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The Disability and Development Gap

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ABSTRACT

International development efforts up to and including the Millennium Development Goals have improved the lives of millions of people over the past 15 years through significant advances in health, education, economic development, communications and human rights. However in this paper, we argue that there has been little attention to the systematic inclusion of the world's one billion persons with disabilities in these initiatives – and because they have not been included they have lagged behind their non-disabled peers. This 'lag' has created what we term here a 'disability and development gap' in many countries where the socioeconomic status of persons with disabilities has remained stationary while the well-being of many of their fellow citizens has moved ahead.

We further argue that unless specific measures are taken to ensure the inclusion of persons with disabilities in current and future international development efforts, including the forthcoming Sustainable Development Goals, the 15% of the world's population who live with a physical, sensory (i.e. deafness, blindness) intellectual or mental health disability are at risk of continuing to live in poverty and social isolation, remaining poorer in both relative and absolute terms as their non-disabled peers rise out of poverty.

Key words

Disability; poverty; inequality; inclusion; development

INTRODUCTION

While international development efforts including the Millennium Development Goals (MDGs) have improved the lives of millions of people in recent decades, there has been little attention to the systematic inclusion of the world's one billion persons with disabilities – 15% of the global population (WHO/World Bank, 2011) - in these initiatives.

In this paper we argue that in many countries and in many domains, this has resulted in an ever-widening 'disability and development gap.' While millions of non-disabled people have benefited from improvements in health, education, economic development, communications and human rights, persons with disabilities who have not been included in these development efforts lag increasingly behind their non-disabled peers.

Unless specific measures are taken to ensure inclusion of persons with disabilities in current and future international development efforts, including the new Sustainable Development Goals (SDGs), millions of persons with disabilities are at risk of living in continuing poverty and social isolation while their non-disabled peers begin to lead more prosperous lives..

THE DISABILITY AND DEVELOPMENT GAP

The concerted efforts made by the international development community – including UN agencies, national governments and civil society – since 2000 through the MDGs and a host of allied anti-poverty and social justice campaigns, have made significant strides in addressing global poverty, hunger and disease. For the first time since

records on poverty began, the number of people living in extreme poverty has fallen in every developing region (World Bank, 2015).¹

While there has been concern that many of these UN statistics are overly optimistic (c.f. Clasen, 2012), and it is universally conceded that there is still far to go, there is no question that global development is on an upward trajectory, with millions living better and healthier lives, and many countries moving from low- to middle-income country status. This progress is anticipated to continue under the forthcoming Sustainable Development Goals (UNDESA, 2015).

However, while millions of people have benefited, one group has been consistently left out of these global development gains. These are people who live with a physical, sensory (i.e. deafness, blindness), intellectual or mental health disability. The World Health Organisation in collaboration with the World Bank recently estimated that 15% of world's population, some one billion people, live with one or more disabilities that have a direct impact on their daily lives (WHO/World Bank, 2011). One household in every four has a disabled member. Moreover, persons with disabilities are consistently among the poorest of all the world's peoples (WHO/World Bank, 2011). They are not only poorer in economic terms but also are comparatively poorer in all domains – health, education, employment, income and social inclusion (Mitra, et al., 2012). If these people are not effectively reached and included in development efforts then many of the development goals that will be set in the forthcoming post-2015 agenda will not be reached (UNDESA, 2011).

¹ According to UN estimates (UN 2012), by 2010 the proportion of people living on less than US\$1.25 fell to less than half the 1990 rate, from 47% to 24%, despite the global increase in population and recent economic downturn (UNMC, 2015). These advances are reflected in many of the key development indicators. For example, maternal mortality decreased by 47% over the past decade, in large measure because of the increase in deliveries by skilled health personnel (from 55% to 63%) and in women receiving prenatal care (from 63% to 80%). Five of the world's nine developing regions reduced under-five mortality rates by 50%, from 12.4 million to 7.6 million deaths per year. Primary school enrolment rates have increased by 43 million children worldwide, with sub-Saharan African rates rising from 58 to 76%. By 2015, 92% of the world's people will have access to safe drinking water, and the percentage of slum dwellers in urban areas will have declined by 100 million people, from 39% in 2000 to 33%.

Why people with disabilities have not been included in development efforts

There seems to be a series of interrelated reasons why persons with disabilities have not been routinely included in development efforts. A primary factor is that many international development policymakers and practitioners, as well as government officials and members of civil society, do not consider the needs of people with disabilities as part of their remit. Among these professionals, disability is still considered – if it is considered at all – as a charitable endeavour or a medical issue rather than an international development concern.

This framing of disability reflects underlying assumptions (models) about disability that go largely unquestioned by the broader development community. In many countries, a charity model still frames the thinking of development and health professionals. In this model – which was the universal way of conceptualising disability prior to the 20th Century – persons with disabilities are seen as vulnerable and passive, dependent on the goodwill of others. Providing services or including persons with disabilities in development efforts is seen as a charitable concern, to be tackled when and if development experts feel they have resources left over after members of the broader population have been reached.

In the early 20th Century, as modern Western medicine improved, this ‘charity model’ was replaced in a number of countries by the equally problematic ‘medical model’ (Groce, 2014), in which people with disabilities are seen as being in ill-health and decision-making for their needs and entitlements is seen as being in the hands of medical experts. These medical experts may be accountable to government, civil society or family, but rarely to the persons with disabilities themselves. In this model, the ‘problem’ lies with the person with disabilities, and the locus of control lies in the hands of others.

This ‘medical model’ has been severely criticised by disability advocates who have reframed disability through the ‘social model’ (Oliver, 1996) arguing persuasively that many of the barriers that exist for persons with disabilities are environmental or social, rather than medical. In this model, the barriers to inclusion are not based on an individual’s disability but exist in the surrounding society through factors such as

negative social attitudes, unequal access to resources and denial of rights and opportunities. It has proven an exceptionally useful framework through which to identify and address discrimination and exclusion.

Most recently a 'human rights model' has evolved out of the social model, which recognises social and environmental constraints and redefines disability as a human rights issue. Persons with disabilities have a right to full participation in society and a right to equal access to resources because, it is argued, this is the right of all human beings (Degener, 2013). The most tangible outcome of this evolving conceptual framework is the United Nations Convention on the Rights of Persons with Disabilities (CRPD) passed in 2006 and now ratified by over 150 countries that legally guarantees the inclusion of persons with disabilities in all development efforts (Article 31; UN, 2006). In all countries, ratification has been accompanied by progressive legislation and increasing attention to disability in government and civil society.

Unfortunately, this progressive reframing of disability from a 19th Century 'charity model' to a 21st Century 'human rights model', has barely begun to permeated within the international development community. Indeed, although the majority of countries have now ratified the CRPD, many development policy makers and practitioners at national and international levels remain unaware that the CRPD exists or that persons with disabilities must be included in all development efforts. This change in knowledge and approach is not being systematically disseminated within the development community. Unlike gender, which is now systematically included in the vast majority of development initiatives, disability is rarely included in national or international UN, bilateral or civil society development initiatives.

For too many development experts, a charity or medical model continues to underlie their decisions regarding resource allocation to persons with disabilities² .

² Indeed, it is quite common for the charity and medical models to exist simultaneously. While Western disability advocates and researchers often talk about a pre-existing medical model being replaced by a more progressive social model, in a number of low- and middle-income countries where modern medical and rehabilitative approaches to disability have never been introduced or have only reached a small percentage of all persons with disabilities fortunate enough to have access to modern

Compounding this, because disability is often still viewed through a charitable or medical lens, when resources are allocated for persons with disabilities, it remains common for the little available resources to be used to improve outdated interventions, for example, building an additional wing on a large institution rather than replacing the institution with community based services, as called for in the CRPD. Additionally, much of the resources that are directed to persons with disabilities are in the form of one-off or pilot projects. For example a pilot project for an AIDS education workshop for a handful of Deaf individuals may be initiated with no plans for expansion to reach the thousands of other Deaf people in the country or for sustainable inclusion of outreach to the Deaf community in on-going mainstream AIDS efforts.

Disability and Poverty

The lack of inclusion of persons with disabilities in global development is of particular concern because people with disabilities are disproportionately poor. While it has long been observed that disability is both the 'cause and consequence of poverty' (DFID, 2000; Yeo and Moore, 2003; Trani and Loeb, 2012; Palmer, 2012), until recently there has been relatively little research on the actual nature of this poverty or the mechanisms that link disability to poverty (Braithwaite and Mont, 2009; Groce et al, 2011; Mitra et al 2011). Now a small but growing body of research shows that there is a complex and nuanced feedback cycle between disability and poverty. We now know that poor people are at greater risk of becoming disabled through lack of adequate housing, nutritious food, clean water, basic sanitation, safe working environments and access to basic and emergency health services. Once disabled, individuals are at increased risk of becoming or remaining poor through restricted access to education, health care, job training and employment opportunities as well as through lack of routine medical care and where needed, rehabilitative services

health facilities, the newer social model is being introduced not in place of a medical model, but rather on top of a pre-existing charitable model that continues to be the dominant conceptual framework among the general public, development professionals and government officials.

and assistive device (e.g. wheelchairs; hearing aids) (c.f. Eide and Ingstad 2013; Hosseinpor 2013).

Significantly however, a series of recent studies are beginning to suggest that in the poorest communities where everyone lives in extreme poverty (US \$1.25 per day or less), there may be comparatively little differences between persons with disabilities and non-disabled persons in terms of access to assets, resources and services (Trani et al 2010; Eide and Ingstad 2011; Groce et al 2013) This is further supported by research undertaken by the Leonard Cheshire Disability and Inclusive Development Centre at University College London which, under the auspices of the DFID-funded Crosscutting Disability Research Programme, found that in the very poorest countries, poverty was a great social leveller, as that there would little statistical difference between levels of poverty and access to mainstream public services between disabled and non-disabled people. The hypothesized disability and development gap either does not exist or is far smaller among those with the most limited resources.

This does not mean that the lives of people with disabilities in these communities are not often more difficult. Inequitable distribution of resources within impoverished households is of concern for people with disabilities, and unwillingness of families to spend limited resources for disabled members is widely reported³.

Furthermore persons with disabilities often struggle against not only extreme poverty but also against prejudice, stigma and social barriers that are not fully reflected in economic terms and against the assumption – often incorrect – that persons with disability can contribute little or nothing to household productivity (WHO/World Bank, 2011; Eide and Ingstad, 2011; UNICEF, 2013; UNDESA, 2011).

Rise out of Poverty: A growing gap

In terms of access to resources and opportunities, a comparative difference between persons with disabilities and non-disabled persons appears to begin as people and

³ For example, while food may be limited for all, even within such households, persons with disabilities may still get less food, less nutritious food or receive food less regularly (UNICEF, 2006).

communities begin to rise out of poverty. The reason for this is clear – when people with disabilities are not included in new efforts to address poverty, they can be left behind. For example, if no school exists and no children in a village receive an education, the life of a child with a disability is little different in many respects from her siblings or peers. But if a school is built and every child in the village, except for the disabled child, now attends school, that disabled child is at a distinct disadvantage. Not only will she be illiterate when literacy is the new norm, but by not attending school, she will be less likely to benefit from school-based health, nutrition and civic engagement programmes. She will be viewed as ‘different’ by former playmates and less likely to be included in social networks as her peer’s transition from school into adolescence and adulthood.

The impact is not only on children. For example, if no women in a community have access to information or capital that will help them grow and sell the vegetables they raise, then all may struggle to bring their crops to market. If a new micro-credit scheme or women’s cooperative provides members with information and funds to help them raise better vegetables and market them more effectively, then the disabled women who are considered poor ‘credit risks’ and excluded from such schemes may lose out to non-disabled neighbours who are able benefit from newly available knowledge, networks and resources.

Poverty is not a simple concept. As a small but growing number of studies now indicate, the nature of this poverty is profoundly multidimensional in nature, and has a disproportionate effect on persons with disabilities. For example, Mitra et al (2013) in a 14 nation comparative study found that persons with disabilities are not only consistently poorer but poorer in multiple domains – including health, education, employment, income and social inclusion. Many of these domains are significant only in communities where development initiatives have begun to introduce such resources. Comparable findings are reported by Hosseinpor et al. (2013) who analyse poverty and disability based on findings from the World Health Survey.

A small but growing body of qualitative studies report comparable exclusion of persons with disabilities from development efforts. For example, Muyinda and Whyte

(2011) find that the exclusion and marginalization of disabled people from essential service development in Uganda results in the needs of disabled people not being met, consequently driving individuals and their families further into poverty compared to their non-disabled peers. Wazakili et al. (2011) reporting on field studies in Malawi and Uganda find ‘a disability perspective is easily side lined in poverty reduction efforts if not specifically incorporated into the process.’

The price of exclusion – where a gap opens with persons without disabilities moving ahead while persons with disabilities remain static, was repeatedly raised in UNICEF’s recent ‘The World We Want (2015) report and the UNICEF and UN Women report on ‘Addressing Inequalities’ (2013).

Findings from these studies on poverty and disability demonstrate the cumulative effects of exclusion and marginalisation throughout the lifecycle and in many domains. Early social exclusion, and limited education and skills training leads to more difficulties in finding and keeping employment and limited career advancement, less access to credit, restricted social networks and limited civic engagement: a host of issues that are of increasing significance in developing communities. These factors, in combination with the effects of traditional stigma and discrimination against persons with disabilities, limit the ability of people with disabilities to acquire the skills, social support networks and political voice needed to be included as development efforts continue to raise expectations for individuals and communities in regards to skills needed, resources available and assets assumed to be basic to live and participate in one’s community.

Compounding this, in all countries, households with disabled members are often poorer than their neighbours due to additional costs of health care, medicine and assistive devices (where they can be afforded at all), previously unavailable to anyone in extremely poor communities (c.f. Erb and Harriss-White, 2001; Mont and Cuong, 2011; Palmer, 2012; Palmer, 2014).

Additional ‘opportunity costs’ add to this disparity. In households with disabled members when non-disabled household members forego income generating activities in order to stay home to provide needed care or support services (Mont and

N Nguyen 2013; Palmer et al 2015) . When children are taken out of school to help or family assets are sold for medical or rehabilitative services, the cost of disability also becomes an intergenerational concern (Mitra, et al., 2015). This is of growing concern in formal money-based economies where time and effort is increasingly defined and valued in terms of wages or income. Braithwaite and Mont (2009) for example, studying the cost of disability in two middle-income countries, estimate that the increased annual cost of disability to a household is 9% in Vietnam and 14% in Bosnia.

In addition to analysis of data bases and field studies, a series of recent reports, including major reports from UN commissions and agencies (WHO/World Bank, 2011; UN, 2013) and a UK-Parliamentary Select Committee on Disability and Development (UK Parliament 2014)⁴ have begun to call attention to the consistent lack of inclusion of persons with disabilities in mainstream development efforts.

Consistent Lack of Inclusion in Development Efforts

Despite growing evidence of disproportionate rates of poverty among persons with disabilities, because disability is so often conceptualized as a charity or medical concern, it has been routinely left out of development efforts. This is nowhere better illustrated than in the Millennium Development Goals (MDGs) where there is no mention of persons with disability in any of the Goals, Targets or Indicators (UNDESA, 2011). Anti-poverty initiatives linked to the MDGs have likewise left out disability. Thus there have been few mechanisms available to hold countries accountable for the inclusion of persons with disabilities.

Indeed, it can be argued that the way progress is often measured based on global and national aggregate data can 'statistically obscure' can perpetuate the problem

⁴ The Select Committee of the House of Commons held a series of formal hearings on Disability and Development to collect evidence from global disability activists and experts concern the current inclusion of disability issues in international UK development work, including both DFID and other major bilateral organisations. Their report, issued 1 April 2014, called for greater commitment to the inclusion of persons with disabilities in all UK international development work and also called for a Framework on Disability to help guide future international funding through the UK government.

by masking increasing gaps in achievement between the general population and groups who are the most excluded – such as persons with disabilities. For example, if the goal is to ‘increase the number of children in school in by 2/3s’ it is easier to go after low hanging fruit and bring in non-disabled children who may require less time and attention in the classroom, pushing a disproportionate number of children with disabilities into the remaining one-third of children who are still not in school.

Current where people with disabilities are included in many development initiatives, it is through one-off, short-term projects to reach specific subgroups, such as an HIV education project for the Deaf or a handicraft livelihoods project for adults with intellectual disabilities. Such efforts usually reach a few dozen, when thousands are in need of the programmes. Almost all are run as ‘pilot projects’ and often are framed by a charity model.

To further complicate matters, disability continues to be viewed as a specialist area - services for children with disabilities, for example, are often considered the provenience of rehabilitation experts and special schools. Such assumptions help justify and perpetuate the exclusion of such children from general health care and public health programmes, despite the fact that they are in equal need of childhood vaccinations, malaria services and nutrition campaigns. A frequent assumption is that the needs of children or adults with disability will be tackled by unspecified education or medical experts or NGOs. Not only is this expressly against the provisions for inclusion in mainstream development efforts set out in the CRPD, but it ignores the fact that such specialised services rarely exist.

Compounding this, when people with disabilities are not part of international development efforts, new development initiatives may significantly increase the barriers persons with disabilities face in their communities and societies.

Inaccessible new buildings, modern transportation systems or latrine blocks – often funded by foreign aid and international corporations – make previously accessible locations now inaccessible, further limiting participation by persons with disabilities now and for decades to come.

When people with disabilities are mentioned in international development efforts at all, it is often as part of a list of ‘vulnerable groups’ enumerated at the end of a long development proclamation or technical report (e.g. ‘women, the disabled, older adults, ethnic and minority populations’) with little or no provision for identifying concrete plans for implementation or for monitoring and evaluation mechanisms to ensure that such inclusion actually takes place.

The result in countries around the world is the same: people with disabilities are routinely excluded from development efforts or denied the supports they need to rise out of poverty throughout the life cycle. These actions, we argue here, create and maintain a disability and development gap.

Compounding the Gap: Transition from Low- to Middle-Income Countries

While discussion and debate around the exclusion of disability issues from international development and global health has been framed largely in terms of the impact at the individual or community level, there is also a broader structural issue.

A growing number of countries are transitioning from low-income to middle-income status. In terms of numbers, more of the world’s extremely poor (those who live on less than US\$1.25 per day) now live in middle-income countries (i.e. Brazil, India, China) than in low-income countries (Sumner, 2010). It can be assumed that people with disabilities are also affected by these same trends, and we can therefore anticipate that more extremely poor people with disabilities now live in middle- rather than in low-income countries. Much more research is needed to better understand how people with disabilities fare in such transitional economies, but we can note here some trends that are of great concern.

Certainly, in emerging middle-income countries, we can anticipate the disability and development gap will continue to widen as rising levels of education, employment and social participation are matched by rising expectations, increased consumption of resources and a shift to more nuclear family households for members of the broader community while persons with disabilities have proportionately fewer or no access to these resources.

Also significant is that as countries shift from low- to middle-income status there is a concurrent structural change in how the poor are conceptualised and their needs addressed. In middle-income countries an increasing amount of responsibility for economic development, education, health services and the needs of at-risk populations, are taken over by government. National systems of education, employment, health care and social protection arise to replace international aid, and local civil society organisations must become more effective in helping those in need where government programmes are not sufficient.

In such countries, people with disabilities face an additional set of concerns. If government ministries approach disability issues with an unquestioned 'charity' or 'medical model', people with disabilities in need of assistance may face barriers. For example, if governments officials maintain a 'charity model' the new social protection programmes they establish may assume that persons with disabilities cannot work. If this is then a required criterion in receiving support, this may restrict persons with disabilities from continuing the work that they already do. Restrictive medical criteria for accessing benefits may reinforce a medical model in which disabled persons must convince health officials or government bureaucrats of their disability status without consideration of the related environmental barriers that are an integral part of disability as defined by the CRPD, to which the majority of countries have signed. Some governments may choose to continue to maintain institutions with no viable community based models proposed.

And there is an additional concern. In some emerging economies where government and civil society continue to rely on a 'charity' model, while the State is playing an increasingly active role in service provision, supports for people with disabilities continue to be supplied by specialised charities (NGOs). Not only are people with disabilities being excluded from the mainstream programmes to which they are entitled, but such specialised charities also often continue to operate on outdated models of disability, with little or no accountability to government or to their consumers.

Into the Future: What Does Inclusion Look Like?

It is estimated the exclusion which results in avoidable unemployment and marginalisation from participation in society, costs nations up to 7% of their GDP (Backup, 2009). In response, the forthcoming SDGs' call to 'Leave No One Behind' holds great promise, but will benefit the world's 1 billion persons with disabilities only if these aspirational statements are translated into effective and measureable action. As with the MDGs, the SDGs will set the global agenda for many international development efforts by governments or civil society for the next fifteen years, so inclusion of persons with disabilities in the SDGs is of paramount importance. The significance of such inclusion has most recently been underscored in the United Nations' High Level Panel on the Post-2015 Development Agenda, which refers to disability throughout the report, as well as in reports such as the recent UK Government Select Committee inquiry on Disability and Development (UK Government 2014). The issue is often not lack of inclusion on paper, but lack of implementation, enforcement, monitoring and evaluation of the inclusion of persons with disabilities in development initiatives.

Of particular importance is the need not just to ensure the inclusion of persons with disabilities in development activities but to ensure that they are ***proportionately represented*** in all development efforts. It is not enough to ask what percentage of all women in a village are reached by a new maternal health programme, but to also ask what percentage of all disabled women in the village are reached by that programme. If a new development programme means that 80% of children in a community are now in school, monitoring and evaluation of that program must ask if 80% of all disabled children are being comparably reached. If this is not done, the disability and development gap will continue and indeed, has the potential to widen in the years to come.

CONCLUSION

We are deeply concerned that an emerging body of data indicates that in low- and middle-income countries people with disabilities are 'standing still' while other citizens are moving ahead. More research is needed to better develop this

hypothesis, but we posit that there is an emerging disability and development gap that cannot continue to be ignored.

Despite ratification of the UN CRPD and national laws that guarantee equity, while lives of millions worldwide improve, and the needs of the general population are being increasingly met by government, millions of persons with disabilities continue to live in poverty and their needs met – if met at all – by one-off projects, unsustainable pilot projects and charities that are often still working on charity or medical models, unaccountable to the government or to disabled individuals themselves.

Unless efforts are made to wed the rights guaranteed under the CRPD to meaningful disability specific and disability inclusive engagement in the forthcoming Sustainable Development Goals and all allied development efforts, persons with disabilities not only are at risk of continuing to live in poverty and social isolation, but also are at risk of facing a widening ‘disability and development gap,’ standing still – poorer in both relative and absolute terms as their non-disabled peers rise out of poverty.

It is heartening to note that the new SDGs declare that we must ‘Leave No One Behind’. However, this statement must be translated into actual progress that can be monitored and evaluated. Disabled people have been described as the ‘world’s largest minority’ (UN, 2008; Goodley, 2011). If this ‘disability and development gap’ is not addressed, many of the new SDG goals will simply not be met.

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