

Disability Data in Sustainable Development Agenda 2030 and their relevance for the UN Convention on the Rights of Persons with Disabilities

Messages from the consultative meeting Bishkek, October 2019

Introduction

The 2030 Agenda for Sustainable Development¹ with its commitment to Leave No One Behind recognises the promotion of the rights, perspectives and well-being of persons with disabilities. The 2030 Declaration makes it explicit that all Sustainable Development Goals (SDGs), targets and indicators are relevant for persons with disabilities: “*People who are vulnerable must be empowered. Those whose needs are reflected in the Agenda include all children, youth, persons with disabilities (of whom more than 80 per cent live in poverty), people living with HIV/AIDS, older persons, indigenous peoples, refugees and internally displaced persons and migrants...*”². Importantly the 2030 Agenda is anchored in human rights: “...we emphasize the responsibilities of all States, in conformity with the Charter of the United Nations, to respect, protect and promote human rights and fundamental freedoms for all, without distinction of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, disability or other status”³. This provides for strong links between SDGs and the UN Convention on the Rights of Persons with Disabilities (UN CRPD). In other words, the UN CRPD should serve as a guiding framework for the implementation of SDGs.

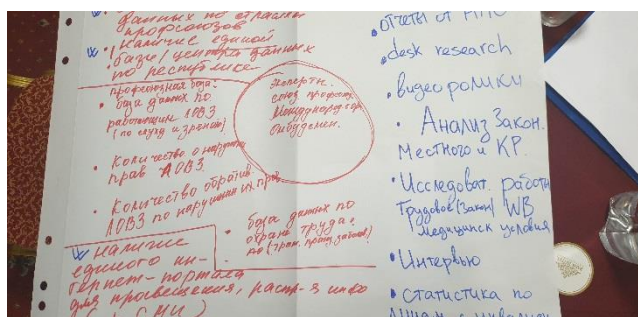


Photo: Disability Data, SDGs and UN CRPD, Consultative meeting, Bishkek, 10 October, 2019

Data collection, both quantitative and qualitative are seen as critical in assessing progress under SDGs and implementation of UN CRPD. Active

localization of SDGs, its targets and indicators is essential for their achievement. Context specific adaptation of global goals, targets and indicators to a national or local level is needed (not a pure copy-paste of global indicators and targets) if transformational aspirations of SDGs are to be achieved. Relevant and good quality data is seen as crucial to provide the evidence of the achievements made. The 2030 Declaration is clear that the progress will be assessed based on “data which is high-quality, accessible, timely, reliable and disaggregated by income, sex, age, race, ethnicity, migration status, disability and geographic location and other characteristics relevant in national contexts”⁴. Likewise, UN CRPD provides for an obligation to collect appropriate information, including statistical and research data to enable State Parties to the Convention to formulate and implement policies in line with the Convention⁵. Importantly, the UNCRPD requires from State Parties to identify and address barriers faced by persons with disabilities in exercising their rights, pointing to the fact that the statistical/quantitative data alone is not sufficient to assess and monitor improvements of the position of persons with disabilities or their effective access to rights.

Kyrgyz Republic is in the process of nationalizing Sustainable Development Goals. It has also ratified the UN Convention on the Rights of Persons with Disabilities on 14 March 2019. Decisive efforts are taken to revise national legal and policy framework, including data collection systems to progressively meet the requirements related to disability inclusive SDG nationalization and preparations for implementation of UN CRPD.

Attempting to support these efforts, ILO organized a consultative meeting with national partners representing Government’s institutions, worker’s and employer’s organisations, civil society organisations representing persons with disabilities and academia.

¹ https://www.un.org/ga/search/view_doc.asp?symbol=A/RES/70/1&Lang=E

²² Ibidem

³ Ibidem

⁴ Ibidem, Para 74, (g)

⁵ UN CRPD, Article 31

Their assessment of existing data, sources and needs for information is presented in this report.

Overview of data & information sources

Most of quantitative data about persons with disability is collected from administrative sources: from Ministry of Labour and Social Development; Ministry of Education and Center of Medico-social Expertise which conducts disability assessment. Given that disability assessment is based on medical approach, and possibly because not all persons with disability undergo assessment procedure, persons with disability constitute 3% of Kyrgyz population.

National Statistical Committee draws the information from administrative sources but it has, in cooperation with UNICEF implemented Multiple Indicator Cluster Survey⁶ with a Washington Group on Disability⁷ set of questions. Importantly, the upcoming Population Census planned for 2020 will include short set of questions based on Washington Group on Disability questionnaire. This will provide for more reliable information and will contribute to the achievement of the SDG 17.8 related to significantly increased availability of high quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics.

Trade unions maintain information about: i) number of employed persons with disabilities (with hearing and sight impairments): ii) number and the type of violations of rights of workers with disabilities and iii) a database about injuries and professional diseases resulting in disability.

Office of the Ombudsman prepared a report analyzing persons' with disabilities complaints about potential discrimination. Most complaints refer to their attempt to find jobs. The analysis of cases presents qualitative assessment of barriers (attitudes, legislation, lack of accessibility, lack of support services) they face at the labour market.

Organizations representing persons with disabilities and international organisations produced a number of qualitative reports analyzing the situation in education, labour market and health. In some cases desk review is supplemented with qualitative data based on interviews with persons with disabilities

which illustrate particular obstacles and point to possible solutions. Importantly, the legislation review, including detailed review of labour law is available.



Reflecting on existing data and information sources, participants concluded that:

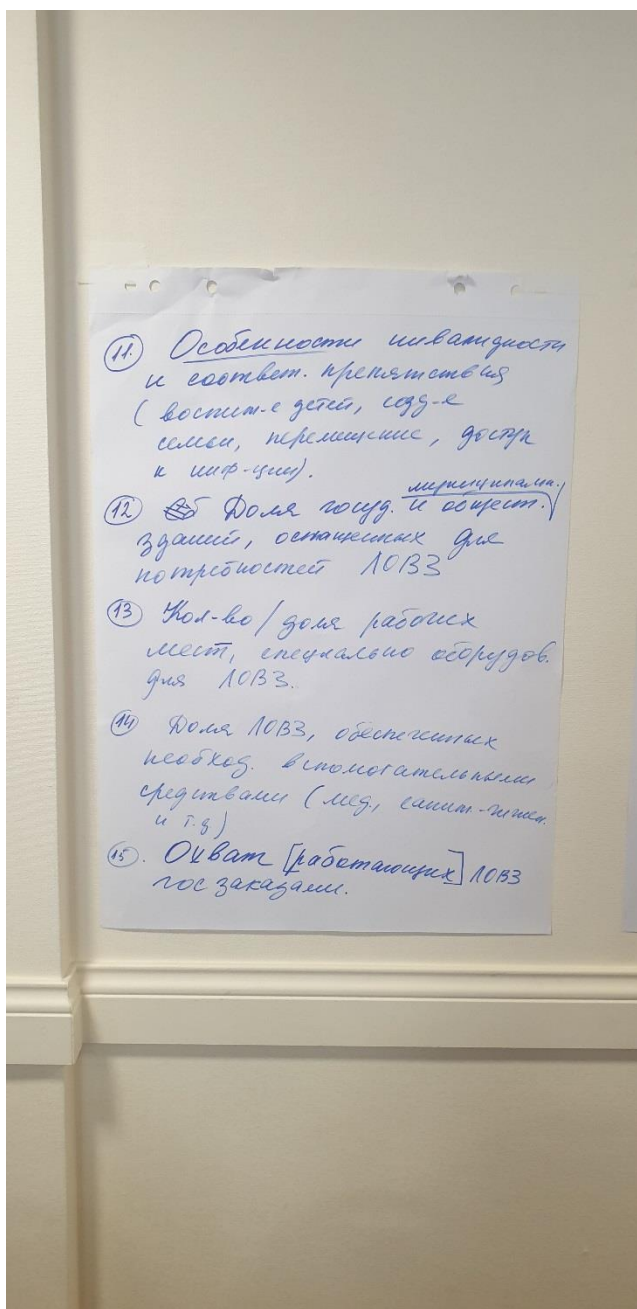
- **The Population Census planned for 2020 is expected to significantly improve the quality and the scope of information, but it will not be enough to set up specific baselines, targets and monitoring indicators for policy design.** National Statistical Committee's data is dependent on administrative data sources, which collect limited type of information based on their particular mandate and based on persons with disabilities with whom they interact. It is recommended that the National Statistical Committee officially requests the ministries and agencies to provide the relevant data on PwD, in line with their mandate.
- **There is a need to conduct targeted survey/s about the situation of persons with disabilities to complement information that will be received from the Population Census.** Persons with disabilities can be described as 'hard-to-reach' population in mainstream surveys. This can be because they are under-represented in sampling procedures due to the methodological design of a survey; questionnaires and methods of interviewing are not accessible for particular groups; self-exclusion due to prevailing social attitudes towards disability and many others. Adequate survey methods and approaches should be developed with participation of persons with disabilities who should also participate in data collection and analysis. National Statistical Office could have important role in this process advising on methodology for data collection in order to make sure that all quantitative data procedures are

⁶ <https://mics.unicef.org/>

⁷ <https://www.washingtongroup-disability.com/>

methodologically robust and adequate to be presented as a segment of national statistics.

• **There is a significant room for improvement of quantitative data collection procedures at all levels and from different sources.** An adequate and comprehensive mechanism/framework for data collection and exchange between administrative sources should be developed. Such framework could be developed as a part of a Roadmap for the implementation of the UN Convention on the Rights of Persons with Disabilities (and it should include SDG targets and indicators).



• **Qualitative information is crucial to contextualize and illustrate quantitative data and to capture complexities of the disability experience.** Analysis derived from qualitative methods exposes complex interactions between impairments, societal and physical barriers and policies. In particular, there is a need for detailed information about the position of persons with intellectual and psycho-social disabilities; the impact of disability on family relationships and living standards

Data & Information Needed



Based on the brainstorm exercise, the participants concluded that for policy development, monitoring and evaluation, there is a need for following data:

• Reasons preventing persons with disabilities from reporting and registering disability; prevalence and causes of disability, and a number of all persons with disabilities (SDG 16&17, CRPD Art 31). The latter should be disaggregated based on age, gender, urban/rural, disability type (group) and incidence due to working conditions; with access to different state guarantees.

• Social attitudes towards persons with disabilities and reasons for the existing exclusion/marginalization (SDG 10, CRPD Art 5; 19; 28). It would be important to capture if/how social attitudes influence on a decision to register disability (particularly when it comes to persons with intellectual and psycho-social disabilities); the information about impact of social attitudes on development and implementation of policies. Equally important is the information about specific position of persons with different disabilities and barriers they face when attempting to access rights.

• Accessibility of public spaces/buildings, transport and information for persons with physical, hearing, visual impairments, intellectual and psycho-social difficulties (SDG 11, CRPD Art 5, 9, 19 and 20)

- **Access to and equality of opportunity in education** (SDG 4, CRPD Art24). The information needed is the share of children with disabilities that are homeschooled (assessed as 10% now), in preschool, primary, secondary schools (assessed as 30%), in 'special schools' and in higher education. Data about the number of students with disabilities in higher education and obstacles when attempting to enroll into higher education are also needed. Qualitative data about engagement of assistant teachers and sign language interpreters, support in doing homework/ or while studying, and opportunities for participation in extracurricular activities are needed to assess potential for participation. All should be disaggregated based on age, sex, type of disability and urban/rural.

- **For the area of health, habilitation and rehabilitation** (SDG 3, CRPD Art (10, 25, 26) data about accessibility of medical facilities; proportion of persons with disabilities with effective access to health coverage; share of households with persons with disabilities among households with catastrophic out of pocket health expenditure; share of persons with disabilities with access to and quality of rehabilitation programmes; access to assistive devices for persons who need them. It was also suggested to consider collecting data about causes of death of children with disabilities.

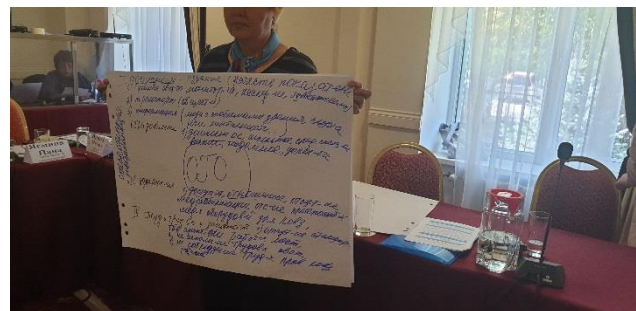
- **Employment and access to jobs** (SDG 8, CRPD Art 27): the share of employed persons with disabilities (of total working age persons with disabilities and among all employed); proportion of self-employed persons with disabilities; proportion of persons with disabilities in 'sheltered' employment; the share of working poor among employed persons with disabilities; average hourly earnings of female and male workers with disability; monitoring system for quota employment; reasons leading to lack of respect of rights of workers with disabilities and quota system); standards for adaptation of workplaces.

- **List of all social protection guarantees available for persons with disabilities, effective coverage and adequacy of schemes would provide more clarity about rights and living standards** (SDG1, CRPD Art.: 28; 19). At present, all registered persons with disabilities are accessing some of the guarantees (because the system registers only those who are accessing the rights). The information about adequacy of different allowances (impact on poverty reduction); the

proportion of persons with disabilities receiving allowances below subsistence level; the proportion of persons with disabilities living in residential care institutions; proportion of persons with disabilities with no access to needed day care; receiving day care in large institutions/at home.

- **Clarification of definitions of legal capacity and mental capacity used in national context is needed since it affects the position of persons with disabilities before the law** (SDG 16 CRPD Art 5, 13). Overall, data about access to information is one of the priorities, in addition to data about accessibility of courts and law enforcement agencies and to interpreters for sign language.

- **Participation in political life** (SDG 16 CRPD Art 29) : the share of persons with disabilities among those with voting rights who vote; physical and informational accessibility of voting stations; share of persons with disabilities among public servants in state/local/municipal public service.



Participants were unanimous that all data should be disaggregated by age, sex, type of disability and urban/rural residence, as a minimum. The need for a single data base that could store all administratively collected quantitative data about persons with disabilities was stressed. Representatives of workers organisations asserted the need for single electronic data registry with information for and by all trade unions branches, which would enhance their work and could significantly contribute to SDG 8 and SDG 1 monitoring. Likewise, all participants agreed that there is a need to develop online portal cataloguing all guarantees for persons with disabilities.

Finally, it could be suggested to develop one disability monitoring and evaluation framework in the context of preparation of a roadmap for the implementation of the Convention on the Rights of Persons with Disabilities. Such a framework would have to be

comprehensive enough to meet all needs of diverse actors implementing and reporting on the CRPD and it should include SDG related targets and indicators.