Submission: Disability in the SDGs: Special Issue

Monitoring and Evaluation in Disability Inclusive Development: Ensuring data *ABOUT* disability inclusive development contributes *TO* inclusion

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Disclaimer

This paper has been conceived and prepared independently, with the intention of contributing to ongoing discussion about disability inclusion across the sector. The views expressed do not necessarily represent those of any organisations with which the author is associated.

Executive summary

There is increasing emphasis on 'data collection' in the disability inclusive development context. Interest in monitoring progress against the new Sustainable Development Goals (SDGs) is extending this emphasis, as disability issues are explicit in the goals and indicators. Global efforts to collect and analyse information about disability issues are engaging more people and resources than ever before. Overall however, this is still a relatively new area of work and there is still much to learn.

In Australia, interest is led by the Department of Foreign Affairs and Trade (DFAT), both for monitoring achievements against its own *Development for All Strategy* and for assessing the performance of funded programs and implementers under the Aid Program. Other international development organisations, from the World Bank to international NGOs are calling for and engaged in data collection as a key or sometimes initial element of their work in this relatively new sector. Australian organisations, including the Nossal Institute for Global Health and some NGOs have begun to test a range of approaches and tools to support this work.

There is no doubt that in many situations and for different purposes, collection of data can help to inform decision-making, policy development and analysis of change. However, data itself does not lead to systemic social change, political will or attitudinal shifts. Change is driven by leaders, collective voices, social movements, changes in legislation and norms/standards and many other forces related to power and culture. These elements respond to all different types of information. Also, care needs to be taken in determining which kinds of data are appropriate to collect and when, how it is analysed or interpreted and by whom. The use of data is also important: with both beneficial and other purposes possible, depending on the values and priorities of those involved.

In the relatively new area of disability inclusive development, there is a risk that lessons learned from other approaches to change and to social inclusion, may be missed in the rush to obtain the data deemed necessary to support various definitions of disability inclusive development. What appear at first glance to be relatively simple data collection efforts, such as counting people with disabilities as a proportion of total populations, may need to be thought through given that definitions of disability and processes for counting are problematic. This is particularly the case in different social, cultural and political contexts, where disability issues can be defined differently across groups and settings. Given that disability is not just about the impairments that individuals have, but about the interaction between people and the social and physical environments in which they live, then more sophisticated approaches to data are necessary to understand the issues and monitor changes.

The timing of questions about people's impairments and lives is also important. Collecting data about people with disability without the foreseeable promise of change or before awareness about the rights of people is raised, could result in even greater alienation and focus on impairments rather than inclusion. A more balanced and nuanced set of approaches is recommended, that takes greater account of complexity in societies, relationships between people, change processes, cultural values, power dynamics and contemporary understandings of disability.

Data collection in disability inclusive development needs to be consistent with rights-based approaches to disability and social inclusion, rather than welfare approaches. Lowest-common denominator type data may suit donor agencies which seek to add up numbers across many

countries for example, but may not be meaningful and useful in individual contexts. Excessive focus on data about individual impairments without essential information about social barriers and research about how best to support cultural change, could undermine efforts to bring about inclusive societies. Principles articulated in the Convention on the Rights of Persons with Disabilities (CRPD) affirm the need to ensure all processes are inclusive, which includes data collection and analysis.

Bringing about disability inclusive societies is a complex change that involves issues of power, politics and leadership, shifts in cultural values, as well as many technical aspects. Data collection approaches need to reflect this complexity and respect the reality of changes sought by international agreements, governments and NGOs. If changes in attitudes and increased inclusion are the key priorities, then research about the approaches that can help bring about such changes in different cultural and political contexts, may well be of greatest importance. Statistics about proportions of people with disability at any one time and in any particular place may be useful for certain purposes, but not essential for determining the nature and extent of inclusion. Disability is part of the human condition in every context and variations are likely for many reasons. Whether 2 or 200 people face mobility issues in a village, the bottom line is the same: the built environment should be accessible and importantly, whole societies will benefit from inclusion, not just those in wheelchairs. Similarly, whether 5 or 500 people have various vision impairments, public information should be accessible.

Changes associated with creating more disability inclusive societies are highly influenced by cultural values. Attitudes towards people who are different from 'mainstream' society reflect values about equality and power, individualism or collectivism, relationships between people and perceptions about uncertainty and risk (Hofstede 1985, 2005). When ideas associated with data are developed in one culture and then applied to others, there is a risk of cross-cultural misunderstanding. Increasing cross-cultural understanding and skills to facilitate and participate in sophisticated conversations about values and change are important for data collection and interpretation.

This paper seeks to add complexity and nuances to the issue of data collection and monitoring and evaluation in the area of disability inclusive development. Three key messages are offered to guide approaches and practice:
- Approaches to supporting and monitoring disability inclusion need to be culturally and politically aware and respectfully negotiated rather than imposed as 'one size fits all'
- Aid agencies involved in both targeted and mainstream disability inclusion need to negotiate definitions and processes applied in different contexts, paying attention to implications for both people with disabilities themselves and communities. Recognising diversity and being flexible are important for increasing inclusion of people with disabilities.
- Disability inclusion needs to be better understood as a process of cultural change and shifting power, relevant to whole societies. It is not primarily a technical issue, with simple technical solutions to identified problems. Simple types of data are not likely to be appropriate. Data collection about shifting attitudes and social barriers is vastly different from data collection about individuals with impairments.

The paper does not advocate that counting people should stop, in the interests of achieving disability inclusive societies, but rather that more balanced and nuanced approaches are taken. Efforts should: consider broader understandings of change (Krznaric 2007); seek deeper and shared

understanding about the politics of knowledge, power and culture in each context (Menocal 2014); reflect the complexity of contemporary, rights-based definitions of disability (CRPD 2008); and generally take more nuanced and context-specific approaches to data and monitoring and evaluation than is implied by the catch all phrase 'data collection'.

1.   Introduction

The achievement of disability inclusive societies represents a major developmental change across the globe. The change is summarised as a shift from a situation where societies create and sustain substantial, diverse and often institutionalised barriers, to a future where societies are inclusive of all people. The change is articulated in the articles of the Convention on the Rights of Persons with Disabilities (CRPD) (2008).

In the last decade, and particularly since the CRPD came into force, increased attention has been paid and resources allocated at many levels towards the range of changes sought.   With this increased activity, attention is now focusing on how to understand the nature and extent of changes over time and in different contexts. It is important to be clear that the changes sought are not focused on the numbers of people with disability being increased or decreased[2], but rather on the extent to which societies, governments and a wide range of services and developmental changes are inclusive of people, so the rights of all people are met and protected.

There is a widespread belief in the field of disability inclusive development that the lack of data[3] on the numbers of people with disability and their particular impairments or levels of 'functionality' needs to be addressed as a first step or high priority towards achieving more inclusive societies[4]. At present, nearly all UN agencies, Governments, NGOs and DPOs[5] as well as many others[6] include some reference to the lack of data or information in their plans in some form or another. The belief is founded on expectations that once there is data on numbers and types of impairments that people have, then this will contribute to governments and NGOs changing policies, introducing or improving services and taking other steps to increase inclusion of those who have been counted. Approaches to data collection have now been developed in this context, including questions for national census processes[7].

Related to this, is the idea that aid programs need to prioritise the collection of numerical data about the people with disabilities who have participated in or benefited from activities and information about their impairments. Among other reasons for such data collection, this reflects a Western cultural view that if this data is available, it will confirm (or not) whether disability inclusive policies

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[2] It is now widely acknowledged that disability is part of the human condition, and while some impairments can be prevented as the quality of public health and medical systems improve, others will increase due to ageing and other factors.

[3] The terms data and information have various definitions in various contexts. For the purpose of this discussion paper, data is understood to refer to simply facts or figures — bits of **information**, but not **information** itself. Information is understood to be the result of the process of processing, interpreting, organizing, structuring or presenting data so as to make the facts and figures meaningful or useful.

[4] Although the language used varies across different organisations.

[5] For example, see Dos Santos and Morgan (2016)

[6] For example, see Mitra, S (2013) and McPhillips (2016)

[7] Many DPOs advocate for the inclusion of disability-related questions in censuses and other population-wide surveys and this may in part reflect the desire to be recognised. Others also seek disaggregated data to learn about differential experiences and outcomes related to various social indicators rather than prevalence per se.

are being implemented by aid agencies[8]. Approaches to data collection within aid programs have now begun to be developed in this context, addressing a range of issues and sectors. It is not yet clear how this data will be used in practical terms to benefit people with disabilities and their communities. A particular question might be whether baseline data about numbers of people in a community and their impairments compared with follow-up data constitutes change. A focus on data in this context may reflect an emphasis in Western cultures about the need to demonstrate 'evidence' to funders/donors or it may also reflect the value accorded to data for bringing about policy or broader change processes. In comparison, many cultures emphasise the value of alternative information such as story-telling for enabling change (Shamrock 2016). This raises an important issue about the 'politics of knowledge' relating to questions such as who determines what kind of knowledge counts, whose definitions apply to terms used and who determines the agendas for change over time in different contexts.

In addition, as Governments, international agencies and aid programs become more focused on how to achieve disability inclusive societies, there is interest in trying to understand the most effective strategies in diverse contexts. This interest covers a wide range of strategies including: how to build policy coherence and implementation; how to advocate for changes in attitude and practice; how to contribute to empowerment and self-representation; how to make public services and facilities accessible; and how to ensure programs are inclusive of people with diverse types of impairments.

Thus, importantly, there is a clear distinction between three very different types of information in this context (see 2.4 below):
- Demographic data about people with disabilities and prevalence or nature of impairments
- Data about changes in the extent of inclusion of people with disabilities as a result of CRPD, Government policies and services, advocacy efforts
- Information about the effectiveness of strategies and the work of aid agencies[9].

This paper seeks to raise issues associated with the purposes of data collection, instruments for measurement, approaches to data collection and analysis and implications for the lives of people with disabilities in societies where aid programs are delivered. Importantly, the paper contextualises these ideas within settings relevant to Australian aid organisations. This includes approaches which aim to achieve change (i.e. more disability inclusive societies), ideas about how change happens in diverse cultural contexts, different approaches to monitoring and evaluation and the practices related to data collection, analysis and use.

This Discussion Paper seeks to raise issues and contribute to discussions about approaches which have been proposed and applied to date. It seeks to build a more nuanced understanding of appropriate processes for assessing actual changes sought, than is evident from current practice.

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[8] Such a view may be based on a belief that there has been a causal link rather than an association between program interventions and such data; or that data about numbers of participants with disabilities in a program tells a meaningful story about the nature and extent of inclusive programs.
[9] These different types of data have often been blurred together under 'data collection' but are vastly different in nature and the differences have major implications for practice.

1.1   Recent history

The experience of these issues and practices is relatively recent, with the Australian Government being among the first to develop a disability policy for its aid program in 2008[10]. While several international agencies have specialised in disability issues for decades[11], few Australian aid agencies had professional skills in this area prior to 2008. This means that most stakeholders in this context are in an early learning stage and there is little definitive evidence available yet about effective strategies, appropriate tools and the connection between data and increased inclusion.

Processes associated with the CRPD and more recently the Sustainable Development Goals (SDGs) (2015) have also generated interest and activity in data collection in relation to disability. International agencies such as International Disability Alliance (IDA) and the UN CRPD Secretariat are increasingly engaged in M&E approaches and issues. Other UN agencies, such as WHO, UNOCHR and UNICEF are also allocating substantial resources to issues associated with data collection.

In 2014, Goujon et al noted that 'no single instrument has the necessary characteristics to both measure disability prevalence and support the design, implementation and measurement of effectiveness of disability inclusive development programs.' Based on this analysis, an Australian team in the Nossal Institute for Global Health, University of Melbourne, developed the Rapid Assessment of Disability (RAD) (Huq et al 2013)[12] which includes a complex set of questions and statistical processes to generate information about both elements. The tool is being applied in several contexts and experience of its application may be helpful to inform future work of this nature.

A recent document by Plan International and CBM Australia-Nossal Institute Partnership for Disability Inclusive Development called 'Practice Note on Collecting and using data on disability to inform inclusive development' (2016) is another important contribution to practice. The Practice Note provides guidance for NGOs working internationally and cautionary comments about avoiding harm.

The UN Secretariat of the CRPD is currently preparing a major report[13] on M&E for disability inclusive development, to be released in 2018, which appears to both cover data on the prevalence of disability and on 'issues relevant to assess progress towards international development goals and the provisions of CRPD.' Again, the two elements are vastly different so require quite different instruments of measurement, or at least two different ways of understanding the content.

It is not yet clear that those agencies encouraging and investing in data collection are making adequate distinctions between the different purposes, types of data and meaning of data in different contexts. For example, Australian NGOs are now required to collect and report on quantitative data about people with disabilities for all Government-funded overseas aid programs, using a definition of disability from the Australian Bureau of Statistics. The definition may suit

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[10] Department of Foreign Affairs and Trade (2008) *Development for All: Towards a disability-inclusive Australian aid program2009-2014* which has been superseded by the current policy entitled: *Development for All 2015-2020: Strategy for strengthening disability –inclusive development in Australia's aid program*
[11] For example, Handicap International, CBM International, Inclusion International
[12] http://dcidj.org/article/view/174/155
[13] See https://www.cdc.gov/nchs/data/washington_group/meeting15/global_network_medd.pdf

Australian cultural values and understandings but may have very little relevance or meaning in other cultural contexts. The complexity of disability inclusion, for example in relation to social values, power and status, politics, identity, justice, poverty and many other frames of reference, do not seem to be acknowledged in current M&E approaches. Interpretation and use of data or information for various groups and the contribution of this to understanding about inclusion is not straightforward.

Now there is wider involvement of Australian and partner organisations in disability inclusive development issues and approaches, as well as greater experience of these concepts and practices, there is an opportunity to reflect, share experiences and deepen understanding. Also, there may be value in sharing Australia's experience with other countries which are beginning a similar journey.

2.   What change are we talking about?

This section seeks to summarise the contexts for considering the issue of M&E for disability inclusive development. It illustrates that there are multiple frames of reference to consider and no single way to understand how M&E can be approached in disability inclusive development.

2.1   Approaches to disability

Key message: There are diverse views about disability and M&E approaches need to match the contemporary definitions and approaches which underpin inclusion efforts.

In the Western world, a major shift in thinking about disability has occurred in recent decades, from a welfare approach (which focuses on provision of goods or services for individual well-being) to a social and human rights approach (which focuses on removing the barriers to inclusion and to ensuring protection of human rights for all people). The latter is exemplified by the universal design movement which benefits all members of a community and society. This philosophical shift has contributed to major changes in policies and approaches across much of the Western world. In Australia, the shift is exemplified by the abolition of highly segregated and specialist care to the provision of support within the community, included in the National Disability Insurance Scheme (NDIS)[14]. Similar shifts have not necessarily occurred at the same pace and in the same ways, in countries where aid programs are undertaken. However, thanks to the CRPD, the SDGs and other international advocacy efforts, there is now widespread understanding of rights-based approaches to disability, even if there is not necessarily shared understanding of the reality of this in different cultural contexts (see 3.3 below).

Current definitions of disability generally identify that it is the result of the interaction between impairments and social barriers. For example the definition of disability in CRPD is: '*disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.*' Using this definition, the changes that could be sought by those involved in development programs, are likely to be an improvement in the way in which these two elements interact, or related changes such as a reduction in negative attitudes. Efforts which seek to reduce the incidence of impairments are often

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[14] See https://www.coag.gov.au/node/497

prioritised in public health or other health-related change programs, rather than by groups representing people with disabilities. The latter generally seek to focus more on reducing barriers to participation and on the human rights of people with disabilities overall.

Within Western definitions of disability, there are also contested ideas. For example, it is possible to portray differences between 'accommodation' of people with disability and truly inclusive societies. The former considers that people with disabilities can be tolerated or accepted into programs, whereas the latter recognises the importance of social diversity overall. The latter end of the spectrum would not be informed by numbers at all. The question about whether aid programs are seeking to assist other countries to accommodate people with disabilities or to work towards genuinely inclusive societies, has major implications for the nature of aid efforts and thus the definition of what 'success' looks like.

As stated in the CRPD, disability is an evolving concept and has different definitions in different settings which reflect cultural values, history, leadership, religious beliefs, community perceptions of and support for people with disabilities and many other factors. Defining the concept in an Australian cultural context and then collecting data against this definition in other settings and comparing it across regions (as noted in Section 1.1 above) may be highly problematic.

This broad shift and current definitions of disability have implications for M&E approaches. National efforts to collect data on disability have largely sought to quantify people with different types of impairments and have involved considerable time and effort in trying to categorise types of impairments. On reflection, this has meant that less attention has been paid to data about the extent and nature of barriers which exist, their interaction and what works well in addressing them. Donor efforts which seek to determine whether disability inclusive programs are effective, both those which target people with disabilities and those which aim to ensure inclusion more broadly (the 'twin-track approach' – see Box 1), have also tended to place greater emphasis on numbers of people with different types of impairments than other essential element in the definition.

Box 1: Twin track approach

This is a combination of both **targeted** activities which enable people with disabilities to access services such as information, education and/or employment; and **mainstreaming** efforts which ensure all projects consider the impact on people with disabilities and actively include people with disabilities. By paying attention to the specific requirements of people with disabilities and providing adjustments ('reasonable accommodation' such as mobility aids, accessible buildings, sign language interpreters and so on) to enable access education, employment and community life, targeted activities enable people with disabilities to participate in and benefit from mainstream community or economic development opportunities.

Depending on the particular context in which information is being gathered, a range of other issues need to be considered, as described below.

2.2   How change happens

Key messages: The concept of change is not defined in the same way across the world. Diverse understandings of change influence the ways change processes and outcomes might be understood, both by people within and outside different contexts. When developing M&E approaches, it is important to focus on the nature of changes sought.

The achievement of disability inclusive societies generally represents a major developmental change and a radical shift in thinking from the current situation where societies create substantial, diverse and largely institutionalised barriers, to a future where societies are inclusive of all people. In each context, the barriers and processes involved in bringing about these changes are different. In particular, the changes sought include the idea that people with disabilities should increasingly participate in and benefit from positive economic and social change, facilitated by aid programs. The processes of change inherent in this shift are diverse, from changing society-wide attitudes to changing physical infrastructure. Governments and agencies interested in achieving these types of change hold many different understandings about the issues involved, changes sought and best ways to bring about change. There is little shared universal understanding about these issues. The diverse range of contexts means that no single approach can be applied to bringing about change.

Contemporary understanding about how change actually happens recognises that 'thinking and working politically' is particularly important (Carothers and de Gramont 2013; Menocal 2014; Booth and Unsworth 2014). There are also other ways of thinking about change[15]. There are also many different ideas about how aid activities can contribute to positive change in different contexts. Technocratic approaches, defined as the application of technical knowledge, expertise, techniques and methods to solve problems, are just one set among many others.

How agencies and practitioners conceptualise change and how change happens in relation to disability inclusion, have significant implications for M&E at many levels. For example, a political approach to change in disability inclusion may require an M&E system that emphasises how decisions were made and by whom, while an anthropological approach may involve M&E tools that generate community level understanding about changes in relationships and status. A technocratic approach may involve M&E systems which focus on the measurement of progress against pre-set and easily quantifiable indicators.

The implications of these different views of change and disability are considered in Section 3 below.

2.3   Definitions of Disability Inclusive Development

Key messages:

The concept of disability inclusive development has largely been developed in Western countries by donor and international agencies.

What success might look like needs to be defined in the context of each setting, as many factors influence both the current situation and the prospects for and nature of change.

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[15] For example, see Krznaric, R. (2007) *How Change Happens: Interdisciplinary Perspectives for Human Development*, Oxfam Research Report
Also, see upcoming book by Duncan Green called *How Change Happens*

The impact of disability inclusion is wider than the impact on the approximately 15% of the population.

Given the concept of disability inclusive development is relatively new, there is not yet a substantial literature available or a wide range of definitions. Disability inclusive development is intended to ensure that governments and societies, and in particular institutions, policies, programs and attitudes, are not the source of barriers to participation for people with disabilities and others. Barriers are any form of limitation which societies have in place (usually not deliberately) which prevent inclusion of people with disabilities or any other particular group. Inclusive societies reduce barriers not just for people with disabilities but for many others, such as those who care for people with disabilities (usually women), those who have temporary mobility issues, older people with declining sight or hearing, children whose behavior or looks attract stigma or discrimination, or parents using a pram on an urban street. Thus, disability inclusive approaches benefit whole communities, societies and economies.

For example, a health service which ensures that people who are blind are able to access its buildings and services may demonstrate that all patients have a right to good quality service and is more likely to treat all patients with respect. It may also reduce the need for people to be accompanied by family members who will therefore have to take less time away from their own education, livelihoods or other activities[16]. Similarly, making schools disability inclusive generates benefits for children who receive an education but is also likely to contribute to improved lives for their parents and families as well as to their classmates who will become a new generation of adults who understand about the rights of all people, and the broader economy, when the educated individual is able to earn their own living and support others financially. The impact of disability inclusion is therefore wider than the impact on the approximately 15% of the population who may have a disability at any one time. Efforts to plan for disability inclusion and monitor progress need to take this into account and therefore focus data collection on information relevant to inclusive policies, programs, services and public goods.

The definition included in the Australian Government's current policy is:

> *Disability-inclusive development promotes effective development by recognising that, like all members of a population, people with disabilities are both beneficiaries and agents of development. An inclusive approach seeks to identify and address barriers that prevent people with disabilities from participating in and benefiting from development. The explicit inclusion of people with disabilities as active participants in development processes leads to broader benefits for families and communities, reduces the impacts of poverty, and positively contributes to a country's economic growth.*

This definition reflects the interests and efforts of the Australian Government in its role as an aid donor. The M&E process for this policy would be expected to reflect the Government's understanding about changes sought as a result of its contributions to other countries' objectives.

Other stakeholders, including NGOs and DPOs, may emphasise or articulate similar or different elements in their own definitions. Definitions may reflect different degrees of ownership of the

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[16] Although it is worth noting that in some cultural contexts, the role of carer is more highly valued than it is in western cultural contexts and the concept of independence may be less valued.

disability inclusive development agenda (e.g. whether they undertake such work to comply with donor requirements or because of their own developmental values) and would also be dependent on both their sense of the existing situation and prospects and priorities for change over time.

CRPD provides a shared global understanding of the rights of people with disabilities and the roles of Governments and others in protecting these rights. In each of the countries where Governments and civil society stakeholders, including DPOs, are involved, policies are being developed and priorities are being negotiated and defined, subject to the normal range of policy influences. Thus, there is no single, shared definition of the changes sought in each context, which would reflect disability inclusion. The implication of this is that in every context, there needs to be a genuine and potentially ongoing discussion about 'what would disability inclusion look like in this context?' rather than an imposition of a single definition imposed from an external source.

2.4   Different types of data

Different types of data are relevant to disability inclusion globally and the work of aid agencies in particular. Three types are addressed here:

- Prevalence data about people with disabilities and the nature and extent of impairments
- Data and information about existing situations and any changes in the extent of inclusion of people with disabilities as a result of CRPD, Government policies and services, advocacy efforts over time (regardless of external interventions)
- Data and information about the effectiveness of strategies used by aid agencies, with a particular emphasis on the contribution or attribution elements.[17]

Prevalence data about the numbers or proportion of people with disabilities in a population may be expected to assist governments (and aid programs) in determining resource allocations for disability-specific services. This kind of data may also be useful as a part of broader demographic data about access to various types of services. However, detailed prevalence data may not be necessary for informing changes in policies about discrimination, access and most other aspects of inclusion. The figure of 15% of a population having a disability (World Report on Disability) is useful as a guide for most purposes. Even if in some countries, the percentage figure may vary (for many reasons) this would not have major implications for the majority of developmental changes sought under the umbrella of disability inclusion. The responsibility for collection of this data rests with governments of countries engaged in implementing CRPD and many agencies are assisting governments in relation to census questions for example.

The extent to which data is collected on specific impairments raises a number of major challenges, particularly in countries where services for people with diagnosed impairments, including welfare payments, medical and other support are not widely available or accessible. Simply asking someone if they have a disability and about the nature of the disability, can cause offence and segregation, let alone distress. If the disclosure does not actually lead to any improved service or changes in social attitudes, then the cost of data collection to individuals cannot be outweighed. In addition, when people are asked to talk about their impairment, the process in itself reinforces a focus on the impairment rather than on the inclusion side of the definition of disability. Data on the nature and extent of impairments does not at any time inform understanding about whether changes have

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[17] These different types of data have sometimes been blurred together but involve diverse meanings and elements and thus require different approaches and expectations in relation to data collection and value.

occurred in disability inclusion.   When this is added to the reality that disability is a highly debated and dynamic term itself, it is difficult to compare data or definitions across different cultural or social or institutional contexts.

Information about changes in the extent of inclusion of people with disabilities as a result of policy and service-delivery changes is more likely to be the focus of most M&E effort related to CRPD and SDG reporting by national governments. Information about changes resulting from advocacy efforts may also be the focus of M&E efforts by civil society organisations, including DPOs, in all countries. Such information could include various data types, including perceptions of changes by people with disabilities and their communities or representative organisations, society-wide attitude changes, reviews of government service protocols and accessibility guidelines, assessment of changes in accessibility and many other elements of change.   Analysis of changes might synthesise data about both changes in the inclusiveness of policies and services as well as changes in numbers/proportions of people being included in various processes. Information about how different groups of people may identify different priorities and perceptions could be considered important for this purpose but prevalence data on its own is not necessarily required in these contexts.

Information about effectiveness of strategies and the work of aid agencies may focus on the quality of inclusion processes (planning, implementation, monitoring etc.) and the extent to which externally supported efforts have achieved outcomes related to inclusion[18]. While prevalence data is unlikely to be highly relevant to this kind of analysis, it may be that data about the extent to which people with disabilities access various services or project processes or about comparisons with people without disabilities is useful, depending on the nature of the intervention. Most aid activities do not seek to bring about changes in numbers of people with disabilities[19], but rather changes in the extent of society's inclusion.

3.   Approaches to M&E

3.1   Many ways to understand change
Key message: There are multiple ways of approaching M&E, which reflect different ways of knowing, disciplines and frames of reference.

Multiple approaches to M&E have been developed in different philosophies and disciplines, as people have sought to understand and make judgements about processes of change. In contemporary development practice, **purposes** for M&E approaches include learning, improving performance and accountability (to program participants and contributors). There is also great diversity in approaches and tools used to understand change processes and assess change itself. Some emphasise expert assessment and others emphasise participant perspectives for example, while some emphasise quantitative data and others seek more qualitative information. Most tools used in aid and development contexts are generated in donor countries. Fundamentally M&E

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[18] compared with the category above which may be relevant regardless of any form of external support
[19] Programs which focus on prevention of disabilities, such as those in road safety, prevention of non-communicable diseases and other public health priorities may well seek to reduce numbers, but are generally not a major element of disability inclusive programs.

processes need to be closely aligned with the kinds of change being sought and negotiated to suit each context.

In the context of disability inclusive development, collecting data about numbers of people with disabilities may be appropriate in relation to understanding inclusion for specific activities, such as counting numbers of children with disabilities who are attending or not attending school, if programs aim to provide access for all. However, population-wide prevalence data on its own is not central to disability inclusive development and the costs and challenges associated with the collection of such data mitigate against efforts to do so, particularly in low-resource settings. Whether 2% or 20% of a population has disabilities or whether the figures change over time or space, has no real relevance to whether attitudes, accessibility or inclusion improves.

Different disciplines emphasise different M&E approaches. For example, in community development, M&E systems generally emphasise participation of community members in defining 'success' and identifying ways of understanding changes (such as through stories). In economic development approaches, M&E systems might emphasise the collection of quantitative data on changes in incomes or inequality. In advocacy-based organisations, M&E systems might emphasise evidence about the extent to which policies and attitudes have changed. There are few universally agreed approaches to M&E across disciplines, but many different approaches and tools to choose from, each with a different emphasis or purpose and a different set of benefits and limitations.

It is worth noting that approaches and tools currently used widely in international development have been developed by Western organisations and researchers and applied in other cultural contexts, so may or may not be culturally relevant (see 3.3 below). Different concepts of knowledge between cultures should at least influence the approaches taken in making judgements about the extent and nature of change. For example, Jane Shamrock's participatory action research (using Photo-voice methodology) of the lived experience of people with disability in Timor Leste, highlighted the importance of story-telling and sharing learning for achieving improvements in disability inclusion (Shamrock, 2016).

3.2   Instruments for measurement

Key messages: Many tools are available for M&E purposes and reasonable adjustments may be needed to ensure they are inclusive. Some specific tools are being developed but it is important to be clear that the tools need to match the issue being assessed, measured or understood and be culturally appropriate.

There is little literature available yet on M&E for disability inclusive development. However philosophical, political and technical issues related to M&E approaches and tool selection more broadly also apply to disability inclusion. For example, there is value in careful consideration of questions about who is deciding on the purpose of M&E; what approaches are best suited; what tools are most appropriate; who is undertaking analysis and through which lens; who owns the information; which type of data has meaning at different times; and how to maximise efficacy and benefits of M&E processes. Current experiences can inform future practice.

As noted in Section 1.1 above, there are no specific, simple or single instruments which can measure the different aspects of inclusion in every cultural context. The traditional simple distinction between quantitative and qualitative approaches to M&E has been replaced with more

sophisticated and nuanced contemporary approaches to researching and understanding change, reflecting ideas about complexity, context and diverse ways of knowing.

3.3   Different cultural values

Key messages: Cultural values influence the way that people and societies, as well as organisations, see issues related to inclusion, such as power and leadership, equality, change and risk. Cultural value differences need to be understood when engaging with change across cultures.

The cultural values that underpin the way people in societies and organisations see the world, prioritise processes and define change are diverse[20]. What one society may value, another may find inefficient and ineffective. Many core development issues, such as leadership, governance, access and equality are influenced by different cultural values (Rhodes 2014). While there is now more commitment to the rights of people with disability, the concept of disability inclusion, and social inclusion more broadly, reflects values about equality that are not necessarily shared globally.

In Western contexts, dominant cultural values tend to emphasise decision-making by individuals as well as leaders and systems which value and seek to bring about constant change, among other things (Hofstede 2005). However, aid programs are usually undertaken in countries where different values prevail. For example, in many Asian and Pacific cultural contexts, collectivism is more likely than individualism; relationship orientation is more likely than task orientation; high power distance is more likely than egalitarianism; and there is more likely to be a greater value given to sustaining the status quo than transformative change. Development, particularly in relation to dominant social values associated with inclusion, cannot be easily controlled by aid donors or development agencies. Changes in fundamental values, such as power distance and individualism, do not generally occur quickly or as a result of a small-scale external contribution, but of course may occur as a result of various globalisation or locally led influences, including social movements.

In Western cultural contexts, individuals generally expect to be categorised in demographic terms by gender or age[21] for example and there is generally little stigma associated with such terms or fixed expectations of 'membership' of these categories. However, in many Asian and Pacific cultural contexts, it may be more likely that an individual's identity and sense of their world is influenced by their membership of groups, defined by family, clan, shared language, island, village, religion or other group[22]. Membership is often characterised by some form of mutual obligation in collectivist societies, and group membership is regarded as essential for identity, protection and general well-being. The experience of disclosing personal information and being categorised in different cultures is not universal. Sometimes the effects can be divisive and disempowering, which in this context are the opposite of disability inclusive principles.

In the context of disability inclusive practice, the issue about whether there is a focus on individuals with impairments or on changes in community attitudes and leadership practices, suggests there is a

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[20] For example, see House R et al (editors), *Culture, Leadership and Organisations: The GLOBE Study of 62 Societies*, SAGE publications
[21] Although self-identity issues in individualist cultures mean that these definitions applied by experts are often resisted
[22] Recognising the importance of ensuring understanding and respect for the diversity and complexity of each context.

need to understand and negotiate appropriate approaches between people who may have different ideas about what is seen as good or bad, what is important or not important and how to achieve change. This also means that there is a need to understand and negotiate shared approaches to assessing the nature and extent of any changes. For example, in many cultures, having a leader tell and show his or her community how to be inclusive may be more effective than trying to raise widespread community awareness; and seeking ways of promoting collective approaches to inclusion may be more appropriate and effective than identifying individuals' priorities.

Of course, people with disability are most likely to share the dominant values of the society in which they live. Changes in perceptions of the status of people with disabilities in any social context might thus require systemic, nation-wide changes. This also means that separating out people with disabilities as 'individuals' in a collectivist society may cause more harm than benefits, depending on the other processes involved. The imposition of external definitions of change, impairment, data and related aid agency processes in the disability sector is potentially as harmful as the imposition of any other external process in any development processes, in the absence of considered and respectful negotiation and collaboration.

Importantly, some DPOs in developing countries are following requests from external partners and donors to collect data about individuals' impairments, without being able to consider whether this is culturally appropriate and to negotiate more culturally appropriate approaches. In collectivist societies and when considering disability inclusive approaches, for example, it may be more appropriate to work at family, household or village levels to identify what steps are already taken to maximise inclusion, rather than single out individuals.

In practical terms, implications of different cultural values for disability inclusion include:
- the need to understand cultural values which underpin societies and community behaviour and norms (in both our own and others' cultures), particularly in relation to change and relationships between people
- the need for programs and practitioners to understand the implications of cultural value differences and other sensitivities related to lives of people with disabilities within their cultural contexts, particularly related to disclosure, labelling, diagnosis and lack of access to services
- the need to avoid applying definitions of disability from one culture onto another, without respectful negotiation
- the need to ensure that any disability inclusive development work and related M&E processes are relevant to the particular context and do not cause harm and increased isolation or separation
- the need to recognise that the pathways from welfare approaches to rights based approaches are not the same in every cultural context, so require development partners to develop deeper understanding of each context, rather than apply donor driven processes which assume shared understanding of terms (disability, development, impairment etc.)
- the need for aid programs to work very closely with local partners to develop cultural understanding and understand effective strategies to support local efforts towards inclusion

- the need to recognise that some data collection and analysis processes are more culturally appropriate than others in different contexts, so need to be negotiated within respectful partnerships, not imposed to suit external audiences.

4.   Purposes of data collection

The previous two sections highlight that disability inclusive development is a relatively new concept and thus the people and organisations involved in the processes of facilitating change are still learning about how they might engage in learning about the nature and extent of changes involved.

The purpose of undertaking M&E work is usually to contribute to ensuring development efforts are effectively achieving plans and contributing to the objectives negotiated to suit each context. Theoretically this implies that M&E processes should contribute to benefits for the specified participants and not only to a donor's understanding about effectiveness of the funds allocated. Data collection is one part of M&E and can be undertaken in many ways. There are many lessons learned about the purposes, benefits and limitations of data collection processes. These lessons need to be understood by those involved in the disability inclusive development context.

Importantly, the question needs to be asked whether the collection of data from individuals with disabilities is actually beneficial to them and their communities or whether it is primarily used for the benefit of others.

Equally importantly, the question needs to be asked about whether the focus on disability inclusive development is for the purpose of improving the lives of individuals in developing countries or improving whole communities. Clearly, the expectation is that both will benefit from disability inclusive work, but the focus of data in each case is vastly different and needs to be considered.

Building on the three types of data mentioned in Section 2.4 above, it is important to be clear about the **purpose and use of data**:

- Demographic data on numbers of people with disabilities and medical information about the prevalence of impairments may by useful for the purposes of:
    o Encouraging governments to recognise the priority of addressing inclusion objectives
    o Government determination of budgetary and other resource allocations for national or local level targeted welfare or service delivery requirements for example in health and education
        ▪ For example, the Australian Government states that 'Nationally consistent information on students with disability is essential to ensuring that Australian schools have the necessary support in place for principals, teachers and other school staff to assist students with disability'
        ▪ For example, country governments may consider whether to initiate a welfare payment for people with disabilities, so knowing how many potential claimants would be important for financial modelling.

- - Generating a sense of being acknowledged or recognised among people with disabilities

- Information about changes/progress in disability inclusion, may be useful for the purposes of:
  - Government and other reporting on achievements against articles of CRPD or other regional or national policies
  - Accountability to members of organisations involved in advocacy and supporting change processes
  - Contributing to positive momentum towards ongoing improvements in legislation and policies to reduce discrimination or ensure services are inclusive and accessible
  - Accountability to organisations funding such processes

- Information about the effectiveness of strategies and the work of aid agencies, may be useful for the purposes of:
  - Accountability to people with disabilities and their communities who participate in aid activities
  - Learning and sharing with others about what approaches work well and thus what to expand or continue
  - Reporting on specific program goals
  - Accountability to organisations funding aid activities

In Australia, it is now expected that policy makers seek data to inform policy development and the design of programs related to developmental change, consistent with the concept of 'evidence-based policy' (ANAO 2001), although there are plenty of challenges involved in contemporary reality (Head 2014). However, as the literature consistently attests, the type of data and the focus of data collection need to be considered carefully to ensure:
- the data collection processes are appropriate for the purpose
- the right kinds of data are being collected
- the data collection process is contributing to benefits and not further disempowering people
- analysis processes reflect appropriate understandings of the issues involved
- the data is used appropriately.

5.   Approaches to data collection

As noted above, in the context of disability inclusive development, data collection raises particular issues, specifically where definitions and understanding of concepts such as disability, inclusion, empowerment, rights and development may not be shared. This section focuses on two of these issues: the focus on counting people and defining impairments; and the complications associated with labelling people in different cultural contexts, where the consequences cannot be easily understood by those external to the context.

Counting people with disabilities ('disability disaggregated data') and categorising them into different impairment types appears to be a major focus of current development agencies and program teams[23]. This type of data collection is actually about only one aspect of disability inclusive development, impairment or the degree of 'function' that an individual person has in relation to various tasks[24], and not disability overall. Disability and inclusion questions should be and by definition are for whole societies, not solely focused on people with disabilities.

Data collection about individuals with disabilities and about their impairments may be useful for governments if there is an intention and ability for services to be provided for specific groups, and if the data is complemented with data about the barriers that society has in place which prevent inclusion. However, in most public policy contexts, demographic data is not sufficient on its own to bring about change. The kinds of aspirational social and policy changes included within CRPD require significant political will, leadership, major changes in budgets, social and systemic changes. The identification of a % figure of a population with disabilities and a detailed analysis of the types of impairments that appear in every population group appear to be of limited value in determining such changes. Use of the 15% figure included in the World Report on Disability is sufficient.

The consequences of counting people with disabilities and trying to categorise their impairments, particularly in diverse cultural and policy contexts, need to be fully understood and managed before efforts are made in this area. As noted in the CBM Practice Note, 'it is very important to make sure that screening or targeted analysis of the situation of people with disabilities does not cause them any harm, shame or stigma relating to being 'labelled' (i.e. publicly or privately identified) as having a disability.' However, there is not yet sufficient understanding about how aid agencies can understand this issue in different cultural contexts and sufficiently manage such risks.

For example, in many collectivist cultures, there is a high degree of shame and low status associated with people with disabilities, so asking for self-disclosure or for others to identify those who might fit certain categories may exacerbate and highlight this low status. While the intention of aid agencies may be to address such values and attitudes, it cannot be assumed that identifying individuals with impairments is the best way to do so.

The issue of diagnosis of medical conditions or impairments also raises issues for aid agencies. For example, in most Pacific countries, the availability of medical specialists is low, so determining whether an individual has an intellectual or learning disability or a psychiatric illness, may be almost impossible. Diagnosis of children in particular is notoriously difficult, even in highly resourced settings. The contexts in which judgements are made can have significant influences on diagnosis issues. For example, an individual who requires a pair of glasses could be categorised as having a disability in a location where glasses are not available but not in an urban setting with optometrists. A person with a short-lived case of depression could be categorised as having a disability on one occasion, but not at another time.

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[23] Such as DFAT's requirement for NGOs which receive Government funding to quantify participants in all international programs according to the Australian Bureau of Statistics definition of disability.
[24] As addressed in the Washington Group's short set of questions recommended for census processes http://www.cdc.gov/nchs/data/washington_group/wg_short_measure_on_disability.pdf

The expertise to make medical diagnosis of health conditions, impairments and chronic illnesses is not generally found among aid workers. Purchasing such expertise is not likely to be feasible for most aid organisations and questions should be asked about the benefits of such inputs for people with disabilities or communities in any case. The key point is that disability, as defined by CPRD, cannot actually be determined by medical diagnosis.

6.   Use of data

Given that disability inclusive development is about changing attitudes and approaches across whole societies and systems so that every person's human rights are realised, as articulated in the CRPD, it would be reasonable to expect that data will be used to contribute to such changes. However, it is not yet clear how governments, DPOs and development agencies, will use the data currently being collected and whether it will actually lead to disability inclusive societies.

Ensuring that any data collected is both meaningful to the changes sought and used in appropriate ways, i.e. to support positive changes, is critical. If data is collected to inform the nature and quality of new policies and programs, then this would be a useful process. If it is used to confirm that the numbers of people with disabilities in any particular location or category are too low to justify the use of scarce resources, then the data collection process would be detrimental to the changes sought. If data is collected in one country for the sole benefit of feeding perceptions in another about accountability, then questions need to be asked about both ethical and practical implications.

Consistent with the concept of 'nothing about us, without us' it is important to ensure that data generated through various processes is actually useful for and used by people with disabilities and their respective representative organisations. Thus, participation by people with disabilities in determining the kinds of data sought and the ways in which it is collected and understood is crucial in every context.

It is easy to argue that to sustainably improve accessibility of information, public spaces and services, it does not matter how many people with disability exist at any one place or time. What could be more important, for example could be views of people with disability about their priorities for access and evidence that their priorities have been met. Or evidence that service providers have been trained in inclusive approaches and universal design and are resourced to deliver inclusive services.

7.   Conclusions

It is certainly important that more is learned about how to contribute to increasingly disability inclusive societies around the world, consistent with the CRPD and the SDGs. The ways that information is collected, analysed and used are important in this process, and care should be taken to avoid 'lowest-common denominator' approaches.

Maximising chances that data actually contributes to improvements in disability inclusion at society level requires consideration of complex issues related to change, culture and power, as well as specific aspects of data collection, analysis and use. The following suggestions emerge from this perspective, including the opportunity to:

- Ask more questions (see below) about **why, when, what kinds of data** and **for whom** data is collected, in addition to **how** to collect data
- Be more politically cognisant about **how change actually happens** in diverse cultural settings, particularly in relation to social and attitudinal change
- Ensure **the voices of the citizens of countries where aid is given** are listened to, including about **what is important.**
- Take a **slower or more timely approach to data collection and analysis**, both to ensure that people in each context are involved in determining what should be measured and why and ensure that relevant information is gathered at the right time in the change process.

The latter point recognises that no-one really knows yet what disability inclusion will look like in each society and how data will be used to actually assist communities to become more inclusive of people with disabilities. Importantly, harm could be caused by the process of 'counting' people with disabilities prior to raising awareness about the rights of people with disabilities and before there is a real prospect of services being provided and inclusive societies being progressed.

To assist those involved in data related to disability inclusive development, a list of questions is proposed, which aim to encourage reflection and discussion with partners and to maximise the likelihood that efforts made will actually contribute to more inclusive societies.

Purpose
1. What is the most important purpose for collecting data?
2. Who is determining the reason for the data collection?
3. What are other purposes for collecting data (that may or may not need to be prioritised)?
4. How can we ensure that the data we collect is relevant to the policy, programming and attitudinal changes that people in the specific context seek to achieve?
5. What information will tell us about the specific changes involved?
6. Who will actually benefit from the information generated?
7. What is the opportunity cost associated with data collection, i.e. would funds needed for a survey be better spent on raising awareness or responding to local priorities for inclusion?
8. Will the data help to raise awareness of the costs of exclusion?

Approaches
1. How can we ensure that M&E approaches and data collection processes will contribute to benefits for people with disabilities and their communities?
2. How can data about individual people and impairments be collected in ways which address challenges associated with disclosure, accuracy of diagnosis, shame and taboo and raising unmet expectations of service provision?
3. How can data about individual people be focused not only on impairments but also on barriers and opportunities to reduce barriers, so there is a more balanced approach?
4. How can approaches include people with disabilities in each context in planning, implementation, analysis and promotion of findings?
5. How are various types of data to be analysed within the context of understanding about each country context and the priorities expressed by DPOs?
6. Are the approaches to be used potentially going to cause distress, disempowerment or further exclusion through labelling or highlighting individuals within their communities?

7. Is the approach proportionate to the expected benefits, in terms of cost and potential negative impacts on people?
8. How can approaches used recognise people with disabilities as citizens of their own countries and part of communities rather than subjects of externally determined programs?
9. How will the data be analysed (through which cultural lens) and by whom?
10. How can M&E approaches be used to contribute to shared understanding about what disability inclusion looks like in each particular cultural context?
11. What approaches can increase shared understanding about a community's most significant barriers and progress made towards the removal of those barriers among local and external stakeholders?
12. Have ethical and confidentiality issues been sufficiently addressed to protect the rights of people with disabilities, especially in cultures different from those in donor countries?

Use of data

1. Are people with disabilities involved in analysis and use of data?
2. What power do the users of this data have to influence change processes?
3. Is the data actually useful to inform decision-making by those with influence in each country/context?
4. In particular, how can data be used to enable local and other DPOs to think and work politically in relation to advocacy programs?
5. How will the data actually be used in different contexts, respecting confidentiality, sovereignty and other ethical considerations?

There are no 'right' answers to these questions, but hopefully the conversations generated and the reflections undertaken will lead to more effective collaboration and relationships, useful and meaningful data and more disability inclusive societies as well as change processes which reflect the reality of each setting and which benefit everyone.

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