**Module 12 Summary : Data on Disability**

CDPF Online Disability Equality Capacity Building Coursebook

**Introduction:** Sixteen percent of the world’s population experience some form of impairment. Of this fifteen percent, disability is said to be prevailing in developing countries. It is recorded that disabled individuals are more likely to experience adverse socio-economic outcomes, like less access to education and poor health outcomes. However, all is not lost as the global awareness of disability-inclusive development is increasing. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) promotes the full inclusion of persons with disabilities in society; with special emphasis on the importance of international development in addressing the rights of persons with various disabilities.

 **The language the CDPF uses**: It is because of the development of the ‘social model of disability’, that persons refer to themselves as “disabled people.” In the nineteenth and twentieth century, it was thought that a disabled person’s medical condition was the cause for their exclusion from society. This approach is now referred to as the “medical or individual model” of disability. The use of the “social model of disability”, is what causes individuals with various impairments to face prejudice and discrimination. Therefore, when talking about the UN Convention on the Rights of Persons with Disabilities, the correct terminology to use would be “people or persons with disabilities.”

**The Importance of Data on Disability**: In order to strengthen disability inclusion, data collection is required to understand and respond to the experiences and situation of disabled people. This includes both collection of specific data on disability impairment, like disability prevalence and impairment types as well as broader information gathering processes within programmes that would need to be implemented in an inclusive way to ensure that the “voices” of disabled people are heard. Disability, until very recently, has been largely noticeably absent from data collection and monitoring mechanisms in international development. The invisibility of disabled people in the mainstream development narrative “resulted in development interventions unintentionally leaving out disabled people from their target groups. Also, lack of data on disability means that policy makers and practitioners are more likely to put disability aside. Another reason why disabled people were massively underrepresented in the data gathered was that the questions used often triggered shame and cultural biases and so disability was also under-reported.

**The Importance of the Different Purposes of Data Collection** are discussed below:

**Disability statistics** as evidence: this provides information about the problem itself. The data is important for policy formation. Policy without valid and reliable data is potentially costly and wasteful guesswork.

**Disability statistics** for choosing a right and cost-effective method for intervention.

**Disability statistics** to target populations for intervention: Information about functional statistics is essential to identify needs, since two individuals with the same impairment may face different types of difficulties in undertaking certain activities.

**Disability statistics** for monitoring the quality of intervention: population disability data is essential for monitoring the quality and outcomes of policies for disabled people.

 **A case study in Uttar Pradesh, India called Parivatan.** This project supports disabled people and their families to understand their rights and access much-needed services, information and training. Helping families negotiate the process of applying for government pensions and schemes has been a key focus, as has setting up an active DPO.

**Data and Policy Formation**: With a broader understanding of disability, disability policy can play a pivotal role in all areas of policy-making and in each stage from development to implementation, to monitoring and assessment of effectiveness, to the analysis.

**Some of the specific information includes**:

Differences in rates of disability between males and females: gender differences may indicate discrimination against a gender regarding service provision in the country.

Differences in service utilization: between the populations with and without disability-Policies may be formulated to increase access of population with disabilities in the different services and facilities.

Identification of physical and social barriers: information on what types and causes of restrictions disabled people for determining the environmental and social barriers that most urgently need to be addressed.

**Common data sources on Disability:** The common data sources are: surveys and census. Surveys are designed to be representative of the population under study, whereas, a census is a nationwide activity with every person enumerated separately and their characteristics recorded separately.

**The Washington Group questions**: The UN recommends using the Washington Group questions to gather disability data consistently across the world. There are many other recommendations for the inclusion of the Washington Group questions in censuses, and government, UN and NGO data collection, and global household surveys such as the Demographic and Health Survey (DHS).

The Washington Group short sets of questions: the group has produced a shortlist of questions to measure disability consistently worldwide, mainly through use in censuses and household surveys. The shortlist includes six questions- five on functional limitation (limitations in seeing, hearing, walking etc.) and one on self-care( limitation in showering or dressing.

The Washington Group Extended Sets: The Washington Group has also developed extended set questions on functioning. In addition, in order to “accurately assess disability in children, care must be taken to use questionnaires specifically designed for the purpose.”

**Difficulties in measuring disability**: disability is complex and therefore difficult to measure. Measuring child disability is particularly difficult as children develop at different speeds, which make it difficult to assess function and distinguish significant limitations from variations in normal development.

Some challenges in collating disability data include: availability of data, date of data, ability to compare the data, methodological issues and verification.

**Disaggregating data by disability**: Disaggregation of data is the intentional process of breaking down data into subgroups and comparing data from each of these subgroups. For disaggregation by disability, this requires identifying disabled people within existing surveys or other data collection methods. Disaggregating data by disability, sex and age can bring to light critical issues that might otherwise remain invisible in general community level data. Data on disabled girls and women is essential to understand the double discrimination and intersectional inequalities they experience.

Women are at an increased risk of becoming disabled because of ongoing gender inequalities due to inequities in economic status and access to healthcare; in addition women live longer on average than men which may put them at high risk of age-related functional limitations. Vulnerability to intimate partner violence also increases the risk of becoming disabled as can early pregnancy and poor reproductive health. Lastly, disabled women and girls are prone to forms of abuse, like forced marriages and sexual abuse, and disabled people are generally denied sexual education, which can obstruct the recognition of abuse as well as the seeking of support. Inclusion in education is an important and vital first step to inclusion in general. Disabled children who have had limited access to education often face many challenges accessing work due to missing out key educational milestones.

**Case Study Zimbabwe:** The tools chosen to measure disability to a population mirror the conventional wisdom of the day. Thus, a census from 1980 to 1990 would reflect the disability paradigm of the time. This one-dimensional, cause and effect model focuses primarily on impairments and, based on a medical, normative approach, begs some variant of the questions: Do you have a disability? or Are you disabled in any way? Accordingly, this approach was reflected in census questions used in Zambia in the 1990 census i.e.

‘Are you disabled in any way? Yes or No, and what is your disability?

Blind; deaf–dumb; crippled; mentally retarded; multiple disabilities.

Because of stigma and shame around disability this led to a prevalence of 0.91% in 1990 and with some more detailed questions 2.7% in 2000 out of a population of around 11 million.

The six questions of the Short Survey from the Washington Group were asked to a representative sample. A total of 5751 households were included in the final sample, representing 28,010 individuals or approximately 0.24% of the Zambian population (ca. 11.5 million). Three thousands and ninety individuals (11%) of the sample population were identified as having a disability. Once adjusted following: a sample of in depth interviews the level of inclusion for disability prevalence is “at least some difficulty” in carrying out at least one of the six WG domains, a prevalence rate of 17.8% is achieved and if a slightly more conservative cut-off was selected at the level of “at least some difficulty” on at least two of the six domains, the resultant national prevalence rate was 13.4%. Degree of difficulty D1, at least some difficulty; D2, at least a lot of difficulty; D3, unable to do it at all. Most severe level of disability (the individual is unable to do at least one of the six domains) was found to be 2.4% in line 2000 census.

**Case Study: World Bank**

The World Bank signed the Inclusive Data Charter in July 2018, towards mobilizing political support to improve the quality, quantity, availability, and financing of disaggregated data.

Ultimately, these data improvements will support the World Bank Group’s ambition of ending poverty and boosting shared prosperity, as well as help monitor the Sustainable Development Goals (SDGs). With support from the Trust Fund for Statistical Capacity Building, some of us in the Development Economics Vice Presidency have been working with internal and external partners—such as the Poverty, Education, and Social Protection

Global Practices, UNICEF, the South Africa Statistics Office, and the Washington Group on Disability—to strengthen the collection, applicability, and availability of disability data.

Better disability data is needed to inform policy decisions that can improve living conditions for disabled people worldwide. World Bank’s Inclusive Data and Statistics project, supported by Trust Fund for Statistical Capacity Building, is intended to contribute towards the World Bank’s commitment to disability-inclusive development, the Department for International Development’s data disaggregation action plan, and the SDGs’ “leave no one behind” principle.

 **Conclusion:** To conclude, gathering disaggregated data is essential for human rights from the perspective of meeting the obligations of non-discrimination and the equalization of opportunities. Disaggregated data can provide a better comparative picture of what works and what doesn’t work; and can help inform and promote evidence-based policy that would go a long way to ensuring no one gets behind.