



Oxford Policy Management

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

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## List of abbreviations

AHS	Annual Health Survey
CBM	Christian Blind Mission
CBS	Central Bureau of Statistics
CLE	Country-led evaluation
CSO	Civil society organisation
DFID	UK Department for International Development
DPO	Disabled persons' organisation
DRPI	Disability Rights Promotion International
EMIS	Education management information system
HLPF	High-Level Political Forum
ICED	International Centre for Evidence in Disability
IDA	International Disability Alliance
IDDC	International Disability and Development Consortium
IIED	International Institute for Environment and Development
ILO	International Labour Organisation
INGO	International non-governmental organisation
IT	Information technology
LSHTM	London School of Hygiene and Tropical Medicine
M&E	Monitoring and evaluation
MDGs	Millennium Development Goals
NGO	Non-governmental organisation
NPC	National Planning Commission
NPPAD	National Policy and Plan of Action on Disability
ODI	Overseas Development Institute
OHCHR	Office of the United Nations High Commissioner for Human Rights
SDGs	Sustainable Development Goals
Sida	Swedish International Development Cooperation Agency
UK	United Kingdom
UN	United Nations

UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNFPA	United Nations Population Fund
UNHCR	United Nations High Commissioner for Refugees
UNICEF	United Nations Children's Fund
UNPRPD	United Nations Partnership for the Rights of People with Disabilities
UNSD	United Nations Statistics Division
USA	United States of America
WG	Washington Group
WHO	World Health Organization

## Introduction

### Background

In May 2016, the UK Department for International Development (DFID) initially commissioned a scoping study 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). During the inception phase it was agreed to further focus the study on the Leave No One Behind agenda, and specifically on the inclusion of people with disabilities. Through this study, DFID was seeking 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 (CLE) processes and systems**. The purpose of the study was to answer the guiding question:

**‘What approaches by donors will support good quality CLE systems and processes that can feed into SDG follow-up and review processes, to ensure that the interests and perspectives of people with disabilities are taken into account?’**

This question has two components:

1) Good quality CLE systems.

This implies a need to define CLE and to explore national-level evaluation systems and their capacity as well as understanding the institutional context within which CLEs are conducted (that is, the **general effectiveness of the evaluation system**).

2) Specific issues people with disabilities may encounter in the context of CLEs (**inclusivity of the evaluation system**).

Assessing inclusivity requires analysing government and donor evaluation systems and mapping out the level of involvement of, and engagement by, disabled persons’ organisations<sup>1</sup> (DPOs) and civil society organisations (CSOs) in institutions and the wider policy context.

To guide the framing of the gathering of evidence to answer this question, the analytical framework rested on **four major conceptual areas**:

- **Evaluation and evaluative thinking** – to shift the mind set from evaluation as a single systematic and objective assessment of a project, programme or policy towards a process of critical thinking applied in the context of evaluation.<sup>2</sup> This involves exploring assumptions and pursuing deeper understanding through reflection to inform and improve decisions.
- **Evaluation systems and capacity** – to explore and understand how capacity needs to be addressed at different levels (institutional, organisational and individual) and

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<sup>1</sup> DPOs are commonly understood to be CSOs that are led by and that include people with disabilities. Note that there are also CSOs (non-governmental organisations (NGOs) and faith-based organisations) which work with and for people with disabilities.

<sup>2</sup> For relevance to SDG, see Schwandt *et al.* (2016).



within different dimensions (independence, credibility utility, inclusivity) in order to deliver robust systems that are able to deliver robust evidence for policy-making (making use of the Heider Framework).<sup>3</sup>

- **CLE and stakeholders** – to analyse how country-led processes that include stakeholders with different capacities, agendas and power capital can deliver more accurate and robust data while increasing sustainability and making duty-bearers more accountable; country-led is understood as meaning led not just by government but by a multi-stakeholder platform.
- **The challenges of the Leave No One Behind commitment** – to assess how marginalisation and exclusion (with some specific issues related to disability) raise barriers to inclusive CLEs.

In order to answer the guiding research question, the study was framed around **three sub-research questions**:

1. What are the **lessons learned from civil society experience** through their work to make national evaluation systems and processes country-led and inclusive for people with disabilities?
2. What are the **lessons from donor and international development agency experience** in supporting country-led national evaluation systems and processes to be inclusive for people with disabilities?
3. What **insights (processes, approaches etc.) are identified as good practice in supporting CLE systems to be inclusive and supportive of people with disabilities** by donors, CSOs and national stakeholders?

The World Report on Disability<sup>4</sup> estimates that, globally, there are over 1 billion people living with a disability, representing just over 15% of the world's population. Around 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<sup>5</sup>. Moreover, the prevalence of disability is growing due to ageing populations and the global increases in chronic health conditions and non-communicable diseases.

There is a clear link between poverty and disability, with disabled persons more likely to be found among the poorest categories in society in both high- and low-income countries, although in greater numbers in the low-income context (WHO and World Bank, 2011). A strong cycle of disability and poverty exists, with those in poverty more likely to become disabled due to poorer access to health care, low quality housing, reduced access to safe drinking water and sanitation for example. Similarly, those with disabilities are more likely to be poor as a result of systemic institutional, attitudinal and environmental barriers that have an impact on their opportunities to participate in economic, social and political activities.<sup>6 7 8</sup>

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<sup>3</sup> Heider (2010)

<sup>4</sup> WHO and World Bank (2011)

<sup>5</sup> United Nations Office of the High Commissioner for Human Rights. (2007)

<sup>6</sup> Yeo, R. and Moore, K. (2003)

<sup>7</sup> Mitra and Vick (2012)

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 (UNCRPD), 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, UNCRPD)*

The human rights approach to disability promotes the assumption that people with disabilities have the right to participate in all development activities 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 taking steps to mitigate them. Traditionally, the needs of people with disabilities have been treated as 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 interventions.<sup>9</sup> The emphasis for inclusion under the human rights approach is placed on reducing barriers and promoting opportunities for participation, rather than expecting people with disabilities to ‘fit in’ as best they can.

In 2015, DFID reaffirmed its commitment to the promotion of disability as an important development issue with the publication of its Disability Framework. In this Framework, DFID takes a clear human rights approach, focusing on the barriers that exclude people with disabilities from active participation:

*‘The UN Convention on the Rights of Persons with Disabilities (UNCRPD) explains that disability is an “evolving concept”, because “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others. An impairment becomes disabling when individuals are prevented from participating fully in society because of social, political, economic, environmental or cultural factors. For example children with disabilities can be denied access to education because of the discriminatory attitudes of their parents, school teachers or fellow pupils, or inaccessible classroom infrastructure, sanitation facilities or learning materials.”’*

This Framework makes it clear that DFID aims to ensure that its ‘...policies and programmes are inclusive of and accessible to people with disabilities...’ (p. 5), which is very much in line with the new international development targets (SDGs) underpinned by the ‘no one left behind’ agenda.

A key part of the participation process is consultation with people with disabilities. It is in this sense that supporting and engaging with representative organisations of disabled people (DPOs) becomes an important strategy. DPOs are CSOs 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). What

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<sup>8</sup> Banks and Polack (2014)

<sup>9</sup> Coe and Wapling (2010)

is important in this context is that they are organisations that represent and voice the concerns and needs of people with disabilities and therefore have a key role in engaging with local, national and international processes. 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.

## Methodology

Data collection consisted of a literature review, semi-structured interviews and a CSO workshop in London. Methodological details on the literature review process, the interview questions, and questions explored during the workshop are provided in the Annex 1. We consulted about 140 references<sup>10</sup>, consisting of academic papers, policy documents and grey literature. We conducted 45 semi-structured interviews across a wide range of actors: DPOs, donors, academics, and national statisticians, CSOs, NGOs, and international NGOs (INGOs). Nine interviews were specifically focused on Nepal, which is a DFID trail blazer country, in order to develop a mini country case study. Four interviews were also conducted in Nigeria as one of the team members attended the National Evaluation Conference on the SDGs in Abuja in November 2016. 16 CSO representatives attended the workshop in London. All the interview data have been anonymised.

The interview notes were read multiple times by team members in order to extract a number of recurrent thematic areas, which were then used to structure the findings. The initial list of findings was discussed with our disability issues expert, validated during the CSO workshop and triangulated with findings from the literature as far as was possible within the budget available. However, this remains a scoping study that uses qualitative methods. It is not a rapid evidence review or a systematic review and the findings from this study should be considered accordingly. We feel confident that the findings in this report are representative of our 45 interviews. We recognise that while there is broad consensus on some issues others were identified by only one or two individuals. Thus, throughout the report some issues or themes are linked to a number of interviews while some represent the view of only one person. We have clarified where this is the case through the use of footnotes and within the report to support the reader to understand and interpret feedback by interviewees. We believe that though some views may not be representative of the majority view, they still address relevant issues and provide insights which are worthwhile highlighting within a scoping study, in order to enrich the debate.

**When the study was initially commissioned it did not include a focus on the exclusion of people with disabilities.** Thus, initially, 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. However, as interviews with key informants

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<sup>10</sup> The search strategy is included in Annex 1 .

unfolded, the subtle specificity around the field of disability came more and more into focus. Subsequent input from an additional team member's experience of and expertise around disability helped us to refine our language, understand better the historical context of the development of Disabled People's Organisations (DPOs), including the long, exhausting battles of people with disabilities to become more visible and have their rights recognised. However, there is no doubt that our limited knowledge in the field of disability may have restricted our analytical capacity.

This experience also taught us that though we may be cognitively and conceptually aware of difference and diversity and the need to be respectful of people's needs there are different levels of awareness: because, culturally and politically, people with disabilities have been historically excluded from our immediate worlds it is easy to forget, to overlook or under-plan. These limitations that we face should not be barriers to engaging in the world of disability with people with disabilities, as long as we stay cognisant of our limited awareness and are not afraid to ask for advice or to accept uncomfortable questions. However, we must recognise the limits of our insights. We are grateful to have received support from Disability Expert Lorraine Wapling, who reviewed the summary of the literature review as well as our findings. This input was limited to a few days and was included in the final phase of the research, after the data collection and initial analysis.

**Also, there was a need to expand our literature search beyond the originally imagined scope.** We have researched databases such as EBSCO and Cochrane for search terms. However, it quickly became apparent that this approach would not result in a reasonably exhaustive list of publications. Thus, in addition to the approach suggested in our inception report, we browsed the websites of the most prominent NGOs and DPOs that are internationally active in low- and middle-income countries for publications on research they conducted and projects and programmes they undertook.

**While so far few evaluations have been conducted, we sought to reflect the debate and the lessons learned that are discussed in conferences, project documents, and other publications.** The scarcity of peer-reviewed literature on the effectiveness of different approaches pursued by civil society and donors must be borne in mind when using this literature review to inform policies. In addition to browsing DPO and NGO websites for insights into what approaches worked, we searched for (independent) evaluations. However, we found only six such evaluations. We can only make assumptions as to why this was the case. The first section of the report contains a description of DPOs and explains why they are relevant to this study. Apparently, where pioneering approaches had been brought to the fore it was too early to conduct evaluations. While the interviews of experts in the area of evaluation, SDGs and disability, and the CSO workshop provided an opportunity for triangulation and validation, we do not claim that our findings are representative of situations everywhere but instead they provide some insight into issues and possible areas to attend to in future programme and/or policies.

Methodologically, we struggled as a result of not grounding this study within a number of specific country case studies. Initially, we considered trying to review different experiences of CLEs in different countries, with the aim of generating some form of typology of countries and types of national systems according to a list of criteria: we thought this would give us information about institutional and organisational hurdles that might explain the level of performance of, and appetite for, CLEs within different country settings. As the focus of the

study shifted from CLEs to how to include people with disabilities in CLEs our interviews and reading shifted from national systems towards DPOs, people with disabilities and exclusion. While the level of interest expressed by respondents underlined the relevance of this study and its focus, this study became more of an exploratory exercise. The interviews and workshop highlighted a number of issues that are important for non-specialists to be aware of, but that perhaps are already known to people working in the field of disability. This highlights two points: 1) the need to include disability expertise in the team in order to develop more advanced analytical questions; and 2) the focus on learning about the more generic disability issues perhaps distracted from focusing more on, and understanding better, the challenges faced by national systems and countries to comply with their SDG evaluation commitments.

**The study generates a number of recommendations that aim to increase the inclusion of people with disabilities, DPOs and disability within national systems but offers limited evidence on how best to support the development of national systems.** This outcome reflects in part the exploratory nature of the work as discussed above, but also the need to establish some baselines for future work.

**The first section of the report focuses on exploring issues around disability, evaluation and inclusion that DFID needs to consider if it wishes to increase effective engagement with people with disabilities;** this discussion essentially presents the findings that emerge from the interviews and the literature review. The second section reflects on the **programmatic implications of the issues explored** in the first section for inclusive CLE processes and **highlights a number of tangible and practical possible avenues** for moving forward towards more effective inclusion of people with disabilities.

# 1 The challenge – how to involve people with disabilities in Country Led Evaluations of the SDGs?

This section of the report presents findings and emerging themes from:

- a) The rapid literature review;
- b) 45 interviews with stakeholders who work in monitoring and/or evaluation for multilateral agencies, bilateral agencies and Non-Governmental Organisations and;
- c) A workshop with representatives from disability focused civil society organisations.

## 1.1 The challenges of (in)visibility

The overwhelming message that emerged from the various data sources (interviews and the literature review) is that people with disability are largely invisible in monitoring and evaluation (M&E) activities. The review also found that donors have prioritised supporting disability-inclusive evaluation systems in few projects.<sup>11</sup> This invisibility of people with disabilities can be articulated around two sets of issues: **1) they are invisible because the number of people with disabilities is not adequately recorded in national statistics and their needs, experience and views are not captured in evaluations; and 2) they are invisible because people with disabilities experience stigma and discrimination, and are marginalised rather than invited to participate in mainstream decision-making.** Thus, invisibility is a consequence of barriers to participation. Analysis of invisibility needs to focus on the barriers that prevent inclusion and participation.

The invisibility and marginalisation of people with disabilities in development is in many respects a consequence of the individual/medical approach to disability which has dominated the sector until very recently. The way disability is conceptualised by governments and in programmes influences how people with disabilities are treated.<sup>12</sup> Individual/ medical approaches are a manifestation of negative attitudes towards impairments and people with disabilities and coincide with beliefs that people with disabilities are ‘abnormal’, have less to offer society (and in fact are more of a drain on resources) and are unable to derive benefit from mainstream services. Groce, Chamie and Me (2000) observe how, if the resources and access that people with disabilities need in order to participate are not available, their being a ‘drain on society becomes a self-fulfilling prophecy’. In this situation, people with disabilities are afforded almost no power – since they cannot contribute they cannot expect to influence decisions. This attitude affects how policies are formulated and how resources are distributed.<sup>13</sup> Education for children with disabilities is a typical example of how attitudes towards disabled people have impacted on policies and practices. Special education and the establishment of impairment-specific schools or classes are a result of individual / medical-based thinking. Attitudes towards people with disabilities in low- and middle-income countries

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<sup>11</sup> Dr Valerie Karr’s research tags projects by DFID and World Bank for their disability relevance and confirms that there is no system of disability-inclusive evaluation systems and there is only break down data on the subject in a few projects (Karr *et al.*, Undated). DFID has started to tag projects for disability relevance and UKAid grant projects ask for beneficiaries with disabilities. However, while both are steps in that direction neither constitutes an inclusive evaluation system.

<sup>12</sup> Lang (2007)

<sup>13</sup> Coe and Wapling (2010)

can be even more extreme and the degree of stigma and shame can be higher than in high-income contexts.<sup>14</sup>

By contrast, the social / human rights approach promotes the assumption that people with disabilities should participate in **all** development activities since they are members of communities. However, this requires that the attitudinal, environmental and institutional barriers to inclusion are identified and mitigated in order to facilitate inclusion.<sup>15</sup> A key factor in marginalisation therefore is understanding what barriers are preventing people with disabilities from actively participating in decision-making fora. The human rights approach, rather than the medical model, is aligned with the United Nations Convention on the Rights of People with Disabilities (UNCRPD).

### 1.1.1 Not being counted, engaged or included in evaluation: ‘The invisible minority’<sup>16</sup>

Although our study focused on disability-inclusive CLE of the SDGs, it became clear early on in the study that before issues of evaluation can be explored, more fundamental issues around data collection and monitoring of people with disabilities need to be addressed. Thus, many comments in this section tend to refer more to data collection and monitoring than evaluative processes. However, since many types of evaluation are based on existing monitoring data, issues identified around monitoring remain valid for these types of evaluations.

One of the major issues which has been commented on by all respondents and also commented on in the literature is that **the numbers of people with disabilities in most countries are under-reported and inaccurate**. The lack of accurate data is a significant and complex problem. Without an evidence base, policy-makers, development agencies and donors have been unable to develop economic justifications for focusing on disability and have struggled to understand how best to include people with disabilities. Following the logic that ‘what does not get measured does not get managed’ (or receive resources), the lack of data has led to assumptions that the need is, correspondingly, not that significant.<sup>17</sup>

The issue with collecting disability disaggregated data, however, is more complex than is initially evident. It might seem like a straightforward thing to identify how many people with disabilities there are in a population – but simply asking people to state if they have a disability is not effective and usually results in very low prevalence rates. When data from across the world are compared there can be very significant differences in reported prevalence – compare the less than 1% figure in Kenya with the 20% figure in New Zealand, for example, as a result of the problems around how people conceptualise disability in these types of questions. It is also important to recognise that different countries have different definitions of disability, and this makes comparisons between countries challenging.<sup>18</sup>

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. For

<sup>14</sup> Mont (2014, p. 24)

<sup>15</sup> Coe and Wapling (2010)

<sup>16</sup> Appellation borrowed from Interview No. 26.

<sup>17</sup> Eide and Loeb (2006)

<sup>18</sup> Mont (2007)

example, some people, if their disability has not been recognised by a medical practitioner or they are not officially registered as a person with a disability, may fail to report their disability when questioned. In many developing countries, disability is a stigmatising label, one that people or families may work hard to avoid. In these circumstances the person with a disability may actually be hidden away and not declared in a survey or the person may try to hide their disability and not openly admit to it when questioned. Similarly, the severity of disabilities varies considerably and is to some extent contextually relative. People may compare their situation to others and feel that their particular limitations are not severe enough to be reported as a disability.<sup>19</sup>

The lack of comparable and robust data on disability that reflect the human rights approach led to the formulation of the Washington Group (WG) set of questions. The WG have developed a series of question sets, the most commonly used being the short set of six questions (WG-6) which are intended to be used in existing population-based surveys, such as a census or household surveys, and that provide a general prevalence rate. Rather than focusing on individual medical details the WG-6 concentrates instead on an individual's level of functioning against six domains and focuses on functioning rather than impairment. Consequently, they are more closely aligned to the social than medical model.

The questions themselves focus on the six core domains of seeing, hearing, walking, remembering, self-care and communicating, which are ranked on a scale from *no difficulty* to *cannot do at all*. The WG recommends that the population identified as having a disability should include all those with difficulty *in at least one domain* recorded at *a lot of difficulty* or *cannot do at all*. This cut-off point gives the most accurate representation of the population that has an impairment which is significant enough to cause some level of activity limitation (in other words, a disability).

This barrier approach means that it is possible to collect disability prevalence data without having to use the term 'disability' – a factor which contributes significantly to the variations in rates described above. **A recent review of some 65 countries where the WG-6 questions were implemented as intended (i.e. without any kind of modification) found an overwhelming improvement in the overall quality of estimations of prevalence and in comparability.**<sup>20</sup>

As good as they are, there are some limitations to the use of WG-6, although these are being mitigated to a large extent through the development of additional question sets. The WG-6 is designed primarily on the basis of adult respondents ( $\geq 18$  years) so it is less accurate at capturing disability in children. To capture disability prevalence among children there are two specially designed tools: the Child Functioning tool for children aged 5–17 years, and the Child Functioning tool for children aged 2–4 years. In addition to the WG-6 there is an extended set of questions for use with adults ( $\geq 18$  years) which captures a wider range of domain limitations, such as those involving the upper body, pain, fatigue and anxiety conditions. A more detailed set of questions that aim to identify a wider range of mental health conditions is under development.

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<sup>19</sup> Oliver (2013)

<sup>20</sup> Altman (2016)



The WG-6 was designed to be used as a set of questions embedded within large-scale surveys, such as a national census or household survey exercises. However, they are now being used more extensively by the development sector to support the collection of disability disaggregated population-based data. Thus, they are being added to local household surveys, to community mapping exercises and to questionnaires recording demographic information.<sup>21</sup>

### How invisibility arises and the consequences it has

**Chronic under-reporting:** Some respondents mentioned that in their respective countries the official numbers estimate the proportion of people with disabilities within the total population to be 2% to 3%, while in reality, based on pilot data collections using better tools, the number is around 12%–15%.<sup>22</sup> In some countries data on disability are barely or badly collected and administrative sources, such as population registers and civil registers, rarely include data on disability – and when they exist, registers for people with disabilities are usually services-related and do not include everyone.<sup>23</sup> One interviewee noted that in India there had been no question in the census on disability between the 1951 and 2001. The current prevalence rate of 2.2% derived from the 2011 census is considered to be very low as a result of the fact that it is based on a simple yes/no response to the question ‘Is this person mentally/physically disabled?’.<sup>24</sup> Another interviewee spoke about Mexico testing different tools in its census (among them, the WG-6). The interviewee reported that this confirmed that the prevalence of disability in the population varies greatly depending on the tools used, and that some of the tools were inadequate and greatly underestimated the prevalence.

**Limited skills and awareness among enumerators:** Typically, enumerators for census or other methods of data collections, such as household living standards surveys, limit themselves to ticking boxes during data collection and are ill equipped to explore in detail answers around disability as they are not trained to ask the right question in the right way.<sup>25</sup> Survey questionnaires are often ill designed and do not offer suitable options to tick. A household head who responds to a survey may not recognise an elderly visually impaired or bed-ridden relative as disabled,<sup>26</sup> while the enumerator has limited skills to press for further details. Similarly, disability may be experienced within the household as a stigma and so respondents tend not to report a disabled family member.<sup>27</sup> One respondent used the example of a disabled woman whose brother had built a plywood house in the back garden so that she would be out of sight.<sup>28</sup> It is good practice to support individual data collection (rather than head of household data collection) that includes speaking directly to the person with a disability, rather than a head of household describing people in their home. The WG questions support enumerators to collect data in this way by asking about an individual’s functional capacity rather than whether or not the respondent (or person that the head of household is speaking about) has a disability.

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<sup>21</sup> See, for example, Sightsavers (2015)

<sup>22</sup> Interviews Nos. 26, 28, 29.

<sup>23</sup> Interviews Nos. 18, 40.

<sup>24</sup> Interview No. 26.

<sup>25</sup> Interview No. 10.

<sup>26</sup> Interview No. 26.

<sup>27</sup> Interviews Nos. 1, 9, 11, 14.

<sup>28</sup> Interview No. 7.

**Limited or no administrative records:** Additionally, administrative records – an alternative to census data – also often fail to report disability. When administrative data are available they are often too fragmented to build an overall picture: within a country different ministries may be collecting some data using different criteria, methods or definitions of disability, and, similarly, baseline data collected by DPOs or CSOs are not comparable because they are collected at different scales, using different methods and on different themes or categories of disabilities.<sup>29</sup> In comparison to census data, administrative data are more costly to gather and manage.

Both administrative data and census data are limited in their power to reflect different disability groups and the way their impairments keep them from full participation and access.

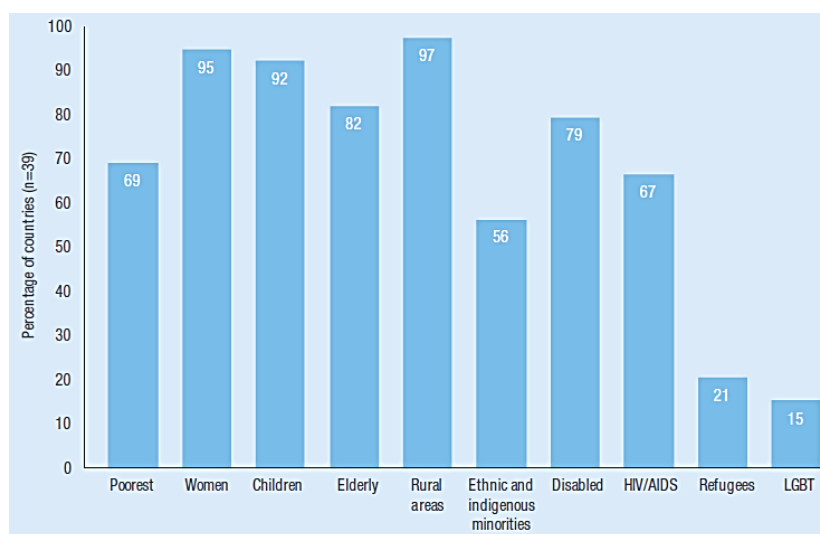
**Limited political commitment:** Ultimately, the level of political commitment plays a role in the efforts invested in gathering better quality data – whether it is prevalence in the population or evaluative evidence about experiences and needs.<sup>30</sup> Countries that have ratified the UNCRPD have an obligation to collect data on disability, which has led to more countries including disability as a marker within their national surveys. The SDGs include seven direct references to the inclusion of people with disabilities in the areas of education, employment, reducing inequalities, inclusive cities and, importantly, in data disaggregation, with nine global indicators. This is in stark contrast to the previous Millennium Development Goals (MDGs), which failed to reference disability at all.<sup>31</sup> This reflects a general increase in political commitment to disability, as well as the visibility of persons with disabilities in the formation of the 2030 Agenda. Given the increased demands placed on governments to increase the participation of people with disabilities in their service delivery and reporting mechanisms it is likely that the issue will continue to gain the political attention it requires.

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<sup>29</sup> Interviews Nos. 1, 3, 5, 6; workshop notes.

<sup>30</sup> Interviews Nos. 34, 22.

<sup>31</sup> Groce, (2011)



**Figure 1: Inclusion of different groups in national development plans (Source: Overseas Development Institute (ODI), 2016, p. 32)**

**Diversity between countries:** Different countries are at different stages in their understanding and recognition of disability-related issues. Two interviewees noted that countries including Mexico, South Africa, the Philippines and Sri Lanka have conducted studies, developed frameworks for inclusive evaluations or set up processes with parliamentarians.<sup>32</sup> These interviewees spoke about Mexico and South Africa having a history of including

a question on disability status in the census. Three interviewees provided feedback that Rwanda and Jordan are countries where there is a genuine political will at the highest levels to improve data quality.<sup>33</sup> DPOs are more likely to be involved in discussions if their participation is a legal requirement (like, for example, Kenya and Uganda).<sup>34</sup> These three interviewees noted that quality of their participation, however, may not be very high as inviting DPOs may be a tokenistic gesture rather than coming from a genuine commitment to inclusion. In many countries disability issues are the responsibility of Ministries for Women and Children and/or Social Welfare, which receive limited funds in many countries. This often gives disability little scope for visibility. Political commitment may provide more resources and may also create the space for institutional changes and collaborations between institutions (see Box 1). When the recorded numbers of people with disabilities are low, it is easy for duty-bearers to dismiss the needs to invest resources in improving people with disabilities' access to their rights. In countries with limited resources, it is easy to question the need to invest in disability ('such a small number') when they are faced with multiple pressing issues, such as health or education.<sup>35</sup> This is also the result of the medical model way of thinking about disability, with an assumption that specialist services will be needed after services have been created for everyone else. This is a fundamental error in understanding disability that is made by many governments. Similarly, organisational commitment is just as important as removing barriers to impairment and this requires financial resources: organisations may publicly claim they are prepared to make this investment, but in practice they often fail to deliver.<sup>36</sup> For example, one interviewee reported that in Nepal only approximately 40% of people with disabilities have official documents

<sup>32</sup> Interviews Nos. 27, 25.

<sup>33</sup> Interviews Nos. 28, 29, 32.

<sup>34</sup> Interviews Nos. 36.

<sup>35</sup> Interviews No. 4, 5, 16, 31.

<sup>36</sup> Interview No. 16.

validating their disability status though the Nepali government has been very supportive of the rights of people with disabilities.<sup>37</sup>

**Invisibility is reflected in government planning:** People with disabilities face entrenched discrimination, which, in many countries, is the result of political choices that have benefited majorities. In their 2016 analysis of National Development Plans, the Overseas Development Institute (ODI) found that only 79% of plans specifically refer to and include people with disabilities, as shown in the bar chart (Figure 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 in Amman, 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 a national-level working group on disability, which includes statisticians, and the census book included some 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: Interview notes for interviews nos. 10, 28, 29. UNICEF 2015<sup>38</sup>

### 1.1.2 Representation and representativeness

One of the consequences of the invisibility of people with disabilities is that the world of disability is not well known and understood by people without disabilities. In addition, rights are often not understood by people with disabilities due to stigma, discrimination and exclusion.

Besides leading to **stereotypes, discrimination, stigma and lack of awareness**, this invisibility results in the common absence of people with disabilities from discussions, debates, and key decision-making processes.<sup>39</sup> **When people with disabilities are represented, two issues emerge: one is related to which group with which impairment dominates and is more visible, and the other is related to who speaks on behalf of whom?**

**People with disabilities are a diverse group but historically people have been compartmentalised according to their impairment.** This is sometimes the consequence of following the 'medical' model of disability.<sup>40</sup> Another false assumption that is often made

<sup>37</sup> Interview No. 4.

<sup>38</sup> UNICEF (2015), 'Annual report Jordan section', [www.unicef.org/about/annualreport/files/Jordan\\_2015\\_COAR.pdf](http://www.unicef.org/about/annualreport/files/Jordan_2015_COAR.pdf)

<sup>39</sup> Interviews Nos. 1, 11, 12, 23, 35. UNPRPD's online consultation included negative attitudes towards people with disabilities as among the main challenges. Source: UNPRPD (2013)

<sup>40</sup> Traditional medical and charitable approaches to disability focus on the disabled individual, rather than on the need for societal change. From Yeo and Moore (2003): '*During the course of the 20th century many different groups and organizations, in different parts of the world, have claimed to be working on behalf of disabled people. Generally this has been through exclusion, segregation and patronizing welfare programs (the charity model); attempts to "cure" the individual disabled person (the medical model); or, most commonly, a mixture of the two. There has been little recognition of disabled people having equal rights, or of the barriers that are faced (the social model).*'

about people with disabilities is that they are all the same. This is not to say that solidarity among people with disabilities is misguided but instead that diversity must be taken into account. Participants in the UN Partnership for the Rights of People with Disabilities (UNPRPD) noted that **lack of awareness about the diversity** of impairments resulted in a limited understanding of the different reasonable accommodation measures that are needed to address them.<sup>41</sup> In the absence of appropriate government services, many DPOs were initially established to provide impairment-specific support and advice, and have thus tended to represent people with one type of impairment. 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**. Just as with any cross-section of society, people with disabilities are of different genders, religions, indigenous groups, ethnicities and sexual orientation. Truly empowering persons with disabilities requires addressing discrimination that arises from the interaction of multiple identities. **However, the evidence both on a lack of awareness of intersectionality and diversity among DPOs is limited and mixed:** One study, published 15 years ago, found that men with physical impairments tended to dominate DPOs in developing countries – a legacy which the disability movement is still working hard to overcome.<sup>42</sup> This study found that people with learning difficulties, leprosy, epilepsy, sensory impairments, and mental and emotional illness, rarely get equal access to cross-impairment groups. The exclusion and poverty faced by these groups of people, and especially by women, is often severe. People experiencing several different areas of discrimination are frequently marginalised from all groups. The scoping study did not find any more recent evidence about whether, how and in which locations this situation may have changed.

As already noted, people with visible impairment are more likely to be noticed than others. Women also tend to be under-represented (in statistics, and also in organisations) and specific vulnerabilities attached to women, especially in the context of gender-based violence, tend to be ignored. On the other hand, major disability-focused organisations and DPO networks – ADD International, International Disability and Development Consortium (IDDC) and International Disability Alliance (IDA) – show awareness and support of different sub-groups and devote resources to them. IDA supports indigenous persons and women with disabilities and there are networks dedicated exclusively to these issues.<sup>43</sup> ADD International conducts research on the intersection between disability and gender-based violence; Disability Rights Promotion International's (DRPI's) manual for human rights monitoring has the need for diversity included in all aspects of their work. It may be that awareness of intersectionality is limited to larger disability-focused organisations and DPOs, and is less of a concern for DPOs operating at more local levels. Alternatively, broad awareness within the disability movement of intersectionality could be a more recent development, and as such one which has yet to manifest itself in the research literature.

One of the ways in which disabled people are excluded is that they often have little contact with other disabled people in their own country, let alone in other parts of the world. This leads to isolation and a lack of ability to learn from others' experiences.<sup>44</sup> In countries where internal communications networks are underdeveloped, DPOs located in remote rural areas

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<sup>41</sup> UNPRPD (2013)

<sup>42</sup> Yeo and Moore (2003)

<sup>43</sup> See also [www.internationaldisabilityalliance.org/61csw-side-event](http://www.internationaldisabilityalliance.org/61csw-side-event).

<sup>44</sup> Yeo and Moore (2003).

are unlikely to ever be invited to the capital city because they are unknown to NGOs, INGOs and government departments. This tends to result in CSOs and NGOs representing people with disabilities in high-level meetings instead of empowering them to represent themselves.<sup>45</sup> It is also important to differentiate between DPOs, which are membership organisations made up of people with disabilities, and CSOs and I/NGOS, which may work on behalf of people with disabilities and may have some people with disabilities on their staff.<sup>46</sup>

**The general marginalisation of people with disabilities is even more acute in M&E processes, whether it is within the SDG or human rights debates.** Their non-participation is partly linked to their invisibility, and to stigma and discrimination, but also to the limited knowledge and awareness of DPOs about CLE processes (see Section 2). Finally, given limited resources, DPOs may choose to focus on specific advocacy or legislative initiatives to enforce rights, rather than on M&E.<sup>47</sup>

## 1.2 The challenges of participation

The **SDGs were seen by all workshop respondents as an opportunity for increasing awareness** of issues faced by people with disabilities. This is unsurprising given that several of the SDG indicators refer to disability specifically (seven targets explicitly reference disability) and in general disaggregation of data by disability is demanded (see Target 17.18). However, among interviewees there was a **general concern** about the **operationalisation of the Leave No One Behind commitment**, and the extent to which **national systems will have the capability** and incentive to develop inclusive CLE systems. **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.**<sup>48</sup> It has been proposed that the follow-up and review processes under the post-2015 framework should extend beyond national governments to a wide range of stakeholders, including private sector enterprises, intergovernmental institutions and multilateral development agencies, and civil society. **The great challenges the SDGs bring up cannot be addressed through traditional ways of producing knowledge** (e.g. experts collect and analyse data and then write up reports for policy-makers). It is considered more effective and efficient if many people, responding to different types of interests, jointly contribute to the creation of knowledge, information and innovative solutions. Similarly, the Leave No One Behind commitment requires new means of M&E to ensure that those previously excluded from being counted and evaluated are included. One interviewee noted that data collection will have to go beyond traditional sources (census, surveys, administrative registers, etc.).<sup>49</sup>

In the context of disability, the invisibility of people with disabilities is compounded by the capacity or limited capacity of DPOs, which have historically focused on service provision rather than on rights advocacy, participation in M&E processes or on

<sup>45</sup> Interview No: 9.

<sup>46</sup> Interview No: 35, workshop notes.

<sup>47</sup> Nigeria case study.

<sup>48</sup> See more on it here <https://sustainabledevelopment.un.org/hlp/fo/>

<sup>49</sup> Interview: No. 10.

*‘Collaborative production enforces social values such as democratisation and empowerment, by enhancing the participation of a variety of actors in the production of data and knowledge, by opening up access to these resources and by promoting more horizontal decision-making. These values favour democratic production of knowledge that empowers and mobilises people.’* Civicus (The World Alliance for Citizen Participation) on Citizen Engagement in Evaluation  
Civicus Argentina 2016: 44

aspects of development. The participation of DPOs and people with disabilities in CLE needs to be examined on three levels: 1) the exclusionary nature of national-level processes, which are oblivious to disability issues; 2) the capacity of DPOs themselves to participate and engage in any multi-stakeholder process at the national level; and 3) the capacity (of DPOs but also CSOs) to specifically contribute to evaluation and M&E processes.

### 1.2.1 Exclusionary processes

**Most DPOs and people with disabilities find themselves marginalised in mainstream decision-making and decisions about data, which makes it hard for them to engage and they remain largely invisible.** This cycle is difficult to break because the legal and organisational national context within which DPOs operate is itself not very inclusive and DPOs have to deal with the additional barrier of social stigma and cultural attitudes against people with disabilities. Workshop participants and two interviewees pointed out that a lot is asked by donors and governments of DPOs but little thought goes into how to support them, improve their participation and make mainstream processes more accessible<sup>50</sup>. Two interviewees noted that smaller, less visible DPOs are often simply not invited to meetings – this is often due to lack of awareness – and this is partly due to very few people with disabilities working in the national-level NGOs<sup>51</sup>. The UK INGO sector is also reflective of this. The literature review identified only one study about this topic and it is 14 years old, so it may be the case that these findings are no longer relevant or appropriate. Yeo (2003) found that internal procedures could disadvantage disabled people at all stages of recruitment. Gaps were found in staffing, access, information, limited resources and organisational working practices. As a result, few people with disabilities were employed by INGOs and awareness of disability issues was low.<sup>52</sup> The ways that many funders operate **can make it difficult for smaller DPOs to be formally registered and able to apply for funding or be officially supported.** Given their limited capacity (compounded by remoteness, difficult communications, and costly or difficult to access transport facilities) means that it may take longer for a DPO to respond effectively to a funding or participation opportunity. Two interviewees reported that for many DPOs' human and financial resource constraints mean that it is challenging for them to respond to funders' programme timeframes or budget lines.<sup>53</sup> For details on financial constraints, please also see the next chapter.

### 1.2.2 Limited capacity and representativeness of DPOs

**While there is a long history of people with disabilities organising together and forming civil society associations, most of these associations have dedicated themselves to social support and self-help.** Similarly, NGOs that do not include people with disabilities but are committed to their advancement have focused on service provision in the absence of government services. In citizen-reported data projects, there is usually no provision for people with disabilities to be trained and take part<sup>54</sup>. An exception to this is Disability Rights Promotion International's system and work to monitor the human rights of

<sup>50</sup> Interviews Nos. 11, 35; feedback from CSO workshop participants .

<sup>51</sup> Interviews Nos. 14, 36.

<sup>52</sup> See [www.bond.org.uk/data/files/resources/153/24june08equalisepres.ppt](http://www.bond.org.uk/data/files/resources/153/24june08equalisepres.ppt).

<sup>53</sup> Interviews Nos. 7, 11.

<sup>54</sup> Interview No. 7.

people with disabilities<sup>55</sup> and to some extent the International Disability Alliance's (IDA's) BRIDGE training, which will be explained below. Workshop respondents highlighted the need for **balanced representation, not just tokenistic representation – as is often the case**<sup>56</sup>.

A paper by Meyers (2014) notes that , **DPOs previously did not frame the needs of people with disabilities in terms of human rights**, nor advocate for the government to fulfil them. Yet, this is what the UNCRPD's conception of DPOs as definers, monitors, and advocates of their rights envisions.<sup>57</sup> The convention re-emphasised DPOs' role: at the national level, states are mandated to designate one or more focal points within government to address implementation issues and to create a framework that promotes, protects and monitors the UNCRPD's implementation. Although DPOs are **not** required to write shadow reports they can be involved as representative organisations. However, holding governments to account entails DPOs being sufficiently financially and technically resourced (that is, 'capacitated, knowledgeable, and networked'<sup>58</sup>).

The general consensus among respondents (which included few DPO members, but many NGO, government and donors representatives who work with DPOs) is that in general **DPOs are organisations that are full of enthusiastic and committed individuals but with limited human and financial resources**. This limits their capacity to mobilise, take part and address multiple issues. Depending on their status in different countries DPOs may not be able to apply for external funding and thus become dependent on CSOs/NGOs, which have comparatively easier access<sup>59</sup>. This dependency reinforces their marginalisation and invisibility.

**Interviewees highlighted that where DPOs are advocates for rights, they tend to lobby for the realisation of rights of specific groups with specific impairments**; this means that **DPOs can be fragmented**, engaged in fragmented work and not sufficiently united<sup>60</sup>. This makes it harder for outsiders to reach out to and identify relevant DPOs, but also harder for DPOs to have a strong voice nationally because DPOs have not been used to speaking with one voice. It is not a given that the interests of one DPO necessarily align with another one; depending on the country context, few interests may be shared and this could explain the fragmentation. However, especially as human rights advocacy is concerned, solidarity among different people with disabilities groups could prove helpful.<sup>61</sup> The feedback from interviewees should be considered in the context of DPOs working in countries with low or absent service provision. In these environments, DPOs often provide services that governments are not and this has an impact on their ability to engage in strategic advocacy activities.

**In conclusion, DPOs' marginalisation, limited capacity, and fragmentation reinforce their difficulty in engaging with national systems. Most DPOs are localised, regional organisations with limited networks or contacts with mainstream organisations or**

<sup>55</sup> Disability Rights Promotion International <http://drpi.research.yorku.ca/>

<sup>56</sup> Workshop notes.

<sup>57</sup> Meyers (2014)

<sup>58</sup> <https://dfat.gov.au/about-us/publications/Documents/disability-rights-advocacy-fund-proposal-2014-17.pdf> page 9

<sup>59</sup> Interviews Nos. 14, 19, feedback from CSO workshop participants .

<sup>60</sup> Interviews Nos. 8, 9, 13, 21.

<sup>61</sup> Interview No. 7



**national-level government agencies.**<sup>62</sup> The disability movement needs to be broad, representative, inclusive and accountable to and for all people with different disabilities.

### 2.2.3: Financial Resources

Finally, **financial resources** were discussed in the CSO workshop and in interviews as a constraint to involving DPOs in country-led evaluations of the SDGs. Young's (2016) literature review<sup>63</sup> summarises different studies that have reviewed barriers to more effective ways of working and engagement by DPOs. **Most of them mentioned lack of financial and human resources as negatively impacting upon the functional capacity of DPOs.**<sup>64</sup> Other barriers included the lack of empowerment experienced by people with disabilities when self-help groups or DPOs were led by professionals external to the group;<sup>65</sup> difficulty in maintaining continuity of group members;<sup>66</sup> attitudinal barriers in society promoting discriminatory practices towards people with disabilities;<sup>67</sup> poor access to DPOs for people with disabilities living in rural areas;<sup>68</sup> difficulty in accessing venues and transport for group meetings;<sup>69</sup> exclusion of people with disabilities from mainstream self-help groups;<sup>70</sup> and lack of accurate raw data on impairment type and prevalence in developing countries.<sup>71</sup> There was little evidence in the studies, however, to suggest the extent to which each of these factors impacted upon the ability of DPOs to function.

DPOs struggle to finance themselves and people with disabilities. Workshop participants highlighted that **DPOs that are consulted by donors and NGOs are often not adequately reimbursed for this effort or their particular needs are not accounted for.** It is certainly difficult for people with disabilities from DPOs to participate in global meetings without donor support.<sup>72</sup> Evaluations rarely budget for the inclusion of people with disabilities and consequently they often do not include sufficient time and resources required for meaningful participation. Given that adjustments are required, one interviewee recommended setting aside a budget line (circa 2%–7% of overall budget in a general evaluation if people with disabilities are included and disability accounted for) to accommodate the needs of people with disabilities (and fund sign language interpreters, etc.). Other interviewees seconded the need for a budget line (not quantified) as well.<sup>73</sup> Checklists for budgets and guidelines are available from specialised NGOs. Other useful tools include accessibility audits and safety audits which look at access.<sup>74</sup>

<sup>62</sup> Interviews Nos. 12, 22.

<sup>63</sup> Young and Grills (2016)

<sup>64</sup> Armstrong, (1993); Hemingway and Priestley, (2006); Griffiths et al., (2009)

<sup>65</sup> Stewart and Bhagwanjee, (1999)

<sup>66</sup> Dhungana and Kusakabe (2010)

<sup>67</sup> Griffiths et al., (2009); Kumaran (2011)

<sup>68</sup> Deepak et al., (2013)

<sup>69</sup> Dhungana and Kusakabe, (2010); Deepak et al., (2013)

<sup>70</sup> Cobley (2013)

<sup>71</sup> Cobley (2013)

<sup>72</sup> Interview No. 11.

<sup>73</sup> Interviews Nos. 43, 8, 14, 15.

<sup>74</sup> The Water Engineering and Development Centre (WEDC) developed these for the water, sanitation and hygiene sector, and uses them for their evaluations.

#### 2.2.4: DPOs/CSOs and limited expertise in evaluation

There was also a general consensus among respondents that **DPOs' knowledge and interest** in the SDGs and how to capitalise on them **remains very limited**. Given their **limited capacity and more immediate issues** to deal with, evaluating the SDGs is not yet a priority for most DPOs. Donors have not prioritised investing in and developing the capacity of DPOs to engage in evaluation, or supporting disability-inclusive evaluation systems and processes. Interviewees reported that while people with disabilities were bypassed completely by the MDGs and are only now accounted for in the SDGs, many feel that the **SDG process is still too recent and it is too premature to mobilise interest**<sup>75</sup>. Similarly, while there is a disconnect between the obligations set by the UNCRPD and how DPOs perceive and experience the reality at national and local levels, there are gaps in DPOs' capacities to understand the complexity of the public policy reform and to influence what states should and can do.<sup>76</sup>

**The UNCRPD and the SDG goals shaped the 2030 Agenda in significant ways, yet both the enactment of the Convention and the achievement of the SDGs require a process of follow-up and review by civil society.** It is clear that on paper at least the provisions made within the UNCRPD align well with the intended outcomes of the SDGs in terms of promoting inclusive development. In fact, Christian Blind Mission (CBM) has produced a compelling infographic that illustrates how the 17 SDG and the 33 core articles of the UNCRPD link together ([www.cbm.org/New-resources-on-Agenda-2030-and-the-CRPD-501728.php](http://www.cbm.org/New-resources-on-Agenda-2030-and-the-CRPD-501728.php)). From an advocacy perspective, DPOs have the opportunity to monitor both commitments concurrently to put pressure on governments and the development sector in general to improve and ensure the inclusion of persons with disabilities. Although this is important it is not DPOs' responsibility to ensure inclusion. Instead, the responsibility for inclusion lies with the agencies implementing actions. All development agencies should be monitoring implementation rather than this only being the responsibility of people with disabilities and DPOs.

The 2030 Agenda for the SDGs will influence the direction of global and national policies relating to sustainable development for the next 15 years, so they will be very significant in shaping responses to the inclusion of persons with disabilities, perhaps even more so than the UNCRPD alone. This is because **if the 2030 Agenda is going to be successful all of the UN Member States – 193 countries – must include persons with disabilities in their national plans for implementation and monitoring, regardless of whether or not they are signatories to the UNCRPD** (and to date 173 countries have ratified the UNCRPD). Progress on inclusive development is the responsibility of all UN Members States. It is necessary for all development actors to be held accountable for their role in supporting and delivering inclusive development. It is the responsibility of a wide range of CSOs, NGOs and other stakeholders including DPOs to hold these actors to account.

Some respondents also argued that the **development by results trend has nurtured a culture of monitoring** focused on accountability rather than on evaluative thinking or an interest in feeding data into national systems: donors who expect results-focused M&E

<sup>75</sup> Interviews No: 1, 13, 20, 22, 32 31 33 35. <http://www.internationaldisabilityalliance.org/content/bridge-capacity-building>.

<sup>76</sup> Page 6 on training presentation [www.internationaldisabilityalliance.org/content/bridge-capacity-building](http://www.internationaldisabilityalliance.org/content/bridge-capacity-building).

frameworks have tended not to fund evaluations by and for CSO/NGOs, and this has resulted in the overall weak capacity for evaluation within civil society.<sup>77</sup>

And, finally, there is also a view held by many interviewees that many CSOs/NGOs who share similar interests to **DPOs are still too focused on service delivery, rather than on human rights advocacy, policy or political participation**. This further weakens the capacity of DPOs to participate in monitoring as they perhaps do not see evaluation as an area that is worth investing in.

A further constraint mentioned in several interviews is the continued systemic exclusion of people with disabilities from key social systems. For example, 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.<sup>78</sup> Efforts are therefore required to increase the numbers of skilled DPO advocates and leaders.<sup>79</sup>

### 1.3 Limited capability of actors

One of the underlying assumptions behind the idea of supporting the development of inclusive CLEs is that national evaluation systems exist and only need additional support to become inclusive of people with disabilities. However, **besides the issues of invisibility and participation** which people with disabilities face due to the particular barriers and exclusionary contexts they face, **other actors, such as governments and national systems, as well as donors, have very weak capability. This is defined** in terms of time, skills, and other resources, as well as sufficient political commitment. For different donors this will be **in different areas and for different reasons**.

#### 1.3.1 National systems

**On a general level, most developing countries have very weak or non-existent national evaluation systems.** While government agencies may undertake M&E activities, in many cases there is no or limited coordination and centralisation of the data within an integrated national system. Interviewees reported that there is also often a lack of coordination between different ministerial M&E systems.<sup>80</sup>

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<sup>77</sup> Interviews Nos. 11, 24.

<sup>78</sup> [www.internationaldisabilityalliance.org/content/bridge-capacity-building](http://www.internationaldisabilityalliance.org/content/bridge-capacity-building).

<sup>79</sup> Interview No. 19.

<sup>80</sup> Interviews Nos. 4, 5, 11, 18, 23.

**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.

**When it comes to disability, there are additional issues that are burdening weak systems:**

**- Lack of training and awareness among statisticians and evaluators**

One of the most common reasons given for not including people with disabilities among development practitioners is the concern that disability inclusion is too difficult and requires specialist knowledge, or that people with disabilities require special programmes. Staff may also feel that they are overloaded and 'don't have time for an additional issue'<sup>81</sup> (or that it is an issue that is only relevant in high-income countries. The Governance, Social Development Resource Centre (GSDRC, 2015) reports that this attitude of development practitioners might be held by their evaluators as well as by staff in government evaluation systems.<sup>82</sup> During our research, it struck us that among evaluation associations and societies and professional evaluators, disability was not a familiar topic, in the way that gender is. Similarly, the focus of statisticians can be narrow and is often more on whether people with disabilities do or can access services. The UN Statistics Division (UNSD) is currently revising the disability statistics handbook, which was last published in 2001<sup>83</sup> so this situation may

<sup>81</sup> Bruijn et al., (2012)

<sup>82</sup> [www.gsdr.org/wp-content/uploads/2015/11/DisabilityInclusion.pdf](http://www.gsdr.org/wp-content/uploads/2015/11/DisabilityInclusion.pdf).

<sup>83</sup> Interview No. 18.

change in the future. As discussed earlier, quantitative data and traditional tools cannot capture the diverse reality of people with disabilities. However, one interviewee noted that the overwhelming response and training interest generated by the WG training sessions in different countries shows that there is a genuine appetite among statisticians to develop their skills<sup>84</sup>

#### - **Inadequate or inappropriate tools to collect information**

Section 2.1.1 highlighted the issue of a lack of accurate disability disaggregated data at national level, which has reinforced the invisibility of people with disabilities from national planning and monitoring processes. This data gap is being addressed, however, and a growing number of countries have started experimenting with the **WG questions, which show promising scope in regard to improving national disability prevalence data**. The most recent meeting of the Inter-agency Expert Group on Sustainable Development Goal Indicators (November 2016) released a document stating their unanimous recommendation that the WG toolsets be used for SDG data disaggregation.

In terms of broader measures around participation and barriers, WG questions **alone will not be sufficient to track the impact of changes as experienced by persons with disabilities**.

The International Centre for Evidence in Disability (ICED) published studies on Cameroon and India with the aim of developing a comprehensive population-based survey methodology about disability. They conclude that **if the aim is to assess the prevalence in a general population, as well as its distributions around socio-economic strata, then WG questions in a census are adequate**.<sup>85</sup> However, for the purpose of detailed planning for services, particularly in areas such as health, rehabilitation and education, more detailed disability surveys, which include clinical screening, may be required. Moreover, while the WG questions will provide comparative data on issues such as education, income/poverty, health or housing, for example, they will not provide answers to questions about what barriers people are experiencing, what interventions are required to increase participation, or how things such as stigma and cultural norms impact on the lives of people with disabilities. The WG questions by themselves are merely one set of indicators for use in monitoring (alongside – ideally – participation measures of people with disability, such as representation in labour force, government, etc.). For the purpose of eligibility (i.e. for grants, state support), simply using the UNICEF/WG Child Module has proven not to be adequate. One interviewee reported that in Fiji, it is used as the initial screener – along with information on learning support needs, including assistive technology but more information is needed to understand experiences and nuanced information about needs.<sup>86</sup> Similarly, in order to get proper data on children and youth with disabilities in education, the more ‘granular’ education management information systems (EMIS) are far superior. With technology advancing, many EMISs are modernising, opening up new possibilities.<sup>87</sup>

**As in all data collection efforts, those collecting data and those using them should be in alignment.** Relationships between disability data experts and information technology (IT)

<sup>84</sup> Interview No. 10.

<sup>85</sup> ICED (2014a) Page 30.

<sup>86</sup> Interview: No. 44.

<sup>87</sup> <http://journal.km4dev.org/index.php/km4dj/article/viewFile/309/385>.

experts are absolutely critical – within long-term funded programmes. Data systems need to build in feedback loops between DPOs and those with disabilities with those who are responsible for identifying and/or data entering disability. The use of data needs to be automated as fully as possible. One interviewee reported that this could be an area where donors and regional agencies could help and could make the inclusion of DPOs conditional for their support.<sup>88</sup>

### 2.3.2 Weak capacity and knowledge among staff in bilateral and multilateral agencies

**Perhaps not surprisingly, the level of awareness of disability within donor agencies is often very weak as well:** in many cases staff are not even aware that it may be a legal requirement to ensure full access to, and participation of, people with disabilities.<sup>89</sup>

Many, **donor organisations based in the capital city have limited links with DPOs,** struggle to identify them, and tend to always involve the same ones, as this is easier.<sup>90</sup> Partly because of a lack of knowledge, staff do not always differentiate between DPOs and CSOs who work on behalf of people with disabilities, and pay limited attention to representation. One respondent commented that when she organises country visits within the context of her human rights work, UN colleagues in countries struggle to reach out to DPOs because they do not have a directory or contacts; when they know where these organisations are located they do not know where to find a sign language translator or accessible transportation.<sup>91</sup>

On a technical level, **there are limited evaluators with disability inclusion experience.** Though the reason for this shortage has not been explored in this study, it could be due to a limited number of professionals with those skills and interests, combined with limited market (i.e. donors) demand for these skills. Existing and long-running programmes have not been designed with inclusion in mind, which makes it difficult to retrospectively gather data on disability. Workshop respondents highlighted that disability needs to be mainstreamed at all levels in the evaluation cycle (from the design all the way to data analysis and sharing of recommendations) but it also needs to consider a more participatory process from regional to national level similar to the Poverty Reduction Strategy Paper process.<sup>92</sup> This would require major changes within evaluation practice: a shift in perspective, awareness of people with disabilities rights and the rights-based model, adequate budgets and processes, and inclusion mandates, where advisable.

More generally, **disability has not been given the same profile or funding as gender by donors.** Gender has been the subject of high profile academic research, with commensurate funding. One respondent felt that this explains why capacity and funding within national systems and the donor community remains low.<sup>93</sup>

Despite all these weaknesses, **donors have had some successes with advocating at a national government<sup>94</sup> level for disability inclusion** and there certainly will be programme

<sup>88</sup> Interview No. 44.

<sup>89</sup> Interviews Nos. 13, 15.

<sup>90</sup> Interviews Nos. 35.

<sup>91</sup> Interviews Nos. 36.

<sup>92</sup> Workshop notes.

<sup>93</sup> Interview No. 33.

<sup>94</sup> DFID in Nigeria and Uganda; OHCHR's efforts; ILO in China.

evaluations in the future. Technical assistance to statistics offices, especially to include WG questions in censuses and surveys, is popular with donors.<sup>95</sup> National efforts to collect data on disability in both developed and developing countries have continuously increased over time, simultaneous with the growth in policies and legislation on the human rights of people with disabilities. While there are many stakeholders on data on disability inclusion in development, UNSD counts itself responsible for the generation of methodological standards as well as compilations of statistics (deposited in the Disability Statistics Database online database). **Public finance evaluation initiatives** have been popular for gender and other groups and are increasingly gaining prominence for the people with disabilities movement. Monitoring of programmes should include budget monitoring, as some of the obligations on states require the allocation of financial and human resources to ensure that positive steps are taken to promote the rights of people with disabilities, and that they are effective.<sup>96</sup> Interviewees felt that many stakeholders including donors are reluctant to identify what is 'best practice' in relation to disability inclusive M&E and there is a lack of clarity about whose responsibility it is to establish best practice for data collection, evaluations and DPO inclusion. Interviewees also highlighted the need for good practice that is shared with all relevant stakeholders.<sup>97</sup>

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<sup>95</sup> An example of a UNSD disability statistics project is 'Strengthening Disability Statistics in the Era of Post-2015 Development Agenda'. There has been no evaluation (yet) as they are just about to start capacity building, after having produced and promoted WG questions by producing a handbook and convening national statistic offices' staff.

In Vietnam, the UN Population Fund (UNFPA) supported the General Statistics Office to collect data on disabilities, and in 2009 the Population and Housing Census included a question on disability for the first time. Full analysis of the data is expected in 2010, with the release of the major findings of the 2009 Census, Sample Results. UNFPA is also supporting capacity building in Sri Lanka and the introduction of new technologies for data collection, capture and processing, leading up to the 2010 census in Sri Lanka, and, in India, has contributed to the development of survey instruments in the forthcoming Annual Health Survey (AHS), which includes questions on disability (Source: UNDG 2011. The United Nations Economic and Social Council adopted a resolution entitled '2020 World Population and Housing Census Programme;' (E/CN.3/2015/6). This resolution stresses that population and housing censuses are designed to generate valuable statistics and indicators for assessing the situations of persons with disabilities. The latest recommendations to collect data on persons with disabilities in censuses are presented in the Principle & Recommendations for Population and Housing Censuses (Rev 2), p. 178.

<sup>96</sup> See Jim Shultz (2002); and 'Fundar, Institute of International Education and International Budget Project, (2004)

<sup>97</sup> Interview No. 43.

## 2 How to move forward?

**Inclusive CLE needs to be understood as a multi-stakeholder process** and capacity building of all stakeholders seems to be the principal starting point. There is a consensus among respondents and workshop participants that **donors, NGOs/CSOs, DPOs and national governments need to increase and improve their awareness, skills and approaches at different organisational levels**. It is also important to understand that different stakeholder groups may need different types of support to increase their capacity.. The bulk of ideas presented in this section emerged from the CSO workshop.

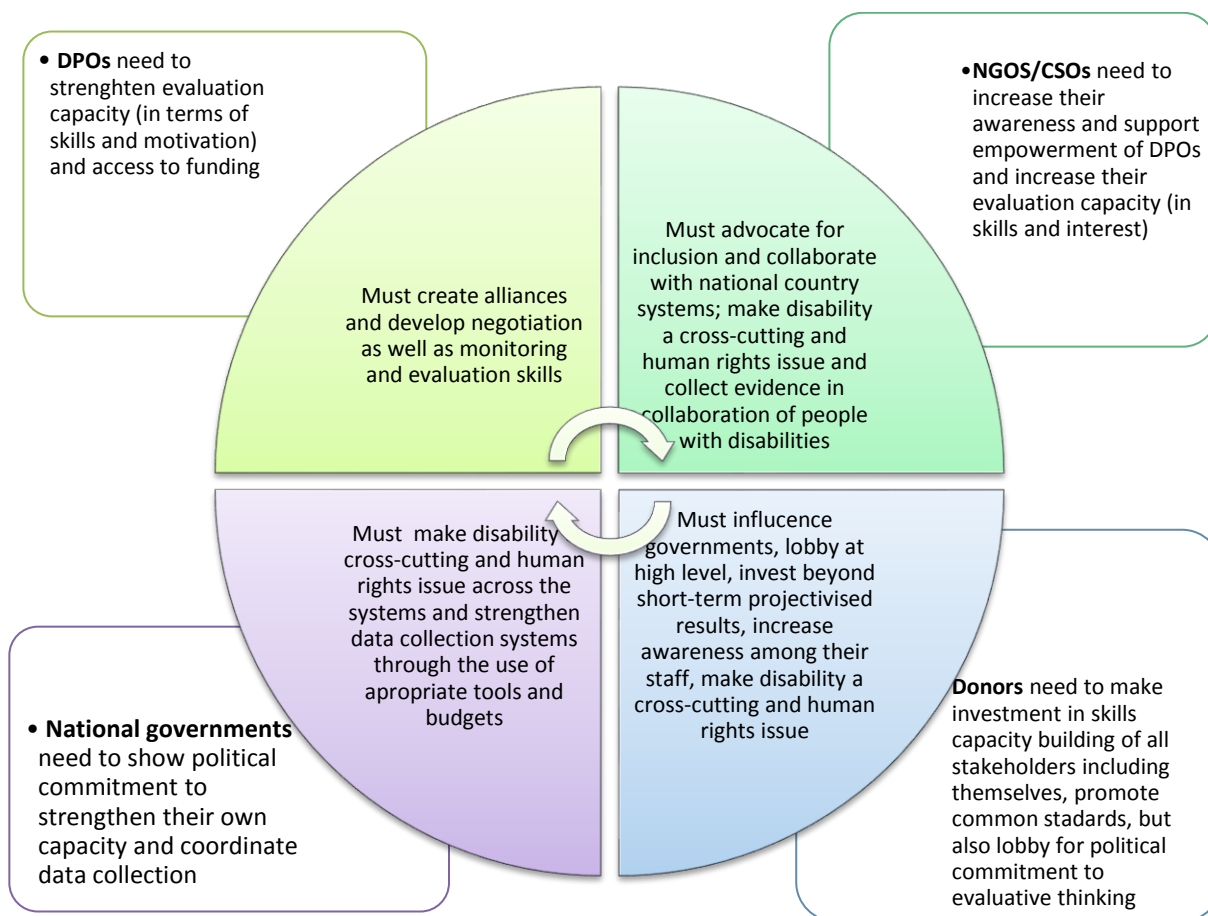
### 2.1 What is needed to build awareness in the wider sense?

The first set of strong messages identified by interviewees, workshop participants and in the literature are:

- a) There is a risk of placing unrealistic expectations and demands on DPOs to reach out and get involved in country-led evaluations;
- b) NGOs, donors, government stakeholders need to build their own capacity and make necessary arrangements to create disability inclusive ways of working on country-led evaluations; and
- c) This will require a shift of mind set towards a rights-based understanding of people with disabilities and a shift of power towards DPOs. It will also require commensurate levels of investment.



**Figure 2 Roles and responsibilities of stakeholders**



Source: Workshop notes

The second set of important messages relates to the **challenges of filling in the gaps in data.**

- a) **More sophisticated tools, in addition to the WG questions, are needed to collect data** which reflect the complexity and the diversity of the realities of people with disabilities.
- b) Understanding participatory methods and monitoring human rights could fill data and evidence gaps. Evaluation tools, including those that capture broader accounts by people living with disability about their lives or realist evaluations of development programmes that explore the impact on people with disability. We believe that this would enrich the work of development practitioners.
- c) More strategic discussions also need to happen around processes to decide what types of data are needed, who will collect the data and at what levels DPOs are involved. Discussions also need to be held about whether it is possible and desirable to develop standardised tools to collect comparative data sets, and what happens to existing or historical data which may be scattered but does exist.
- d) Some respondents have suggested that **UNCRPD monitoring data could also be a starting point, by exploring links between the SDGs, UNCRPD and disability,**

and could also create/strengthen the links between existing data sets and the SDGs data.<sup>98</sup>

## 2.2 What is needed to support disability-inclusive CLE?

The discussions during the CSO workshop generated a ‘three-pillar strategy’ to develop capacity and increase the participation of people with disabilities and DPOs in CLE:

**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 and social inclusion<sup>99</sup>. This includes evaluation and inclusive evaluation policies, and the national evaluation status;
  - 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 CLE 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<sup>100</sup> to see what works, where and why, and sharing lessons widely between countries but also across development partners within countries.
- 
- **Clarify the purpose of, and agree on the definition of, CLE:** While ultimately a CLE will be led by national-level leaders and institutions, the question remains who will be leading the process from a DPO and people with disabilities point of view? How is inclusion defined and how will the voice of people with disabilities be heard when the purpose and objectives of CLE are defined? There may well be a lot of political resistance to supporting the idea of equal participation of people with disabilities or other traditionally excluded and marginalised groups. The systems need to be broader than just disability-inclusive, though people with disabilities face some specific barriers compared to other commonly marginalised groups. It is important to develop a national system where there is co-ownership as there could be a risk of a dual system (DPO/CSO and government-led).
  - **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 respondents. Appropriate participatory tools could be developed in

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<sup>98</sup> Interviews Nos. 11, 33, 34.

<sup>99</sup> Interview No. 8.

<sup>100</sup> See CANADI process in Guatemala.

collaboration with DPOs, disability and methods specialists which better capture the lived experiences of persons with disabilities, as well as being accessible to them.

However, this strategy rests on the assumption that there exists a strong national system in countries that is ready to absorb the participation of DPOs and people with disabilities. As we have seen in the earlier part of this study, this is less than guaranteed and only a handful of countries have politically supported the development of more effective national systems so far. This means that the strategy cannot solely focus on promoting inclusion and strengthening the skills capacity of stakeholders: there also needs to be a concerted effort to develop the political interest in the value of evaluative thinking.

**CLE of SDGs needs support in three areas (see Box 3): capacity building, methodology development and advocacy.**

Capacity building should not be understood only and foremost as skills upgrade. It needs to include a shift from needs to rights, and the political demand and commitment for evaluation generally. This normally comes, depending on countries, from the Ministry of Finance or from the legislature. The Institute for Environment and Development's (IIED's) findings shows that strong national evaluation systems in developing countries typically are driven at the initiative of the finance ministry<sup>101</sup> and pressure for evaluation derives from the need to justify the use of public funds. **In this context, public finance initiatives (budget tracking, expenditure incidence) are highly relevant.** For other groups (children, women) and topics (climate change), public finance analyses are conducted by donors to shed light on a lack of spending and for use as an advocacy tool. There are examples of studies that analyse public expenditure on people with disabilities. However, the literature review has not found examples of studies on public expenditure on people with disabilities being used for advocacy.

**Besides political engagement, CLE needs four ingredients to happen: skilled human resources among all stakeholder groups to generate robust evidence; an inclusive multi-stakeholder process; some appropriate methodologies and tools to collect the data; and strong advocacy to support CLE, evaluative thinking and mainstreaming of disability issues.**

**At national level** the focus needs to be on two areas of skills:

- **Technical skills:** building the strengths and skills of statistics and/or evaluation departments, especially in the area of evaluation. Statisticians are competent in their field but may have limited understanding or engagement with evaluative thinking. Similarly, support is needed to build national systems to coordinate the data collection of different line agencies and standardise methods and tools to ensure comparability and ability to aggregate data. Finally, some familiarisation with the SDG M&E indicators and frameworks may also be required.

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<sup>101</sup> IIED, Eval Partners and EvalSDG (2016)

- **Process skills:** civil servants also need to build their capacity to engage in participatory data collection and evaluation to understand the challenge of multi-stakeholder processes. Though CSOs and DPOs may have more experience and skills in participatory processes, they may also need to strengthen their skills in engaging with government. Setting up a CLE process will take careful consideration around representation and inclusion, especially in the context of disability: this will require skills that go far beyond collecting and analysing data.<sup>102</sup>

CSOs and DPOs will equally need support to develop their M&E and evaluative thinking capacity; there is a need to focus on technical skills in order to be able to design robust data collection and robust evaluations. For all stakeholders, **it is necessary to build the capacity to commission and design evaluations in a systemic rather than *ad hoc* way;** this will require planning and thinking among the stakeholders to conceptualise the CLE as a system, as opposed to a series of evaluations.

### Box 3: Recommendations to donors for inclusion

- **When financing funds, encourage the fund managers to keep (fund) application procedures as simple as possible**
- **Partner with DPOs in programme design**
- **When financing funds, encourage the fund managers to simplify reporting requirements**
- **Adapt communication methods to increase dissemination of information as appropriate, in light of impairment experienced by people with disabilities**
- **Use skilled persons with disabilities to help assess and support DPO grantees**
- **Consider multi-year grants**
- **Start small**
- **Make DPO capacity building an objective in itself**
- **Provide opportunities for training and networking**
- **Support the development of leaders.<sup>103</sup>**

**Source: Wapling and Downie (2012) 'Beyond Charity: A Donor's Guide to Inclusion**

There is also a **need to support the development and strengthening of national evaluation associations<sup>104</sup> as the pool of qualified and experienced evaluators in countries, but also internationally (especially with disability-related experience and skills), is relatively small.<sup>105</sup>** Though this may not have been mentioned specifically in the context of disability, one of the workshop recommendations was also to internationalise the UK-based evaluation expertise. At the moment this is very UK-centric but it has a lot to offer

<sup>102</sup> Brower and Woodhill (2015)

<sup>103</sup> Wapling and Downie (2012)

<sup>104</sup> A review of the most prominent evaluation associations and platforms shows (bettereval.org, evalpartners.org, IIED, etc.) that disability – unlike gender – is not a topic that has gained much prominence in the community of professional evaluators. Dr Marco Segone at UNICEF has published on equity-focused evaluations extensively (and underscored in that regard that evaluation associations are vital in any evaluation system) but has not explored disability specifically.

<sup>105</sup> Interview No. 13.

internationally and could be strengthened by engaging more with the international development context.

**At the methodological level** there is a need to develop and refine existing tools to capture the reality of people with disabilities in terms of collecting the right data. It is important not just to count people but to elicit their stories to understand reality. There is a pallet of qualitative tools available but not all of them would be appropriate to use with people with disabilities, so some adaptation and innovation is needed. Some thinking is also needed to develop mixed methods designs that combine different tools and approaches. Stronger collaboration and alignment with human rights reporting is highly recommended.<sup>106</sup>

Finally, there is **a need for advocacy for inclusive CLEs themselves**, as appetites for, and awareness of, these are low. This means DFID needs to approach political circles and, depending on the country context, find different entry points: DFID could work directly with government agencies to influence practice at the level of policy development directly; or it could support national stakeholders to advocate to parliaments and politicians. Disability needs to become a cross-cutting issue across ministries, while at the same time an understanding of the value added of evaluative thinking needs to emerge and grow if genuine CLEs are to happen. Though it is a formal commitment of the SDGs for countries to conduct CLE evaluations, it should not be a given that there is appetite, skills or political interest to conduct evaluations, let alone make these processes inclusive and participatory.

### **Preconditions for success**

Naturally, supporting the process of CLE will require resources and funding, but it is not only the total amount of funding that will make the difference: the type of funding and the right mechanism for funding is also important.

It was not within the scope of this study to explore specifically what to fund and how to plan funding for disability inclusive CLE, but respondents have raised the following suggestions:

- 1) it is important to find a funding mechanism which will allow small CSOs or DPOs to access the funding, to avoid dominance of larger organisations;
- 2) it is recommended to embed in the mechanism allowances for barriers people with disabilities may face (such as needing more turnaround time, funding appropriate support for participation, such as IT or communication tools).

As far as possible, working directly with DPOs will increase their capacity, but also increase DFID's awareness of DPOs constraints and contexts. 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 bear the responsibility or financial burden of participation exclusively.

Ultimately, **all donor policies and programmes should reflect the principles of the UNCRPD**: inherent dignity, non-discrimination, effective inclusion, respect for differences, equal opportunity, accessibility, gender equality and respect for the evolving capacities of children with disabilities. Participatory research and pluralist/transformational approaches to

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<sup>106</sup> Interviews No. 13, 33.

evaluation are required to assess development impact on people with disabilities. ‘Nothing about us without us’ is as valid as ever. **The meaningful participation of people with disabilities and their representative organisations must be ensured in the formulation and implementation of development policy at all levels. DPOs and NGOs have given valuable guidance on how to do that.**

### 3 Conclusion

The study reviewed existing practices of donors, CSOs and DPOs in relation to the inclusion of people with disabilities in evaluation processes, and especially CLEs of the SDGs. One major issue encountered was that there is still limited experience related to CLEs and the SDGs and thus it is premature to talk about good practice or to draw lessons from innovative experiences with a view to developing specific programmes. However, what became clear during the interviews is that there was a need to first of all take stock of the dimensions of exclusion people with disabilities and DPOs face in regard to being included within existing evaluation processes. A UNPRPD study in 2013 on the main challenges to disability-inclusive development, as identified by people with disabilities during online consultations and interviews, highlighted a broad **consensus on six issues**:

- (1) negative attitudes towards and perceptions of people with disabilities<sup>107</sup> and a need for a human rights-based approach;**
- (2) a lack of disaggregated data;**
- (3) an absence of universal guidelines on disability-inclusive development;**
- (4) an absence of the voice of people with disabilities in decision-making (policy design as well as M&E);**
- (5) a lack of recognition of disability as a cross-cutting issue (instead of, for example, institutionalising it at a social ministry); and**
- (6) a need for political leadership.<sup>108</sup>**

These findings largely corroborate the findings from this study.

As stated in the methodology section that the focus of the study evolved and moved away from being centred on CLE to inclusion issues. Though we do not have a robust country case study of national systems, one clear finding is that in most countries the national evaluation systems are weak. This means that there are many challenges to building strong national evaluation systems as well as many challenges to building systems inclusive of people with disabilities and of most traditionally excluded groups.

Three relevant lessons for this study can be drawn from the information gathered in Nepal:

- While a country can display a policy commitment to disability inclusive evaluation at a higher level this does not always translate into implementation. Thus, even if the institutional framework is conducive to evaluation, work is still needed to develop evaluation practice.
- While there may be some recognition within government ministries and CSOs of the importance of systematising data collections and data systems, this does not equate to a political commitment or interest to use this data for evaluative purposes.
- The priority for DPOs and development actors is to advocate for inclusion and the respect of rights. Evaluation to understand and empower people with disabilities is not recognised as a priority

Most workshop respondents and interviewees believed that CLEs of the SDGs were considered by most government agencies and Civil Society Organisations as a low priority.

<sup>107</sup> Participants described negative attitudes towards people with disabilities, including stereotyping, assumptions and societal perceptions, as a key challenge to inclusive development.

<sup>108</sup> UNPRPD (2013)

In addition, respondents and interviewees also believed that there is low capacity and political commitment to evaluation in most countries. This means that the efforts towards inclusive CLE cannot be limited to building the technical and resource capacity of stakeholders. Instead, it needs to include wider political commitment and engagement with major decision-makers.

It is important to bear in mind that **critical constraints on evaluation systems** (both effectiveness and inclusivity) **are likely institutional and deeply rooted in the political and social context**. This makes it **difficult to solve them straightforwardly** by more organisational capacity development. What this paper has highlighted effectively are multiple forms of exclusion that will be difficult to address systematically

Political leadership by governments is important but should be accompanied by mechanisms to facilitate multi-stakeholder engagement and strong channels of accountability.<sup>109</sup> Within this context it is very important to engage and work with disability focused **CSOs and DPOs**.

And, finally, we can also draw some lessons from the research process, which may be useful to consider for future work.

The most obvious lesson is that we should have included an expert on disability in the team from the outset because this would have increased our awareness but also would probably have shaped our questions.<sup>110</sup> Our awareness of our lack of awareness, however, was slow to develop and it is only when prompted by DFID that we considered it and only when we worked with our Disability Inclusion Consultant colleague that we realised how much we needed to increase our skill set. This is because – and this is the second important lesson learned – we did not understand that disability is a specific form of exclusion. At one level, we understood that disability (like gender) cuts across other social differences, such as gender, age, ethnicity etc. But at another level we are unable to see how disability adds not just another layer of difference but a different type of layer which we still do not fully comprehend. This could be because (unlike gender) in our lives we may not have encountered many people with disability and thus we lack a basic level of familiarity with the issue. This means that increasing our capacity in the area of disability is not just about raising awareness of difference, but about fully understanding the implications of these differences. This work has, however, increased our awareness of the systematic exclusion in a world that is ‘built’ for the able-bodied. Given the multitude of barriers, even the most thoughtful development planner is likely to be blind to some barriers, thus making the inclusion of people with disabilities in the planning process necessary. It is also useful to be reminded of the limitation of traditional data collection methods as counting people with disability does not necessarily increase our understanding of the level of deprivation they may experience and refined tools and approaches are necessary.

From a methodological view point it is difficult to hypothesise how we might have approached this study differently. We may not have tried to be involved in the first place if the disability dimension had been included in the terms of reference from the outset, since we would have considered ourselves less competitive given our limited experience in this area. With hindsight, however, we could have adopted a more participatory approach by

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<sup>109</sup> UNPRPD (2013)

<sup>110</sup> As we have explained in the introduction, the focus on disability became clearer only after the study started; thus, when we put the team together disability expertise was not one of the requisites.



conducting more direct consultation with DPOs based in the UK. We talked to people who talked about DPOs but only talked to a handful of DPO representatives themselves. Additionally, we approached respondents with pre-established questions: these would have been enriched or different if we had conducted a scoping study with people with disabilities as part of the inception phase. Had we done this, our awareness of our lack of awareness would have been obvious from the outset.

## **Annex: Methodology**

### **Literature Review**

The first step in the literature review will be to follow the protocol below for identifying the literature and organize publications (relevance, content, type). Next we analyse the lessons from this literature, using a systematic literature review protocol (quality assessment). Finally, there will be a synthesis of the literature.

Instead of a Rapid Evidence Assessment (REA) followed by an in-depth literature review, we propose to undertake a literature review that will follow a clear protocol and synthesis approach. The literature review will provide policy relevant syntheses of evidence on effective and ineffective approaches to build national disability inclusive M&E capacity and assist country-led evaluations of PWD participation. Research will follow a structured approach and include a quality assessment of the evidence mapped. The purpose is to gain a synopsis of the density and quality of evidence, support policy decisions by providing evidence on key topics as well as identify evidence gaps.

However, the approach will not involve a full systematic literature review. The literature will not be systematic in the sense that the database search could be replicated and yield the same exact selection of publications. First, because the database search is not the only source of publications, we also review publications recommended by Key Informants, CSO participants, colleagues, and publications mentioned in DFID's original TOR. Second, searching databases on the search term listed in the next chapter does not yield straightforward results. Terms like "country-led evaluation" show up in a few publications, but it might be referred to by another name in other publications. However, just because the document selection and review is not fully replicable does not mean efforts will be eschewed. We are confident that this process will render a comprehensive overview of the evidence.

We are confident that the literature review will be done within the stated timeline as it builds on a pre-existing, focused set of questions which asks for evidence on a particular subject within an existing field of research and because of a study designs that features established methods of appraisal.

### **Desk-based review/ literature selection**

In line with the requirement of the review to be systematic we have established a protocol for identifying literature. We will conduct a desk-based literature review encompassing peer-reviewed publications as well as grey literature. Publications originated since 2000 will be included. While the search terms are in English and this will be the language of research,

publications in Spanish and French can also be included. Moreover, as far as relevant secondary sources in other languages are identified in the course of the country case study exercise, they will be included.

Databases EconLit and (via EBSCO) and JSTOR<sup>111</sup> will be browsed for the following search terms in Boolean format:

- "country-led evaluation" AND "sustainable development goals" AND "disability"
- "national monitoring" AND country led evaluation AND "disability"
- "Civil society" AND "National evaluation systems" AND "disability"
- "civil society" AND "sustainable development goals" OR "millennium development goals" AND "disability"
- civil society AND evaluation AND development AND "disability"
- Citizen engagement AND Evaluation AND development AND "disability"
- Sustainable Development Goals OR Millennium Development Goals AND evaluation AND civil society AND "disability"
- SDG AND evaluation AND excluded groups OR marginalized OR excluded population AND "disability"
- Evaluation collaboration AND "disability"
- Donor partner evaluation AND "sustainable development goals" OR "millennium development goals"
- Bilateral collaboration AND evaluation AND "disability"
- "demand driven" AND evaluation
- demand oriented OR demand-driven evaluation AND SDG AND "disability"

We will include new search terms relevant to the research questions as need be. Aforementioned databases give access to journals of economics, statistics, public health, development studies and public policy in general. In addition, we will make use of the sources proposed in the terms of reference (See Annex). However, given the change in topic, we have identified sources beyond the terms of reference that will be relevant. Mostly they are additional donor sources, publications of academic institutes, think tanks, and above all Disabled People's organisations that are relevant to the subject.

Any relevant publications unearthed in the course of the country case studies will be included for analysis. Finally, important literature recommendations from key informants or workshop participants will be included in the final analysis.

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<sup>111</sup> Selected journals for Development Studies, Economics, Health Policy, International Relations, Management & Organizational Behavior, Political Science, Public Health, Public Policy & Administration, Sociology, Statistics.

As emphasized in the TOR, we will also seek to identify areas of convergence and divergence between middle-income states and lower income countries.

### Classification and Quality Assessment

Publications identified as relevant through the database and other publications search will be assessed, using principles of quality, validity, and cogency.

The principles applied to complete the assessments are set out in the following tables in this chapter. The type of research study (primary and secondary) and the research design (experimental, observational, etc.) will be assessed using the criteria set out in Table 3. Note that given the context, we do not expect there to be experimental studies relevant to this research.

#### Research types and Design<sup>112</sup>

Research Type	Research Design
Primary (P)	Experimental (EXP) + state method used
	Quasi-Experimental (QEX) + state method
	Observational (OBS) + state method used
Secondary (S)	Systematic Review (SR)
	Other Review (OR)
Theoretical or Conceptual (TC)	N/A

The quality of evidence for each publication will be tested through the application as a set of classification criteria as given in DFID’s Assessing the Strength of Research Evidence: Summary Guide<sup>113</sup>. This enables us to assess the quality of each publication according to the quality principles in Table 4.

#### Quality Principles

Principles of quality	Associated questions
Conceptual framing	Does the study acknowledge existing research?
	Does the study construct a conceptual framework?
	Does the study pose a research question or outline a hypothesis?
Transparency	Does the study present or link to the raw data it analyses?
	What is the geography/context in which the study was conducted?
Appropriateness	Does the study declare sources of support/funding?
	Does the study identify a research design?
	Does the study identify a research method?
	Does the study demonstrate why the chosen design and method are

<sup>112</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/291982/HTN-strength-evidence-march2014.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/291982/HTN-strength-evidence-march2014.pdf)

<sup>113</sup> Ibid.

Cultural sensitivity	Does the study explicitly consider any context-specific cultural factors that may bias the analysis/findings?
Validity	To what extent does the study demonstrate measurement validity?
	To what extent is the study internally valid?
	To what extent is the study externally valid?
	To what extent is the study ecologically valid?
Reliability	To what extent are the measures used in the study stable?
	To what extent are the measures used in the study internally reliable?
	To what extent are the findings likely to be sensitive/changeable depending on the analytical technique used?
Cogency	Does the author 'signpost' the reader throughout?
	To what extent does the author consider the study's limitations and/or alternative interpretations of the analysis?
	Are the conclusions clearly based on the study's results?

All of the publications referred to in the literature review will be scored according to these criteria (High, Moderate, Low).

### Publication Scores

Score	Abbreviation	Definition
High	↑	Comprehensively addresses multiple principles of quality.
Moderate	→	Some deficiencies in attention to principles of quality.
Low	↓	Major definiteness in attention to principles of quality.

### Key Informant Interviews (KIIs)

The KIIs will seek to obtain additional evidence (beyond what is in the literature) particularly for RQs 2 and 3, with a focus on ongoing and planned initiatives (particularly from CSOs). These will (a) provide us with information about CSO and other initiatives that we may not capture in the literature; and (b) provide additional perspectives from countries and agencies beyond what is in the literature. For the interviews we will prepare a semi-structured questionnaire based on information emerging from the literature review. We are also considering an online survey approach given the number of key informants that have been identified.

An initial list of potential key informants was identified by DFID and was consolidated by the team through personal networks, publication and lists on past international workshops. At the moment the list is skewed towards government representative but this will be rectified as we continue to develop the list. Since the response rate from government staff is always uncertain, we felt it safer to have a longer rather than a shorter list. Please find in the Annex a preliminary list of contacts and their affiliation.

It is expected that the results of the rapid assessment and the documentary review will generate pointers to develop key informant semi structured questionnaires. Areas likely to be explored through interviews will be:

- National level appetite for country-lead evaluations of SDGs and understanding of specific approaches which may be contextually suitable;
- Reflection and comments as relevant, on helpful and less helpful support provided by donors in certain sectors or countries in relation to the inclusion of disadvantaged groups in particular PWDs;
- Capacity bottlenecks at national level for SDGs data quality and management;
- Invisibility (and cause of) of some excluded groups within the national systems (being in data or in evaluation processes) with a specific focus on PWDs;
- Practical and political challenges of developing inclusive systems;
- Experiences of and challenges to develop national systems in a collaborative and inclusive way considering the contribution of CSOs;

Based on the evidence review findings and the initial results from the Nigeria and Nepal country case studies, we should be able to refine the questionnaires which will also be adapted to different categories of stakeholders.

### **Civil society dialogue workshop**

Through the KII we will endeavour to understand from CSO representatives what will be the most effective way to develop a dialogue and structure the first consultation workshop. In other words, we will let CSO representatives use the workshop as a space for them to design their own agenda (rather than us pre-empting the agenda) and we will also try as far as possible to include southern NGO's concerns in the workshop as well.

A one-day CSOs-focused workshop in the UK to gather views of UK based NGOs especially those involved in these issues with partners in the Global South. This workshop will be used to elicit information whilst at the same time facilitate an initial dialogue amongst UK based CSOs and between CSO and DFID. We acknowledge that this runs the risk of eliciting a UK centric view on issues related to country ownership, as opposed to gather South-centric views about concrete ways forward. Though the final focus of the workshop would be refined based on evidence findings and initial primary data collection, it is anticipated that this workshop would essentially be focused on challenges faced by CSOs in country to 'get a seat at the table' either during the design of national systems or during the evaluation processes. The objective would also be to help identify concrete recommendations for country centric donor support.

## Interview Questions

Author(s):	...
Question	Answer
1. Can you tell me a bit about your work generally and in relation to the SDGs and or disability in particular?	
2. What has been your experience with national level monitoring and evaluation systems? (in general not specifically linked to MDG or SDG)?	
a) What has been your experience with national level monitoring and evaluation systems? (in relation to SDGs)?	
3. What would you say are the lessons you could share with others about your experiences of increasing capacity with national level evaluation systems?	
a) And then what about disability? Any specific issue/experiment/interest?	
4. What are the bottlenecks/barriers for PWD to get involved; what is needed to develop a more inclusive country led system for PWD?  What barriers are faced by people leading/managing evaluation systems & processes in including and consulting PWDs?	
5. What are the main messages you would like to send to DFID; what are the main lessons from your experiences (good and bad), what should DFID keep in mind, watch out for, any suggestion about the methods – i.e. how to go about it?'	

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