Based on lessons learnt, how to effectively mainstream disability in development and to achieve the SDGs for persons with disabilities?

Introduction

1. The Sustainable Development Goals (SDGs) offer new hope for the inclusion of persons with disabilities in mainstream development. As many of the speakers today will no doubt note, the inclusion of persons with disabilities in the SDGs is of particular importance because the absence of any mention of disability in the MDGs meant that persons with disabilities were often left out of the global and national development agendas.

2. In this paper, I have been asked to speak about lessons learnt by Leonard Cheshire Disability and by the wider global disability community on how to effectively mainstream disability in development. Let me offer here today several examples of lessons learnt but let me also use this opportunity, to expand upon the assigned discussion of 'lessons learnt' to also raise a series of questions that remain unanswered – because this is an equally important challenge - *what are we NOT asking regarding the inclusion of disability in the SDGS that is critical for us to know*.

Lessons Learnt

3. Country governments and the international community used the MDGs to prioritize their development efforts in the period between 2000 and 2015. Because disability was not included – and specifically because data on the inclusion of persons with disabilities was not part of the regular and required reporting on progress towards the MDGs, there were few activities that effectively involved disability issues or persons with disabilities[1]. A key component of what we have learned over the past 15 years then is accountability - the need to make reporting – (governments, NGOs, UN agencies) – a *requirement*.

4. And this *requirement* must have teeth – failure to include or a deliberate attempt to exclude persons with disabilities must have consequences. For example, countries sanctioned, funding withheld – and so forth.

5. Part of the effort moving forward requires the consistent collection of data on inclusion – to make sure that persons with disabilities are being reached and served by development efforts at the same rates as their non-disabled peers. But this requires not only better data collection but – importantly - data analysis and uptake. Collection of data means little unless this data is then analysed and fed back to government, funders and civil society – including DPOs and persons with disabilities in formats that make the information useable for real social change and economic inclusion, and unless there are systems in place to take the information provided and use it for the next round of SDG monitoring and evaluation[2].

6. Another key lesson is that we cannot assume that development professionals understand disability from a social/ human rights perspective. Even those who realize that disability is an issue of concern often continue to view it as a medical issue or a charitable issue – (i.e. children with disabilities have the right to an education and we'll get to these children as soon as all other people have been served). We need – as the global disability community to make a much more consistent effort to educate the global development community – (both current policy makers and practitioners and the next generation of practitioners) – to really understand and not just give lip

service to disability issues – and we must be consistently vigilant to ensure that those we work with in the broader development community really understand disability issues and concerns.

7. Another key lesson is that we need to more critically think about the concept of what successful mainstreaming really looks like. Over the past decades there has been a great deal of discussion about inclusion - but we need far more discussion about what such mainstreaming actually looks like and what key factors must be put in place to ensure *sustainable* mainstreaming.

8. We often cite the 'twin track approach' – an important concept in which disability issues are included both in mainstream development efforts and where needed, in disability-specific development programmes. (This by the way is a common approach in public health and development where general programmes are supplemented by programmes targeted at harder to reach populations). But we now know that there is a range of ways that inclusion can occur – and we may be better off discussing/ approaching disability inclusion as a range of options/ a continuum rather than being boxed into an 'either mainstream OR disability-specific' choice.

9. Finally, we have learnt that nothing 'stays fixed' – that inclusion of persons with disability requires constant vigilance at all levels. It will always need to be carefully watched and constantly evaluated.

Questions still to be raised – Let me turn now to questions that remain unanswered or were not raised by the MDGs – but that will require attention if the SDGs are to be truly effective. In other words, what we do not know:

a. What are the criteria by which we are judging the effectiveness of mainstreaming disability? As a sector, do we need to agree what our goal is?
b. We often cite the gender model as a good example of inclusion – but we need to think this through more carefully, as gender inclusion has not been wholly successful and there are strengths and weaknesses in such a facile linking of gender and the more complex issues involved in disability
c. Because of the large number of SDGs key stakeholders are already talking about prioritizing the work that will need to be undertaken. What would prioritization mean for disability, and how should disability groups and organisations prioritize? Do we need a consensus on this in the first place, or will different disability groups find their own way?
d. Disability is a cross-cutting issue – what is the most effective way to combine disability with gender/ with ethnic and minority issues?
e. And there are key arenas that we have only begun to look into but which require more discussion and evidence to ensure development truly transforms the lives of persons with disabilities. For example:
   i. Employment - it is not just a question of finding work but also about the ability of persons with disabilities to build the job into a viable career that will last them a lifetime and provide them with the means to rise out of poverty and to support not only themselves but their households. What do we know of this, particularly in poorer communities in low and middle-income countries?
   ii. Education – How does education – (both school based and also education for skills/ on-going adult education) – translate into action that will enable people with disabilities to stay ahead of poverty?

iii. Social protection programmes –what does it mean to establish a social protection programme. How do such programmes differ? What do they need to be effective? What voice can persons with disabilities and their organisation have in such programmes?

iv. Housing/ transportation are key components of society - and there are major components of the SDGs that relate specifically to housing and transportation. Yet this sector, aside from a small number who specialize in accessibility – has given very little attention to disability, particularly in low and middle-income countries. With more than 50% of the world's population now living in urban areas, it is of particular concern that disability has been so rarely addressed by major agencies such as UN Habitat; that fleets of older inaccessible buses are being bought by less developed countries and transferred from developed to developing communities, that new schools, court houses and office buildings are rising up all over the developing world with little or no attention to accessibility, despite what progressive legislation and the CRPD may say[3]. How can urbanisation be made to work for persons with disabilities?

v. Finally, once changes have been made under the SDGs, how do we successfully maintain these changes?

Conclusion

The discussion here can only begin to cover the complexities and nuances that we will need to consider for the successful inclusion of disability in the implementation of SDGs. It is imperative that we ask not only what do we already know, but also – what are we currently missing – if progress is to be made. Leonard Cheshire Disability is working to answer some of these questions, and would like to partners with others in this room to find scalable solutions.

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[1] See Groce N, Disability and the Millennium Development Goals, United Nations New York, 2011, and Groce, N. and Kett, M. (2014. forthcoming). The Disability and Development Gap. Working Paper 23. London: Leonard Cheshire Disability and Inclusive Development Centre

[2] Leonard Cheshire Disability captures data regarding its inclusive education project in Kenya using an online database that is expected to be part of a larger, Government managed national database. Our Research Centre, with support from DfAT, is also supporting the work of the Washington Group to strengthen the collection, analysis and use of disability data.

[3] Leonard Cheshire Disability's inclusive education and livelihoods projects have consistently identified persons with disabilities unable to attend school or retain a job because of inaccessible transport or public buildings. Dispanshu, for example, a young man we support in India stopped attending primary school because the school was inaccessible due to uneven roads and steep steps, and because the schools toilet facilities were also inaccessible. Our research has also shown that in the UK, intimidating behaviour from bus drivers or a lack of space for wheelchairs has driven persons with disabilities off public transport into more expensive options (including taxis) or left them unable to travel at all.