

Editorial: Disability and the SDGs: is the battle over?

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The Sustainable Development Goals (SDGs) were agreed in September 2015 after a long period of negotiation and debate. While disability is not one of the agreed goals, it is for the first time mentioned in reference to five of the Goals: education; employment; reducing inequalities; sustainable cities and communities; and data collection. This represents an important step forward from the previous Millennium Development Goals (MDGs), which did not specifically mention disability or track whether the Goals were achieved for people with disabilities. This means that it is impossible to know whether people with disabilities benefitted from the advances made through the MDGs or were in fact left behind.

Much of the impetus for the inclusion of disability came through strong lobbying, with many calling the previous exclusion of disability from the MDGs a ‘missed opportunity’ (UN, 2011) amidst other calls for ‘inclusive development’ and more recently ‘disability inclusive development’. It is, though, important to emphasise that this lobbying was borne from the disability, and not from the development sector. Lacking too, was critical reflection on the previous MDGs and lessons learnt from impacts on other populations (e.g. women). While the MDGs were considered a success by many (see UN, 2015), criticism by critical development scholars, activists and others was not scarce, including that highlighting persisting extreme poverty, increasing inequality (not accounted for in the emphasis on aggregate growth) and gender disparities (see Fehling et al. 2013). Others such as Grech (2015) questioned the potential disabling impacts of development itself, including the neoliberal agenda guiding development, one emphasising cost-cutting, weakening of states, privatisation, exportation, and extreme individualism, invariably impacting those weakly positioned to participate in individualistic neoliberal markets.

It is too early to determine the extent to which the SDGs will impact (if at all) the poorest and most marginalised (including people with disabilities). However, they cannot be ignored in discourse and practice focused on disability in the global South, not least because these goals set the development agenda, priority areas and consequently budgets. They also cannot be approached and celebrated uncritically if genuine well-being, inclusion, poverty reduction and equitable growth are to be achieved, and if measures are to be taken when benefits are not reaped for people with disabilities on their own terms, wherever they may be. Mentioning disability in the SDGs is not enough. This needs to translate into concrete action

if it is to improve the lives of people with disabilities and their families. It is therefore important to reflect critically on what the inclusion of disability within the SDGs actually means in practice while putting forward a number of questions over space and time. These include: will development now become truly inclusive or is it just tokenistic? Will equity and equality be adequately prioritised? Are national resources and commitment in place to ensure these SDGs are fulfilled?

We embarked on addressing some of these issues in the 2016 Symposium entitled ‘Disability in the SDGs: Forming Alliances and Building Evidence for the 2030 Agenda’ held at the International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine. The conference welcomed more than 250 delegates who presented and reflected on some of these questions. One of the emerging issues and conclusions was the need for a more critical space to bring people together to raise questions, debate and work towards critically reflective practice.

This special issue is a continuation of this conference, and offers us an opportunity to pause one year on and take stock of where we are and to look forward. It is undeniable that the inclusion of people with disabilities in development efforts is not happening on a large scale. The paper in this issue by Kerr, as an example, shows that only 5% of the World Bank’s active social protection programmes include people with disabilities as target beneficiaries. Moving forward, several pieces of the puzzle are needed to be in place for the words around disability inclusion to translate into action. A strong evidence base is needed to highlight if and when people with disabilities are being left behind, not included or persist untargeted, and to work in informed and inclusive ways to develop strategies that may close these gaps. The drivers of national policy and programmes need to be committed to disability, and dedicated budgets need to be in place to support inclusive activities. Crucially, people with disabilities need to be centrally involved in plans and strategies to ensure that actions promoting inclusion are relevant, acceptable, and lead to genuine change.

The articles in this special issue and those presented at the 2016 Conference, consider the evidence base around the inclusion of people with disabilities, particularly with respect to health, poverty and education. Emerging evidence suggests that despite marginal changes in discourse, people with disabilities continue to be left behind in these areas, while emphasising the need for inclusive development that moves beyond mere rhetoric. Yet, large data gaps remain, and data collected so far is not always comparable. Qualitative research also remains scarce. The SDGs, in particular Goal 17, advocates for the collection of high quality data that is disaggregated by disability. Such data would show where people with disabilities are left behind, and also whether the SDGs are successful over time in closing these gaps. It is, though, important to emphasise that data collection and disaggregation depends on the routine measurement of disability. Furthermore, the heterogeneity of social, economic, political and cultural contexts, and personal circumstances, make the generation of

comparable data profoundly difficult, if not impossible. The article by Eide et al. in this special issue discusses some of these emerging concerns in the bid to attempt to measure disability. Numbers are also not enough, and therefore information collected must use mixed methods with genuinely inclusive and participatory methodologies. The meaningful inclusion of people with disabilities in collecting data is in keeping with the “Nothing about us, without us!” slogan of the disability movement. The article in this special by Greenwood puts forward one mechanism by how this can be achieved to ensure that research on inclusive development has at its heart the voices of people with disabilities.

This issue and the conference highlight major critical issues in what it means to ‘include’ and how to go about this. Among contextual, semantic and conceptual concerns, are also practical ones, not least those of checks and balances guiding how governments and also the development community operate. This presents the research community with key challenges, including how studies can address discourses around cost-effectiveness too often raised by governments and organisations. Without this information, those lobbying for inclusive development will struggle to make a convincing case to those guiding policy and programme that inclusion of people with disabilities is realistic, needed, a duty and a question of rights, and not a ‘waste of money’ and to persuade them to dedicate budget lines to these activities. This is not an easy gap to fill, since different approaches work in different contexts, and people with disabilities are not a homogenous group, so there will not be a one-size-fit all solution to inclusion.

Another issue is that although the SDGs are cited individually, they are inter-connected and the achievement of one, is contingent on and will impact the achievement of another, perhaps particularly for people with disabilities. This is highlighted clearly in the articles in this special issue – access to education is often dependent on adequate access to health care; poverty reduction depends among others on inclusion in labouring opportunities; and health care access relies on effective poverty alleviation. It is therefore important to think beyond these silos to look at disability as well as the SDGs holistically, cross-sectorally, and to remain critically aware of the various intersectionalities.

The inclusion of disability within the SDGs is an important step forward, but is by no means the first and only achievement of the disability movement. The UNCRPD has been a game-changer in highlighting the rights that people with disabilities must enjoy. However, and in a similar of fashion to the SDGs, rights, legislation and conventions are far from enough in contexts where rights are violated on a daily basis, too often with impunity. The absence of critical questioning on the impacts of the CRPD in practice, continue to compromise the way research, theory, policy and practice develop and change, and also impact lobbying efforts (see Soldatic and Grech, 2014). Other questions persist, including the relationship between the CRPD and the SDGs and the ways in which they may or may not work together. Activist and practitioner Diane Kingston tackles some of these issues in her short reflective article

This special issue is far from a complete project. It is little more than a small step in starting to engage in critical debate on research and practice, on developing discourses. We hope that others will take these initial critical debates on disability and the SDGs forward in ways that can lead to genuine and concrete inclusive action. To reiterate our previous point, like anything else, having disability on paper is just a start, and is far from enough. We need genuine and ongoing spaces for critical thought, for research that provides evidence on the extent to which inclusion is happening on the ground, and to ensure that interventions are kept in check, that they are respectful of the rights of people with disabilities, that no one is left behind, and above all that they emerge from the needs and demands of persons with disabilities. Real disability inclusive development does not start and end with the SDGs. It is a long and tumultuous process, and being inclusive means engaging with those voices raising and demanding critical questioning and critical 'solutions' that are adapted, adaptable and malleable to accommodate all. We believe that ultimately, an inclusive approach will make development efforts better for all, beyond people with disabilities, and help with the successful achievement of the SDGs.

References

- Fehling, M., Nelson, B.D. et al. (2013) Limitations of the Millennium Development Goals: a literature review. *Global Public Health*, 8(10), 1109-1122.
- Grech, S. (2015) *Disability and Poverty in the Global South: Renegotiating Development in Guatemala*. London: Palgrave Macmillan.
- Soldatic, S. and Grech, S. (2014) Transnationalising Disability Studies: Rights, Justice and Impairment. *Disability Studies Quarterly*, 34(2)
- UN (2011) *Disability and the Millennium Development Goals: A Review of the MDG Process and Strategies for Inclusion of Disability Issues in Millennium Development Goal Efforts*. New York: UN.
- UN (2015) *The Millennium Development Goals Report 2015*. New York: UN.