**DATA to Influence Policymakers**

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“Data are the lifeblood of decision-making and the raw material for accountability.” – Data Revolution Report.

If we want inclusive policies for all, we need high-quality data and the use of them to provide the right information on the right things at the right time to the right people.

In this session, I will focus on how Disabled People’s Organisations, DPOs, can use data to influence our policymakers, hold them accountable, and make better decisions for people with disabilities in their countries and communities.

To achieve sustainable development goals, we need disaggregated data by disability, gender, age and location. Disaggregation of data by disability is necessary, but it is not sufficient to ensure, “nothing about us, without us”.

The participation of persons with disabilities should be ensured to develop, implement and monitor the progress of a policy that affects their lives. They need data for evidence-based policy influencing. For better a policy, they need reliable data.

However, data have to be available, accessible and affordable. If we want to gain the benefit of 2030 development agenda and SDGs, a person with disabilities in a rural area should have access to data. Then they can hold the local government that the social protection programme should reach to every one of the communities, who is eligible. They should inform the policymakers to improve health services.

I can give you an example of Bangladesh, where I came from and where Disabled People Organizations - the disability movement is active in policy influencing.

Bangladesh has a thriving health programme – the Community Health Clinic throughout the country. These clinics provide basic primary care. They so there were do not have disability-specific services. We implemented a project where DPOs collected data called the people generated data interviewing the community people, and reported to the Ministry of Health regularly to improve the services of the programmes.

I can give another example. Bangladesh has made remarkable achievements by ensuring access to education. The country’s net enrolment rate at the primary school level is 98 per cent in 2015. Bangladesh has achieved gender parity in education - boys and girls are equal – 50:50.

However, a study done by CSID in 2002 showed that only 10% of children with disabilities were enrolled into schools. DPOs used this data to influence policymakers. Then national budget 2008 allocated resources as a stipend for the education of children with disabilities. The National Education Policy 2010 focused on Inclusive Education. The Bangladesh Government Primary Education Report 2014 showed 59% of children with disabilities were enrolled in primary school by 2013.

Sources of data: DPOs can use official data, and people generated data. Along with these, a case study or a story of their own life can be powerful evidence to inform policy and influence the policymakers.

The Census gives us an overview of how many persons with disabilities live in the country. Household survey data can be of enormous value in using to inform policy. For example, the House Hold Survey 2016 of Bangladesh shows that 3.89% have some eyesight disabilities. Most of them are suffering from cataract, which can be cured by simple surgery. DPOs can take this data to the policymakers for cataract cure programme throughout the country.

How can we present them to the policymakers?

First and foremost, identify an issue. It can be education, employment, social protection, political participation or emergency response where persons with disabilities have no access or limited access because of the negative attitude of the society or the discriminatory policy of the country.

Second, collect reliable data from different sources. It can be an official data of the country along with the citizen-generated data from the community where persons with disabilities live. Toilets are not accessible to children especially girls with disabilities to not continue classes.

Third, develop a message to inform policy, prepare a position paper on the issue and write a short policy brief for the policymakers.

Fourth, present them in public speaking, one to one meetings with members of local governments, Members of Parliament or relevant people who can influence the policy, and the media.

Fifth, identify allies and network for policy influencing and empower persons with disability with data for a more comprehensive campaign of an inclusive society.

Capacity Building of DPOs on Data: they need skills in two areas:

1. Empowering people with disabilities with data literacy to reduce data divide. Marginalised people don’t have access to information. Information is the most valuable asset of this century. As a result, they remain poor, and they can not challenge and change the process of discrimination. The dedicated programme should be introduced to improve data literacy of persons with disabilities.
2. Strengthening the capacity of DPOs in all areas from data collection to use of data and the meaningful participation in the review of CRPD and Voluntary National Review of SDGs at the country level.

Conclusion: Persons with disabilities should not be only counted, but they contribute to informing the policies that affect their lives and hold those whose decisions had no impact to improve their situations. Disaggregated data and the use of them are crucial to leave no one behind!