

Disability, inequality and the Sustainable Development Goals: Challenges for data collection and evidence

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Inequality is a barrier to human development. It can threaten social and political stability, and impacts economic growth (UN 2014). Inequality is also morally indefensible, as underscored by the principles of universality underpinning the Sustainable Development Goals (SDGs), and their theme: ‘leave no one behind’.

Inequality is impacted by gender, age, ethnicity, socio-economic status and—an important but often overlooked factor—disability. This paper examines the significance of disability as a cause of inequality, the direction provided by the SDGs in addressing this issue, and the particular importance of collecting and using accurate data to better understand its impact and to guide good practice. It will also present strategies for collecting and using data to inform disability inclusive development.

Disability, poverty and inequality

Around 15 per cent of the world’s population have a disability, which could include sensory, physical, intellectual or mental impairment. The prevalence of disability within the poorest communities is estimated to be closer to 22 per cent (WHO and World Bank 2011), making consideration of the role of disability in perpetuating inequality and poverty a vital part of reducing poverty and achieving development goals.

The term ‘disability’ describes the experience whereby people experience inequality on the basis of the impact of having one or more impairments. It is conceptualised in the UN Convention on the Rights of Persons with Disabilities (CRPD) as a consequence of the interaction of *impairments* with *barriers*—be they environmental, institutional, attitudinal or communication—that impede people with impairments from accessing their basic rights and participating fully in their communities on the same basis as other people, thus disabling them.

Because people with impairments are disabled by barriers, they experience unequal access to social, political, cultural and economic life, including within development programs. This is true for people with disability across most countries and contexts, although it is important to recognise that the experiences of individuals with disability vary widely according to gender, age, ethnicity and socio-economic status. This variation means it is important to gather specific information about local contexts, in order to guide inclusive development practice.

Development was originally conceived as a narrow economic growth paradigm, measured in GDP growth. As a result of this, inequality is also often considered only from an economic perspective, whereas it is important to recognise the non-economic elements. But even when looking at inequality from a largely economic standpoint, there is clear evidence of the impact of disability on poverty, and vice versa. A 2015 review of evidence from low and middle income countries found that 80 per cent of studies reported a link between poverty and disability (Banks and Polack 2014).

People who are poor are more likely to be born with or acquire a disability, due to poor nutrition, hazardous work and housing conditions, and limited access to health care, for example. Similarly, people with disability are more likely to be poor because they face barriers to, and are excluded from, education, which limits their opportunities for employment, and because they and their families face higher costs for aids and devices, medical treatment and rehabilitation.

The impact of such exclusion is significant: for instance, it is estimated that in Bangladesh, the exclusion of people with disability from the labour market leads to a loss of US\$891 million per year (Banks and Polack 2014). Thus promoting

the inclusion of people with disability is vital to addressing inequality both for individuals, and at a national and international level.

An economic or income-based approach to inequality can make it easier to quantify the impacts of exclusion of people with disability and the costs of inequality. It can also help to illustrate the likely economic benefits that will accrue from reducing inequality and promoting inclusion of people with disability. However development theorists such as Amartya Sen have noted that economic growth cannot provide a true measure of a person's wellbeing, nor capture 'the full rigour of social deprivation' experienced by people with disability, whose 'freedom to live a good life is blighted in many different ways' (Sen 2009:260).

Addressing disability and inequality: A human rights approach

If the goals of development are freedom (Sen 1999), emancipation and that which enhances political and legal 'equality' (Kingsbury 2007), then development paradigms that enhance freedom are those that promote 'development' in the fullest sense by bringing about the processes that maximise those ends. Equality is also important—it is the foundation upon which freedom is constructed (ibid). Civil and political rights, such as those set out in the CRPD, provide a framework for ensuring equality of opportunities and removing constraints on individual agency to act.

The level of inequality faced by people with disability compared to those without disability is often extreme. This includes being denied the right to an education or access to health care, including access to assistive devices that would improve mobility or communication. Women and girls with disabilities face particular vulnerabilities, being at far greater risk of violence and mistreatment than those without disability.

Additionally, the ability of people with disability to obtain redress for inequalities can be constrained by discriminatory laws, practices and policies, lack of accessible legal systems, and cultural and community attitudes. These inequalities will continue unabated unless concerted efforts are made to 'leave no one behind'.

The entrenched inequality faced by people with disability was a significant reason for the development and adoption of the CRPD, to articulate clearly how governments and the global community can ensure that people with disability achieve their rights on an equal basis with others. It was the first human rights treaty to include an article on international development and cooperation, which provides even further impetus to use international development efforts to support CRPD signatory governments to achieve the ends called for in the treaty.

The Sustainable Development Goals

Inequality is explicitly addressed within the SDGs, including recognition of the fact that disability can be a source of inequality. Further, the need to explicitly target people with disability is recognised within the targets of six of the goals,

and arguably across all goals by virtue of the principles of interconnectedness and universality that underpins the SDGs. The specific recognition of and reference to disability within the goals stands in contrast to the Millennium Development Goals, which were widely criticised for not including reference to people with disability.

Goal 10 aims to reduce inequality within and between countries, setting targets which address both economic and non-economic measures of inequality. Achieving income growth of the poorest is targeted, as well as empowerment and 'social economic and political inclusion of all, irrespective of age, sex, *disability*, race, ethnicity, origin, religion or other status' (emphasis added).

Other SDG targets which explicitly reference disability include those with a focus on education (Goal 4); employment and economic growth (Goal 8); and access to cities, water resources, transport systems, and public spaces (Goal 11). Additional targets also mention 'the vulnerable' or those in vulnerable situations, a designation now understood to include people with disability.

Goal 17, which focuses on means of implementation for the goals, specifies that data should be disaggregated by disability (as well as many other characteristics). It also calls for building the capacity of developing countries to collect these statistics. This focus on data is part of a larger trend, also driven by CRPD Article 31 (on statistics and data collection)¹ and requirements by donors, including the Australian Aid program, which are now expecting or mandating disaggregation by disability as part of monitoring processes.

Many development agencies, as they deepen their practice on disability inclusion, are also seeking to incorporate measurement of disability and disability inclusion within their own monitoring and evaluation processes. This is a means to understand the level and degree of inequality faced by people with disability in the poorest communities, to identify specific issues, attitudes and barriers prevalent within particular communities, and also to measure progress on disability inclusive programming.

Improving understanding of disability and inequality

Recognition of the importance of a nuanced understanding of disability inclusion as a means of reducing inequality has many implications for development agencies. Key among these is the need for a sharper focus on evidence—not only in terms of collecting evidence on the interrelationships between disability, inequality and development to inform practice, but also in terms of evaluating and documenting the approaches and methods that are used to collect evidence.

A focus on evidence is important for several reasons:

- There has historically been a lack of reliable data about disability, including an underestimation of disability prevalence and impact, which has undermined efforts to improve disability inclusion.
- Many approaches to project planning and data collection have tended to treat people with disability as a homogenous group, ignoring a vast diversity of experiences and perspectives.

- Due to stigma and exclusion in many communities men, women, boys and girls with disability are ‘hidden’ or less visible, and often have not participated in planning or data collection activities.
- The complexities of understanding and measuring disability and the different communication modes used by people with disability require consideration of appropriate data collection approaches and methodologies.

These are important considerations for data collection approaches, which need to avoid reinforcing discriminatory structures and norms, or causing shame or harm to individuals.

The remainder of this paper explores issues around the collection of data relating to disability (including but not limited to disaggregation by disability) in order to understand and address inequalities in development contexts. This draws upon the Practice Note on disability inclusive data collection developed by Plan International Australia and the CBM-Nossal Partnership for Disability Inclusive Development (Bush et al. 2015).

Principles for disability inclusive data collection

A few key principles serve as a starting point to guide agencies in the process of disability inclusive data collection:

- Genuinely engaging with diversity and addressing inequalities in populations requires agencies to move beyond a ‘compliance’ mindset of meeting the requirements of donors, which are often focused on counting or quantifying people with disability involved in specific activities. Inclusive practice requires practitioners to understand and redress various inequalities that exist between (and within) different groups of people. This could include challenging attitudes and practices, not just counting or promoting the participation of a particular group. Program planners and managers need to be clear about what evidence they need in order to understand complex situations and to inform their disability inclusive practice, recognising that this will vary between locations, sectors and different stages of a project.
- Programs should aim to collect data that will inform—and allow for monitoring of—inclusion at three levels: whether women, men, girls and boys with disability have *meaningful participation* in a project; whether they are equally *benefiting* from projects targeting them or their communities compared to people without disability; and whether there are *changes in their communities and households* which support greater inclusion beyond the project.
- Data collection approaches should recognise and seek to understand the diversity of experiences of people with different types of disability, and the intersections of exclusion based on sex, age, ethnicity, disability and other factors of marginalisation.
- Disability inclusive practice and the collection of evidence to underpin it are ongoing journeys. Each project cycle will involve several rounds of collecting data, learning, adapting/improving and taking action, and then repeating this process again to further strengthen disability inclusion and refine data collection approaches. Regular opportunities should be built into this cycle to

share learnings and continually improve project strategies and data collection approaches.

- The participation of women, men, girls and boys with disability in designing, adapting and implementing data collection methods is a key principle of disability inclusive practice, in line with CRPD principles. This might require specific support/training to build the capacity and confidence of people with disability to be involved.
- Action is needed to raise awareness among project and data collection staff. The ability of programs to collect data effectively and respectfully is dependent on staff having positive and sensitive attitudes and behaviours towards people with disability.
- Data collection methods and tools should be adapted in collaboration with people with disability to fit the local context, and ensure that all methods include a focus on disability inclusion and gender equality.
- Disability inclusion requirements including costs need to be incorporated into research designs or terms of reference.

It should also be acknowledged that addressing these considerations will require some time and resources, which might not be possible in every context. However, there are always some steps which can be taken without large resource requirements which can provide a starting point for strengthening inclusion and designing appropriate data collection methods.

Collecting data relating to disability: Tools and methods

A variety of tools and methods can be used to collect data with, from and about people with disability. It is important that agencies feel confident in deciding what information is actually most relevant in particular program or project contexts; understanding how data gathered will inform their disability inclusive practice; and in having the capacity to analyse and use information. There is also potential for data collection and analysis processes to address inequalities through the very process of including people with disability as active participants and decision makers, thus addressing issues of stigma and discrimination as components of inequality.

Gaining a more nuanced picture of disability inclusion will require the use of both qualitative and quantitative methods; the use of existing data, where this exists; the adaptation of existing methods and tools (to address the principles discussed above); and possibly the use of disability-specific data collection tools. It should involve collecting data from women, men, girls and boys with disability themselves, their carers and household members, Disabled People’s Organisations and other groups, disability service providers, local NGOs, community leaders, government representatives, and a range of other community members. Data should be disaggregated at a minimum by sex, age and disability to reflect diverse experiences and enable comparison of outcomes between groups.

Collecting data about disability often involves the identification of people with disability, typically for the purpose of disaggregating data or categorising participants

in data collection processes and project activities. Given the stigma and discrimination often associated with being labelled 'disabled' in some communities, specific approaches should be used when identifying people with disability to avoid causing any harm or shame or drawing particular attention to their impairment.

International agencies have developed questions on 'functioning' that ask people about basic activities or major body functions, such as whether people have difficulty walking, seeing or communicating with others. These questions (for example, the Washington Group Short Set of Questions on Disability) avoid using the language of 'disability' but enable identification of most people who are likely to have a disability. They can be incorporated into various data collection processes.

It is far easier to adapt existing data collection processes to capture information about disability than to establish separate systems of data collection focused on disability. It could involve adding questions to existing surveys and monitoring tools, asking about disability inclusion in existing qualitative methods such as focus group discussions, or specifically seeking out people with disability as participants. A range of disability-specific or adapted tools are available to aid in this process such as disability identification tools, disability inclusion surveys, methods for collecting data with and from children with disability, and participatory methods which have been adapted and tested.

For all methods, procedures and tools should be adapted to the specific local and project context, and developed in consultation with local people with disability or advisory committees. It is important to:

- consider the physical accessibility of data collection venues or meeting places;
- ensure documents and information are available in accessible formats (e.g. Braille/large print or electronic versions and sign language interpreters are available), and that translations of tools are meaningful and respectful in local cultural contexts; and
- select culturally appropriate and sensitive meeting places and groupings of participants.

Procedures for child protection, informed consent and confidentiality, as well as staff awareness of implications in

practice, are also vital to avoiding harm and avoiding stigmatising people with disability.

Conclusion

The SDGs provide a strong framework for recognising and addressing disability as a source of inequality, including through improved data collection. Specific guidance on appropriate collection and use of data can help guide development agencies and programming. Development workers need to seek to understand the nuances of exclusion and inequality faced by people with disability in specific communities, and improve their development practice to ensure they challenge this exclusion and promote the full realisation of the rights of people with disability. Only in this way can we ensure we truly 'leave no-one behind'.

Note

- ¹ Article 31 reads in part: 'States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention'.

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