

Scoping Study: Donor Support for Disability-Inclusive Country-Led Evaluation Systems and Processes

Executive Summary

By: Lorraine Wapling, Marlène Buchy and Elisabeth Resch.
August 2017

In May 2016, the UK Department for International Development (DFID) commissioned a scoping study to seek insights into how donors can support evaluation capacity development in ways that enable the voices of people with disabilities to be heard and reflected in country-led evaluation processes and systems. This document is a summary of key findings and lessons learned. The intended audiences are international development practitioners, particularly those with responsibility for monitoring and/or evaluation.

Initially the study had been considerably broader; to identify effective ways of developing the capacity of nationally led and owned evaluation systems with a particular reference to the Sustainable Development Goals (SDGs). But during the inception phase it became clear that the *Leave No One Behind* agenda was raising challenges around what processes might now be required to meaningfully include the most marginalised. In recognition of these challenges, DFID decided a specific focus on people with disabilities would be more appropriate and so the final study is presented in terms of what donors need to be aware of and promote, in supporting the development of country-led evaluations that are inclusive of and accountable to people with disabilities. The study included a rapid literature review; interviews with 45 stakeholders who work in monitoring and/or evaluation for multilateral agencies, bilateral agencies, national governments and NGOs; and a workshop with representatives from disability focused civil society organisations.

In shaping the study in this way, DFID encountered an interesting problem – the agency tasked with conducting the study was extremely well placed in being able to assess and advise on developing inclusive national evaluation processes: however it had little experience of disability from a rights perspective and limited insight into its own capacity to fulfil the research brief.

...our team did not include disability experience and expertise as we tended to treat disability like any other form of exclusion. Within the team we capitalised on extensive knowledge and expertise in relation to participatory and inclusive research processes and therefore did not immediately anticipate that disability presents specific nuances that require specific attention.¹

Notwithstanding the reports findings, this experience in itself has provided significant learning for DFID (and the agency involved), applicable to agencies across the international development and humanitarian aid sectors, in the unique way that disability challenges standard approaches. As the research progressed it became clear that the implementing agency required additional technical assistance specific to disability inclusion in order to more accurately interpret the information they were uncovering.

What this experience and the final report highlights are that:

- Disability from a rights perspective is still not well understood by many practitioners working within international development agencies;

¹ Scoping Study: Donor Support for Disability-Inclusive Country-Led Evaluation Systems and Processes: Synthesis Report (2017).

- Experience of evaluating programmes from a disability inclusion perspective is still relatively scarce amongst mainstream evaluation practitioners; and
- DFID and other commissioners of research and evaluation need to be explicit about definitions and expectations in relation to disability inclusion when they commission studies and evaluations. It is also important to ensure that agencies leading these research studies and evaluations have demonstrable technical capacity in disability inclusive work.

In the interests of moving the debate forward and with the full support of the implementing agency, this executive summary will present both the outcomes of the scoping study as well as the lessons learned from the process.

1. Context

This report is framed by the human rights approach to disability. It is important to note that the concept of disability has undergone considerable revision over the past 40 years, moving from an individual, medical-based perspective characterised by a focus on physical deficits (impairments), to one that recognises the attitudinal, environmental and institutional barriers that limit or exclude people with impairments from participation. This social or human rights approach underpins the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which considers people with disabilities to be:

'...those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.' (Article 1, CRPD)

The human rights approach to disability promotes the understanding that people with disabilities have the right to participate in all development as active members of communities, which may need to be adapted for accessibility and inclusion. This implies that different social agents take responsibility for understanding what barriers may exist for people with disabilities and implement strategies to mitigate them.

By contrast, the medical or charity based approaches, whilst recognising vulnerability, articulate the problem in impairment terms (the barrier to inclusion is disability). This leads to responses that treat the needs of people with disabilities as being separate and specialised, putting them outside of much of mainstream development programming, with little voice or power when it comes to the design of programmes or evaluations (Coe & Wapling, 2010). The emphasis for inclusion under the human rights approach is on reducing barriers and promoting opportunities for participation, rather than expecting people with disabilities to 'fit in' as best they can.

The CRPD is the only international rights framework to have so far made specific reference to the right for people with disabilities to participate in and benefit from development and humanitarian aid.² This framework helped ensure the SDGs pay particular attention to people with disabilities, in contrast to the Millennium Development Goals (MDGs) which lacked any reference to disability (Groce, 2011).

Awareness around the impact disability can have on development outcomes is gradually increasing. As data collection methods improve it is becoming clear that disability affects considerable numbers of people either directly or indirectly. Globally, there are estimated to be more than one billion people living with a disability, representing just over 15% of the world's population (WHO & World Bank, 2011). Almost one household in every four includes a person with a disability, which means that well over 2 billion people live with the impact of disability on a daily basis.³ Moreover, the prevalence of disability is growing due to ageing populations and global increases in chronic health conditions and non-communicable diseases (WHO & World Bank, 2011).

² See Articles 11 and 32 specifically

³ United Nations Office of the High Commissioner for Human Rights. (2007)

The link between poverty and disability is well established (Elwan, 1999; DFID, 2000; Yeo and Moore, 2003; Gooding and Marriot, 2007), although the actual mechanisms through which this happens are only just being documented (Loeb et al., 2008; Palmer, 2011; Groce et al., 2011; Mitra et al., 2012; Graham et al., 2013; Mont & Nguyen, 2013; Palmer et al., 2015; Kiregu et al., 2016). People with disabilities are more likely to be found amongst the poorest quintiles in both high and low income countries but in greater numbers in low income countries.

A strong cycle of disability and poverty exists, with those in poverty more vulnerable to disability due to reduced access to health care, low quality housing, and less access to safe drinking water and sanitation for example. Similarly, those with disabilities are more likely to experience poverty as a result of systemic institutional, attitudinal and environmental barriers that impact on their opportunities to participate in economic, social and political activities (Yeo & Moore, 2003; Mitra et al., 2012; Banks & Polack, 2014).

Promoting the right to development also implies that there are processes in place which can measure inclusion and track benefits specifically in relation to people with disabilities. Now that disability is recognised as a factor in development outcomes it needs to feature in plans and accountability mechanisms – whether at international, bilateral, government, or programme level. Just as gender, age and health status can be factors in marginalisation and vulnerability so too is disability and as one of the universal markers for marginalisation it is something that needs to feature in the analysis of development outcomes.

In 2015, DFID reaffirmed its commitment to the promotion of disability as an important development issue with the publication of its Disability Framework⁴. In this Framework, DFID takes a clear human rights approach, focusing on the barriers that exclude people with disabilities from active participation. The Framework states that DFID aims to ensure its ‘...policies and programmes are inclusive of and accessible to people with disabilities...’ (p. 5), which is consistent with both the UK’s CRPD commitments and more recently, with the *Leave No One Behind* agenda promoted by the Sustainable Development Goals (SDGs). It also implies that for this to be successful DFID will need to be able to measure, monitor and evaluate access and inclusion across its aid portfolio which will inevitably impact on data collection and evaluation processes.

2. A rights based understanding of disability

A significant finding of the review is the continued invisibility of disability as a development concern alongside the marginalisation of people with disabilities from planning and accountability mechanisms. At the root of the invisibility seems to be the persistence of the individual based (medical/charity) understanding of disability.

Individual based understanding reinforces negative attitudes towards people with disabilities and coincides with beliefs that people with disabilities are ‘abnormal’, economically dependent, and offer little in the way of contributions to communities. Groce, Chamie & Me (2000) note that this can then become a self-fulfilling prophecy

⁴ Disability Framework, One Year On: Leaving No One Behind, DFID (2015)
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/554802/DFID-Disability-Framework-2015.pdf

– where expectations are low, the resources required to facilitate independence are not prioritised and people with disabilities remain marginalised and essentially reliant on others. In this situation, people with disabilities are afforded almost no power – since they cannot contribute they cannot expect to influence decisions.

In this respect, the assumed barrier to participation *is* disability rather than understanding what barriers preclude people with disabilities from participating. This manifests in areas related to policy development, planning, resourcing and the collection of data. The scoping study highlights for example that:

Only 79% of national development plans recognise people with disabilities as marginalised⁵

This illustrates that there is still not universal acceptance that disability can impact on development outcomes or that people with disabilities have a right to benefit from and participate in development processes. If national plans fail to acknowledge the the impact of disability then country-led evaluations will not be designed or implemented in ways that allow this factor to be analysed.

3. Limitations of data about people with disabilities

One key consequence of the lack of rights based understanding has been a gap in the availability of national and international data on disability. The report highlights that many types of evaluations are based around existing data sets but that **the numbers of people with disabilities in most countries are under-reported and inaccurate**. The lack of data has led to assumptions that the issue is, correspondingly, not significant (Eide & Loeb, 2006). Without an evidence base, policy-makers, development agencies and donors have been unable to develop economic justifications for focusing on disability.

The word ‘disability’ is not a neutral term, which means when presented with the simple yes/no question (*do you have a disability?*) people tend to respond in very different ways. The lack of comparable and robust data on disability that reflects the human rights approach led to the formulation of the Washington Group set of questions. Rather than focusing on individual medical details the Washington Group questions concentrate instead on an individual’s level of functioning, which has made it possible to collect disability prevalence data without having to use the term ‘disability’⁶. Evidence is now emerging that when countries implement the Washington Group questions without modification, the reliability and comparability of data improves and a more accurate picture of prevalence is recorded (Altman, 2016).

The review highlights emerging evidence that being statistically visible helps to reinforce positive political economy around disability as a development issue. Qualitative information suggested that Mexico, South Africa, the Philippines and Sri Lanka have carried out studies, developed frameworks for inclusive evaluations or set up processes with parliamentarians designed to improve general understanding around the barriers faced by people with disabilities. Rwanda and Jordan are countries where there is growing political will to improve data quality. Rising political commitment helps increase resources and helps create the space for institutional

⁵ Scoping Study: Donor Support for Disability-Inclusive Country-Led Evaluation Systems and Processes: Synthesis Report (2017)

⁶ Washington Group on Disability Statistics (2016) <http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/>

changes and collaborations between institutions which can go beyond just considering disability (see Box 1).

Box 1: Learning from the Jordanian example

Jordan is an example of a country where political will has resulted in concrete progress on increasing the visibility of people with disabilities. In 2013 Jordan hosted the 13th meeting of the Washington Group on Disability Statistics. Discussions between the UN Children's Fund (UNICEF), the National Statistics Office and the Higher Council of People with Disabilities led to the inclusion of Washington Group questions in the 2015 census. There is now a national-level working group on disability, which includes statisticians, and the census guidance included information on how to ask questions on disability. The five-day training provided by the Washington Group before the census also included information on how to administer a survey, good practice for interviewing people with disabilities and how to analyse the data.

Source: Scoping Study: Donor Support for Disability-Inclusive Country-Led Evaluation Systems and Processes: Synthesis Report (2017)

4. Capacity and capability within organisations and people: national evaluation systems, evaluators and disability actors

National evaluation systems

Although this review focused mainly on the difficulties experienced by people with disabilities in participating in evaluation processes, it does raise important issues around the general capacity (skills, people, processes and structure) of national evaluation systems. One key consideration is the ability to access, understand and use data and research being carried out by various ministries across government. This review highlighted that whilst individual ministries may be undertaking monitoring and evaluation activities, in many cases there is a lack of coordination or centralisation of the data within integrated national systems. Responsibility for monitoring or evaluating anything related to disability typically falls to single ministries (usually linked to social welfare) which have no mandate or resources, to monitor across government (Kidd et al., 2017). Nepal (see Box 2) provides a good illustration of the difficulties this presents for inclusive country-led evaluations:

Box 2: The case of Nepal

Interviewees in Nepal reported that despite the existence of a National Planning Commission and agencies such as the Central Bureau of Statistics, the national evaluation system remains weak. Nepal has monitoring guidance in place - the Results-Based Monitoring and Evaluation Guidelines, 2067 (2010) which is being institutionalised via a Monitoring and Evaluation Bill currently being drafted. The system is considered weak because in practice, despite a policy and institutional framework, data from different ministries remains fragmented and not sufficiently disaggregated with limited overall political support for evaluation.

In the case of disability, this lack of integration means that nationally, important research and data on disability and the experiences of people with disabilities is not being used to inform national processes. So, whilst there is a National Policy and Plan of Action on Disability (NPPAD) (2006), its scope is limited to monitoring activities implemented by the Ministry of Women, Children and Social Welfare, where disability issues are located. Much of the analytical work is output related rather than including evaluation and impact analysis. Given that the Ministry of Women, Children and Social Welfare also receives limited funds, it cannot play an effective role in monitoring disability inclusion policies across ministries and therefore at national level there is a lack of overall accountability for inclusion.

This may also impact on how effectively the government is going to be able to monitor and evaluate inclusion in its SDG processes. For example, the disability working group facilitated by UNICEF is not currently looking at the SDGs and is focusing its work on mainstreaming disability and targeting existing disability specific programmes.

Scoping Study: Donor Support for Disability-Inclusive Country-Led Evaluation Systems and Processes: Synthesis Report (2017)

Evaluators and statisticians

A lack of awareness amongst development practitioners on the rights based approach to disability also has an impact on statisticians and evaluators. In a review that was completed in 2015, the Governance and Social Development Resource Centre discovered that among evaluation associations, societies and professional evaluators, disability was a largely unfamiliar topic. This is quite unlike gender which has a large pool of experience from which to consult and collaborate. Since many mainstream programmes continue to regard disability as a niche issue that requires specialist knowledge, interventions and resources, experience in implementing disability inclusive development is still quite limited (GSDRC, 2015).⁷

Similarly, the focus of statisticians has tended to be rather narrow focusing mostly on documenting the extent to which people with disabilities are accessing services rather than using disability as a marker for analysis or to explore issues like educational attainment, literacy, income levels, access to safe drinking water or employment for example. The UN Statistics Division (UNSD) is currently revising the disability statistics handbook, last published in 2001, so this situation will likely change but the skills gap remain.

With the advent of tools like the Washington Group questions, quantitative data is just being updated to incorporate a disability rights perspective but a lot of traditional tools remain unable to capture the diverse reality of people with disabilities. For example, to what extent do current tools that measure the economics of households take account of the direct and indirect costs to families of having a member (adult or child) with a disability? Do these measures account for the costs associated with needing accessible transport; of buying and maintaining assistive devices or personal support; of having to make frequent visits to health centres to undertake habilitation/rehabilitation; of having to forego economic activities to undertake caring responsibilities?

While there is considerable effort and attention focused on improving quantitative data collection tools, there remains a need to develop existing or create new qualitative tools which increase the participation and empowerment of respondents. The scoping study advocates for qualitative evaluation tools to be more widely developed and used in inclusive ways. Appropriate participatory evaluation methods and tools could be developed in collaboration with Disabled People's Organisations (DPOs), disability and methods specialists which better capture the lived experiences of people with disabilities.

Donors such as DFID can play a significant role in improving both the technical capacity and the tools available within the sector. They can do this by being explicit and more prescriptive over expectations in relation to understanding and experience of disability inclusion when they commission studies and evaluations and ensure that

⁷The Governance and Social Development Resource Centre, 2015 www.gsdr.org/wp-content/uploads/2015/11/DisabilityInclusion.pdf.

agencies have demonstrable technical capacity in disability inclusive work. DFID has already made a significant contribution to raising awareness and use of the Washington Group data collection methodology within the UK development sector, with increasing numbers of agencies choosing to use this to help produce disability disaggregated data. As information technology advances there are also interesting opportunities for building in more disability related data into standardised processes at national level that can be used to inform evaluations. For example, the Washington Group is working with UNICEF to develop an Education Management Information System (EMIS) that is capable of providing a basic level of monitoring of disability inclusion across school systems (UNICEF, 2016).

Disability actors

A key issue this study raises is that people with disabilities face considerable barriers when it comes to participation: whether that is in national accountability processes, in civic engagement generally as well as engaging in evaluation systems and processes. Whilst the SDGs are regarded as offering real potential for increasing the visibility of disability in development outcomes (seven targets specifically reference disability for example) there remain concerns that operationalising the *Leave No One Behind* commitment may prove problematic without considerably changing the way national systems currently function. Evaluation of the SDGs – as part of the 2030 Agenda and the SDG follow-up and review process – implies participation of stakeholders beyond the traditional sphere.⁸ In the context of disability, this means being able to properly identify and mitigate barriers which may be completely unfamiliar to those outside of the disability sector.

Lack of representation

Aside from the attitudinal barriers already noted above in relation to a lack of rights awareness, people with disabilities face negative attitudes from within the communities they live. This cultural stigma can be particularly difficult to overcome and manifests in people with disabilities being routinely excluded from local decision-making and information processes: people with disabilities are often simply not invited (UNPRPD, 2013). In citizen-reported data projects, there is usually no provision for people with disabilities to be trained or to take part.

This lack of familiarity with disability issues leads non-specialists to make broad generalisations and to miss the diversity that exists within the disabled population. For example, participants in the UN Partnership for the Rights of People with Disabilities (UNPRPD) indicated that lack of awareness about the diversity of impairments resulted in a limited understanding of the different reasonable accommodation measures that are needed to improve inclusion and participation (UNPRPD, 2013).

With notable exceptions, people with disabilities in developing countries face considerable challenges with respect to representation. This study found respondents still likely to raise the issue of a lack of representativeness within the disability movement as being problematic with some impairment specific groups doing better than others. While there is a long history of people with disabilities organising together and forming civil society associations called Disabled People's Organisations (see Box 3), most of these associations have dedicated themselves to impairment specific social support and self-help.

⁸ United Nations Sustainable Development Knowledge Platform, 2016
<https://sustainabledevelopment.un.org/hlpf/follow-up>.

Box 3: Disabled People's Organisations (DPOs)

DPOs are civil society organisations that are *led by* people with disabilities and are made up of members who are mainly people with disabilities (sometimes they also include 'concerned individuals', such as parents of children with disabilities). There are a variety of different types of DPOs, ranging from impairment specific groups whose members share (or are concerned by) a specific impairment, to cross disability organisations which include members with a variety of impairments. They can exist at different levels, from grassroots to global, and can sometimes share other characteristics, such as women or youth empowerment groups, or HIV/ AIDs groups. Federations or national unions are networks of impairment specific DPOs positioned so that they can lobby and influence national or international policy.

This has to some extent led to the fragmentation of DPO advocacy activities along impairment lines while missing key intersectional issues such as gender, ethnicity and age, for example, which more accurately define the identities of people with disabilities. Because of assumptions about disability and capability, people with visible physical impairments are still more likely to be included in consultation processes than those with other less obvious disabilities such as mental health related disabilities. Moreover women and young people with disabilities also tend to be under-represented. Whilst consulting with DPOs is a good start for statisticians and evaluators, they are not necessarily representative of people with disabilities in general.

Lack of resources and human capacity

Representative groups of disabled people remain largely under-resourced. A literature review by Young et al., (2016) analysing barriers to effective DPO engagement found that a lack of financial and human resources were most likely to be mentioned as negatively impacting on the functional capacity of DPOs. This study also highlighted a range of other difficulties DPOs regularly encounter in their day-to-day operations, any one of which could have an impact on their ability to engage in country-led evaluation processes. These include: a lack of empowerment experienced by people with disabilities when self-help groups or DPOs were led by professionals external to the group; difficulty in maintaining continuity of group members; poor access to DPOs for people with disabilities living in rural areas; and difficulties in accessing venues and transport for group meetings. It is valuable for evaluators and agencies commissioning evaluations to consider these challenges when designing and delivering evaluations.

The study also found a general consensus among those consulted through interviews and the Civil Society Organisation workshop that DPOs' knowledge of the SDGs and what they might be able to contribute in terms of progress reporting remains limited due to their limited resources and capacity. Many donors have not prioritised investing in and developing the capacity of DPOs to engage in evaluations, or supporting disability-inclusive evaluation systems and processes so experience and awareness is limited on both sides.

A further constraint is the continued systemic exclusion of people with disabilities from key social systems. DPO advocates describe the impact that exclusion from

education has on the skills that members of the disability movement have to engage in actions that challenge widespread discrimination. A lack of exposure to education not only restricts abilities such as literacy and numeracy but also important social and political skills, leaving them with reduced levels of social capital on which to draw – a key motivation behind IDA's BRIDGE training (see Box 4).⁹ On the whole, DPOs are trying to increase their understanding of the complexity around public policy reform and identify what they can do to influence those processes.¹⁰

Box 4: International Disability Alliance - BRIDGE CRPD-SDG

From 2010-2013 the International Disability Alliance (IDA) began work supporting national level DPOs to monitor implementation of the CRPD. From this experience IDA in collaboration with the International Disability and Development Consortium (IDDC) created a more specific training course bringing together the human rights and inclusive development agendas in the form of BRIDGE CRPD-SDG. The training has two core modules: Module 1 focused on developing the skills and knowledge of people with disabilities to understand and analyse development from a CRPD perspective; and Module 2 on building people with disabilities skills and confidence to take action through a range of different advocacy routes including legal harmonisation, budget tracking, inclusive programming and promoting disability data and analysis. Key to all of this has been to ensure that all the training is designed and delivered in ways that are accessible to all persons with disabilities. That means encouraging and facilitating the inclusion of under-represented voices such as those of people with cognitive impairments, deaf-blind and people with psycho-social impairments by ensuring the application of inclusive training methods which can then be used by disability activists to ensure their own messaging and advocacy are inclusive. Whilst this remains a 'work in progress' the commitment to reflect and learn from experience is constantly ensuring this training is reflective of the issues faced by people with disabilities in effectively engaging with public policy reform processes.

Source: IDA BRIDGE training presentation

5. Recommendations for supporting disability inclusive evaluation systems

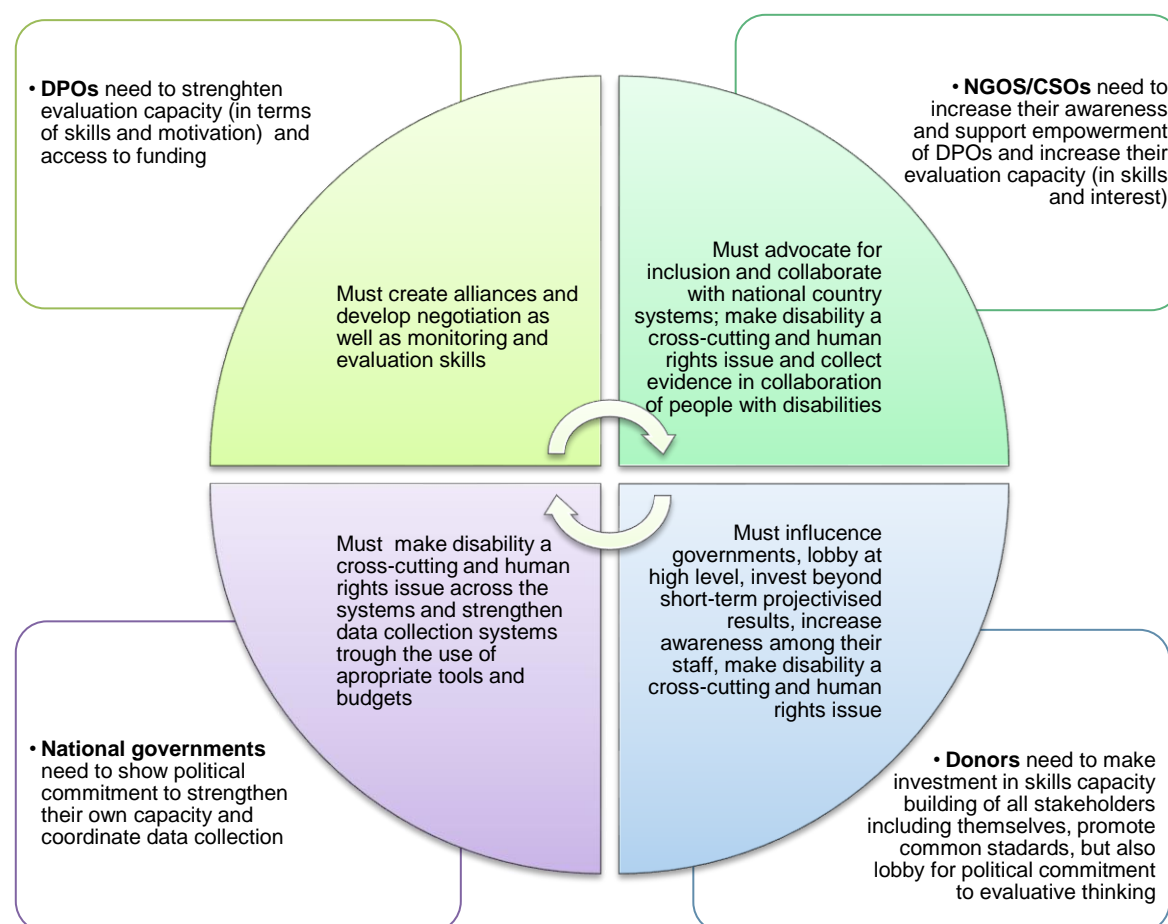
Inclusive country-led evaluation needs to be understood as a multi-stakeholder process (see Figure 1) with capacity building of all stakeholders a positive starting point. There is some level of consensus presented by this review that donors, Non-Governmental Organisations (NGOs)/Civil Society Organisations (CSOs), DPOs and national governments would benefit from increasing and improving their awareness, skills and approaches towards disability inclusive processes.

It is also important to understand that different stakeholder groups may require different types of support to increase their capacity. NGOs, donors, and government stakeholders need to build their own capacity around the rights of people with disabilities to development and make necessary arrangements to create disability inclusive ways of working on country-led evaluations.

⁹ www.internationaldisabilityalliance.org/content/bridge-capacity-building.

¹⁰ See p.6 of training presentation www.internationaldisabilityalliance.org/content/bridge-capacity-building.

Figure 1 Roles and responsibilities of stakeholders in an inclusive country-led evaluation process



Firstly, it is important to highlight that any recommendations around supporting disability inclusive country-led evaluation rests on the assumption that there is a strong national system that is ready to absorb the participation of DPOs and people with disabilities. This means that any set of recommendations cannot solely focus on promoting inclusion and strengthening the skills capacity of stakeholders: there also needs to be a concerted effort to develop political interest and commitment to the value of evaluative thinking across the sector.

The review makes three strong recommendations for agencies commissioning evaluations that aim to support disability inclusive country-led evaluation systems and processes:

1. Assess the country context to understand what is the structural position of disability within government and policy, and the capacity of the disability movement. This includes:

- Investigating the policies regarding discrimination, social inclusion and disability, and those relating to national evaluations and inclusive processes;
- Understanding of the accountability mechanisms within the country from a human rights perspective;

- Identifying where disability issues are located structurally within government, who is doing what within ministries, what kind of data are collected by who and how;
- Undertaking an inventory of existing disability-related interventions and an assessment of the national human resource capacity (facilitators, specialists support people available);
- Mapping the stakeholders involved in the country led evaluation process to understand roles, responsibilities, power relations and agendas of different stakeholders and how this affects data collection and analysis processes; and
- Documenting country case studies to identify emerging learning around what works and why, and sharing lessons widely between countries and across development partners within countries.

2. Ensure marginalised people are involved in developing inclusive country-led evaluation frameworks from the start

While ultimately a country-led evaluation will be led by national-level leaders and institutions, important questions should be asked about how the voices of marginalised people are being accommodated. How is inclusion defined by the process and how will the voice of people with disabilities for example be heard when the purpose and objectives of country-led evaluations are defined? There could be a lot of political resistance to supporting the idea of equitable participation of people with disabilities or other marginalised people because of prevailing cultural beliefs. Progress will be strengthened by supporting the development of national systems where there is co-ownership between marginalised peoples and government representatives from the beginning.

3. Develop tools in an inclusive way

While there is much effort being expended to improve quantitative data collection tools, there remains considerable space to develop new qualitative tools which would increase the participation and empowerment of people with disabilities. Appropriate participatory tools could be developed in collaboration with DPOs, disability and methods specialists which better capture the lived experiences of persons with disabilities, as well as being accessible to them.

Working directly with DPOs will increase their capacity and increase donor awareness of the constraints experienced by DPOs. At the same time it is important to reiterate that it is not DPOs' sole responsibility to drive this process. These are small organisations with limited resources that need to be at the table but not exclusively bear the responsibility or financial burden of participation.

Ultimately, all donor policies and programmes should reflect the principles of the CRPD: inherent dignity, non-discrimination, effective inclusion, respect for differences, equal opportunity, accessibility, gender equality and respect for the evolving capacities of children with disabilities. This review concludes by noting that participatory research and approaches to evaluation are required to assess development impacts in relation to people with disabilities. The meaningful participation of people with disabilities and their representative organisations must be ensured in the formulation and implementation of development policy and the measurement of impact at all levels.

6. Lessons Learned

Despite the focus of the study being to learn lessons from civil society, donors and international development agencies around what works in implementing disability inclusive national evaluation systems, it actually highlights an important gap in knowledge. The inclusion of disability alongside gender, age and health status as a factor in marginalisation that can impact on development outcomes, is only just being recognised by mainstream agencies and governments. This means that as yet there are insufficient practical experiences on which to base any broad analysis. Interestingly, the scoping study reinforces the call from the disability sector of the need to work more proactively with people with disabilities to ensure they are able to benefit from and contribute to development; including having a voice in accountability processes at all levels. It also raises the prospect of the need for more focused evaluation and research to identify the specific barriers experienced by people with disabilities in citizen based accountability processes and national led systems.

The study also prompted a questioning of perceptions and attitudes held by the researchers themselves. The review is candid in describing the process they went through in coming to terms with the unique way that disability challenges standard approaches. On a basic level the researchers understood that people with disabilities would most likely be excluded but conceptually they were approaching it in transactional terms rather than in relation to denial of rights. So in the words of one of the researchers, their original focus had been to try and find out "...how could we get information from people we cannot easily talk to?". What they had not anticipated was the scale and depth of the exclusion experienced by people with disabilities. As they started to better understand disability from a rights perspective they became much more concerned about the lack of preparedness within the development and evaluation sectors to implement participatory processes that build in sufficient time, resources and expertise to genuinely include people with a range of impairments alongside other marginalisation factors.

This prompts some very important learning about the process of disability inclusion: that disability from a rights perspective is still not well understood by practitioners; that experience of evaluating programmes from a disability inclusion perspective is still relatively scarce amongst mainstream evaluation practitioners; and that DFID and other donors should be explicit about expectations in relation to disability when they commission studies and evaluations and ensure that agencies have demonstrable technical capacity in disability inclusive work.

Bibliography

Altman, B. (ed.) (2016) *International Measurement of Disability. Purpose, method and application*. Springer International Publishing. Switzerland.

Banks, LM and Polack, S. (2014) *The Economic Costs of Exclusion and Gains of Inclusion of People with Disabilities – Evidence from Low and Middle Income Countries*. CBM and London School of Hygiene and Tropical Medicine.

Coe, S. and L. Wapling (2010) 'Practical Lessons on inclusive development', *Development In Practice*: Issue 27, September 2010, pp. 879–886.

Department for International Development (2000) *Disability, Poverty and Development Issues Paper*. DFID, UK.

Department for International Development (2015) *Disability Framework: Leaving No One Behind*. DFID, UK.

Eide, A. H. and Loeb, M. E. (2006) *Reflections on disability data and statistics in developing countries*, in Albert, B. (Ed.) *In or out of the mainstream?* The Disability Press, Leeds.

Elwan A. (1999) *Poverty and Disability. A survey of the literature*. World Bank. From <http://siteresources.worldbank.org/DISABILITY/Resources/280658-1172608138489/PovertyDisabElwan.pdf>

Gooding, K. and Marriott, A. (2007) *Social Assistance and Disability in Developing Countries*. DFID and Sightsavers International.

Graham, L., Moodley, J., & Selipsky, L. (2013) *The disability–poverty nexus and the case for a capabilities approach: evidence from Johannesburg, South Africa*. *Disability & Society*, 28, 324–337.

Groce, N.E. Chamie, M. and Me, A. (2000) *Measuring the Quality of Life: Rethinking the World Bank's Disability Adjusted Life Years*. *Disability World* 3.

Groce, N. (2011) *Disability and the Millennium Development Goals: A review of the MDG process and strategies for inclusion of disability issues in Millennium Development Goal efforts*. United Nations, New York.

Kidd S., Wapling L., Schjoedt R., Gelders B., Athias D., Tran A., (2017) *Leaving No-One Behind: Building inclusive social protection systems for people with disabilities. Forthcoming from DFID*.

Kiregu, Joshua; Murindahabi, Nathalie K.; Tumusiime, David; Thomson, Dana R.; Hedt-Gauthier, Bethany L., Ahayo, Anita (2016) *Socioeconomics and Major Disabilities: Characteristics of Working-Age Adults in Rwanda*. *PLoS ONE* 11 (4), April 2016.

Loeb, M.; Eide, Arne H.; Jelsma, Jennifer; Toni, Mzolisi ka and Maart, Soraya (2008) *Poverty and disability in Eastern and Western Cape Provinces, South Africa*. *Disability and Society*, Vol. 23, No. 4, June 2008, 311-321.

Mitra, S.; Posarac, A. and Vick, B. (2012) *Disability and Poverty in Developing Countries: A Multidimensional Study*. *World Development* Vol. 41, pp. 1-18, 2013.

Mont, D. and Nguyen, C. (2013) *Spatial Variation in the Disability-Poverty Correlation: Evidence from Vietnam*. Working Paper Series No. 20, Leonard Cheshire Disability and Inclusive Development Centre, University College London.

Palmer, Michael (2011) *Disability and Poverty: A Conceptual Review*. Journal of Disability Policy Studies 21 (4) 210-218.

Palmer, Michael (2013) *Social Protection and Disability: A Call for Action*. Oxford Development Studies, 41:2, 139-154.

Palmer, M.; Groce, N.; Mont, D.; Nguyeb, Oanh Hong and Mitra Sophie (2015) *The Economic Lives of People with Disabilities in Vietnam*. PLoS ONE 10 (7).

UNICEF (2015) *Annual report. Jordan section*
www.unicef.org/about/annualreport/files/Jordan_2015_COAR.pdf

UNICEF (2016) *Technical Guidance: Guide for Including Disability in Education Management Information Systems*, UNICEF Education Section, 2016

UNPRPD (2013) 'Towards An Inclusive And Accessible Future For All. Voices of persons with disabilities on the post-2015 development framework inter-agency'.

WHO and World Bank (2011) *World Report on Disability*. Geneva: WHO.

Yeo, R. and Moore, K. (2003) *Including Disabled People in Poverty Reduction Work: "Nothing About Us, Without Us"*. World Development Vol. 31, No. 3, pp. 571–590

Young, R., Reeve, M. and Grills, N. (2016) 'The Functions of Disabled People's Organisations (DPOs) in Low- and Middle-income Countries: a Literature Review', Disability, CBR and Inclusive Development www.dcidj.org, Vol. 27, No.3, 2016