Disability Inclusion Helpdesk Report No: 85

Query title	Disability inclusive social protection programming: data collection and disaggregation
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Query	Guidance note on good practices around data collection and disaggregation for and within social protection programming, to support FCDO country offices staff working on social protection in their influencing work around disability inclusion.
Enquirer	**FCDO Social Protection Team**

"There is no data, therefore there is no problem to solve"

This note provides an introduction to key concepts and tools to promote disability inclusion in the collection and disaggregation of data for social protection. Disability inclusive social protection is a complex area and FCDO social protection teams are advised to seek more guidance from experts on specific issues that arise.

Why does data collection and disaggregation need to be inclusive?

A key factor in the continued exclusion of persons with disabilities from social protection schemes is the lack of disaggregated data. Social protection schemes' coverage is often based on data, such as national household surveys, that often do not disaggregate by disability or use unreliable metrics.[1] The lack of disaggregated and adequately analysed data within national surveys and information systems reinforces the exclusion of persons with disabilities, lowering awareness of their levels of exclusion and

seemingly reducing demand for services. This lack of inclusion leads to an underestimation of need and a lack of understanding around the specific requirements for inclusive social protection in terms of resourcing, design and implementation, as shown in Figure one on the right (Barca et al, 2021).
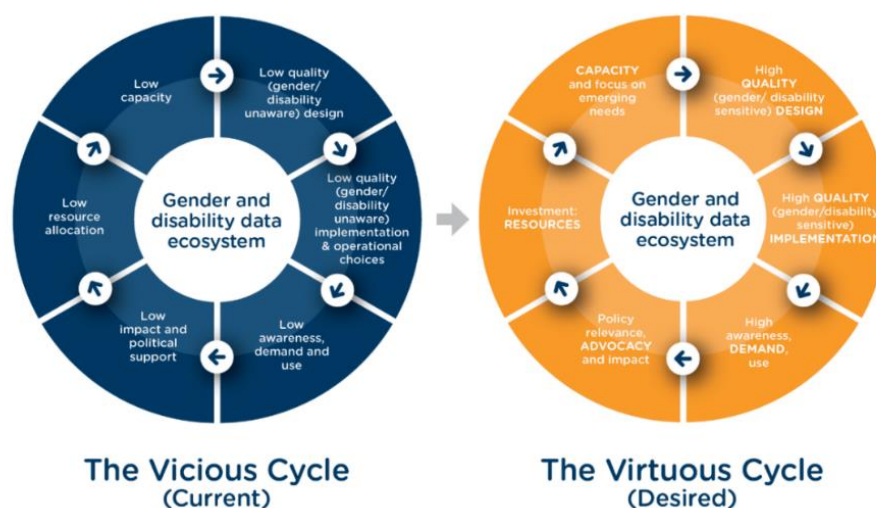

Figure 1: Gender and disability data ecosystems (Barca et al., 2021)

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[1] This includes national household surveys, or census data, and/or labour force, poverty and other national and local surveys. Until very recently, these types of population surveys typically did not disaggregate by disability status. Those that do often use unreliable metrics such as the binary 'yes/no' responses to questions such as 'Do you have a disability?' and/or will provide a list of predefined disabilities, impairments and/or health conditions. Such an approach leads to low prevalence estimates capturing mostly persons with very significant disabilities and missing others, including many older people, who do not self-identify as having a disability (Côte in Schüring and Loewe, 2021).

Collecting, analysing, and using quality disaggregated data is critical to understand and address requirements, coverage, barriers to access, and impacts of social protection on the lives of persons with disabilities and their households (ILO, 2012). This in turn supports better design and adaptation of social protection policies and programmes so they are more accessible and effective. Collecting data disaggregated by disability (and other intersectional factors such as gender, ethnicity and geography) are also key for ensuring accountability (IDA, 2021; UN, 2020). Collecting disaggregated data on persons with disabilities is an obligation for State Parties to the UN Convention on the Rights of Persons with Disabilities (CRPD). Collecting qualitative data, including through grievances and complaints mechanisms, can also help understand what are the barriers that persons with disabilities face, including their experiences with social protection schemes in accessing social protection.[2]

FCDO Social Protection teams can advocate for a shift to a 'virtuous' cycle where information systems consider disability inclusion, promoting equal access, the identification and response to disability-specific needs and empowerment.

Data collection tools for the identification of beneficiaries

In line with the Disability Inclusion and Rights Strategy, FCDO Social Protection teams can encourage governments and multilateral partners to integrate internationally recognised methods to disaggregate data by disability status, age, and sex and determine the prevalence of disability into population censuses and surveys,[3] information and monitoring and evaluation.

A rights-based disability disaggregated data approach will provide prevalence data which can be applied to outcome indicators such as levels of poverty, education, employment etc, inclusion and exclusion rates, and income rates. It will give programmes a sense of whether the right people are gaining access to the schemes in adequate numbers.

The FCDO Disability Inclusion and Rights Strategy recommends the use of the Washington Group Questions. Other approaches to disaggregated data involving binary categorisations of disability ('yes/no') and/or the use of predefined categories lead to unreliable and incomparable datasets. The Washington Group on Disability Statistics set of questions (which removes the word 'disability' and instead refers to difficulties with functioning) is more representative, reduces bias in reporting, and allows comparability. The Strategy recommends the use of the Washington Group Questions (WGQ) enhanced short set but the short set or extended set may be more appropriate in certain situations. For children, the recommended tool is the UNICEF-WG Survey Module on Child Functioning and Disability. The WGQs have several additional benefits, including: being self-reported, not relying on the technical capacity of an assessor;[4] and not requiring multiple in-depth assessments or expensive procedures.

When disaggregating data it is important to keep the following principles in mind: respect for dignity, personal autonomy, choice, control over one's life, confidentiality and privacy (ILO and IDA, 2019; CRPD, 2006; ILO, 2012). Engaging with OPDs can help ensuring the questions are

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[2] Qualitative data can also help understand the extent of their awareness of the schemes, the barriers they encountered accessing them and benefiting from them, and how they were treated by staff.
[3] Such as household income and expenditure surveys, labour force surveys, and demographic and health surveys (ILO and IDA, 2019).
[4] However, enumerators need to be adequately trained in administering the WGQs.

adequate and non-discriminatory. It is crucial to use accessible methods for persons with disabilities to consent to use of their data. Persons with disabilities should made aware with whom their data is being shared.

It is also important to assess the potential risks, including the potential for profiling as very high levels of data disaggregation make beneficiaries highly identifiable, with important implications for data protection and safeguarding. When this happens because of gatekeeping and eligibility mechanisms, individuals might be obliged to disclose publicly their disability status in order to obtain support, which may result in discrimination in the community (Barca et al, 2021).

Promising practices

> **Ghana's flagship social protection programme and disability inclusion:** the recommendations of a Rapid Scoping Study of the Government of Ghana's flagship social protection programme, Livelihood Empowerment Against Poverty (LEAP), discussed jointly with the Government of Ghana and organisations of persons with disabilities, led to the development of an Action Plan owned by the Government. Priority actions to strengthen disability inclusion from policy and design included using the WGQs in two national questionnaires. Progress is already being made under the Action Plan with training of enumerators to use the WGQs (FCDO, 2022).

> In the Dominican Republic, the inclusion of WGQs in the SIUBEN (Sistema Único de Beneficiarios) survey enabled families of children with disabilities eligible for support to be identified more rapidly during the COVID-19 crisis (ILO, 2021).

Alternative methods for additional beneficiary identification

Alternative methods to be used together with the WGQs, include sharing basic criteria through advertising such as sending SMS/WhatsApp messages, using outreach through community-based organisations to instruct people to call for an assessment, and using door-to-door collection of phone numbers for follow-up assessments by phone (Wapling and Meaney-Davis, 2020).

The COVID-19 crisis has highlighted the importance of inclusive social protection information systems, including national disability registries, to channel benefits to people with disabilities. Some countries are carrying out innovative assessments at the community level with simple assessment tools and the possibility of referrals to reduce the costs to people with disabilities of accessing the system (UNPRPD et al. 2021 in ILO, 2021). For example, in Vietnam, village committees have access to simple assessment instruments to determine eligibility of people with disabilities though the identification of functional limitations and/or the person's support requirements in carrying out basic daily life activities; a medical assessment is used only in the event of an appeal or when the decision is not clear. A similar approach has been adopted in Fiji with social workers using simple instruments (Côte in Schüring and Loewe, 2021).

Influencing partners around data disaggregation by disability

When discussion disability inclusion, and in particular data disaggregation, in social protection programming with partners, questions can be posed, and recommendations put forward such as:

> Does the monitoring framework for the scheme/programme allow for disaggregation by disability and assessment of the extent to which the programme promotes the participation and inclusion of persons with disabilities and sub-groups within this category? This may

require the data collection of additional factors such as gender, economic status and location of the individual. (ILO and IDA, 2019).

> Recommendation: include disability-specific indicators to monitor the inclusiveness of social protection programmes and the system as a whole, and further disaggregate this data by gender or other relevant characteristics.

Eligibility criteria and disability assessments for disability-targeted schemes

Defining disability and eligibility to disability-specific social protection programmes is complex, and it can be controversial, as different approaches can be taken. The type of mechanism often reflects the prevailing notion of disability within a country (Kidd et al., 2019). A rights-based or functional approach, which incorporates an assessment of how social and environmental factors affect an individual's ability to carry out their daily lives, is often regarded as preferable to a medical approach which measures only the level of impairment. The latter, and the conflation of disability with the incapacity to work and/or live independently (which is relatively easy to measure but perpetuates 'charity' approaches to disability), still dominate in most disability-targeted (or disability-relevant) schemes across low- and middle-income countries (Kidd et al., 2019).[5] Persons with disabilities should be supported in work and still be able to receive disability benefits needed to cover disability-related costs.

The WGQs were designed for population estimates and not as a disability assessment tool to determine eligibility to disability-specific benefits. Using the WGQs for this purpose could lead to significant inclusion or exclusion errors. Instead, stand-alone surveys, needs assessments, disability-specific modules can provide detailed information on the situations of people with disabilities and the barriers they face. These include the WHO Model Disability Survey and ILO Model Labour Force Resources. Different countries have taken the functional approach listing a series of activities, which can lead to the determination (or not) of disability, or a score that leads to different degrees of benefits.[6] The tools can significantly change between countries and there is not a one-size-fits-all tool.[7] This review did not find any assessment processes that include gender, which represents a significant data gap.[8] In order to implement disability assessments effectively, good-quality assurance and proper training of assessors are essential.

As the right to a disability benefit often relates to the person's work capacity, functional capacity is often central to establishing a framework for assessing eligibility for the benefit. The WHO's International Classification of Functioning, Disability and Health (ICF) is a fair, neutral and equal way to assess individuals' functional capacity and ability to work (UNESCAP, 2021).

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[5] Brazil integrated an assessment of the social and environmental context alongside a medical assessment (Kidd et al., 2019).

[6] For example, Fiji uses the Functional Independence Measure (FIM), an instrument that was developed as a measure of disability for a variety of populations and is not specific to any diagnosis. The FIM instrument Includes measures of independence for self-care, through an 18-item, seven-level, ordinal scale.

[7] For example, in Oman, if a person is not able to plan her/himself a family picnic, they might have a cognitive disability. Another example is the inclusion of albinism in certain countries in East Africa due to the cultural context, while albinism would not be considered in other countries.

[8] In certain contexts, a woman might say she is not able to go by herself to the market, but it might not be due to a disability, rather to gender norms.

However, disability benefits determination should move away from capacity to work, as it is not compliant with CRPD.

Using disaggregated data for inclusion of persons with disabilities in Information Management Systems

Disaggregated data and a robust calculation of disability-related costs, which vary between countries and impairments, will help structure the delivery of social protection in a fairer and more efficient manner.

The collection of disaggregated data requires the development of adequate information management systems and national registries, which would provide timely and critical information to support policy makers and OPDs to design relevant policies and schemes, determine adequate benefits, and facilitate planning and budget, by extending social protection (ILO and IDA, 2019). They can also eliminate the need for repetitive assessments (Côte in Schüring and Loewe, 2021). Some countries have developed systems to use this information to inform policy planning, such as the Equal Opportunity Card in Senegal which is linked to the disability registry, and the national information system for all the centres in charge of disability assessment in France (Barca et al, 2021; Côte in Schüring and Loewe, 2021).

Expert Contributors

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