Disability Inclusion Measures

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1. Introduction: Defining Terms

Following the Convention on the Rights of Persons with Disabilities, the goal of disability and development interventions is clear: to build a world in which disabled people enjoy a good quality of life, and are included on an equal basis with others (WHO 2011). This usually means a twin-track strategy, where disabled people are included in mainstream services and activities, together with targeted interventions to meet any particular needs, such as rehabilitation (DFID 2000). The outcomes of this twin-track - mainstreaming plus targeting - strategy is that disabled people are part of ordinary society, able to flourish on the same basis as anyone else, despite any particular health issues they might have.

To measure progress towards this goal, it would be desirable to have a simple set of 'Disability Inclusion Measures', so that different strategies could be compared and evaluated, in terms of cost-effectiveness and impact. This would also enable Value for Money comparisons to be made between different projects and proposals (Loryman and Meeks 2016). Disability Inclusion Measures would therefore be very helpful for a development agency such as DFID.

In general, DFID's Results Framework operates on four levels (example given for Box 1):

- Level one: indicators representing development outcomes to which DFID is contributing, alongside other partners;
- Level two: indicators directly attributable to DFID interventions;
- Level three: indicators relating to DFID operational effectiveness;
- Level four: indicators relating to DFID internal corporate processes.

Disability inclusion measures seem to relate most closely to level one and level two indicators, although there would also be a need for measures of DFID's own corporate processes in terms of accessibility, employment etc. For example, how far are DFID's investments in other areas, not just disability-focused ones, truly inclusive of persons with disabilities? The DFID Strategy for Disability Inclusive Development 2018-2023 requires all parts of the agency to make efforts to mainstream disability. DFID operates to a delivery plan, and reviews progress against the strategy on a quarterly basis, based on the proposed OECD-DAC disability inclusion and empowerment marker.

Box 1. Evaluating environmental funding

A question such as ‘Sustainability’ is obviously important to DFID projects, in a world where environmental degradation and climate change is an issue for many communities. Hence DFID environmental funding is evaluated via impact measures, guided by a theoretical framework. For example, DFID commissioned a review of evidence on indicators for investments in agro-eco systems, which found conceptual weaknesses in monitoring of initiatives relating to agriculture, poor definition of target, sampling, measurement, study design, uncertainties, trade-offs, data sharing, cost-effectiveness of monitoring etc. These may be familiar, as may be the over-riding conclusion: “surprising lack of evidence for the impact of monitoring initiatives on decision-making and management.” (Shepherd et al, n.d., 8)

While the overall goal of Disability-Inclusive Development is clear and desirable, reflecting Article 32 of the Convention on the Rights of Persons with Disabilities, any discussion of Disability Inclusion Measures suffers from the difficulty that there is often a lack of clarity as to what is meant by ‘Disability’, ‘Inclusion’ and ‘Measures’. It would therefore be helpful to unpack these three terms.

i) Disability is a multi-dimensional and scalar concept (Shakespeare 2006).

There is controversy as to how it should be defined. The 2006 Convention on the Rights of Persons with Disabilities (CRPD) declined to define disability, stating instead that:

“Persons with disabilities include 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.”

Thanks to the International Classification of Functioning, Disability and Health (ICF) (WHO 2001), influenced by the social model approaches developed by the disabled people’s movement, the focus of the disability conceptualisation is on functioning, whether at the individual level or at the level of participation in society, rather than simple medical diagnosis. In the ICF, “Disability” refers to the whole process of disablement, as well as to any element of it (Body functioning and structure; activity limitations; participation restrictions). This has the merits of neutrality, but also avoids commitment to a particular definition. As Madans et al say, "as disability is not a singular static state, there is no simple, singular way to collective disability data" (Madans et al 2017, 1165).

Any prevalence measure is highly reliant on the method used to achieve it (WHO 2011). The Washington Group on disability statistics, basing their work on the ICF suggest:

"Disability represents a complex process and is not a single, static state. It refers to the outcome of the interaction of a person and his/her environment (physical, social, cultural or legislative) and represents a measure of the negative impact of environmental factors on one's ability to participate." (Madans et al 2011)

The first part of this phrasing captures how, as in both CRPD and ICF, disability is the interaction between the person and his/her environment. However, the final phrase does not seem quite correct. We know that environmental factors can enable as well as disable. But more importantly, according to the ICF, the interaction referred to results from personal factors, environmental factors, and the health condition itself. So in some circumstances it might be the health condition, rather than the other elements which is causing the limitation, regardless of any environment (e.g. the experience of chronic pain).

This is captured in people's subjective beliefs about disability. For example, when the British Social Attitudes Survey 2009 (Staniland 2009) explored public opinions about what disability meant, the greatest proportion (46%) thought that attitudes and barriers in society as well as health problems comprised disability. Disabled people, however, were more likely than non-disabled people to explain their exclusion in terms of health problems (46%) than in terms of attitudes and barriers alone (15%).

Box 2: The Washington Group Short Set

The stated ambition of the Washington Group was

"…to develop questions that would address the issue of whether persons with disability participate to the same extent as persons without disabilities in activities such as education, employment or family/civic life." (Madans et al 2011).

The ICF distinguishes between capacity and performance. The former is the 'ideal' functioning within optimal conditions; performance represents how people function in their everyday conditions. Because performance and participation vary between and within countries, due to different environmental contexts, the Washington Group chose to explore capacity (Madans et al 2017, 1166). Defining disability on the basis of functioning allows participation to be measured and compared between people with and without disabilities in different countries. But in everyday practice, the Extended Set is too long a module to include in censuses or use for disaggregation.

Disaggregation required a comparatively quick and simple method for disaggregating "persons with disabilities" from "persons without disabilities", always remembering that disability is a scalar concept, and the group "persons with disabilities" is an artefact of the procedure used to measure it. The Washington Group short set of six questions asks about "difficulties…doing certain activities, because of a health problem", and then goes on to specify seeing, hearing, walking or climbing steps, remembering or concentrating, self-care and communicating or being understood by others. Four answers are possible to each question (no, some, a lot of difficulty, or cannot do). Disability can then be disaggregated by separating those who have little or no difficulties, from those who have significant or complete difficulties in at least one area. The Washington Group say that by thus defining a group of "persons with disabilities", this short question set can then be used to monitor the Convention, by monitoring participation of the "persons with disabilities" sub-population in domains of life (Madans et al 2011): this is the group at risk of exclusion.

For valid disaggregation, the short set has to identify the majority of people who have significant difficulties in functioning. The short set questions have known deficiencies – for example, because they have no domain of psychological functioning, they do not identify people with mental health conditions or intellectual disabilities very well. As Madans et al (2017, 1174) show, there are choices as to how disability is defined, producing prevalence from 2.1% (one domain of 'unable to do it') to 40.6% (one domain of at least some difficulty).

The short set has been adopted by many agencies and organisations, including the International Disability Alliance, even though the questions take what would traditionally have been considered "medical model" approach. The difficulty being that even though people would prefer to define disability as an interaction, it is such a slippery and contextual approach that it is easier and quicker to revert to a rather orthodox sense of disability as "things people cannot do". Madans et al (2017, 1173) talk of the short set identifying "a population that is 'at risk' of a participation restriction due to limitation in these core domains", although this depends on assistive devices, environmental barriers and other resources.

There are other, more complex, ways of measuring disability available – such as the WHO Model Disability Survey, or the Washington Group Extended Set. But the Washington Group Short Set has the great merit of being simple and easy, taking less than two minutes to complete, so it is now widely accepted (Groce and Mont 2017)

i) ii) Turning to what inclusion might mean, terms such as "inclusion" and "participation" are widely used, but rarely with conceptual precision.
They are often deployed as synonyms for each other, and indeed, both have a sense of "being part of" or "joining in". The aim of a disability-inclusive development project could be inclusion in specific programmes (education, health or more specific to a particular project). For example, the term "inclusion" is probably most familiar from the world of educational inclusion – indicating whether or not a child with disabilities attends school. "Inclusion" is the opposite of "segregation", it means being included, or not being left behind. For example, it is also common to talk about "Gender inclusion":

> "A way forward is to scrutinize programs and policies through a gender lens, to challenge gender discrimination and to implement and promote gender equal

> measures through gender mainstreaming.” (UNESCO http://www.unesco.org/new/en/social-and-human-sciences/themes/urban-development/migrants-inclusion-in-cities/good-practices/gender-inclusion/).

To be genuinely inclusive, we need to think about inclusion across the programme cycle – inclusion in planning for the service, delivering for the service, monitoring the services, assessing impact of the service.

However, “inclusion” could also refer to inclusion in the general population. Often, the term here is “social inclusion”, as in efforts to reduce the problem of “social exclusion”. The World Bank state:

> "Social inclusion is the process of improving the terms on which individuals and groups take part in society' and 'improving the ability, opportunity, and dignity of those disadvantaged on the basis of their identity to take part in society".

One might argue that it is better to talk of “participation”. It is important to note that people may be excluded from wider society because of multiple reasons, such as gender, poverty, age, being indigenous, migration etc, not just a health condition. The World Bank reference to “identity” suggests this might be a matter of discrimination. But it might be about failure to provide childcare, accessibility, which is more akin to indirect discrimination than direct discrimination.

The ICF defines participation as both “involvement in a life situation” and “the lived experience of disability” and this imprecision has been criticised (Eyssen et al 2011). The ICF differentiates “activity limitations” and “participation restrictions” (comparable to the International Classification of Impairment, Disability and Handicap) distinction between “disability” and “handicap”), but the ICF then blurs the distinction between “activity” and “participation”, so it is hard to retain a sense of “participation” as referring to areas of life. In particular, Whiteneck and Djikers (2009), Eyssen et al. (2011) and Pisker et al. (2014) all critique the lack of a comprehensive definition of participation, the poor differentiation from the ICF concepts of activity limitations and environmental factors, and the difficulty in measuring consistently.

In this paper, we take “Inclusion” to refer to inclusion in particular programmes or projects, in other words, programmatic inclusion. We take “Participation” to refer to participation in society, being part of everyday life, which is sometimes called “social inclusion”. Both “Inclusion” and “Participation” can be achieved by removing barriers, on the one hand, and addressing individual needs, on the other. Individual needs might be medical, or educational, or simply the need for empowerment.

While it would be possible to show progress using these approaches, it would not be easy to state what constituted success. Potentially, if all CRPD Articles had been implemented, all Sustainable Development Goals achieved, then full participation in society could be said to have been reached. The Washington Group suggest:

> “From a theoretical perspective, if opportunities have been optimized then participation should be equal between persons with and without disability.” (Madans et al 2011).

This is the social model goal: once all disabling barriers have been removed, then disability disappears (Thomas 1999). Others would argue that what Thomas calls “impairment effects” are likely to remain, and that some impairments are limiting in themselves, and always will be regardless of context (Shakespeare 2006). The Washington Group hope of equal participation (Madans et al 2017) may be naïve. Even where all opportunities are equal, reasonable accommodations have been made, and no barriers remain, then participation may not be equal. For example, equal opportunities in employment may not result in equal participation in employment. Impairment has an impact, because fatigue or pain or inability may prevent people participating as much as others or as much as they would like. Also, personal preference has an impact. Not all people want to participate in the same way.

This is where Amartya Sen's Capabilities Theory (Sen 1999) becomes particularly relevant. First, because the approach is based on individual's freedom to decide for themselves. It is not what they can do that is most important ("Functionings"), it is what they are free to do, namely, their Capabilities. The goal is to maximise their Capabilities. Second, Capabilities Theory is attractive because Sen highlights "Conversion handicap", namely the additional difficulties someone might have in participating because of the difficulties associated with having an impairment or being a woman or other differences in a particular society (Sen 2004). Different people derive different benefits from the same amount of cash. The same amount of resources does not achieve as much if you face barriers or difficulties because of your impairment. This has implications, for example, for assessing the impact of social protection strategies, as the same cash transfer may have less impact for a person with disabilities than one without, as a result of the extra costs of being disabled (e.g. cost of assistive devices, accessible transport).

In any case, it is not at all clear to what extent equal participation is the appropriate goal. For example, in healthcare, one would expect *more* participation, because all persons with disabilities have health conditions, and some of those health conditions require targeted treatment or rehabilitation. In employment, one would expect *less* participation. UK evidence suggests one third of disabled people in work, and two thirds of disabled people out of work are limited in the type or amount of work they can do. Therefore, even with equal opportunities, and efforts to reduce the disability gap in employment, it is likely that some groups – particularly people with intellectual disabilities and mental health conditions – will be less likely to be in formal employment. For example, someone with dementia may be unlikely to be in the labour market.

If we are thinking about participation in communities, then the complexity of disability becomes most evident, and the intersection with multi-dimensional poverty becomes clear. A community or neighbourhood could be formally "barrier-free" or "age-friendly" – in that buildings and transport are accessible – but far from inclusive. A person with disability, particularly intellectual disability or mental health condition, could experience exclusion. Negative attitudes and lack of opportunities could mean that they are isolated in their own dwelling, and may fear participation in transport or in leisure activities (Bates and Davis

2004). Many people with intellectual disabilities or mental health conditions lack friends or networks. The evidence on friendship with non-disabled people is very stark in these situations (Shakespeare 2014). Some people, for example some people with autism, may not access friends or networks in the same way, or may need to avoid sensory overload (Robeyns 2016, Rodogno et al 2016). Participation means different things to different people. Here again, a Capabilities approach is helpful, because it respects diversity and attends to the subjective dimension of flourishing.

This is why questions such as stigma, prejudice and discriminatory attitudes become so important. Social capital theory is relevant, talking about challenging stereotypes and promoting positive relationships (Bates and Davis 2004). Depending on availability of resources, it may be easier to provide kerb cuts and low floor buses than it is to change attitudes of schoolchildren or promote opportunities for people with intellectual disabilities. Evidence on stigma – felt and enacted – becomes relevant. Felt stigma is when individuals feel negative about themselves, usually as a result of the cultural messages or negative treatment they have experienced or expect to experience in public. Enacted stigma are the actual examples of cultural messages and negative treatment. The Van Brakel et al (2012) Indonesian survey of people affected by leprosy found that 35.5% anticipated stigma. In this study, stigma was associated with participation restrictions. Stigma may lead people to isolate themselves, reinforcing stereotypes that, for example, leprosy is a shameful secret, and leading to psychological and relationship problems and interrupting treatment and recovery. This survey found that stigma particularly led to problems in employment and in finding a romantic partner, with a higher percentage being single than in the community at large.

One problem however is that existing stigma scales are often too generic – they do not distinguish the different aspects of stigma (e.g. shame, guilt, negative attitudes), nor the experience of people with different types of impairments, let alone settings, roles etc. Goffman (1966) famously highlighted how some people have obvious differences, and have to manage the stigma that arises in interaction. Other people have hidden differences, and have to manage potentially stigmatising information. This highlights how discriminatory attitudes can sometimes be avoided, but also how people with invisible differences – epilepsy, HIV, dyslexia – may anticipate negative treatment if their difference is disclosed.

Studies have explored how social inclusion can be improved for people with disabilities. The Campbell Collaboration rapid evidence assessment for DFID by Howard White et al (2018) found 16 eligible primary studies of interventions to promote social inclusion and only one that addressed empowerment across 12 low and middle income countries. This suggests there is very little rigorous evidence, especially given that most studies were of poor quality, with only three attaining moderate quality. Outcome measures were not comparable, and mostly focused on improved social skills not social inclusion. One of the recommendations of the review was to adopt consistent definitions and measurement of disability, as well as consistent definitions and measures of social inclusion and empowerment.

There is an important difference between those approaches that seek to skill-up or support individuals (e.g. friendship training, advocacy services) and those approaches that seek to alter society. Most interventions in the White review tried to improve human capital, by focussing on implementing individual-level changes of people with disabilities, rather than on transforming society. By putting the emphasis on individuals to solve their own problems, rather than the obligation of society to become more inclusive, interventions could be criticised from a disability rights perspective. However, it is easier to measure change in individuals than it is to assess change in societal processes, and it may be quicker to achieve. Importantly, at a fundamental level, poverty is an underlying driver of isolation and low quality of life among people with disabilities, as it is among people without disabilities. It would be possible to provide access and challenge attitudes and leave poverty levels untouched, so that important barriers to social inclusion remained. However, conversely, if people have confidence and if they have networks, they may be more likely to find livelihood opportunities and thus enjoy more economic security.

Wolff and De-Shalit (2013) point to two important features of disadvantage. First, it is important to attend to the sustainability of wellbeing. If people do have a salary, but it will evaporate as soon as the donor funding ends, then their participation is precarious. Often, disabled people find that their situation is precarious: all it takes is a recurrence of their illness or impairment, or the failure of an electronic ramp or an elevator, or the absence of a sign language interpreter, or the end of a development project, and they are instantly rendered excluded again. They have fewer choices, and more people and technologies to rely on. If any one of these fails, they may be excluded from participation. Second, and related to this, Wolff and De-Shalit highlight how disadvantages are often clustered. People may face discriminatory attitudes, and live in poverty, and have no access to transport, and lack employment. Disrupting clusters, so that disability is not associated simultaneously with all these disadvantages can be a progressive move. Conversely, disability inclusion (in a programme) or participation (in society) may be dependent on a cluster of advantages, and if one of those fails, the goal is imperilled and the person with disability is excluded.

iii) Turning finally to measures, a number of options are available, each of which could be qualitative or quantitative.

A *process* measure for Disability-Inclusive Development would assess the extent to which physical and information and attitudinal barriers have been addressed in a particular project or programme. So at a minimum this would include, for example a multi-dimensional access audit, supplemented by an attitude scale. Perhaps also a wider assessment of whether society was welcoming – was there appropriate civil rights legislation – and whether relevant professionals and other staff had appropriate skills. These instruments would have to be relevant to all classes of impairment – not just physical and sensory, but also mental health conditions and intellectual impairments, to the fullest extent possible.

However, it would be possible to achieve a lot of process indicators but not change outcomes, which must surely be the important measure. On the other hand, as noted, preferences and innate abilities also differ: even with appropriate accommodations (Madans et al, 2017, 1169), participation levels may not be equal. People who are frail or who have fatigue are never likely to participate as much as those who are young and/or full of energy, even in an environment which is barrier free and where appropriate accommodations – such as accessible transport – have been made. In this case, perhaps outcome data are not the best source. Process data, which captures information about accessibility and services, might indicate a maximally enabling environment, which individuals are free to participate in – or not – as they choose, in line with Capabilities

Theory. So the measure would be of the extent to which Capabilities are maximised through a programme.

An *outcome* measure would assess the extent to which persons with disabilities were included in and benefitted from the particular project or programme (inclusion) or in wider society (participation). This approach has the advantage of focusing on what really matters, namely the difference made to lives of persons with disabilities. For example, we could measure the proportion of disabled people receiving a service, as compared to the prevalence of disability. But as stated, some disabled people may have additional needs, whereas others might be expected to have lower rates of participation (most people with intellectual impairment do not participate in higher education) so disabled people would not be expected to be represented in proportion to prevalence of their condition. Moreover, a simple measure of service uptake might not convey the outcomes that matter to people. For example, a child with disability could be present in school, but might not be receiving a good education or enjoying friendships. A person may have access to health, but might face ignorance and even abuse within healthcare. A person may be employed, but in a 'make-work' job where they are not properly part of the workforce, or else they might be in a job where they are victims of harassment and abuse. So the outcome measure must be about the quality of the provision, as well as coverage of the provision.

These outcome measures could be either subjective or objective. Examples of *objective* measures are healthcare coverage or education or employment inclusion, where the population of persons with disabilities could be compared to the general population. But this would require either existing or new data on the general population for comparison purposes. Moreover, as noted, there could be a problem of 'presenteeism'. People with disabilities may be included in, for example, schools or workplaces, which is a superficial success. However, if they are not getting qualifications or doing meaningful work, then this inclusion is tokenistic. This points to the need for better measures (qualifications, not educational participation) or even subjective indicators. However, these measures are rarely used. The ICED Rapid Evidence Assessment (REA) on education review, for instance, identified only one study that assessed educational outcomes for children with disabilities (18).

As another example, studies investigating access to WASH (water, sanitation & hygiene) have largely measured whether a toilet or water point is available, but not whether people with disabilities can access these facilities, let alone use them in a way that is appropriate, safe, and with dignity. An analysis by International Centre for Evidence in Disability across five studies found that there was no difference in *availability* of WASH facilities at the household level between people with and without disabilities, but that there were more difficulties in *accessing* facilities by people with disabilities (Mactaggart et al 2018). ICED then developed a new tool to measure quality of WASH access (e.g. could the facility be used without assistance and while preserving hygiene and dignity), and found large differences between people with and without disabilities in Guatemala and Nepal (Kuper et al 2018).

A *subjective* measure would be where you would set out to ask people whether they felt included, whether they were satisfied with the inclusion, or felt they had a good quality of life, via interviews or questionnaire. This might deal with the problem of 'makework' and workplace bullying. It would also tend to be a measure of societal participation, rather than simply the impact of a particular programme. For instance, a vocational training programme for young people with intellectual impairments in Kenya led to 9 out of 10 becoming employed, which could be considered a success. Yet most of the young people disliked their jobs, and wanted others, and this important aspect would be neglected if only objective measures were used (Makanya et al 2014). The emphasis on subjective preference comes through in the Capability Theory approach, which is why the approach talks of maximising capabilities – the possibility of doing something – rather than functionings – the actual doing of it. However, it could suffer from the 'happy slave' problem, where people who report satisfaction may have low expectations, and are not aware of what they could be receiving: objectively, it could be judged that their situation is not equal. Alternatively, there is the problem of negative affect – certain types of people may be more likely to say they have poor functioning (disability) and poor inclusion, compared to others.

In general, measuring negative things – such as exclusion - is easier than measuring positive things – such as participation. For example, the World Bank Social Inclusion Assessment Tool is all about identifying excluded groups, exploring why and how they are excluded, and taking action to overcome exclusionary barriers. So taking a process approach and identifying barriers seems easier than appropriately measuring wellbeing, quality of life or satisfaction. Eyssen et al. (2011)'s review of the literature determined that tools developed to measure participation fall into three broad groupings: measures of participation accomplishment (for example, "*how often are you able to*.."), measures of participation problems ("*how difficult is it for you to*..") and measures of participation satisfaction ("*how satisfied do you feel with your ability to*.."). Notably, the latter concept of participation satisfaction – i.e. to what degree the person feels they are able to perform the social roles they identify with – is not incorporated in the ICF, an omission strongly critiqued in the literature. But, given the need to measure positives as well as negatives, it should be a priority. In the remainder of this paper, we review what others in the field have done, and make recommendations for developing new measures to evaluate disability inclusion and participation.

2. What Tools Are Available?

Programmes may already collect Monitoring and Evaluation data that could be useful for process and outcome assessment of inclusivity. They may use different scales to measure aspects of inclusion and/or participation. It would be a step forward if all DFID-funded programmes used the same metrics. Consideration also needs to be given as to which tools are appropriate to use in research studies, specifically those that are designed to measure the impact of interventions and thereby what works to promote inclusion and participation.

Many relevant scales have often not been tested in LMICs. For example, a systematic, scoping review of measures of participation in disability and rehabilitation research was conducted by Seekins et al. (2012). The authors identified 67 distinct instruments, only 9 of which had been used in more than one study and without reporting whether their use was in population-based surveys and/or in LMICs. Of these, the two most commonly used tools (three studies each) were the Community Integration Questionnaire and the child-specific Paediatric Evaluation of Disability Inventory. Both tools were developed in high-income settings, and there is no evidence of their use in population-based surveys in LMICs.

Finally, in addition to these scales or sets of questions, participation can be assessed through reported access to, and experience of, activities that an individual may value. For example, education, work, political and social events. Moreover, standardised, cross-culturally applicable modules on access to and experience of livelihoods, education, health-care etc. can be found in large population-based surveys including the above mentioned Surveys on living Conditions, the USAID Demographic and Health Surveys or the World Bank Living Standards Measurement Study surveys.

Administrative and other government data

Administrative data is widely available and at lower cost than specific surveys. Administrative data may be informative about general population level processes. For a range of reasons, disabled people may not be included in administrative data, or there may be systematic biases. For example, schools data may be incomplete because children with disabilities are not in school. Or else it might not be possible to disaggregate data by disability, or other relevant data about outcomes are not included. Other administrative data may refer directly to targeted disability programmes: these might be useful for evaluating success of programmes, but may not include non-disabled comparators. Census and Labour Force Survey data may be useful, if disability can be disaggregated.

The Convention on the Rights of Persons with Disabilities

This treaty has been ratified by 181 countries. If indicators could be developed related to the 50 Articles of the Convention then this would give a picture of the extent to which a country promoted, protected and ensured the human rights of persons with disabilities. The Committee on the Rights of Persons with Disabilities have assessed states parties compliance with CRPD, including shadow reporting from civil society. These reports are hard to assess and compare, as there is little consistency or objectivity in how data are gathered or presented. A project of the European Union and the Committee on the Rights of Persons with Disabilities is developing structural, process and outcome indicators for all the relevant articles, so progress could be assessed more systematically. Some of these data are already collected, others would have to be especially collected. The project was not complete at time of writing, but the indicators for Article 28 Work and employment, were shared with the authors. 26 indicators had been identified for this domain; multiplication by nearly 50 substantive articles, and then further disaggregated by gender, this suggests a large number of indicators, which might be unfeasible to measure. A prioritisation process could presumably lead to the selection of a shorter set of indicators and proxy indicators that would show progress on disability inclusion outcomes.

The Participation Scale

An 18 item Participation Scale, focusing on problems, has been developed by Van Brakel et al (2006), based on the nine Activity and Participation domains of the ICF, and has been field tested in Nepal, Brazil and India, although not in population-based surveys. However, validation studies were limited to participants with leprosy, spinal cord injuries and polio, and further studies to determine validity amongst participants with other impairments, or with participants without disabilities as in a population-based survey, are lacking.

The Participation Scale is generic, client-perceived, cross-cultural, and can be administered by non-professionals. It is a subjective measure of the extent to which a person with disabilities faces barriers in different aspects of daily living. With only 18 items, it is a comparatively easy tool to administer, although it may be too long to add to other surveys.

From experience of administering the scale, there can be confusion between items: for example, item 5, “Do you take part in major festivals and rituals”, appears to overlap with item 7, “Are you as socially active as your peers are? (e.g. in religious/community affairs)”. Similarly, item 6, “Do you take as much part in casual recreational/social activities as do your peers?” appears to overlap with item 13 “In your village/neighbourhood, do you visit public places as often as other people do?”, especially as drinking tea with friends appears as an answer to both questions in the Users Manual (Participation Scale Development Team, 2010). This suggests more parsimony could have been achieved. The distinction between small problems, medium problems and large problems will be different for different people, an indication of the extent to which answers may not represent comparable situations. The “no problem” response appears straightforward, but people might be ashamed (for example for not having a spouse) and minimise difficulties. This is a generic problem in all subjectively scored measures.

SINTEF

The “*Surveys on living conditions among people with activity limitations in developing countries”*, coordinated by SINTEF in collaboration with local partners and stakeholders, has covered ten countries in Africa and one in Asia to date. The survey methodology includes disability screening using the Washington Group Short Set, followed by in-depth questionnaires at the household and individual level for identified persons with disabilities, alongside matched controls. Within the individual questionnaire, a participation module provides data on ability to complete core tasks (such as self-care or tasks of daily living) in line with the participation domains of the ICF [158]. This tool also uses the participation problem approach. One drawback is that this is a cumbersome tool, at 20 pages long, which would be onerous to complete in every programme.

Sustainable Development Goals

Unlike the Millennium Development Goals which they superseded, the 17 Sustainable Development Goals are inclusive of disability. There are targets (169 in total), with 232 indicators. Several of the Goals mention persons with disabilities specifically. Disaggregation of outcome data by disability status is a core principle (Madans et al 2017). The emphasis of the SDGs is on structural forces that exclude people. However, key areas are missing, for example, the health goal (SDG3) does not mention disabled people specifically (Hashemi et al 2017). However, it is unlikely that the targets of reducing mortality and improving access to healthcare services for all could be met without inclusion of disabled people. Inclusion would require specific strategies to address greater need and greater vulnerability. It may again be possible to prioritise relevant indicators to form a composite disability inclusion measure, but this would be rather partial and incomplete.

Washington Group

The Washington Group questions are not designed as screening tools, but as population level disaggregation tools. Girls Education Challenge (GEC) is a DFID programme that has used the Washington Group Short Set of Questions and the Child Functioning Set of Questions to collect disaggregated data. This has reported a prevalence of 5% of children with disabilities in mainstream schools. However, across the portfolio of GEC projects, the disability prevalence is reported at 10.8%, showing how systematic targeting increases uptake. In addition, the Washington Group is developing an education module assessing participation restrictions among children in and out of education, and an inclusion in employment module, but these are not yet available.

WHO

WHODAS 2.0 is a validated WHO assessment of disability across 6 domains of functioning, which comes in a full, 20 minute version and a brief 12 item 5 minute scale. WHODAS 2.0 is compatible with the ICF. The ICED review of tools for measuring the impact of rehabilitation recommends WHODAS 2.0 for measuring Activities in adults, and WHODAS 2.0 or the Participation Scale for measuring Participation in adults (Alavi et al 2010). The review concludes that at that point, there were no widely used or available activity and participation tools for children in LMICs.

WHO-QOL is a validated WHO survey of quality of life of persons with disabilities. Associated with it is the Attitudes to Disabled People tool, as well as a tool that explores persons with disabilities' own assessment of their quality of life. Both tools have been tested by ICED. Another tool in the same suite of instruments allows the person with disability to give a subjective assessment of the quality of any services they receive. The same ICED review recommended WHOQOL for adult quality of life and SF-36 for measuring health status (Alavi et al 2010).

The Model Disability Survey, developed by the World Health Organization and the World Bank, is a general population survey that provides detailed information on the lives of people with disabilities and the barriers that hinder their participation in society (https://www.who.int/disabilities/data/mds/en/). It allows direct comparison between groups with and without disability. It is another extensive instrument which takes a considerable time to administer: even the brief version has 39 questions. Modules are included within the Model Disability Survey on inclusion in employment, health-care, empowerment and overall well-being. It is designed for adults, and so does not have a focus on educational inclusion.

These instruments have been tested for reliability and validity in different cultural settings. In addition, the WHO is responsible for the CBR Manual, which outlines a set of outcomes, 52 indicators and questions for evaluating CBR, some of which have been taken from validated surveys. The questions involved both objective ('Which school do you attend?') and subjective questions. The process has gone through expert appraisal and then a pilot cross sectional survey in China, Egypt and Guatemala, involving 801 participants.

3. Conclusion

There is no easy, obvious disability inclusion measure available to be recommended either programmatically or for impact evaluations. Therefore PENDA will develop and/or refine some specific quantitative tools which can be used in our own impact evaluations, and in other people's work, and to be used in routine programme monitoring.

First, a simple, easy to use process inclusion measure is required. This would enable any programme to be quickly assessed and compared in terms of every dimensions of accessibility – physical, information/communication, attitudinal. This would not be a full access audit as these are often cumbersome and impractical, but would be a simple tool for quick assessment, preferably by a disabled person themselves. There is nothing appropriate currently available. This output could draw on existing work, and would be a useful output both for PENDA, the DID programme, and for DFID more widely.

Second, a set of tools are required to assess inclusive outcomes, specifically in the domains of health, education, and employment, as these are the key focus of most disability inclusive development programmes. There will obviously be common themes. These tools will combine objective and subjective elements, but as a quantitative measure. The aim is to measure not just access to the service but also quality and the social experience of receiving the service. The starting point of education and employment seems simple: are you learning in mainstream school, do you work at a real job. But for health, there is no common starting point, because everyone has a different set of health needs and priorities. Potentially, a cross-domain inclusion outcome tool could be developed in addition. There are other relevant dimensions to true inclusion, for example, how you are treated by peers.

Third, in addition, a wider measure of participation/social inclusion outcomes would be required. Using existing tools, it is possible fairly easily to disaggregate disabled people's responses in a population or user survey, so compare the experiences of disabled people and non-disabled people and thus assess the wider impact of any population or targeted interventions. ICED have considerable experience in this approach, but it is costly in terms of time and resources. The intention of the PENDA programme is to draw on Capability Theory, and multi-dimension measures of poverty to construct a new tool. We would additionally need tools to measure attitudes, currently lacking, and the freedom someone experiences to choose the lifestyle they want. The result would offer an assessment of how far capabilities are maximised in a particular country or region.

Appendix A: Table of Measures

	Inclusion in programme	Inclusion in society	Process	Outcome	Objective	Subjective	Notes
Administrative data		▨		▨	▨		
CRPD		▨	▨	▨			
Participation scale		▨		▨		▨	
SINTEF		▨		▨		▨	
Washington Group			▨	▨		▨	Also modules for children, employment
WHO-QOL	▨	▨	▨	▨		▨	
WHO-MDS		▨		▨		▨	
Accenture	▨		▨			▨	Manager report; not LMIC
DFAT	▨		▨			▨	Manager report
CBM-MOI	▨	▨	▨	▨		▨	Field tested LMIC
HI-SCOPEO	▨		▨			▨	

Appendix B: What have other agencies or initiatives done?

This section highlights some of the approaches to disability inclusion and participation and its assessment taken by other agencies. It offers a brief selection, presented in alphabetical order, not by importance: while it is not a comprehensive summary of activities and methodologies, one of the authors has conducted a search of key disability websites, looked at different NGOs and agencies, and has talked to key informants.

Australia: Department for Foreign Affairs and Trade (originally AusAid)

AusAid was a pioneer of disability inclusion, reviewing their own operations and developing a disability inclusion strategy, *Development for All: Towards a disability inclusive Australian aid program 2009–2014* (DfA1), followed by a second strategy for the 2015-2020 timeframe. During this period, AusAid was dismantled, and incorporated into the Department for Foreign Affairs and Trade (DFAT), but the disability inclusion emphasis continued. These initiatives made disability inclusion less ad hoc or opportunistic, and as a result, disability is now a cross-cutting priority.

Two parts of the DFAT performance management system were used to evaluate progress: Annual Program Performance Reports (APPRs) for country, regional and other programs; and Aid Quality Checks (AQCs)[2] for individual investments. Of these, the latter proved most useful. Aid Quality Checks evolved over the period, but most recently comprised the following questions:

"D 1 The investment actively involves people with disabilities and/or disabled person's organisations in planning, implementation and monitoring and evaluation.

D 2 The investment identifies and addresses barriers to inclusion and opportunities for participation for people with disabilities to enable them to benefit equally from the aid investment."

In other words, AusAid relies on process measures of programmatic inclusion, not outcome measures of participation in society. Moreover, these appraisals are gathered through selfreport from managers, not through independent assessment or obtaining the perspective of people with disabilities. While percentages of disability-inclusive investments declined over the appraisal period, this appears to be because the standards for disability inclusion had improved, and so the projects were being measured against tighter criteria and more challenging expectations. Currently 40% of investments are assessed as being disability-inclusive, ranging up to 55-73% of inclusive investments in the education sector, but down to only 17% in the infrastructure sector, while one third of humanitarian investments have been assessed as inclusive. Generally, investment managers underestimated opportunities for inclusion: they rated 27% of projects as having high need for inclusion, against 68% of projects being thus rated by the evaluation team.

Principles such as the twin-track approach, reasonable accommodation, and the participation of disabled people's organisations have been central to this work, however DFAT acknowledge that there has been less success at involving the private sector. CBM Australia has been a partner in achieving many of these successes. Important factors in success have been sustained effort; DPO capacity building; technical expertise; senior leadership and funding for reasonable accommodation. One of the priorities for DFAT in the next period is developing more comprehensive tools for evaluating programmatic disability inclusion, and they also highlight the need for other outcome measures to assess inclusion for persons with disabilities.

BOND

The Bond Disability and Development Group (2016) have produced *Leave No One Behind: the value for money of disability-inclusive development*, which makes the case for efficient, effective and equitable investment, which is also inclusive of disabled people. The document features important principles for judging disability-inclusion, but no actual tools.

CBM

CBM recently conducted a review of their own programmatic tool for assessment of inclusion. The "Monitoring of Inclusion Tool" (MOI). This is a set of questions developed to capture the perspective of the individual, and caregiver, on their experience of inclusion and participation. It also includes a module on community attitudes towards disability and an organisational assessment of inclusion. This has been recently field tested in Rwanda in January 2018, but is not yet openly available.

EU DG ECHO Inclusion of persons with disabilities in EU-funded Humanitarian Aid Operations

This guidance considers four elements for designing humanitarian interventions, based on the CRPD:

1. Prioritise safety and dignity and avoid causing harm
2. Meaningful access
3. Accountability
4. Participation and empowerment

Under each heading, barriers should be removed, reduced or mitigated; enablers and capacities should be strengthened. In terms of needs assessment and outcome measures, the Washington Group short set is recommended. Process indicators at specific objective level are the percentage of beneficiaries that report that humanitarian assistance is delivered in a safe, accessible, accountable and participatory manner.

Humanity and Inclusion (HI)

HI have a tool "Measuring quality of life, safety, and social and family participation of project beneficiaries: The ScoPeO tool" (http://www.hiproweb.org/uploads/tx_hidrtdocs/PG15Scopeo.pdf). This is a programmatic tool developed by the NGO, focusing on measuring quality of life and social participation, and including a module on Participation in society and family life. The tool is targeted at delivery to people with disabilities, and highlights that the CRPD emphasises the full and effective participation and inclusion in society as a fundamental principle. The tool uses the terms 'participation' and 'inclusion' interchangeably, without clarifying definitions, but mostly addresses the 'participation' in society rather than programmatic inclusion. The tool appears to be based on quite extensive field consultation across seven countries, although it has apparently not be subjected to robust independent validation processes.

Netherlands: Light for the World

Light for the World Inclusion Lab, in the Netherlands have created *Count Me In*, a guide for NGOs to promote disability inclusion in development projects (https://www.light-for-the-world.org/count-me). This focuses on process inclusion measures, including gathering data on beneficiaries, training staff to raise awareness, knowledge and skills, identifying barriers, budgeting for inclusion etc. It includes a checklist to monitor disability inclusion in policy, human resources, planning and M&E, programmes, accessibility, advocacy, and capacity building, enabling an organisation to grade itself at level 1, 2, 3, 4, and identify gaps. There are a lot of valuable ideas and tips in this document.

USA: National Center on Health, Physical Activity and Disability

The US National Center on Health, Physical Activity and Disability has developed Guidelines for Disability Inclusion for physical activity, nutrition and obesity programmes in the US (https://www.nchpad.org/fppics/Guidelines_Disability_Inclusion_Physical_Activity_Flyer.pdf). These Guidelines specify nine areas against which a programme could be assessed for inclusivity:

1. Objectives include people with disabilities
2. Involvement of people with disabilities in development, implementation and evaluation
3. Program accessibility
4. Accommodation for participants with disabilities
5. Outreach and communication to people with disabilities.
6. Cost considerations and feasibility
7. Affordability
8. Process evaluation
9. Outcomes evaluation

These resources include a simple one-page accessibility checklist.

OECD

The ‘Better Life Initiative’ of the OECD, the Organisation for Economic Co-operation and Development was launched in May 2011 (http://www.oecdbetterlifeindex.org). Instead of using Gross Domestic Product (GDP) as a measure of national success, the aim of this initiative is to track wellbeing, both in the present day and historically, by looking at eleven dimensions, which include both objective (e.g. wealth) and subjective measures (e.g. happiness), and so is compatible with a participation outcome:

1. Housing: housing conditions and spendings (e.g. real estate pricing)
2. Income: household income and financial wealth
3. Jobs: earnings, job security and unemployment
4. Community: quality of social support network
5. Education: education and what one gets out of it
6. Environment: quality of environment (e.g. environmental health)
7. Governance: involvement in democracy
8. Health
9. Life Satisfaction: level of happiness
10. Safety: murder and assault rates
11. Work-life balance

In future, the level of national inequality will also be added to the Index. However, given that the Index does not include connectedness, it could be hypothesised that a country could be doing well, yet people are still not feeling included. Moreover, this initiative does not disaggregate disability, although it might still be useful as an exemplar. However, it certainly provides a baseline against which individuals with disabilities in OECD countries could be compared, on various dimensions, as well as highlighting that wellbeing is more than national or individual income.

World Bank

In 2018, the World Bank group launched a Disability Inclusion and Accountability Framework to support mainstreaming of disability in the World Bank’s activities (http://documents.worldbank.org/curated/en/437451528442789278/Disability-inclusion-and-accountability-framework). The Framework is based on four main principles:

- Non-discrimination and equality
- accessibility
- inclusion and participation
- partnership and collaboration.

It outlines six key steps toward disability inclusion:
(1) apply a twin-track approach for recognizing persons with disabilities among the beneficiaries of all projects while also carrying out specific projects to address the main gaps to their inclusion;
(2) adopt explicit references to disability in general policies, guidelines, and procedures;
(3) identify focus areas for disability-inclusive projects and advisory services;
(4) collect data to improve the evidence base on the situation of persons with disabilities;
(5) build staff capacity and organizational knowledge on disability inclusion;
(6) develop external partnerships for implementing the disability inclusion agenda.

World Bank disability inclusion can have a significant impact in transport, urban development, disaster risk management, education, employment and other sectors. For example, simply referring explicitly to disability cannot be enough. It is important that operations have to consider impact on disabled people, and remove barriers to participation in deliberations. It is stated that:

"Project outcomes for and impacts on persons with disabilities, their families, and communities can become part of standard monitoring and evaluation procedures through the development of disability-specific indicators for projects' results frameworks." (2018, 6)

At this point, these indicators do not appear to have been produced. However, in general the World Bank recommends multi-dimensional indicators, including attitudinal surveys to assess who gets included and excluded and on what terms. In general, it is worth noting that the World Bank Group tend to be parsimonious when it comes to indicators, allowing a maximum of 3 outcome indicators per project, with 3 or 4 process indicators. A long list of disability outcome or process indicators is likely to be unwieldy: what is required is a relatively short set of questions which can be easily completed and compared, both between projects and over time.

At the 2016 Disability Summit, the World Bank made ten commitments, including:

1) Ensuring that all Bank-financed education programs and projects are disability-inclusive by 2025.

2) Ensuring that all Bank-financed digital development projects are disability sensitive, including through the use of universal design and accessibility standards.

3) Scaling up disability data collection and use, guided by global standards and best practices, such as using the Washington Group's Short Set of Questions on Disability.

4) Introducing questions on disability into the *Women, Business and the Law* survey to better understand the economic empowerment of women with disabilities.

5) Ensuring that all projects financing public facilities in post-disaster reconstruction are disability-inclusive by 2020.

6) Ensuring that all Bank-financed urban mobility and rail projects that support public transport services are disability-inclusive by 2025.

7) Enhancing due diligence on private sector projects financed by the International Finance Corporation (IFC) regarding disability inclusion.

8) Ensuring that 75 percent of Bank-financed social protection projects are disability-inclusive by 2025.

9) Increasing the number of staff with disabilities in the World Bank Group.

10) Promoting the *Disability Inclusion and Accountability Framework* among World Bank staff as a way to support the WB's new Environmental and Social Framework (ESF).

These commitments will therefore require mainly process inclusion indicators, for instance, ensuring that programmes are accessible, but also indicators for monitoring of progress.

1. Private sector initiatives

Accenture, in association with Disability:IN and the American Association of People with Disabilities, has created a Disability Equality Index, so that 145 US corporations (2018), employing more than 7 million employees, can compare each other in how they respond to the challenge of disability inclusion in their businesses (disabilityequalityindex.org). Every corporation is given a score ranging from 0-100. This index is scored as follows:

- Culture & Leadership (30 points)
    - Culture (20 points)
    - Leadership (10 points)
- Enterprise-Wide Access (10 points)
    - Enterprise-Wide Access (10 points)
- Employment Practices (40 points)
    - Benefits (10 points)
    - Recruitment (10 points)
    - Employment, Education, Retention, & Advancement (10 points)
    - Accommodations (10 points)
- Community Engagement (10 points)
    - Community Engagement (10 points)
- Supplier Diversity (10 points)
    - Supplier Diversity (10 points)

These measures are therefore mostly in the category of process inclusion indicators. The number of enterprises getting maximum ranking is currently 62.7%; compare 2015, when the top score was attained by 22.5%, and 2016, when 50.6% gained the maximum. This suggests business are improving their performance when it comes to disability inclusion. The scorings are publicised in terms of 'best places to work for disability inclusion', meaning that they are more likely to attract the best employees with disabilities, or indeed without disabilities, as well as promoting the corporation more generally. However, these items are assessed by a panel, they are not responses from employees with disabilities, who may have a more nuanced and indeed critical approach. Moreover, this measure is conducted in High Income Countries, and may need some modification for other settings.

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