Case study: Disability mainstreaming – identifying and engaging people with disabilities

Introduction

Disability inclusive development is essential to the reduction of poverty and the delivery of the Sustainable Development Goals. All those in receipt of FCDO funding through UK Aid Direct and UK Aid Match grants are expected to be mainstreaming disability inclusion across their project cycle to ensure that they are contributing to this issue through their work. This means that considerations of disability inclusion should be built across the project design and implementation of activities, how different groups are consulted and able to share their perspectives on the project, how results are measured and how the project responds and adapts to learning from this.

This case study showcases how different grant holders have approached the complex issue of identifying and engaging with people with disabilities in their projects.

Case study context

As a starting point for mainstreaming disability inclusion, it is obviously important to identify people with disabilities among project beneficiaries and target populations to understand their specific needs and any adjustments needed during project design and implementation to address those needs. Disability disaggregated data is needed for monitoring and evaluating how people with disabilities are benefiting from project interventions and whether they are benefitting equitably.

Identifying people with disabilities among project beneficiaries and target populations can be challenging because disability is understood in relation to perceptions of 'normal functioning' and is therefore influenced by social and cultural norms and contextual factors such as age and sex. For example, older people may not think of themselves as having a disability even though they experience considerable difficulties in functioning because they perceive these challenges as normal for their age. Similarly, parents or caregivers who answer questions about their children may not accurately report their difficulties in functioning either because of stigma and fear of admitting difference, or because of perceptions of what is considered normal functioning at different stages of development. The way that questions are asked about disability (for example, face-to-face or by questionnaires) and the kind of questions that are asked (focused on impairments, 'disability', or difficulties in functioning) can also influence the extent to which people with disabilities are identified in any given population.

The World Health Organisation (WHO) developed the Disability Assessment Schedule (WHODAS 2.0)[1] to address the challenges of identifying people with disabilities. The Washington Group Questions (WGQs)[2] and UNICEF/Washington Group child functioning module[3] were also developed to generate more robust data on adults and children with disabilities in census and household surveys. Disability prevalence data are generally considered more reliable when these tools have been used in general population surveys or censuses and then followed up by a disability-focused survey to verify the results or by including WGQs in project registers and then following up with a disability assessment for the provision of benefits and services. Nine UK Aid Match projects report having used WGQs or WHODAS 2.0 to identify and engage with people with disabilities.

Why was the collection of disability data important for projects?

People with disabilities are likely to be among the poorest and most excluded in any community or population targeted by UK Aid Match and UK Aid Direct projects, for example among poachers, waste pickers, subsistence farmers, women not accessing maternal and child health services, women survivors of sexual violence, women and girls and boys experiencing violence.

Disaggregated data on people with disability enables projects to identify people with disabilities among project beneficiaries and target communities, to monitor their participation and to report on how they are benefiting. It also enables projects to learn from people with disabilities about how the project activities can be adapted to ensure equitable access and empowerment of people with disabilities. Projects have used WGQs and WHODAS 2 in the following ways:

- Project registers, beneficiary surveys and evaluations: Using WGQs when registering patients enables Sightsavers to determine whether eye health services are reaching people with different severity and difficulties in functioning and whether there are gaps in coverage. They also enable disaggregation of patient survey data to determine whether training and behaviour change initiatives among health professionals have resulted in changes to discriminatory norms experienced by people with disabilities in hospitals. WHODAS 2.0 questions are used by Mercy Ships to determine changes in degree of disability pre- and post- operations as it includes questions relevant to people experiencing stigma and exclusion as a result of disfigurement and not only as a result of difficulties in functioning.

[1] WHO. 2012. Disability Assessment Schedule 2.0

[2] The Washington Group Questions Short Set asks if a person has 'no difficulty', 'some difficulty', 'a lot of difficulty' or 'cannot do at all' in six domains of functioning: vision, hearing, mobility, cognition (remembering and concentrating), self-care, and communicating (understanding and being understood).

[3] UNICEF and the Washington Group. 2016. Module on child functioning. New York

- Household surveys: Traidcraft, Village Water, Tree Aid and Send a Cow all incorporated WGQs into household surveys administered at baseline and at periodic intervals throughout project implementation. This enabled identification of people with disabilities among targeted populations and adaptation of project activities to ensure accessibility and inclusion. It also enabled monitoring of differences in project outcomes and experiences for people with disabilities.
- Volunteer or community worker recruitment: Using WGQs in recruiting community workers allowed WasteAid to ensure it was reaching people with disabilities among community members who were being trained and employed by the project and enabled adaptations to ensure their full participation and inclusion.
- Group activities: WGQs or WHODAS 2 questions can also be used to screen participants in focus group discussions or other types of community consultations and group activities such as self-help groups, training and capacity building. This enables project teams to determine the prevalence of disability among target groups and to carry out follow-up consultations both to identify necessary adjustments in project activities to enable inclusion and to monitor participation and outcomes for people with disabilities differentiated from people without disabilities.

What are the main learning points from these approaches?

Washington Group Questions and WHODAS 2.0 cannot replace disability assessments that are used to support access to health, education or social protection programmes; however, they help build an understanding of the prevalence of disability in a population. They need to be used in conjunction with survey and census data or with administrative data if the goal is to understand whether people with disabilities are being reached equitably by project interventions. They offer a way of defining people with disabilities; for example, as people who 'have a lot of difficulty' or 'cannot do at all' in at least one domain of functioning. This can help projects to monitor disability inclusion and to understand if they might be excluding people with particular functional impairments. This is especially important for projects that are targeting the whole population in a community with services or benefits that should be accessible to all (such as water, sanitation and hygiene services; waste disposal). Contextual and comparable population data is essential to interpret figures on disability prevalence and to understand how the experiences of people with disabilities differs from people without disabilities.