, particularly persons with disabilities; and ensuring equal access to education for persons with disabilities and enhancing the welfare of persons with disabilities is noted in this document.\(^2\)

Most recently, the call for accurate data on disability was found in the UN High-Level Panel on the Post-2015 Development Agenda, which refers to disability throughout,

\(^1\) A/RES/68/3
\(^2\) A/res/66/288, The Future We Want, paragraphs. 43, 135, 229 and 58. Additional references addressed the responsibilities of States to respect, protect and promote human rights and fundamental freedom for all (paragraph 9).
including in the call to “leave no one behind” while ending extreme poverty. In referring to
the requirement for a “new data revolution”, the report calls for the need for data gathered
to be disaggregated by disability alongside gender, income and other categories.

In setting targets and indicators, high priority must be given to the most
marginalised population groups to track progress in reducing inequalities. For maximum
impact, it is necessary to approach and work with many entry points in the post-2015
development framework as possible.

Methodological and data challenges to measuring progress of persons with disabilities

The lack of clear picture of the linkages between disability and development –
including, effects of disability on poverty and vice versa, reflects both the dearth of
adequate quantitative information and the difficulty encountered in collecting accurate data
on disability.

There are several challenges to gathering disability data and generating accurate
indicators and statistics on the situation of persons with disabilities. These range from
conceptual challenges in the “definition” of disability used in different countries to social
and cultural responses to disability due to stigma and prejudice.

In order to address and include persons with disabilities in new and on-going
development efforts, it is necessary to build a clearer picture of disability, including better
understanding of the numbers of individuals living with a disability and their needs; their
access to all mainstream policies, systems and services (education, health, social inclusion,
transport to mention a few). Accurate data on disability is also required in order to measure
how successfully persons with disabilities are reached by current programmes and policies
and to inform future development initiatives.

Ongoing efforts to improve data collection

The number of countries including questions of disability in the most recent census
round has increased significantly compared from previous years. This demonstrates both
willingness and demand from countries to gather information on persons with disabilities.
However, in majority of the cases the data collected is grossly inadequate to provide a full
picture of the situation of persons with disabilities. In addition to this current efforts do not
allow international comparisons.

Since 2001, there has been an international effort to collect internationally
comparable disability data through the United Nations’ Washington City Group on
Disability Statistics (the “Washington Group”). The main purpose of the Washington
Group is, therefore, the promotion and coordination of international cooperation in the area
of health statistics focusing on disability measures suitable for censuses and national
surveys. The Washington Group on Disability Statistics developed a short set of questions on disability that address the issue of assessing equalization of opportunity, primarily for use in census formats. Some 35 countries included the short set of questions, or some variant, in their recent census rounds.

The Washington Group has also developed an extended question set on functioning to be used as a component of population surveys, as a supplement to short set of questions. The Washington Group and UNICEF are developing two extended survey modules; (1) on child functioning and disability and (2) on environment and participation in school. The two modules compliment each other and aim to provide comprehensive information on children’s functional limitations as well as their interactions with the environment.

The Model Disability Survey (MDS) is being developed by WHO and the World bank with the involvement of a broad range of stakeholders. The aim is to provide data on all aspects of disability - impairments, activity limitations, participation restrictions, related health conditions and environmental factors.

III. EXPECTED OUTCOME

The Expert Group Meeting will work to:

- Take stock of ongoing efforts and create stronger linkages between existing efforts among different partners of the United Nations system;
- Draft with a list of recommendations— a “road map” for post-2015 goals, targets and indicators to be disability inclusive
- Develop a policy brief to strengthen data collection efforts to promote evidence-based policy making
- Discuss the technical/strategic issues involved in where/when/how to make suggestions recommendations to the ongoing discussions on targets and indicators being developed for the post-2015 development framework
- Establish a collaborative working group with DESA, other UN Agencies and the post-2015 group to foster strategic thinking and planning on the post-2015 and disability;

IV. ORGANIZATIONAL AND ADMINISTRATIVE MATTERS

The Secretariat for the Convention on the Rights of Persons with Disabilities of the United Nations Department of Economic and Social Affairs (UNDESA) in collaboration

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3 E/CN.3/2014/10
4 A/58/61
5 E/CN.3/2014/10
with UNESCO will organize the EGM at UNESCO Headquarters, Paris, France, on 8-10 July 2014.

Approximately 15 experts will be identified and invited by DSPD and UNESCO to the two and a half day Expert Group Meeting in Paris, France. In addition, representatives of international organizations, United Nations Departments and agencies, as well as civil society organizations will participate as observers.

VI. LANGUAGE OF THE MEETING

The working language of the meeting is English. Pre- and in-session meeting documentation will be provided in English in accessible formats, through Internet-enabled resources or both.

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